

WHAT YOU DON'T KNOW ABOUT AIDS COULD FILL A MUSEUM

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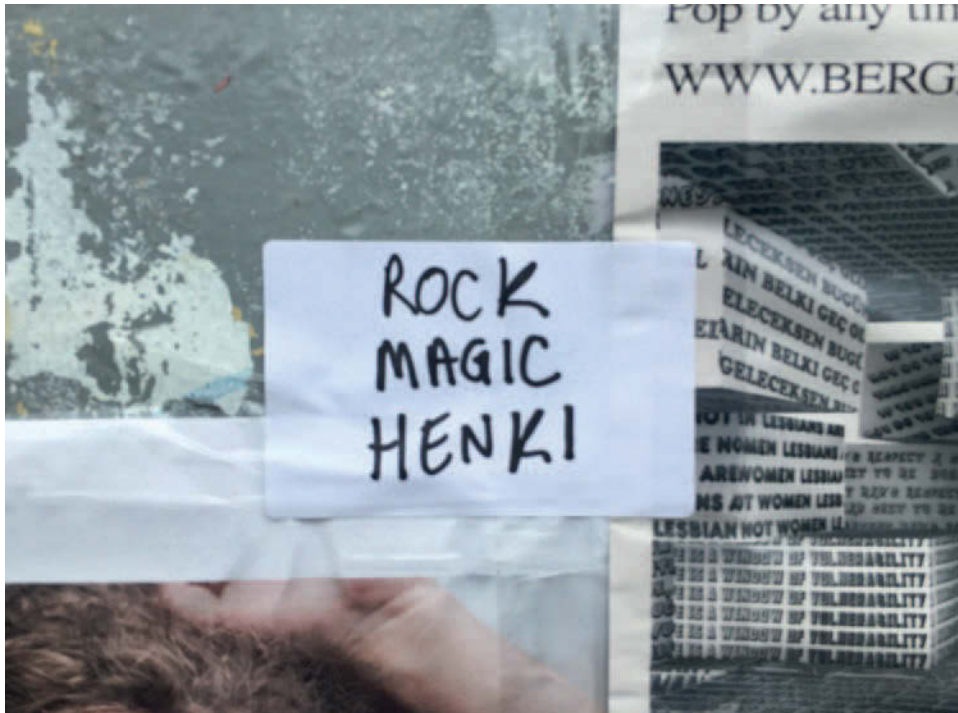
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Introduction

Editorial

What You Don't Know About AIDS Could Fill A Museum: Curatorial Ethics and the Ongoing Epidemic in the 21st Century

Theodore (ted) Kerr



Rock Hudson, Magic Johnson, and Henki Karlsen, three men with HIV who have changed how people in various parts of the world think about the virus, and what we know about the ongoing epidemic. To learn more about how AIDS has impacted the museum culture and the way we discuss AIDS in culture, check out the essays in the COLLECTING section of this issue.

This issue of ON CURATING began trying to find a place for an essay I had written about AIDS to appear within a curatorial context. From there, it bloomed into WHAT YOU DON'T KNOW ABOUT AIDS COULD FILL A MUSEUM—a collection of essays, conversations, visual projects, reprints, and personal reflections from academics, artists, activists, writers, and others from around the world committed to the ongoing response to HIV. The over 40 entries in this issue explore and wrestle with AIDS-related culture in the 21st century, through four themes: forgetting, seeing, collecting, and making, all of which reflect on both the historical turn in contemporary AIDS cultural production, and the ongoing need to keep an eye on the present.

The title of this issue comes from a 2014 panel I put together as the programs manager at Visual AIDS, a New York-based AIDS-focused art non-profit. At the event, writer

Hugh Ryan said something that I think reflects the spirit of this journal when he argued for transparency from curators, and museums:

The museum becomes the objective voice, which doesn't exist. That's one of the big things, how do we forefront the people behind museums—the ethos behind the museums. How do we let people know what is the voice? Who's in the room making this exhibit? What are they drawing from? That helps us understand what we're actually looking at because there is a voice, there is a perspective, and to pretend there isn't I think it weakens everything.¹

His quote came months after *The New York Times* published his op-ed, *How to White-wash a Plague*, which called into question the exclusionary nature of *AIDS in New York: The First Five Years*,² an exhibition at the New York Historical Society curated by Jean S. Ashton that Ryan felt left out the foundational role of activists and the LGBT community in the story of AIDS. The article came out during a heady time, in which much about AIDS culture and history was being debated. Several critics called into question the lack of diverse representation in the Oscar-nominated documentary, *How To Survive a Plague* (David France, 2012)³; there were concerns about Jared Leto's performance as a trans woman with HIV in *Dallas Buyers Club* (Jean-Marc Vallée, 2013); there was unsavory cross-generational conversation inspired by a poster made by historian Ian Bradley Perrin and artist Vincent Chevalier that read, *Your Nostalgia is Killing Me* (2014, for PosterVirus); debates were had about the creation of an AIDS memorial in New York City⁴; and during the first run of the nationally touring exhibition, *Art AIDS America* (co-curated by Jonathan David Katz, and Rock Hushka, 2015), the Tacoma Action Committee staged a die-in calling for more black representation in the show and systemic changes around racial bias at the museum.⁵ These conversations, which as you will see in reading the rest of this issue, continue to reverberate to this day, and are rooted, I think, in both the end of a prolonged absence of AIDS-related culture in the public realm, which was then followed up by an intense onslaught of cultural production regarding AIDS history. I have come to dub this twinned phenomena the "Second Silence" and the "AIDS Crisis Revisitation," and over the last six years, working with academic and filmmaker Alexandra Juhasz, we have populated the terms with meaning.⁶ We have come to understand that the Second Silence begins with the availability of life-saving drugs in 1996, causing people in the media and beyond to think that the crisis was over. For over a decade, the epidemic continued, but compared to the highly broadcast cultural production of ACT UP, Keith Haring, and other media and mark makers from the decade prior, within the Second Silence, experiences of the virus were quiet, siloed, and privatized. This shifted with the Revisitation. Cultural production broke through the silence, with films like *Sex Positive* (Daryl Wein, 2008), *United in Anger* (Jim Hubbard, 2012), and *We Were Here* (David Weissman, 2013); exhibitions like *ACT UP New York: Activism, Art, and the AIDS Crisis, 1987–1993* (curated by Helen Molesworth and Claire Grace for The Carpenter Center for the Visual Arts and the Harvard Art Museums, 2009) and many other examples. This resulted in an uptick in AIDS-related conversation in public, reunions between estranged activists, cross-generational conversations, new projects, and backlash along with counter-Revisitation centered on the narrowness of the Revisitation's early focus: urban middle-class white gay-centric communities from the East or West Coast of the US.⁷



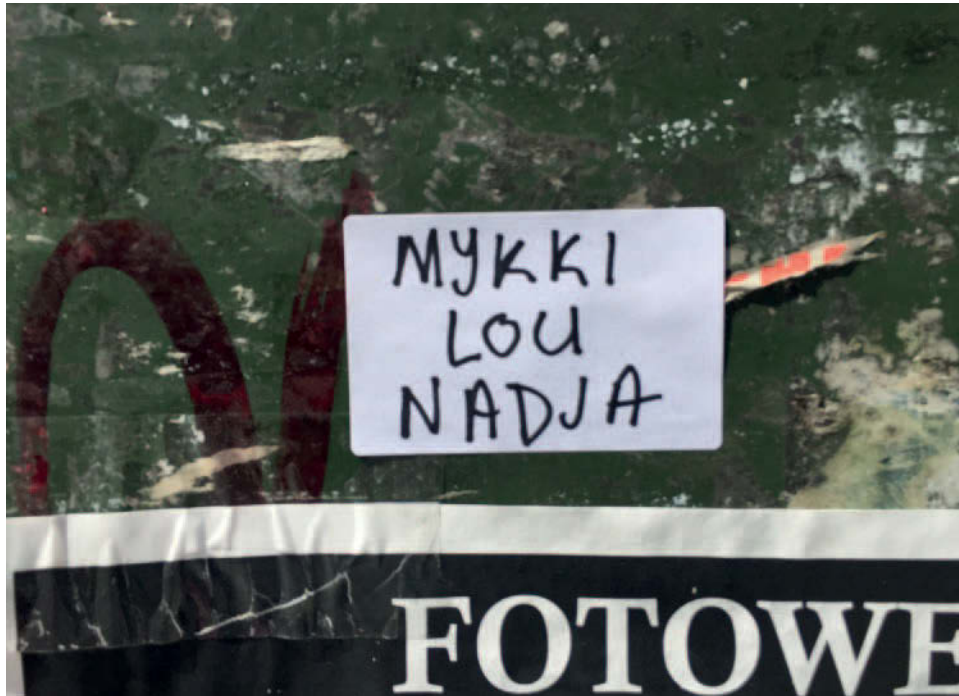
Arne Røed, Bente Røed, and Robert Rayford are all people with HIV who died before 1981, and whose lives and deaths can help us reconsider the ongoing epidemic. To think about the importance of storytelling, tradition, and oral culture within the AIDS response, spend time with the entries in this issue's first section, FORGETTING.

As it happens, the release of this journal coincides with the Revisitation on full view in Europe. This summer alone there are two AIDS-related exhibitions in Zurich: *United by AIDS—An Exhibition about Loss, Remembrance, Activism and Art in Response to HIV/AIDS*, curated by Dr. Raphael Gygax, at the Migros Museum für Gegenwartskunst, and *Problem gelöst? Geschichte(n) eines Virus*, compiled by Rayelle Niemann for the Shedhalle. Then, less than 1400 km away in Liverpool, there is a major exhibition of Keith Haring's work at Tate Liverpool, including many of his AIDS-related works; meanwhile the Schwules Museum in Berlin is working on a large-scale, trans-European AIDS-related exhibition, and the German capital will be host to a conference entitled *Living Politics: Remembering HIV/AIDS Activism Tomorrow*, which will showcase some of the research coming from the "Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health" research team (EUROPACH).

Considerations of the relationship between silence, attention, and action is, of course, nothing new when it comes to AIDS. Around the same time much of this issue was being edited, scholar and critic Douglas Crimp died. Within his work, Crimp was attuned to the nuances of many things, including culture and AIDS. In his book, *Melancholia and Moralism*, he argued that avoidance was a default status of the public when it came to HIV/AIDS. "The turn," he wrote, "was a response to the epidemic from the moment it was recognized in 1981."⁸

In his stern generosity, Crimp reminds us that a common refrain throughout the epidemic has been, "AIDS is not over," a reaction from those on the ground to the constant threat of the public and the government pulling their attention and resources. Examples include the 1989 sticker from Little Elvis that read: "The AIDS Crisis Is Not Over"; to the Visual AIDS exhibition title, *Not Over*; to artist Gregg Bordowitz's brilliant turn of phrase, "The AIDS Crisis Is Still Beginning."

Given that AIDS of course is still *still* not over, what is the role of curators and other cultural producers? As the editor, it is my hope that WHAT YOU DON'T KNOW ABOUT AIDS COULD FILL A MUSEUM offers some suggested and meaningful ways forward. And as such, this issue of is built upon a belief, laced with slight trepidation, that history and culture play a vital role amid the work to find a cure for HIV, to prevent further premature deaths, and to improve life chances and the quality of life for people currently living with HIV and those understood to be most at risk.

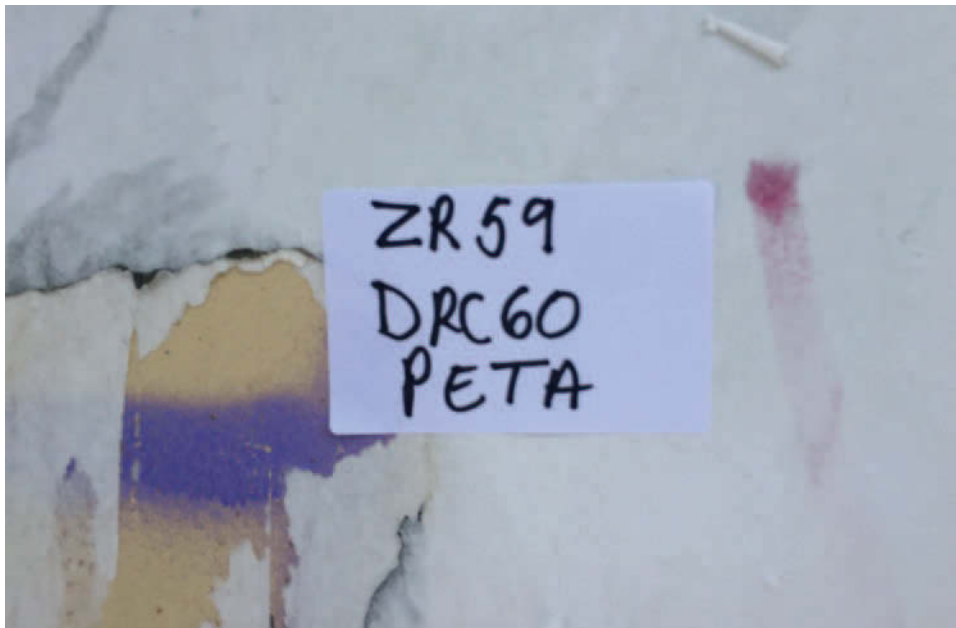


Mykki Blanco, Lou Sullivan, and Nadja Benaissa through their art and lives illustrate the many different ways living with HIV can construct a life, for better or worse. Learn more about Mykki in the SEEING section of this issue.

Central to this AIDS work is the centering of people living with HIV and communities deeply impacted by the crisis. The journal begins with a series of entries that offer up lenses through which one can better understand and consider the rest of the issue. These entries include Abdul-Aliy A Muhammad and Louie Ortiz-Fonseca's conversation, "A Brief History of HIV," and Sheldon Raymore's project "Waniyetu Wowapi and HIV/AIDS." Together, they offer a brilliant orientation to AIDS history, by pushing against chronology as being the de facto rule to knowing the past and asserting the role of tradition as a vital form of archiving. In their conversation, Muhammad and Ortiz-Fonseca share their stories as two influential and tireless activists and cultural producers within the AIDS response and how that relates to them being vital-voiced, queer people of color living with HIV. Through their mutual respect, love, jokes, and frustration, a reader is better prepared to read the rest of the issue; similarly with Raymore's artwork "Winter Count," which provides an AIDS timeline rooted in First Nation experiences of the virus. By placing this near the front of the journal, curators as readers are invited to consider what it would mean to privilege the voices of the most experienced within the crisis, who are also often the most side-lined.

The contributions of Muhammad, Ortiz-Fonseca, and Raymore are in the first section of WHAT YOU DON'T KNOW ABOUT AIDS COULD FILL A MUSEUM, which is titled FORGETTING. Given that this journal can be considered part of the AIDS Crisis

Revisitation, it is interesting to consider the relationship between silence, remembering, and forgetting. In this section, archivists, activists, and academics alike take up this consideration, reflecting on how time, history, and representation relate to change-making tactics, community, and visual culture. What gets dragged forward? What is the role of context in exhibition? How do we save with loss—be it people, ideas, or hope? These are questions across all the entries in this section, including Rahne Alexander's personal and informative essay, "The Lost & The Found," in which she introduces the reader to Louis, a long-term AIDS cultural activist who has used his own story to keep AIDS on the agenda, even when people would have preferred to look away. Common themes bond Adam Bardu and John Paul Ricco in their conversation, "Inheriting AIDS: A Conversation," in which the two scholars engage in an intergenerational dialogue that navigates the stickiness of trauma, desire, and exhibition-making over time. Pairing nicely with this conversation is "Luckiest Guy," a visual work and statement by artist Michael McFadden that reflects on the importance of 1996 and 2012 in terms of medical breakthroughs and cultural reckonings.



Zaire 1959 and Democratic Republic of Congo 1960 are the names given to the oldest surviving HIV samples, which belonged to people who lived in that region at the time. Peta is the name of the person whose hand can be seen in the infamous photo of David Kirby on his deathbed. These three people remind us that most people with HIV are not often given the option to be named or represented, on their terms or otherwise. Consider the MAKING section of this issue to read about ways that artists, faith leaders, and others work to better include a diversity of voices and experiences when it comes to HIV.

Thinking about forgetting in a different light are entries in this section that consider archive through the lens of collection, criticism, and recall to great effect. Pushing against erasure, artist and archivist Siân Cook has long been saving HIV-related ephemera and shares it through her project, "Graphic Ephemera Lasting Impact: Building an Online UK HIV/AIDS Design Archive," much of which predates the accessible use of the Internet. From around the same time period, AIDS philosopher and artist Avram Finkelstein does a deep dive into an iconic work, providing historical context along the way, in "AIDS, Coca-Cola, and the Tompkins Square Park Riot." In the same vein, art historian Kate Hallstead provides readers a glimpse at the tender possibilities of exhibition in her essay, "Corporeal Materials, Presence, and Memory in Jerome Caja's Exhibition *Remains of the Day*."

Ending on an emotional note, I am very honored to include a beautiful note from once Brooklyn Historical Society Director, David M. Kahn. It was a staff-wide memo he shared prior to the opening of the 1993 exhibition, *AIDS/Brooklyn*, in which he works to ensure that people living with HIV feel comfortable visiting the exhibition, making an emotional plea for decency while evoking the loss of his partner who had HIV. The FORGETTING section fittingly concludes with “In Case You Forgot How I Looked,” a visual project/poem by artist Dudu Quintanilha, which can also be read as a script between two people fighting against forgetting and for a right to remember, and “*Legacy: A Timeline of HIV/AIDS*,” the script of artist Carlos Motta’s video of the same name on view at *United by AIDS* in Zurich.

The second section is SEEING, which of course is not just an activity with the eyes, but rather a practice of vision, imagination and—when it comes to HIV/AIDS—negotiating that which has been rendered silent, absent, and erased, be it from history or the gallery. The section begins with activists and friends Emily Bass and Yvette Raphael, who come together for “Looking for the Faces of Our Friends,” an affirming conversation about the limits and possibilities around how women in Africa are rendered within the AIDS response. In the conversation, Raphael asserts a call for radical subjectivity in the face of activism, which is also at the heart of “The Denver Principles.” Written in 1983 by people living with HIV, naming the terms of their coverage, the Principles are reprinted here, with an introduction from the Sero Project’s Sean Strub, as a reminder and talisman for our work.

Running through the rest of the second section is an emphasis on the role of artists in cultural production, and the practice of conversation as a means of making issues, people, and ideas visible. There are four conversations in this section (maybe a comment itself on how visibility happens): artist Kelvin Atmadibrata’s relationship with HIV is teased out by oral historian Benji de la Piedra in “HIV Ambivalence and Game Playing Influence”; the multi-talented trio of Luiza Kempnińska, Hubert Zięba, and Szymon Adamczak add visibility to the virus within their home country in “AIDS and Poland”; artist Carlos Motta and critic John Arthur Peetz suggest that what we are envisioning when it comes to PrEP is not actually HIV but something else, in “Because PrEP is Not About AIDS”; and in a tender exchange entitled, “Fingerprints, Unfinished,” artist Mavi Veloso and anthropologist Nicholas D’Avella come together to discuss Veloso’s work while tackling influence, nationhood and ways of seeing and representing oneself.

Included in SEEING is scholar Edward Belleville’s current observations about (in) visibility of HIV through the work of a beloved superstar, “Stones and Water Weight: Working Out with Mykki Blanco”; Stamatina Gregory’s essay “Shooting Up in the Museum: Intravenous Drug Use in Brian Weil’s *The AIDS Photographs*” is a study in what museums are often too scared to have on view, and my own essay, “From Tactic to Demand: HIV Visibility Within a Culture of Criminalization.” Like Forgetting, SEEING ends with a creative project, this time by artist and writer Charan Singh, who mixes advocacy, memoir, and creativity in a play and glossary entitled “Among Four Friends: Conversations Before and in a Hospital Waiting Room.” It is a clever expression in which a community of people witness each other, calling into question the need to be seen by others when it comes to survival. Coming from a different but related point of view, reprinted in this journal are Demian DinéYazhi’s powerful images that serve as a reminder that, “HIV Affects Indigenous Communities.”

The third section is COLLECTING, and here, curators, researchers, and public intellectuals argue, converse, reflect upon, and consider best practices, personal

experiences, and recent examples of curating AIDS, be it in book, gallery, museum, or memoir form. It is here that Hugh Ryan may find much of what he is looking for, examinations into the ideas, experiences, and feelings behind AIDS exhibitions. Dominating this section are explorations around the way cultural institutions have been shaped by attempts to include HIV/AIDS. This is specifically meaningful as it marks how the path towards the AIDS Crisis Revisitation was taking shape within the Second Silence. Essays in this section include Marika Cifor's "Status = Undetectable: Curating for the Present and Future of AIDS"; Catalina Imizcoz's "Precarious Structures: HIV, Museums, and History"; Sandrine Musso, Renaud Chantraine, and Florent Molle's "AIDS Politics of Representation and Narratives: A Current Project at the Museum of European and Mediterranean Civilizations (Mucem) in Marseilles, France"; Dr. Manon S. Parry's "AIDS and the Medical Museum Gaze: Collecting and Exhibiting Science and Society"; and Ricky Price's "Viral Memories: The Making of Institutional History and Community Memory in the HIV/AIDS Crisis."

Thinking about collecting from other angles, including the ethics of inclusion, history-making, and accounting for difference and emotion are other contributions to this section. In a wide-ranging conversation, Jean Carlomusto, Hugh Ryan, and Alexandra Juhasz discuss their joint curatorial practice in "Abiding Relations Through Recovery, Restoration and Curation," which dovetails nicely with Heather Holmes' exploration of a personal project, "Public Ruptures, Public Readerships: AIDS in Writing." In reading the two pieces together, the reader is exposed to an interesting array of concepts around representation of people and ideas, in time, through form.

Collecting from an artists' perspective is central to Lyndon K. Gill's review, "Field Notes from the Afterlife: Lyle Ashton Harris' Living Archive" and curator and artist Nelson Santos' visual project, "Love Happened Here." Here, we see the impact of accumulation, the archive as aesthetic and way of life, and the role of the visual in representing nuance, care, and love within the epidemic. Relatedly, the section ends with a reprint of the Tacoma Action Committee's press release, "#StopErasingBlackPeople," which they released in response to the Art AIDS America exhibition, a document we can see as a commentary on the need to retain the humanity within our curatorial practices.

Lastly, MAKING. This section asks the question: How to have cultural production in an ongoing epidemic? It begins with advice from experience. Artist and organizer Jordan Arseneault provides well-earned insight in "How To Have a Lecture Series in an Epidemic"; Alper Turan gives an intimate look into his groundbreaking exhibition about HIV in Turkey in his essay, "Positive Space"; Greg Thorpe looks back at his work at bringing HIV/AIDS into nightlife in "On Nightlife"; Jaime Shearn Coan gives a postmortem after editing a journal dedicated to HIV/AIDS in "How to Catalogue a Crisis: An Afterword to *Lost and Found: Dance, HIV/AIDS, New York, Then and Now* (2016)," Michael Miuro shares his experience, looking at what both the disability and HIV communities need to do to be more inclusive in "Disability, HIV, Art, and, Culture"; and in "Thoughts on How to Include Spirituality in Exhibitions about HIV and AIDS," Rev. Michael Crumpler sheds light on the need for spirituality within exhibitions about AIDS. These texts when read together provide a meaningful and meaty primer to any upcoming AIDS-related production.

In terms of MAKING, the section also includes texts around how AIDS can make a person, a friendship, or a bond as in artists Kairon Liu and Manuel Solano's conversation, "Could I Be A Happy Person?"; how AIDS can make a family, as in critic Emily Colucci's "Touch Across Time: Familial Loss and its Remains in Art During the Ongoing

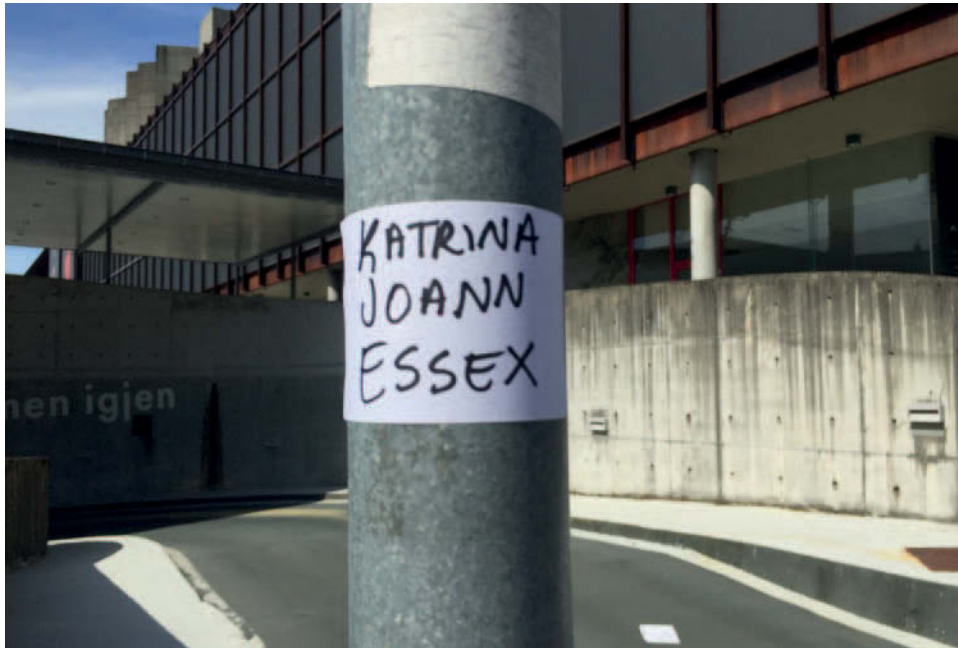


Matthew Shepard, Bryn Kelly, and Roxana Hernández complicate what it means to die with HIV. Shepard was left for dead, frozen on a fence in Wyoming, Kelly took her own life, and Hernández died while in US Immigration and Customs Enforcement custody. Their lives remind us that HIV is an intersectional issue beyond the virus. Making space for complicated lives and deaths is part of representing AIDS in public in the 21st century.

HIV/AIDS Pandemic” an essay that looks at artists creating work about having HIV in their families; and finally, how HIV can be used to make sense (or not) of the world, in curator Vladimir Čajkovic’s essay “How to (Dis)quiet a Vampire.”

Both the journal as a whole and this section end with grounding advice. Before they died in 2017, I.n. Hafezi was inspired by the artist Chloe Dzubilo and produced a lovely tribute that offers sage advice for would-be culture workers in “[*INSTRUCTIONS FROM CHLOE*], curatorial statement.” Just as profoundly, in 2014, a hard-working handful of people working at the front line of the AIDS response—Cecilia Chung, Olivia Ford, Deon Haywood, Naina Khanna, Suraj Madoori, Charles Stephens— came together to produce, “Intersectionality, HIV Justice, and the Future of Our Movement.” And finally, with the belief that this journal is a resource as much as anything else, WHAT YOU DON’T KNOW ABOUT AIDS COULD FILL A MUSEUM ends with a series of prompts to read before doing the work, “Twenty-One Questions to Consider When Embarking upon AIDS-Related Cultural Production (2018),” from the collective What Would an HIV Doula Do?.

This issue was a year and a half in the making. The process took so long in part because this was largely a volunteer experience. I, and the majority of the contributors, did not get paid. It also took a long time because I kept on adding contributions due to both a real investment in the work, and a desire to bring in as much thought-provoking and relevant work as possible (with an awareness that many voices are still missing). The near never-endingness of the project, and the constant additions relate to my curatorial vision when it comes to HIV: making culture about AIDS should mirror the social experience of AIDS; it should be an assemblage; messy, social, and replicable. It should involve risk and discomfort, but also new and expansive ways of seeing the world, and it should be interactive and intimate. It should inspire connection, and be political in nature, even when it seems it is not. Finally, it should be challenging, leaving a reader, a curator, or an activist to ask questions, spark conversation, and keep the conversation and action alive.



Katrina Haslip, Joann Walker, and Essex Hemphill are three of countless names from our collective AIDS archives whose names and contributions should be known. In thinking about WHAT YOU DON'T KNOW ABOUT AIDS COULD FILL A MUSEUM, whose work would you wish more people knew about?

The images in this text are from a project I did in anticipation for a talk I delivered as part of The Parliament of Bodies, on the occasion of Bergen Assembly 2019 at the invitation of Paul B. Preciado and Viktor Neumann, with special thanks to Anne Szefer-Karlsen.

Notes

- 1 You can read the transcript here: <https://visualaids.org/events/detail/what-you-dont-know-could-fill-a-museum-activism-aids-art-and-the-institutio>.
- 2 You can read the piece here: <https://www.nytimes.com/2013/08/04/opinion/sunday/how-to-whitewash-a-plague.html>.
- 3 Important criticism of Revisitation-based media includes *How to Survive: AIDS and Its Afterlives in Popular Media* by academic Jih-Fei Cheng, which problematizes representation in David France's film *How To Survive a Plague*.
- 4 I have written about the new generation of AIDS memorials and monuments, within a historical context, for *C Magazine*: "How to Have an AIDS Memorial in an Epidemic," <https://cmagazine.com/issues/142/how-to-have-an-aids-memorial-in-an-epidemic>.
- 5 To learn more about the Tacoma Action Collective's demonstration of *Art AIDS America* due to the show's lack of black representation, visit *Hyperallergic* for an article called "A History of Erasing Black Artists and Bodies from the AIDS Conversation."
- 6 To read some of our work on these subjects, check out: Alexandra Juhasz and Ted Kerr, "Home Video Returns: Media Ecologies of the Past of HIV/AIDS (Web Exclusive)," *Cineaste* (2014); Alexandra Juhasz and Ted Kerr, "Stacked on Her Office Shelf: Stewardship and AIDS Archives," *The Center for the Humanities* (2017).
- 7 For more information read *#StopErasingBlackPeople* from the Tacoma Action Collective in this issue of *On Curating: Under the Rainbow* by Tyrone Palmer in the July 28, 2015 issue of *The New Inquiry*; and *How to Survive the Whitewashing of AIDS: Global Pasts, Transnational Futures*, from Nishant Shahani in *QED: A Journal in GLBTQ Worldmaking* (2016).
- 8 Douglas Crimp, *Melancholia and Moralism: Essays on AIDS and Queer Politics* (Cambridge, MA: MIT Press, 2002).

Framing The Issue

Theodore (ted) Kerr



Poz Since 1492, Demian DinéYazhi' (to learn more about this work, please see below)

**The HIV pandemic is not on track to end,
and the prevailing discourse on ending AIDS
has bred a dangerous complacency and may have hastened
the weakening of global resolve to combat HIV.**

This is a key finding in a recent executive summary from the International AIDS Society published by the medical journal, *The Lancet*, on the occasion of the 22nd International AIDS Conference in Amsterdam in 2018. While such documents can feel like report cards, the IAC summary reads like a rallying cry from the belly of the Global AIDS administrative body, begging for attention to be paid to both the ongoing crisis, and how AIDS has been—and is currently being—discussed. I depart from a more traditional *OnCurating* introduction to share it because I feel that for curators, it is also a good review of how HIV is currently being positioned by the guiding forces of the global response, at a time when almost as many people on the planet are currently living with the virus—37.9 million people—than have ever died with the virus—39 million people.

I am suggesting that before one dives into this issue and reads what artists, academics, activists, curators, critics, and others deeply involved in the world of AIDS and culture are thinking, it is worth it to get a bird's-eye view of how HIV is being positioned on a global administrative level.

The IAS summary begins broadly—inspiringly even—reflecting on the virtuous goal of achieving sustainable health and development for all, primarily through the global work of “attaining universal health coverage.” HIV is placed alongside tuberculosis, malaria, as well as maternal and child health, as big picture issues that we, as a global community, can address together. Embedded in this message is an argument: HIV is part of a constellation of other global health issues—it is not special. As if to prove this point, HIV does not stand alone in the text until the third paragraph, in a line that deserves unpacking: “Although the number of new HIV infections and AIDS-related deaths have markedly decreased since the epidemic peaked,” the summary authors state, “little progress has been made in reducing new infections in the past decade.”

This two-pronged sentence begins with an acknowledgment that within the span of the epidemic's first decade, the medical and scientific community went from knowing little about an unknown illness, to identifying it as a virus, coming up with a test, and producing effective life-saving medical treatments (HAART, highly active antiretroviral therapy) and prevention methods (PEP and PrEP). The second half of the sentence—“little progress has been made in reducing new infections in the past decade”—is less dense, but no less intense: globally, when it comes to HIV, a plateau of progress has been reached. While new diagnosis have been reduced by 40% since the peak in 1997, according to UNAIDS, the rate of reduction has slowed since 2010, hovering at about 2 million new cases of HIV a year globally. (2.1 million new HIV infections in 2010, 1.7 million new HIV infections in 2018.)

From there, the summary gets dramatic:

Without further reductions in HIV incidence, a resurgence of the epidemic is inevitable...Allowing the HIV epidemic to rebound would be catastrophic for the communities most affected by HIV and for the broader field of global health.

The point here, as exemplified by the end of the statement, seems to double down on positioning HIV as part of a larger network of concerns, while also situating the success of the HIV response as key to future “global health.” The IAS, in all their power and glory, is wrestling, like many of us, with the epidemic's meaning and power decades into the crisis, while trying to figure out how to move forward amid the ongoing situation. Key to their concerns seems to be around questions of representation, and how to talk about the plague.

They are not alone, even on the global stage. In 2017, the influential and path-making AIDS research and philanthropy organization American Foundation for AIDS Research (amfAR) released a report that began: “Recent years have seen advocates and researchers forecasting the ‘end of AIDS’ and setting target of an ‘AIDS free generation.’” AmfAR is coming out as being against such language, advising that, “Advocates must guard against declaring that the fight has been won.”

A prime example of what amfAR is talking about comes from the global HIV body, UNAIDS. In 2014, they released their 90-90-90 targets, a trio of stated aims that globally by 2020: 90% of all people living with HIV will know their HIV status; 90% of all people

with a diagnosed HIV infection will be on sustained antiretroviral therapy, and 90% of all people receiving antiretroviral therapy will have viral suppression. Currently, the project is not on target. As of 2018, more than 10% of people living with HIV have not had their status confirmed, and of the people that know they are living with HIV, only 62% were accessing treatment, and 53% were virally suppressed.

So, what does this mean? Should UNAIDS give up? Is IAS and amfAR right to be calling for a recalibration on language? What does this mean for all of us, as concerned and contributing members to the global community, invested in HIV?

For me, as someone who has been working at the intersection of art, AIDS, and culture for over fifteen years in the USA and Canada, both within AIDS service organizations and art organizations, and as a writer, curator, activist, and artist, I am invested in thinking about how liberating it may be for AIDS movements to consider how it is too late, too complicated—and stigmatizing even—to “end AIDS.” As I see it, standing between that goal and the truth are the millions of people living/suffering/thriving with HIV, specifically, the 8.1 million people living with HIV globally who do not know or wish to confirm their positive status. We don't know who the latter group of people are per se, but we can assume they don't take to social marketing, public health messaging, or any other mass media intervention that may bring them closer to the AIDS response or treatment. And we can assume that they are a heterogeneous group that, while not having much in common beyond their positive status, are doing their best, and nonetheless—like everyone else—weighing their best options at a good life, a meaningful death, and some joy in between.

In thinking about this group, who may or may not be big museum-goers, one is invited to consider how the bulk of AIDS cultural production lies far outside what currently will ever appear in most exhibitions about the epidemic. Paintings, videos, photos, performance ephemera, and a smattering of approved activist and AIDS service paraphernalia are what currently serve as the bulk of AIDS representation in most museums and galleries, all of which are nothing compared to the digital and analog detritus of state public health messaging, news reports, fundraising calls, NGO reports, and pharmaceutical advertising that make up the bulk of HIV-related public communication. This feast of work is not only sadly under-exhibited, it is also under-theorized and not meaningfully considered enough since the work of Cathy Cohen, Simon Watney, and Cindy Patton in the 20th century.

These neglected troves of AIDS ephemera, along with the shift in global AIDS discourse, and the 8.1 million HIV-status-refuseniks tell us something when we look at them together. They signal not only that we need a cultural shift when it comes to the epidemic, we are indeed, already are living within one. It is this fact that fuels WHAT WOULD YOU DON'T KNOW ABOUT AIDS COULD FILL A MUSEUM.

Notes

- To read the 2018 executive summary in full, as well as well as related articles in the special issue of *The Lancet*, go to: [https://doi.org/10.1016/S0140-6736\(18\)31070-5](https://doi.org/10.1016/S0140-6736(18)31070-5) (free, but you must register)
- For HIV statistics used in this text, visit UNAIDS: <https://www.unaids.org/en/resources/fact-sheet>
- Other sites for HIV statistics: <https://aidsvu.org/>
- The amfAR report can be read at: <https://www.amfar.org/how-cures-can-fail/>

- Learn more about UNAIDS's 90-90-90 work, here: <https://www.unaids.org/en/resources/909090>
 - Some additional AIDS information resources:
www.thebody.com
www.hivjustice.net
www.gnpplus.net
www.poz.com
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Artist statement from Demian DinéYazhi'

POZ SINCE 1492 (alternate title "The First Infection") is a digital print I created in 2016 that digitally manipulates a painting of the first Thanksgiving "that really situates the AIDS crisis in a larger transnational historical tendency of disease and plague to be the by-product of white colonization [Christopher Columbus reached the New World in 1492]." -Danny Orendorff (curator of *One day this kid will get larger* at De Paul Art Museum). This work was shown in the exhibition, *One day this kid will get larger*, and was written about in the October 2017 issue of *Art in America* by manuel arturo abreu : "The artist, who often addresses the HIV crisis, coined the phrase 'POZ SINCE 1492' to reframe the discussion. His efforts shift attention away from racialized victim-blaming and onto settler colonialism, an ongoing 'infection' that physically and conceptually afflicts Natives and other people of color." See more of Demian's work in the SEEING section of this issue.

Forgetting

A Brief History of HIV: A Conversation Between Two Friends

Abdul-Aliy A. Muhammad and Louie Ortiz-Fonseca

In 2017, Abdul-Aliy A. Muhammad refused to take their HIV medication until Nurit Shein, the Executive Director of the Mazzoni Center, Philadelphia's LGBT clinic, was fired. It was under her tenure, that people living with HIV had been abused by medical staff and let down by the organization as a whole via systemic bias. Muhammad's demonstration was successful. Shein stepped down.

As a co-founder of the Black and Brown Workers Cooperative, Muhammad was already known within East Coast organizing circles, yet merged from the medication strike with even more followers. They used this larger platform to further draw attention to racial, gender, class and sexual based bias, and increase the general public's awareness of the specifics of living with HIV in the present, often with a focus on desire, disclosure and surveillance. Two of their widely read essays are *Desiring Intimacy After an HIV Diagnosis, in a Time More Naked Than Sexy on The Body*, and *Grindr of Gears: An App for the Surveillance State for The Gran Varones*.

Muhammad's writing talents do not end with essays and journalism. Last year, they also released a chapbook of poetry entitled, *A Flower Left to Wilt*. Around this time, they released a series of beautiful and erotic photographs of themselves taken by Ero Rose. While the images were a work of art on their own, they also reinforced a message: Muhammad is a sexy, sensitive, political person living with HIV who will not be ignored.

Similarly, Louie Ortiz-Fonseca is a force to be reckoned with. Long a voice within AIDS activism, the last five years has seen Fonseca focus his vision into a multi-prong project called The Gran Varones that, as the project tag line makes clear, works to amplify "Queer & Trans history and the stories of Latinx & Afro-Latinx Gay | Queer | Trans | Bisexual Men & Bois." This is done a variety of ways, including a network of information-sharing via links on social media platforms, hosting conversations, and Fonseca's own writing about HIV and culture. Within his writing, Fonseca blends a love and knowledge of media, and HIV history that rivals most of his contemporaries, with the deft skill of a culture worker who knows how to use nostalgia, affect, and shared knowledge to cultivate interest and understanding. Some highlights from his writing include *That Time A Sitcom Beautifully Handled HIV Disclosure*, about the under-watched show, *Half and Half*, and his running commentary on the TV series *Pose*.

Related to the connections that Fonseca creates online is the work he does to build community offline. Fonseca recently launched a YouTube show, *Kikis with Louie*, made in partnership with Advocates of Youth, which provides fresh perspectives and information to viewers around sexuality, race, gender and other pillars of contemporary lives. Similarly, Fonseca has started the GV Fellowship, an opportunity for a new generation of activists to learn, be listened to, and make a positive impact. In looking at Fonseca's output, a driving force seems to be ensuring that the work of world-building continues and that the past is not forgotten.

With all of this in mind, it should come as no surprise that Muhammad and Fonseca are friends, and support each other not only in their work but also supporting each other in life. In the conversation below, the pair begin by working through a terrible situation Muhammad went through, as Fonseca first listens, and then provides his own perspective. Together, the two end up discussing what it means to be queer, black, brown, and living with HIV, including, the role disclosure, families, and cultural pressure play in their lives.

While the conversation has historical content, it also dives into contemporary issues, including the HIV prevention medication Truvada known as PrEP (pre-exposure prophylaxis); and the slogan U = U, created by the Prevention Access Campaign, which stands for Undetectable = Untransmittable, a short way of saying if a person living with HIV is on a treatment that reduces their viral load to a medically approved minimal amount, then the virus is no longer transmittable.

To the uninitiate in the world of HIV, the conversation may bring up a lot of questions, but for people long in the life, the conversation offers itself as a salve, a healing contribution to the ongoing global response to HIV that too often is not about the inner lives of people with HIV as this conversation is.

– Theodore (ted) Kerr

Abdul-Aliy A. Muhammad: We live in a world that doesn't know how to show up for HIV positive people, or for black people. I am reminded of it every time I am rejected for my status. Like the first time I disclosed to someone, in the middle of a date and saw their whole body language shift. Their response was "Oh, you know, you're a nice person. Thank you for that. We can be friends." It was painful. It just adds to that constant feeling of being inadequate but also feeling criminalized and policed by my friends.

Louie Ortiz-Fonseca: Right, like you courted disaster.

AAAM: But here is the thing, it shouldn't matter. But as we know. It does. Like that time I got to Chicago for this event, and this person said I could stay with them, and this person was—I will just say it—attractive. We were having a conversation all night on the couch, and I was under the impression that I was supposed to sleep in this person's room, and that they were going to sleep elsewhere. But it became clear at some point that something changed. Next thing I know, the person started disrobing me. It happened so fast. And then we had to have the disclosure conversation later, on the phone, when I was back in Philly. They became irate and started saying because I lied to a black person about my intentions, I was upholding white supremacy. And I am like, how am I a white supremacist because you are AIDSphobic? And it did not stop there. The word rape got used. I got really scared, now the chance of law enforcement getting involved is closer. But also, we had sex consensually.

LOF: Was that the end of it?

AAAM: No. Because then I reached out to a friend for support, they said something like, *no, I can't support you. It was rape, I worked in the domestic violence movement, and I know what consent is.* As a seronegative person to say something like that to me at that point... I mean, I was done...but the world wasn't, because then the social sanctions happened. I was made to feel predatory, dangerous, and criminal. Mediation was brought up, and I was willing. Regardless of how I feel, if this person feels harmed, I am going to listen and be accountable. Meanwhile, they made a social media status about

that night, and because people are so misinformed it comes down to me, as the poz person, left holding all the burden of responsibility, not just for my health, but for the health of the sexual partner and the community. What are your thoughts about that?

LOF: So, first, let's name the obvious. That is a lot to go through. Thanks for sharing that with me. Second, I am going to respond, but let me get there. Okay?

AAAM: Of course.

LOF: Okay, so whenever there is some HIV news breakthrough or AIDS-related headline, I am almost always upset by how supposed AIDS-aware people react. I see in their reposting and comments that they still frame HIV as a one-sided thing. And you know what, it is so often people with access to advanced social justice language who frame their misinformation and judgments as intersectionality. HIV exposes the limit to so many people's analysis around race, class, gender.

AAAM: People have it on their minds that we are predators who don't need or get to have intimacy, and that HIV is something we invited in just by living our life. Like, before we are human, we are a walking vector, a risk to public safety, and yet hardly any of these social justice warriors are stopping to question who is this public they are speaking of? I remember working at Mazzoni, Philadelphia's LGBT health center, and a lot of people working in the testing program would say things about people who didn't disclose to their sexual partners, and it became clear to me that the staff did not understand the very real fears of rejection and retribution facing people living with HIV, regardless of how non-transmittable the virus is. The staff just failed to see people with HIV as fully human, and so how incredibly strange it is to have to disclose anything to a stranger or a loved one, let alone something like HIV. I am not trying to go medical before we hook up.

LOF: I remember in the late nineties when a friend of mine who seroconverted came to me to tell me that he wanted to get tested for an STI. This was years before I found out my own status, and in my head I thought, bitch, you didn't learn. I, like so many other people, thought that HIV was a lesson that you had to learn. You know what I mean?

AAAM: I feel like it comes down to it, people feel that HIV is something you have to make amends for, or, maybe, it is proof that you need to make amends for something, a sign you have harmed yourself and everyone around you.

LOF: I compare it to recovery, as there's no room for slipping. Once you name your status (be it poz, sober, or both), you have to be inspirational. That is how you make amends. And I think as queer men we just accept this, like, we just accept that once we disclose it is supposed to be our life's mission to END AIDS, with no real consideration what it means to END it, and what an END means for the living. I feel this especially for black and brown folks. We are supposed to just be working for redemption in order to find love after great failure.

AAAM: Right! Like you are supposed to be handing out condoms and lube—ALL THE TIME! It is such a fucked up feeling. Immediately after testing positive, my first two thoughts were: I need to see a doctor, and I need to give back to the community. Like, why the fuck was I socialized to think that way? Any other person when trauma happens to them are given space, provided a chance to step back and begin to recover.



Louie Ortiz-Fonseca, 2018. Courtesy of the artist.

LOF: But not black and brown people with HIV. Nope, we have to volunteer, share our story, be of service to the AIDS service organizations. And this way of being works for a while because you make a community, but there is a limit to how much service I can do after the shock of diagnosis is over. The fatigue kicks in.

But listen, I also need to say this: disclosure matters. And I am talking about how we reflect and show up for each other. Over the years, I have seen how when you know more people living with HIV, it changes your relationship to the epidemic. Think about it, less people get dragged on social media for a positive status now than they did ten years ago. Disclosure is not a perfect arrangement, because it still puts the responsibility of ending stigma and the virus on us, but there is some power in seeing others and not feeling alone.

AAAM: Yes, and within that work we all have different ways of making it happen. Like, for example, there are some people who really take on the HIV STOPS WITH ME rhetoric, or the people living with HIV who are really into being on the PrEP squad or talking about U = U all the time.

LOF: True, true, which brings up something I want to talk about: maybe a sign of progress is that HIV-positive folks can be problematic now, too. You know what I mean? I see so many people with the virus who cultivate, what I call, a third status, which is, they are positive but feel the need to declare as much as they can that they are undetectable. They think it makes them attractive.

AAAM: That's interesting, the idea of the third status. Like, a 21st-century way of creating a division between the "good people" with HIV, and "the bad," creating a divide among the already oppressed, without taking into consideration health access and the difference in people's ability to take and respond to treatment. But, I mean, now that



Ero Rose, *Abdul-Aliy A Muhammad*, 2018. Courtesy of the artist.

you mention it, we see this kind of division happening when it comes to HIV criminalization laws. Some folks are trying to modernize the laws so they reflect the U = U science, so instead of criminalizing all people with HIV it just criminalizes people who are not undetectable, and to me that is bad. We don't need the laws modernized, we need them abolished.

But wait, can we switch gears? I have a question for you that I will preface a bit. So, as you remember, in 2017, I refused to take my meds until Mazzoni Center CEO/ Executive Director Nurit Shein stepped down after years of allowing abuse of people happen under her watch. And #humble brag, it worked, and I resumed my medication. What I have realized since then, is that it was that activism that put my positive HIV status on people's radar. And then I started to get a lot of hits and messages on social media, much of it intense. You, of course, are the founder of Gran Varones, a cross platform and network that amplifies trans and queer pop culture history and the stories of latinx and afro-latinx gay|queer|trans|bisexual men and bois, and so I am wondering that since in the work you are also public about your status, what are some of the weirdest questions you have gotten about HIV?

LOF: I have gotten random and misinformed questions, but never downright malicious comments or anything. The thing that happened to me was, my status was disclosed in a tweet, by me. I was still trying to figure out what Twitter was, and I put my status in the last tweet of a thread assuming it would be buried. I didn't know that the tweet alone could be retweeted.

AAAM: But you had shared your status before, right?

LOF: Yes, but because people read the way they do, it was glanced over. And I was okay with that, because what I had not told my family.

AAAM: Because you were afraid?

LOF: No, I just didn't want to be a burden, I didn't know how to be that vulnerable. Of course, once my family found out, they were supportive, as much as they could. I was worrying about nothing, but not really, because you never know.

AAAM: I had the same experience. I didn't want to tell my mother. The first person I told was my younger sister, Badriyah. We were watching BET, and something came up about HIV. My body got hot. I knew this was an opportunity, so I was like, Badriyah, I have to tell you something: I am HIV positive. I think she cried. We had a moment. And then I told her that I didn't want her to tell my mother because my mother was dealing with cancer at the time and, as you know, later passed from it. So, I had similar thoughts about being a burden, in part because since I was a gay teen, people always told me to be careful, referring to the streets in general, but a lot of warning from older people about HIV.

LOF: Oh, I can relate. When I was in the hospital with pneumonia, in the ICU, my mom called me out of the blue. She didn't know I was in the hospital. She said, God told me to call you. What's going on down there? And let me tell you, I was too weak to walk but not too weak to keep up a facade. I wanted to protect her, and I didn't want her rushing up from Florida to see me. That, for me, would have confirmed that I was dying soon, and I was not ready. But eventually I did tell my aunt Janet. She was like my best friend, and she was dealing with cancer. I was in DC, and she had just found out she was stage four. She was not okay, and so I said, Janet, I'm gonna tell you something, and I need you not to cry. I'm only telling you because a lot of what you're feeling I have felt, too... I just wanted to make the world less shitty for her. We navigated her being sick and me disclosing. And I'm glad that I told her because she is really important to me, and she is someone connected to my mother. So, I didn't tell her as a form of burden, but to share.

AAAM: You have a beautiful way of telling stories, like all the ones about your brother.

LOF: I think you relate to those stories because your relationship with your brother is very similar to mine with Nicholas, one filled with frustration, resentment, but an awareness growing up that we are all we had. So, maybe you understand how telling stories about him has been about letting him off the hook. I know that he didn't create all the systems that have impacted him. You know what I mean? Like, for years I blamed him and my mother. I would see Nicholas making decisions that I wouldn't have made, and I almost let it get me depressed. Like, sometimes I was literally killing myself over the fact I couldn't change him, or anyone. I had to learn that you can love someone, but you can't make decisions for them. And your frustration about what they're doing does nothing to shift how they move in the world. It just makes you more embittered. Which is hard because there was a lot of projection going on at the time. I was making decisions I wanted him to be making. But here is the thing, in the end, we ended up in the same place, we are both living with HIV, making our lives work. So, it is confusing. I thought by making different choices, I could avoid everything I wanted me and my brother to be saved from. But it didn't work. And you know why, because I was still doing all the same shit he and everyone else was doing, but I was doing it in secret.

AAAM: I hear you, and it makes sense to me.

LOF: And looking back, I get it. I understand why I had these narratives of about my brother, and about me, and these ideas about how we were going to beat the odds or whatever. It was due to the bad ways we are taught history. We get all these stories about great people, but no context, no web of relationships, no nuance. And so I thought we could control our fates through individual choices. But that is not how it works. Our lives are interconnected. You know what I mean?

AAAM: Yes, I do, and this kind of big picture to look at things that I am talking about. With your social media presence, and Gran Varones, you provide the fuller picture when you are talking about your family, or HIV history, or even when you talk about celebrities (people forget that pop culture matters, that it provides context.). You provide a place for me to feel myself, and to see myself reflected back at me.

LOF: Thank you for saying that, and you are naming something vital to me. Like, I love the work of Joseph Beam and Essex Hemphill, and I love hearing their stories, and telling their stories as interconnected. I love the way they exist as history together, it is amazing, and I love that they were friends and were creative together. It is a good reminder, people have friends, and witnesses, and lovers.

AAAM: Yah, I cannot get behind that historical trend of isolating people. Like, we know Bayard Rustin was not alone being gay in those streets, or James Baldwin. And we know that even when people do isolate parts of themselves to protect their loved ones, their loved ones are part of the story. I am thinking about all the House Ball mothers who dealt with HIV in silence because they didn't want to be out about their status, fearing their children, who were also poz, would leave. These mothers, even in their silence, were in community.

LOF: I mean, this brings me back to thinking about my mother, and I just have to say, it's not that I was protecting her, I don't think I sat down and said, let me not tell my mother about my HIV status because I want to protect her. It was more like breathing; I was socialized not to be a problem, and rather, to be of service. The message growing up was: if we are needed in the world, then the world won't take us out so quickly. I think that is a story within the existence of blackness. Like we need to be more special than the next person. You know what I mean? It's always like, let me do this, because if I die now without doing that thing for you, what makes me different from any other motherfucker that died on the block?

AAAM: Ooh, wow. I want to talk about that. Did you ever read *The Calendar of Loss: Race, Sexuality, and Mourning in the Early Era of AIDS* by Dagmawi Woubshet? There is a great quote from the book:

The recurrent practice of enumerating the dead in mass in social media seems to conform to the logics of accumulation that structure racial capitalism, in which the quantified abstraction of black and trans deaths reveals the calculated value of black and trans lives through states' grammar of deficit and debt.

For me, what Woubshet is saying, is that the counting of the dead, if we are not careful, can fall in line with capitalism. Like, in capitalism we need numbers to track, count, and validate. And so, his example of trans women is powerful because the media right now only reports about their lives in terms of compounded loss. It gets to a point where the reporting does not seem like it is about bringing humanity to the women, or casting light on what we could be doing to save lives, but instead each report seems to

validate the last one, as if accumulation is justification. But for me, I am like, should we only care because there was a high loss of people? As if one death isn't enough.

I think this can be similar to concerns around self-worth. We get trapped into thinking we need to matter in order to be cared for, and let's be honest, the bar to mattering is unstable and ruled by market forces. How do we know when we matter? Is there is a number? Like, today was the 34th anniversary of the MOVE bombing. And I was just thinking, do I need the number 34 to remember that black radicals are targets? Do I need enough people on Facebook to share a story about MOVE in order to be reminded? People can write eloquently about what happened, but is it real for them? Because for me, that moment in time is my life right now, and I can't chart that, or quantify for anyone to understand.

LOF: Right, like does HIV only matter because millions of people have died with the virus? Or—going back to HIV-positive influencers—do we only pay attention because they have a blue mark by their name? All of this makes me think about the ACT UP days, and how they were fighting against the pharmaceutical companies and then pharmaceutical companies said, “okay, well help us—join our team.” And some people did, and that caused fracturing within the movement. Now some folks were co-opted; they were on the side of pharmaceutical companies feeling important because they were being flown to talk about how their activism got pharmaceutical companies to lower their prices. Meanwhile, other people were not included in that conversation, in part, because they didn't have a story to market, or they didn't want to curate a narrative for consumption. And these same dynamics are alive today. I see it online, the race to be the AIDS poster child. And I'm like, okay, if that is your brand.

AAAM: I was part of a social media fellowship, and it was really shocking to me how people were being pushed into becoming sponsored activists. It should not have been surprising since I worked in the nonprofit world of Philly, but it was strange to see how people were hoping for Gilead to sponsor them.

LOF: I get it. But I have no patience when a sponsored activist comes for me, my work, or someone I care about.

AAAM: Agreed. Let's do one more swerve and then we have to wrap this up.

LOF: Okay.

AAAM: So, here is the thing, we are two people who have gone through a lot, and try to give a lot. We have figured out that we can be of service not because we have to be, but because we can and we want to be, and we can do it on our own terms, in ways that are for us and by us.

LOF: Yes. And I think we understand that all of this work within the field of HIV response is more than just meds. Like, we have not even really spoken about medication, I think because we both come from this place where we understand we need to have access to healthcare that involves choice and getting what we need before we lose more t-cells.

AAAM: We need healthcare so I am not just waiting until I find myself in the emergency room, because now I am not thinking about money because I am almost dying.

LOF: And I think for us, we are interested in where does that healthcare start? I see the work you do, and I think for you maybe it starts in the street...

AAAM: I mean, it starts where people are. So, yah, the street, if that is what is needed. But also in the home, and online. I think most of my work, or the times I am most happy being of service is when I am just talking to people, and we are showing up for each other. Sometimes that is connecting people to services, or organizing a demo, or writing an article, but honestly, sometimes it is just this: talking about everything.

LOF: My work is also where people can access it. I think meeting in person is great, but also social media is big for me.

AAAM: Online is important.

LOF: We work through so much within digital spaces when we can really show up for each other, and share information we might not get.

AAAM: Okay, now you are starting a whole new conversation about access, geography, and so much more, BUT WE HAVE TO GO TO BED!

LOF: Ok. I love you very much.

AAAM: And I love you. But one last thing, did you see Paula Abdul almost slice that woman's head off with a fedora during that dance number?

LOF: That is how you enter a room!

AAAM: And how to wrap up a conversation.

Louie A. Ortiz-Fonseca is an HIV Positive Queer AfroBoricua award-winning HIV activist and artist. For over twenty years, he has worked with influential, nationally recognized agencies and has been an integral part of HIV prevention and youth development programming in Philadelphia. He is the Director of LGBTQ Health & Rights at Advocates for Youth, where he works in partnership with young people living with HIV to combat stigma, and hosts a YouTube series for LGBTQ youth, *Kikis with Louie*. Outside of the organization, Louie is the creator of *The Gran Varones*, a digital storytelling project that amplifies queer history and is a Ford Public Voices Fellow.

Abdul-Aliy A. Muhammad is a black queer HIV+ non-binary jawn from Philadelphia, PA. They're a cofounder of the Black and Brown Workers Cooperative, which focuses on workers' rights and racial justice using an intersectional framework. Recently they released a poetry project, *A Flower Left To Wilt*, a work interested in intimacy, Blackness, bodily autonomy, and HIV. When they're not organizing, they write for various outlets about state surveillance, impacts of displacement, and institutional white supremacy.

Waniyetu Wowapi and HIV/AIDS

Sheldon Raymore

– Reprint

In the Lakota-Sioux language, the words "Waniyetu Wowapi" translate to "Winter Count." As a form of communication, Winter Counts mark notable occurrences amongst the Sioux people as a timeline of significant events. Grouped together, the images create a Winter Count catalogue that features the traditionally etched, painted, and/or drawn images on deer, elk, antelope or buffalo hides (later on muslin fabric) that serve as what some people may call a traditional history book. Winter Count is a way of preserving information for generations to come that is being revised and reclaimed.

Working within a community of people impacted by HIV/AIDS, artist Sheldon Raymore has created a Winter Count to preserve the story of HIV/AIDS for Native Americans on Turtle Island. The moments are part of a large buffalo hide that Raymore has shown on many occasions, including at the recent 2 Spirits & HIV Conference for World Pride 2019.

Below is a selection of notable occurrences within the story of HIV gathered by Raymore. For a look at the project and the full listing of notable occurrences, please visit: prepahhon-toz.com/winter-counts.

– Theodore (ted) Kerr

1978 - FIRST SYMPTOMS AND THE SPIRIT MEDICINE COME BACK WINTER

- People begin showing signs of what will later be called HIV/AIDS.
- The American Indian Religious Freedom Act was passed, protecting the spiritual practices of Native Americans.

1986 - WINTER OF SHAME

- Willie Bettelyoun, from South Dakota is diagnosed as HIV positive. He was harassed and discriminated against in his workplace, the tribal offices of the Rosebud Sioux Tribe.
- Published report on AIDS urges sex education as a means of HIV Prevention.

1989 - WEEWAH AND BARCHEEAMPE WINTER

- WeWah and BarCheeAmpe are founded in NYC, bringing together Native queer people to challenge settler colonialism and defend Native peoples within pan-tribal alliances. The group drew non-Native queers of color into antiracist queer alliances committed to Native decolonization. Their work showed that queer politics of race, culture, or citizenship will fail to explain their condition unless they theorize settler colonialism, as Native activists did by challenging liberal multiculturalism as a method for naturalizing settlement. WeWah and BarCheeAmpe are also active in AIDS activism in the United States and Canada.
- FDA authorized pre-approval of Retrovir for the treatment of pediatric HIV disease.
- After 2 years of intense ACT UP over the price of AZT - Burroughs Wellcome lowers the price by 20%.

1990 - RED CROSS WINTER

- At the 3rd International Native GLBT Gathering in Winnipeg, Canada, the Two-Spirit identity was defined. Toronto organizers quickly adapted Two-Spirit identity by renaming themselves Two-Spirited People of the First Nations (later, Two-Spirits) and also committing themselves to serve Native people affected by HIV/AIDS.
- Keith Haring, renowned artist and activist, dies.
- Ryan White, teenager and AIDS activist, dies at 19. A True Hero whose legacy lives on.
- Congress enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act – the largest federal government program to address the unmet health needs of People Living with HIV.

1997 - WINTER OF FIRST VICTORY

- New HIV Drugs are Working!, CDC reports annual AIDS death dropped in the U.S.
- "It was a lot easier to prepare for death, now I have to think about living," said a person living with HIV.

2013 - BLUE PILL WINTER

- American Indian House (AICH) hires a new community educator who presented the first ever PrEP and Pep presentation at the AICH.

- HIV was passed to the Mississippi baby from her mother during pregnancy. The child was treated with intense antiretroviral therapy within 30 hours of birth. After missing regular treatments, which would normally result in high levels of the HIV virus being detected in the body, tests show that the virus remains undetectable in the girl. This raises hopes of a functional cure for HIV. However, in 2014, HIV is once again detected—sadly, the girl's remission has ended.
- 25th Annual International Two Spirit Gathering is hosted by Northeast Two-Spirit Society in Camp Dewolf, Long Island, NY.

2017 - TAKE THE PILL WINTER

- A new approach to HIV/AIDS Prevention is created by PrEPahHontoz, a Lakota Two-Spirit through her multimedia art. She will use performance art by combining Native American sign language, projections, and vogue dancing as a way of educating the public about pre-exposure prophylaxis. Blue wooden PrEP pills adorn her dress as she belts it with bottles of Truvada.
- HIV organizations around the world endorse the "Undetectable = Untransmittable" slogan launched by the Prevention Access Campaign.

Sheldon Raymore is a member of the Cheyenne River Sioux Tribe and lives in New York City. Since 2014, his mission has been to increase HIV/AIDS awareness, sexual health education, and accessibility of PrEP services for the Two-Spirit community and beyond. He is the creator of www.PrEPahHontoz.com which provides an enriching awareness experience, with culturally competent and appropriate methods of increasing PrEP awareness. The PrEPahHontoz Tipi project decreases social and cultural stigma's associated with HIV/AIDS, and HIV Prevention. It also disseminates accurate information about HIV and its history in the Native American community, while utilizing "culture as prevention." He's currently the Deputy Director and HIV Project Director for the American Indian Community House. He also serves on a Native American "Ending the Epidemic" Advisory Group with the AIDS Institute of New York State and serves on NMAC's Native Constituent Advisory Panel (CAP).

Luckiest Guy

Michael McFadden
– *Artist Project*



Michael McFadden, *Luckiest Guy*, 2019. Courtesy of the artist.

I can't think of the year 1996 without welling up. It's a clear line that marks before and after. For more than a decade, a plague ravaged through communities with little reprieve. But for those able to endure, 1996 presented what seemed to be magic. Protease inhibitors became more widely available, and in turn, people reemerged from their deathbeds. Hospices, once overrun and consumed with mortality, needed to quickly shift into transitional living facilities. For the first time in a long time, there was a glimmer of hope. Yes, HIV continued to devastate. Antiretrovirals maintained toxic side effects. People of color and impoverished communities continued to bear a disproportionate burden. But for a moment, a brief moment, there was a possibility to exhale.

The last display of the entire AIDS Memorial Quilt was in October of 1996. The Quilt covered the entire National Mall in Washington, D.C. By chance, I was in town the same weekend. I was overcome wandering between the narrow pathways of fabric adorned with personal artifacts: sequins and rhinestones, t-shirts and leather vests, teddy bears and tiaras; remnants punctuating the inadequacy of objects left behind to truly capture the complexity of a lost loved one. Crafting and stitching became a method in which to process grief. Tens of thousands of 3 feet by 5 feet panels, the approximate size of an average grave, underscored the incomprehensible personal and communal loss. The Quilt is now too large to be shown in a singular location: the expansive shroud both recording suffering while honoring life, no longer able to be fully expressed.

After I graduated college, I moved to DC and worked at a non-profit organization that delivered meals to individuals living with HIV. The walls of the office were lined with photos of clients who had passed away from the disease. Our large conference room was a war memorial to unarmed men. I'd often go in to sit alone, gazing at the beautiful portraits, the strikingly handsome faces staring back at me. So many lost. Intrinsicly I knew, had I been a few years older or come out a few years younger, I would have been among the departed hanging on the wall.

Like 1996, the approval of PrEP in 2012 signaled yet another historical line of demarcation in the epidemic. This singular, daily pill presents the option to preemptively ward off contracting the virus. While far more complex than misleading analogies to vaccines and birth control, it does provide some with a sense of

proactive safety, a means of reducing anxiety, an instrument to empower.

For me, PrEP allows me to fuck and to be fucked without death as my threesome. It provides me the ability to play and explore and connect, to give and receive pleasure that has not seemed possible for the entirety of my life. It has allowed for a regression to the sex of the '70s, but with all of the awareness of the trauma that was to come.

For the past two years, I have been working towards my Master's in Fine Art at the International Center of Photography-Bard program in New York City; I knew I wanted to create an art piece for my thesis exhibition that addressed the inherent complexities of both 1996 and 2012. I wrestled in my head with how these two dates could converse with each other and commune with the viewer. I sat for hours doodling on bar napkins, somehow always winding up with tears streaming down my cheeks.

*Can I get you another glass of wine?
– No thank you, I'm all set. But can I have a few
more napkins?*

Sketches in my journal marked the evolution of my ideas: shapes of possible light bulbs, notes from phone calls with fabricators, explorations into cheaper alternatives like neon or sequins. But two things remained consistent throughout: the acerbic date of 1996 and the seductive, hypnotic hue of Truvada blue.

As the opening to my solo show encroached, I had no viable options in front of me to bring into reality the vision I had in my head. The hours spent weaving through crowded storefronts on Canal Street researching metal casings and non-flammable synthetics seemed for naught; my ill-equipped attempts at verbal illustration further confused by flailing hand gestures to shop workers brought me no closer to resolution.

After one particularly defeating day of investigation with a plastics laser cutter, I retreated to a nearby coffee shop to escape the cold. I resigned myself that this 3-D incarnation of my sketched creation was not feasible, at least not in time for my show. I thawed myself and scrolled through Google fonts on my laptop, one last effort at denying the inevitable. Several pages deep into the typographical catalog, the font I'd been envisioning, doodling, confronted me. Its name: The Luckiest Guy.

And with that, resolution was near. Within days, I ensured this essential piece of my show was crafted. This far-flung notion manifested before me: an enchanted golden box, both emanating anguish and bewitching allure, commanding us to participate through our reflection, our likeness, our gaze.

I recently dined with a group of friends, gay men a few years my senior, a generation heavily hit by the AIDS crisis. Over a shared meal, our spirited conversation interwove life lessons, modern politics, and ribbing humor with panged stories of lovers and dear friends no longer with us. One gentleman, once given '6 months to live' when diagnosed at age twenty, contrasted the side effects of his current meds to poisonous sensations he experienced when on AZT. Another shared how aging has stirred up feelings of being sexually invisible; feeling of expiration, further complicated by a palpable survivor's guilt. Our coming together was bittersweet: there was deep gratitude for the opportunity to commune, mixed with the gutting recognition of those who could not. The present punctuated by the past.

Michael McFadden (Chicago, IL) explores and celebrates sexual freedom as a form of resistance to multilayered stigma and trauma, both historical and ongoing. He worked within community health centers and social services for over fifteen years, focusing primarily on LGBTQ health and the provision of HIV/AIDS services. He brings this process and awareness into his art practice. Michael received his BA and MSW from Loyola University Chicago and is a recent graduate of the ICP-Bard MFA program.
www.michaelmcfaddenphotography.com

The Lost and The Found

Rahne Alexander

"Sometimes you have to create your own history."

- *The Watermelon Woman* (Cheryl Dunye, 1997)

Louis Hughes looks spectacular on the Senator Theater stage, wearing a brilliant white dashiki. It's '80s night at the Stoop Storytelling series, and Louis stands in front of a packed theater in Baltimore to tell a part of his story—specifically his perspective on living through the rise of HIV, his participation in the Multicenter AIDS Cohort Study, the groundbreaking longitudinal gay men's health study at Hopkins (which is still ongoing), and his perspective on building organizations supporting gay and black populations in Baltimore for more than forty years.

I'm in the audience to cheer him on. I nominated him as a speaker to the Stoop Storytelling organizers, and they welcomed him eagerly. I'd been lucky to meet Louis a few years earlier, as I was beginning to assemble an installation at the Baltimore Museum of Art which was focused on the domestic sphere of the Baltimore LGBT community. It's thrilling to see him welcomed with thunderous applause. I remember how things used to be.



Louis Hughes, sitting on a larger-than-life bed, as part of *Queer Interiors*, at the Baltimore Museum of Art, conceived and produced by Rahne Alexander and Jaimes Mayhew, courtesy of the artist.

The dim lighting in the theater makes it a little hard for me to get a decent image of Louis on stage with my phone, but I take a few snaps anyway, posting the best to Instagram.

It's intermission, and Louis is being lauded. There's a nurse who just retired after devoting thirty years of her career to caring for patients with HIV. She expresses apprehension about leaving her job: "The doctors and the nurses who are coming in now, they have no idea what it was like. They have no sense of the history." She's going to continue to offer her advisory services for time, she says. "When I go, there's going to be no one left who has this knowledge. The institutional memory is gone. I don't know if you're old enough to remember," she says. "I worry about what the loss of this memory will mean."

"Oh, I remember," I said.

I'm not sure when, exactly, I "came of age," but I started college in the late 1980s, starting to come out as queer and trans as Ronald Reagan was finally getting around to acknowledging that AIDS was a public health crisis. I had every reason to believe that I wasn't going to live very long. The sex panic of the '80s seemed to target me directly as I began to come to understand what it meant to be a queer trans woman. Femininity was brutally punished in people like me, and the atmosphere of blunt hatred and cruel humor that permeated the common discourse around HIV and homosexuality was inescapable.

Coming out of the closet is always hard, especially when, as was true for me, the family religion had little compassion for gay people. At the time, there was no common discourse around transsexuality or transgenderism. My secret felt monolithic, unscalable. The idea of connecting sexually with anyone seemed impossible, and I internalized the cultural message that I wasn't worthy of love and intimacy. I barely had the language to explain myself to myself, much less to help someone understand how to navigate my body. I kept to myself, the easiest way to minimize my considerable risk.

I'd been shocked awake in my first year of college, raising my consciousness via feminism and an interdisciplinary class on HIV and the history of plagues, taught by an epidemiologist who was working directly with the virus. Our copies of *And the Band Played On* were hot off the press. *My Beautiful Laundrette* offered me my first images of gay intimacy. I couldn't believe my eyes: living, breathing gayness was finally visible. It was riveting, even though it was so far removed from my context.

In short order, we were given *The Boys in the Band*, contextualized as a complicated historical document. "This is what it was like before the closet doors were blown open," my professor advocated. I surely wasn't the only student in the theater still sequestered in her own closet that night, but still the film seemed like ancient history. And then came *Parting Glances*, which was shocking for its depictions of gay men in community, and particularly of men with HIV. The film's lack of despair and hopelessness still stands out, thirty years on. Its humanity was invigorating, catalyzing. I came out of the class measurably less fearful of the disease, and of what I was up against in the culture.

My first overt political action was to participate in a reading of the names on the steps of the college chapel on World AIDS Day 1988. As I read the names, I wondered so much about these people—who they were, who they wanted to be. I wondered how long it would be until I might be reading the names of people I knew, how long it might be until someone was reading my name.

But reading those names catalyzed me into coming out, to connecting with a small handful of other queers on campus bold enough to come out, making ourselves visible and vulnerable. Faceless cowards vandalized our event flyers, then our vehicles, then our dorm rooms. Some of us were followed by cars on campus. A professor had a cross burned on her lawn. We started organizing, creating "The Coalition to End Homophobia." We got t-shirts emblazoned with big pink triangles on the front. On the back, the shirts read, "Sometimes It Pays To Be Indiscreet." It was terrifying, but we weren't backing down.

The administration wasn't much help. We were told by a dean we were the first gay students to attend their century-old college. How is an institution supposed to remember something it never knew in the first place?

Years later, the name-reading rituals continue, but now we are reading the names of mass shooting victims, and we are reading the names of murdered trans people, a list overwhelmingly comprised of trans women of color. HIV remains at crisis levels in the community, but the more urgent concern is murder. So much unnecessary death, so much preventable violence against the vulnerable. In this way, it feels like nothing has changed, and in fact, the brutality of the current moment feels like a cultural regression has occurred.

As the '90s rolled on and HIV treatments became more effective, the focus shifted and I found myself programming a wider variety of queer community events: vigils and legislative responses. I was becoming an *activist*.

The New Queer Cinema revolution of the '90s finally put gay actors in gay roles and increasingly placed tools of production in queer hands, but not before the disease had claimed so many artists: Marlon Riggs, Derek Jarman, Jack Smith. David Wojnarowicz. Arthur Russell. Jobriath. Freddie Mercury. I think a lot about how AIDS ravaged an entire generation of artists, limiting access to crucial memory and leaving a lot of us without mentors and guides. The loss of historical perspective is always worrisome in any circumstance, but queer communities seem especially vulnerable to ahistoricity.

I tried to interpolate myself into the furious films of Todd Haynes and Gregg Araki. The California punk rock aesthetic of *The Living End* appealed to me, but its nihilism and its lack of focus on women left me cold. *Poison* terrified me: I saw myself only in the 'Horror' chapter as I fretted about my future navigating medical transition. The films addressing trans and lesbian characters were period pieces, or tragedies, or both: *Entre Nous*, *Desert Hearts*, *The World According to Garp*. I don't know exactly what sort of representation I was looking for in those days, but I wasn't finding it.

Then came *The Watermelon Woman*. Cheryl Dunye's debut feature didn't play my town in its initial run, so I wound up creating and programming a screening series so that I could see it.

The Watermelon Woman is a mock documentary starring Dunye as a filmmaker exploring the hidden lesbian history of a black entertainer and early Hollywood actor. Even now, the microbudget feature is incredibly convincing, making me believe that the invented title character is drawn from history, until the end intertitle that bursts the bubble: "Sometimes you have to create your own history. *The Watermelon Woman* is fiction."

We who live with suppressed stories (including those of us living with *immunosuppressed* stories) know this how this works. We have to dig to find our role models and icons to find hope. We read between the lines to find our stories until, of course, we are well-versed enough to lay it all out on the page.

It's 2016, and I'm installing some of Louis' personal artifacts in an installation at the Baltimore Museum of Art. The exhibit is an investigation into the mundane, ordinary, domestic aspects of what it is to be LGBTQIA in the city of Baltimore. Part of the exhibit is a "video quilt," an evolving, crowd-sourced community portrait. Any and all LGBTQIA Baltimoreans are invited to submit their photos and home videos to populate the quilt. The images are projected in a grid on a hanging quilt.

"Do you think you have any video?" I ask, and Louis shakes his head. "No, I never had anything like that." He tells me that downsizing over the years has left him with fewer and fewer things; everything he has left is imbued with meaning. A lot of what he has left is going on display in the museum.

Louis provides me all of what he has: photo albums of his family stretching back to the mid-19th century, just after slavery had been abolished. His yearbooks, in which he is pictured alongside his classmates depicted in *Hidden Figures*. Louis is a co-founder of Baltimore's gay community center and of Chase Brexton, the gay-focused health clinic that became a key resource for HIV treatment in Baltimore.



Louis Hughes ephemera, part of *Queer Interiors* at the Baltimore Museum of Art, conceived and produced by Rahne Alexander and Jaimes Mayhew, courtesy of the artist.

I've begged the community for images stretching back as far they can find. I get a tiny handful of still snapshots from the '70s and '80s. I get a banker box of photo albums from one longtime lesbian community organizer. I get to delve into the archives of the community center, finding hosts of images untraceable to their subjects and photographers for permission.

The question of what happens to our personal archives looms. A lot of us have grown up distrustful of institutions. A lot of us came up distrustful of each other in our communities. Where do our archives go when we pass? Who then gets to interpret our stories?

I lay out the images in the grid. Cell phone video of a gay man playing with his toddler nephew, and of a friend finishing his David Wojnarowicz tattoo. From the '80s or '90s, camcorder footage of a trans woman playing catch on a beach; meanwhile two trans men from this year make crème brûlée. But most of the images are still static: Lesbian Avengers pose to intimidate. Another dyke leans laughing out of a U-Haul. A gay marriage is performed on a Baltimore city corner. A queer couple and their children have a holiday dinner. This shapes up to be a collection of images of queer life as I've always seen it, and it becomes clear that I'm not alone in this.

"I felt seen in a way I rarely do," wrote Kate Drabinski in the Baltimore *City Paper* in a review of the exhibition. "This is a much bigger quilt than what you're seeing, that the scenes are many, and each one is just a snapshot of a life that has its own twisting array of scenes. For a group of people often denied their complex personhood, reduced to simply 'being' their sexuality, this is a big deal."

One of my contributors submits some of his '80s candid stills, showing himself in loving contact with another man. They have similar mustaches and coy smiles. I ask the contributor, who seems single, to sign a release to use the images. He signs, and a few days later he responds to tell me that he's been in touch with his ex, who has also signed a release, and this is when I realize that I had begun to construct an assumption that because he was no longer in the picture, and because the images were so loving, that perhaps he had passed, perhaps from HIV. This story I told myself was based in a reasonable assumption, but it was a warning that even with pure intentions, my assumptions and biases exist, and they can still deeply undercut the stories I hope to tell.

Back in my undergraduate quagmire, a semester after our Coalition was told that we were literally the pioneers of gay identity at the school, a gay alum came to campus to talk about his own battles with HIV. He'd graduated twenty years earlier, a classmate of the very administrator that had flattered us so. We pioneers watched her closely throughout the event, while she did everything she could to maintain her tenuous control over her domain without conceding her recalcitrant homophobia.

When it was over, we retreated to the office we shared with the Womens' Center, MEChA, and the Black Student Union. We plotted our next events. We already knew we weren't the first lesbians and gays to attend the school. We had evidence! Our office had a shelf full of photo albums from the past. The names and the narratives behind the fading stills weren't readily available. We were left to make up our own stories from these images, to imagine what it had to have been like then if it was still so hard to be heard.

This institution, which we all paid for, was incapable of telling its truth, because it didn't know its truth. Its forgetting and its deliberate disposals conspired to slow progress. We learned that lesson the hard way, and it would be far from the last time that institutional failures would floor me.

My favorite of Louis' stories is his coming-out story, in which he comes out to his mother in 1974. Soon after, she introduces her son to the performer Sylvester, who would become an iconic disco star just a few years later. I can't do the story justice; it's Louis' to tell.

I have rarely met a person so consistently gentle and warm as Louis Hughes; he can talk to anyone, and so as the BMA exhibit rolled towards closure, we set aside an afternoon open house for Louis to present his archives and tell his stories. The turnout was modest, but he wasn't dissuaded, sharing his stories with every patron who would listen. In many ways, I think this is the best sort of community activism. Of course, I wished for a larger attendance. In a just world, Louis would fill theaters every time he speaks—but then again, in a just world, Louis may not have nearly as many stories of struggle to share.

It's Oscar season, winter 2017, and Louis sends me a text: "*Moonlight* won the Oscar. I'm so happy." I can only imagine what it's like for him to see this happen in his lifetime. "It's about time," I write back.

"Call your old friend sometime," Louis writes back, and now it's up to me to respond. And I do, when I can. It's up to me to maintain the connection and carry his legacy forward.

Rahne Alexander is a multimedia artist, producer, musician, and performer. Her video art has been screened in galleries and festivals across the country, and she is an alumna of Signal Culture and the Experimental Television Center. *Queer Interiors*, a year-long collaborative multimedia installation was commissioned by the Baltimore Museum of Art in 2016. A component of this installation, *The Baltimore LGBTQI+ Home Movie Quilt*, was awarded a Saul Zaentz Innovation in Film and Media Fund fellowship. She has appeared in numerous films and videos, including *Hit and Stay*, *Riot Acts: Flaunting Gender Deviance in Music Performance*, *Milo's Misfits*, and *Her Room*. Rahne performs and records with several bands, including *Santa Librada*, *Guided By Wire*, *50'♀*, *Flaming Creatures*, and *the Degenerettes*. She is occasional comedian and essayist, with publication credits ranging from the *Baltimore City Paper* to the Lambda Literary Award-winning anthology *Take Me There: Trans and Gender-queer Erotica*, and the 2018 Lammy-nominated *Resilience Anthology*, to date the largest-ever anthology of trans women and AMAB non-binary writers. She is a former organizer for the Transmodern Festival and the Maryland Film Festival, where she served five years in charge of operations and development. Rahne has since lent her organizational and development assistance to several organizations, including Baltimore Office of Promotion & The Arts, FORCE: Upsetting Rape Culture, Venus Theater, and Wide Angle Youth Media. rahne.com

Inheriting AIDS: A Conversation

Adam Barbu and John Paul Ricco

Adam Barbu: *Art AIDS America* and *One day this kid will get larger*, two recent group exhibitions that focus on intersections between contemporary art and the politics of HIV/AIDS, seem to employ a similar methodological approach. With *Art AIDS America*, curators Jonathan Katz and Rock Hushka establish a narrative of American art that is “expansive and revisionist” while questioning the ways in which AIDS led artists “to think about representational practices first and foremost *strategically*.”¹ Danny Orendorff, curator of *One day this kid will get larger*, considers “what it means to have been brought up in the shadow of the AIDS crisis, as young queer people, and how artists today are revisiting their feelings and experiences.”² Ultimately, both projects are interested in bringing to light issues that are overlooked and artists that are under-recognized within the existing art history canon. Perhaps we can begin by thinking through the different ways this formula of inclusion can be problematized.

John Paul Ricco: Being familiar with the work of Jonathan Katz, one of the curators of *Art AIDS America*, it seems to me that the exhibition is firmly situated as an art historical project, one that attempts to develop a certain kind of counter-canon. *Art AIDS America* and his earlier exhibition *Hide/Seek* share an art historical agenda that has to do with intervening in venerable, long-standing, and authoritative institutions. Both assert the claim that one should find a place at the table, the table of the major and the hegemonic, and further, that this table is a rightful place for gay and lesbian and/or HIV positive artists and art historians. *One day this kid will get larger* seems to have been presented in response to *Art AIDS America* by focusing on non-white and alternative queer perspectives. What strikes me as curious are the conceptual and categorical rubrics that the two exhibitions utilize. They employ two sets of very different categories that nonetheless speak to a common political and aesthetic agenda.

AB: A certain visibility/invisibility binary comes into play.

JPR: This is what they share. The same claims that I am attributing to Katz regarding an art historical agenda about inclusion are evident in *One day this kid will get larger*. The difference is that the latter tries to expand on the idea of who exactly gets to be included. Now, of course, there is nothing wrong with wanting to be included. But it is important to understand how this is a logic that operates through an identitarian premise of visibility, representation, and recognition.

AB: A logic that seeks to visualize AIDS and put a face to cultural identities that supposedly belong to AIDS.

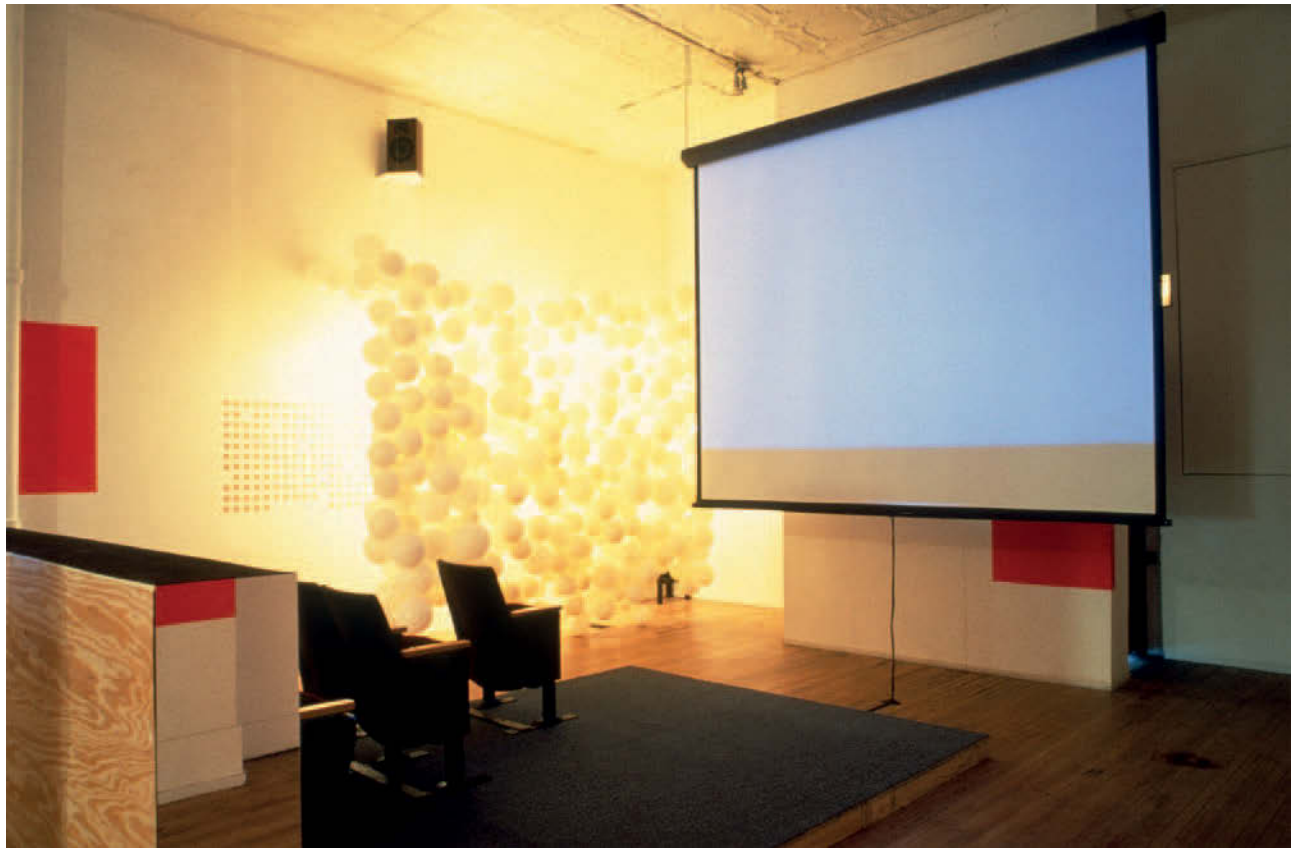
JPR: Yes, by operating within the realms of identity and subjectivity, these exhibitions ask the question: *What* does AIDS look like, and *who* does AIDS look like? In this regard, they seem to already know their subject, and now it is simply a matter of manifesting or materializing an already given sociological category or cultural entity. Here, I find myself necessarily wading into the critique of representation and representational politics. I understand that their agenda is to question stereotypes and complicate or reveal new facets of identity. Nonetheless, I maintain the belief that art's

potential is impoverished and reduced when it is claimed that one of the most important things that art does is provide us with images of social identity.

AB: Perhaps we can turn to our own projects and think through this idea of curating AIDS beyond inclusion, beyond representational logics, beyond the visibility/invisibility binary. Could you speak about the genesis of your 1996 exhibition *disappeared*?

JPR: With *disappeared*, I wasn't interested in envisioning an art historical moment, nor was the exhibition framed as an art historical project. It was a theoretical philosophical project about aesthetics and politics in which I made claims that developed into the notion of a "disappeared aesthetics."³ Bringing Tom Burr's sex club furniture installation *Approximation of a Chicago Style Blue Movie House (Bijou)* into conjunction with Derek Jarman's *Blue* was important because it staged the meeting of what I saw as the coincidence between the problem of representation and the fact of erotic sociality. The works share a tremendous amount having to do with withdrawal, retreat, and disappearance—what I call the logic of the lure. On opening night, Tom joked and said that someone might walk in and assume that they were looking at a show on minimalism. This point is key.

In creating *disappeared*, I was influenced by several other projects. In 1993, two films came out that completely shifted my thinking about queer artistic practice, about AIDS, and about representation: Derek Jarman's *Blue* and John Greyson's *Zero Patience*. In terms of genre and form, these are very different films, yet they share an aesthetics



Installation view of *disappeared*, Randolph Street Gallery, Chicago, featuring Tom Burr's *Approximation of a Chicago Style Blue Movie House (Bijou)*, 1996, and Derek Jarman's *Blue*, 1993. Courtesy of John Paul Ricco.

and a claim about disappearance. Then, of course, there were so many other young queer artists working at the time who were drawing from abstraction and minimalism—many of which I included in *disappeared*. Although his work wasn't included in the program, Felix Gonzalez-Torres' argument about pedagogy, audience, and legibility was central to my thinking. Finally, two books came out in 1996 that were highly influential to me: William Haver's *The Body of This Death: Historicity and Sociality in the Time of AIDS* and Alexander Garcia Düttmann's *At Odds With AIDS: Thinking and Talking About a Virus*. In terms of a philosophically informed approach to theorizing the problem of AIDS, these two books did something that no book had ever done before, and I would say, hasn't been done since. Haver's work in particular became seared into my DNA, and I am still trying to figure out where his thinking ends and mine begins.

AB: A few years ago, we met at a small Toronto café, and I vividly remember you recommending that I find *The Body of This Death*. After reading the text, along with your book *The Logic of the Lure*, I quickly realized that nothing could be the same. Faced with these difficult questions on the limits of identity and visibility, my own curatorial practice had to change. In other words, I developed an approach to curating based on works that I was not able to forget—works that I continue to return to today.

JPR: We need to underline this fact. As a philosophical project, there is no one part of *The Body of This Death* that is explicitly about curating. Yet it is part of our history and part of a form of curatorial practice we—you and I—share. This text has forced us to question what it is about something like AIDS that renders representation impossible. Operating within this register, the task of curating is to embrace that impossibility as the condition and ground upon which to begin one's work. In short, AIDS betrays representation, and we should not betray that betrayal. We should be truthful and respect this traitorous quality that is so confounding. One of the common criticisms of this kind of work is that it is too abstract, too conceptual. In fact, this difficulty and lack of presupposition or categorization is utterly tangible and material. It is *that* movie screen, *those* movie seats, etc. With *disappeared*, I was responding to very real things, particular films, particular works of art, and particular texts, all of which represent different forms of material practice.

AB: Another text by Haver that I return to often is *Of Mad Men Who Practice Invention to the Brink of Intelligibility*, where he traces a reading of pedagogy that embraces queer sociality as “the thought of an originary erotic contamination conjugated with a proliferation of languages.”⁴ Two of my previous exhibitions, *A minimal doubt* and *The Queer Feeling of Tomorrow*, extend from this place. The projects were not simply about identifying trends in art practice or making historical arguments about the visibility of certain artists over others, but the pedagogy and ethics of curating itself. I wanted to explore a sense of skepticism regarding instrumentalized political curating—specifically, the idea of representing queer politics in art exhibitions. I addressed this skepticism by posing the impossible question: Who or what is or is not considered to be a political subject of AIDS? With *A minimal doubt*, I approached this problem with an attention to art historical discourse. By contrast, with *The Queer Feeling of Tomorrow*, I focused on staging scenes of everyday experience.

Overall, it seems as though Haver's work has guided us to think through forms of praxis that exist outside of traditional institutional demands of visibility.

JPR: It should also be noted that Haver's arguments regarding what remains unsayable and unseeable about AIDS were at stake in Foucault's reading of *Las Meninas* in the opening chapter of *The Order of Things*. The discussion centers on the infinite task of understanding the extent to which we do not see what we say, or say what we see. This infinite task is founded on a fundamental split between the sayable and the seeable.

The kind of curatorial practice that we are describing is not interested in what has been said and what remains unsaid, which is a form of art historical and archival inquiry. *Art AIDS America* and *One day this kid will get larger* uphold an agenda to make the unsaid said and the invisible visible—an intellectual position that can be defended (and probably should be defended). By contrast, our task has been to question what is sayable and what is unsayable, which is an ethical question related to witness and testimony. This is an engagement with potentiality not actuality—the potential that something is sayable or the impotential of the sayable, in other words, of that which is unsayable—and may remain so, indefinitely.

AB: We might figure this embrace of the unsayable and unseeable aspects of AIDS as a pursuit of the curatorial impossible.

JPR: Yes, and it offers us the chance to think the thought of a de-instrumentalized, inoperative curatorial praxis, one that is unmotivated by theoretical arguments and philosophical claims about visibility and inclusion.

AB: I thought we could further explore the historical distance between our curatorial projects, particularly as it relates to this reading of curatorial ethics.



Installation view of *The Queer Feeling of Tomorrow*, Art Gallery of Guelph, Guelph, featuring Sunil Gupta's *SunCity*, 2010, John Hanning's *I Survived AIDS*, 2015, and Shan Kelley's *Mostly Blanks*, 2012. Courtesy of the Art Gallery of Guelph.

JPR: My shift in thinking about art and AIDS took place during the early nineties, a time filled with great public anxiety about pharmacological advances and the future of the illness. Then, in July of 1996 at the 11th International AIDS Conference in Vancouver, an announcement was made regarding the emergence of the protease inhibitor, the so-called “cocktail,” that was to change AIDS treatment forever. Several months later, Andrew Sullivan’s infamous *New York Times Magazine* article, “When Plagues End,” was published. These discussions were taking place just before *disappeared* was set to be presented. I find the coincidence of the timing fascinating.

AB: I find myself returning to the question of what it means to inherit AIDS as an intellectual project, particularly when one is born into a generation removed from the earlier years of the AIDS crisis. With *A minimal doubt* and *The Queer Feeling of Tomorrow*, one of my central concerns was to examine the fact that this sense of historical distance could not be repaired or recovered within the space of an art exhibition. This is one of the ways that I have chosen to engage with AIDS as an impossible object of representation. Of course, AIDS is not over, and there is much political work to be done in the here and now. Yet even considering the shifting cultural, political, and medical realities of the HIV virus, this sense of impossibility is something we share across generations.

JPR: It is interesting to think about this language of transmission across immunological and historical lines, partly because it concerns the inheritance of an ethics that is itself impossible to hand down. And this question of inheritance is central to our discussion. To think it further, I am of the generation after Haver, and you are the generation after me. There are three generations at least, if not more.

That being said, I can’t help but think about the longer history and future genealogies of AIDS. For example, one might consider how Jarman’s *Blue* also appears in *Blue Black*, a recent exhibition curated by Glenn Ligon for the Pulitzer Arts Foundation in St. Louis. Using Ellsworth Kelly’s wall sculpture *Blue Black* as an anchor, the exhibition presents itself as a curatorial response to race relations in America. It is one of the more impactful recent meditations on color, abstraction, and politics. *disappeared* and *Blue Black* share a certain kind of aesthetic argument. In this way, the film has a place in both.

AB: The film finds a place in both because, for Jarman, AIDS bears so much more than the scientific term “HIV/AIDS” would seem to suggest. AIDS is a social condition that troubles representational logics and insists we think at the limits of the sensible. It does not belong to any proper body or identity category. Drawing once again from Haver, a claim that you echo in *The Logic of the Lure*, “In the time of AIDS, we all live and die ‘in AIDS’ (as one is said to live and die ‘in religion’), whether or not we die ‘of AIDS.’”⁵

Notes

1 Jonathan D. Katz, “How AIDS Changed American Art”, in Jonathan D. Katz and Rock Hushka, eds., *Art AIDS America*, (Seattle and London: University of Washington Press, 2015).

2 Danny Orendorff, “Press Release: One day this kid will get larger,” Artsy, 2017, accessed January 11, 2019, <https://www.artsy.net/show/depaul-art-museum-one-day-this-kid-will-get-larger>.

3 John Paul Ricco, *The Logic of the Lure* (Chicago and London: The University of Chicago Press, 2002).

4 William Haver, "Of Mad Men Who Practice Invention to the Brink of Intelligibility," in William F. Pinar, ed., *Queer Theory in Education*, (Mahwah, NJ: Lawrence Erlbaum Associates, 1998).

5 William Haver, *The Body of This Death: Historicity and Sociality in the Time of AIDS* (Stanford: Stanford University Press, 1996).

Adam Barbu is an independent writer and curator based in Ottawa, Canada. His current research focuses on queer theory and the politics of spectatorship. In 2015, he was the recipient of the Middlebook Prize for Young Canadian Curators. His recent exhibitions include: *The Queer Feeling of Tomorrow*, Art Gallery of Guelph, Guelph (2015-16), *A Minimal Doubt*, Videofag, Toronto (2015), and *Bad Timing*, V-Tape, Toronto (2015). His writings have appeared in publications such as *Canadian Art*, *esse*, *Espace art actuel*, *Momus*, and *Journal of Curatorial Studies*.

John Paul Ricco is a theorist and writer working at the intersection of contemporary art, queer theory, and continental philosophy. He is the curator of *fag-o-sites* (Gallery 400, University of Illinois-Chicago, 1993), *disappeared* (Randolph Street Gallery, Chicago, 1996), *Love in a Time of Empty Promises*; and *Sex Is So Abstract* (V-Tape, Toronto, 2007-08) and most recently, *2016, 1996* (Visual AIDS, NYC, 2016). Ricco is the author of *The Logic of the Lure*, and *The Decision Between Us: Art and Ethics in the Time of Scenes*, and the organizer of Sex, Ethics, and Publics, a collaborative research working group based in Toronto. He is Professor of Art History, Comparative Literature and Visual Culture at the University of Toronto.

April 20, 1993

David Kahn, Brooklyn Historical Society

– *Reprint*

While often subjects within exhibitions about the virus, people living with HIV are seldom centered as visitors to exhibitions about the virus. Such was the case in 1993 with the Brooklyn Historical Society (BHS)'s *AIDS / BROOKLYN*, an exhibition conceived of by BHS's executive director David M. Kahn. According to exhibition literature, Kahn felt that at the time museum exhibitions created in response to the crisis had not dealt with the disease in a way that was comprehensible to the general public. In response, he wanted BHS to make an exhibition that was rooted in "the daily lives of people affected by AIDS." Curated by filmmaker Robert Rosenberg (*Before Stonewall: The Making of a Gay and Lesbian Community*), the exhibition included oral histories of Brooklyn residents living with and impacted by HIV/AIDS; ephemera from the front lines of the epidemic in Brooklyn procured largely by a community advisory board and partnering organizations; and local AIDS education material.

For Kahn, the exhibition was personal. As he often noted at the time when talking about the exhibition, his partner Ron Rosenberg died with HIV in 1991. Kahn's lived connection to the virus comes through in the document below, a memo to all BHS staff that was part of "the blue binder," BHS's staff orientation for all exhibitions.

I came across Kahn's memo a few years ago when I had the chance to index the *AIDS / BROOKLYN* oral histories in anticipation of historian Julie Golia's 2019 BHS exhibition, *Taking Care of Brooklyn: Stories of Sickness and Health*. Upon reading the memo, I was moved first by the candor of a person in his position on such sensitive topics such as love, death, and loss; but more so I appreciated how Kahn used his position to center the needs and comfort of people living with HIV. Even when addressing fears—highlighted by an unknown person in this surviving copy of the memo—Kahn is thinking about how precautions impact people living with the virus.


In reading the memo, it becomes clear that every exhibition is not only an opportunity to engage with the public, but to also do outreach and education within an institution.

The memo appears courtesy of the Brooklyn Historical Society.

– Theodore (ted) Kerr

April 20, 1993

Memorandum

To: All Staff
From: David Kahn 
Subject: "AIDS/BROOKLYN"

I would like to thank everyone for working so hard to make "AIDS/BROOKLYN" a reality. Since the show opens on Wednesday, I thought it would be a good idea to review a few points.

There will undoubtedly be a substantial number of PWAs (People with AIDS) and HIV positive people visiting the exhibition over the next eight months or so. As you all undoubtedly know, it is impossible to contract AIDS via casual contact with people who are ill. No special precautions will, therefore, be necessary in interacting with visitors who come here to see the exhibition. Any individual visitor may or may not be a PWA or HIV positive. And it should not matter to any of us whether a particular visitor is or isn't.

There is some possibility that some visitors may appear to be unwell. I would like to make a special plea that such visitors not be stared at or made to feel uncomfortable in any way. The degree to which you might treat such a visitor in a friendly, warm way will be a credit to you and to The Brooklyn Historical Society. It will also be greatly appreciated by the visitor. The last thing we would want would be for a PWA not to feel welcome when coming to see "AIDS/BROOKLYN."

As many of you know, my own lover Ron Wogaman died of AIDS in 1991. When he wasn't at his best, I remember him telling me how much he was upset by people staring at him in the street because he was thin or walked slowly. When you think of how you might feel if people were staring at you, I am sure you can understand how important it will be to treat all PWAs in a sensitive manner.

I hope everyone will take the time to carefully go through the exhibition. The section on facts/fictions about AIDS may address any questions or doubts individual staff members might have about the project. In addition, Robbie Rosenberg, the exhibition's guest curator, will present a sensitivity workshop on "AIDS/BROOKLYN." Fabiana will announce the date and time in the near future. All staff are invited to attend. All front desk staff will be required to attend, since those at the front desk will have the most interaction with the public over the life of the exhibition.

Please let me close by saying the subject may not be an easy one for everyone on the staff. But I hope I can count on all of you to do your best to make each and every one of our visitors feel welcome. Thank you very much for your cooperation.

Graphic Ephemera

Lasting Impact: Building an Online UK HIV/AIDS Design Archive

Siân Cook

– *Artist Project*

Historical accounts of HIV/AIDS in the UK seldom look beyond the “official” government public campaigns or the work of larger London-based organisations. Nor have the graphic output and communication strategies employed by diverse community groups, activists, and small charities during the eighties and nineties been analysed extensively.

In her 1990 AIDS Social History Programme survey, archivist Janet Foster identified twenty-eight organisations—such as Scottish AIDS Monitor, Immunity and Aled Richards Trust—that held materials relevant to the social history of AIDS.¹ However, the main content of these archives was written documentation, with few samples of visual AIDS ephemera—leaflets, posters, condom packs, postcards, and flyers, etc.² The majority of those organisations have now closed, merged, or restructured; their archives redistributed or destroyed. Libraries that hold the remaining collections tend to be accessed by academic researchers rather than those involved in current AIDS activism or designing new health promotion interventions, and there are few publications that show what original campaign materials actually looked like.

My own collection began because I was involved with HIV/AIDS organisations in the nineties as a volunteer graphic designer, collaborating on campaigns and producing printed matter. I was therefore initially looking for examples of good practice, but became increasingly interested in the visual language and alternative design approaches that I found. I started collecting in 1994 by writing to over 170 UK organisations requesting sample materials and devising a personal cataloguing system that also recorded print and production methods.

Retrospectively, this fit with aspects of a feminist approach to archiving—using what cultural studies academic Kate Eichhorn refers to as “dirty” methods of

collecting, i.e., contaminated by the personal involvement of the collector and not aiming for completeness or authority.³

“For Foucault,” writes Eichhorn, “the archive is an authorizing apparatus—a structure that determines which statements can and do *act* in and upon the world.”⁴

The importance of “*act*” in this instance has since become the practical application and sharing of the archive. Through my website, I make my collection widely available online as a visual resource. This also provides the opportunity to compare “official” government and health authority messages with those produced by smaller organisations.

The selection shown here illustrates how concerned communities attempted to fill local communication gaps, employing peer education methods and often working with very limited means, but with an urgent agenda and an inside understanding of their audiences. The use of the visual and verbal vernacular of their target groups resulted in often innovative and sometimes controversial designs for a health promotion context.

For example, inmates at a Scottish prison were involved in producing a harm-reduction leaflet incorporating simple cartoons and local dialect (fig. 1). This was used as an alternative to the “official” leaflet issued by the Scottish Prison Service, which was a dense, text-heavy publication, given to a population with very low literacy levels. The Naz Project was able to show explicit content by using contemporary Indian Mughal images, which were culturally acceptable for their audience (fig. 2). GMFA published deliberately provocative imagery to differentiate themselves from more mainstream organisations when they emerged as “Gay Men Fighting AIDS” (fig. 3). Many of these groups took a “by and for”

approach⁵—prisoners, women, gay men, drug users, etc. Identifying as audience insiders, they were well placed to test and develop an appropriate visual language and tone of voice for discussing difficult issues around sexual behaviour and lifestyles.

There is no natural “home” for this type of AIDS ephemera. Items are scattered across various LGBT+ or medical archives, but information aimed at minority groups such as prisoners, drug-users, and sex workers tends not to have been preserved. Without access to these resources from the past, it becomes more difficult to both start addressing comparable situations in the

future, but also to track the distance travelled in changing attitudes. With this in mind, my hope for the archive is to establish it as a reliable online source of inspiration and information. But to also connect with a wide range of activists, educators, researchers, and health professionals as a way to keep adding content and reflection. This project came about through identifying a need to locate and archive examples of design practice across *all* communities that were affected by HIV/AIDS in the UK, in order to examine what can be learned from their unique responses to the epidemic.

<http://www.hivgraphiccommunication.com>

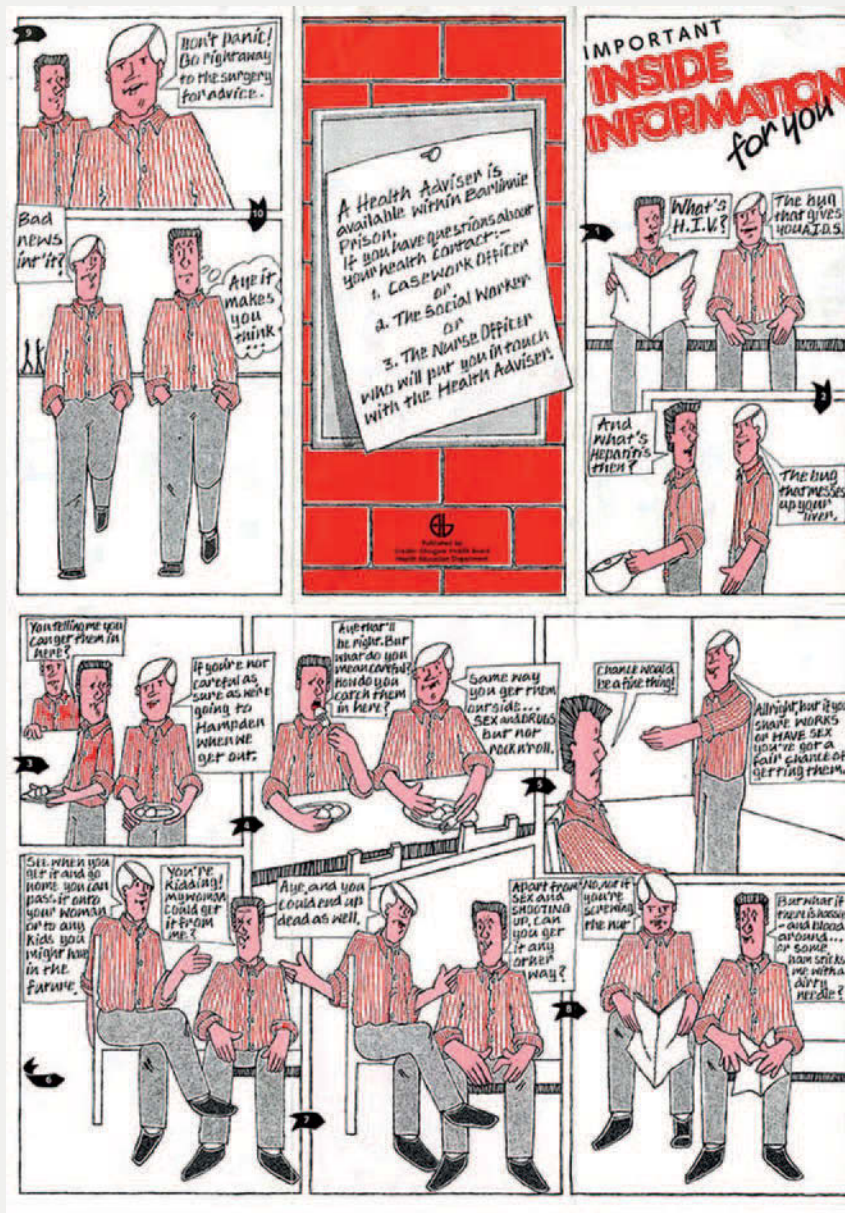


Fig 1. Unknown, Important Inside Information For You, early 1990s: leaflet © Greater Glasgow Health Board.

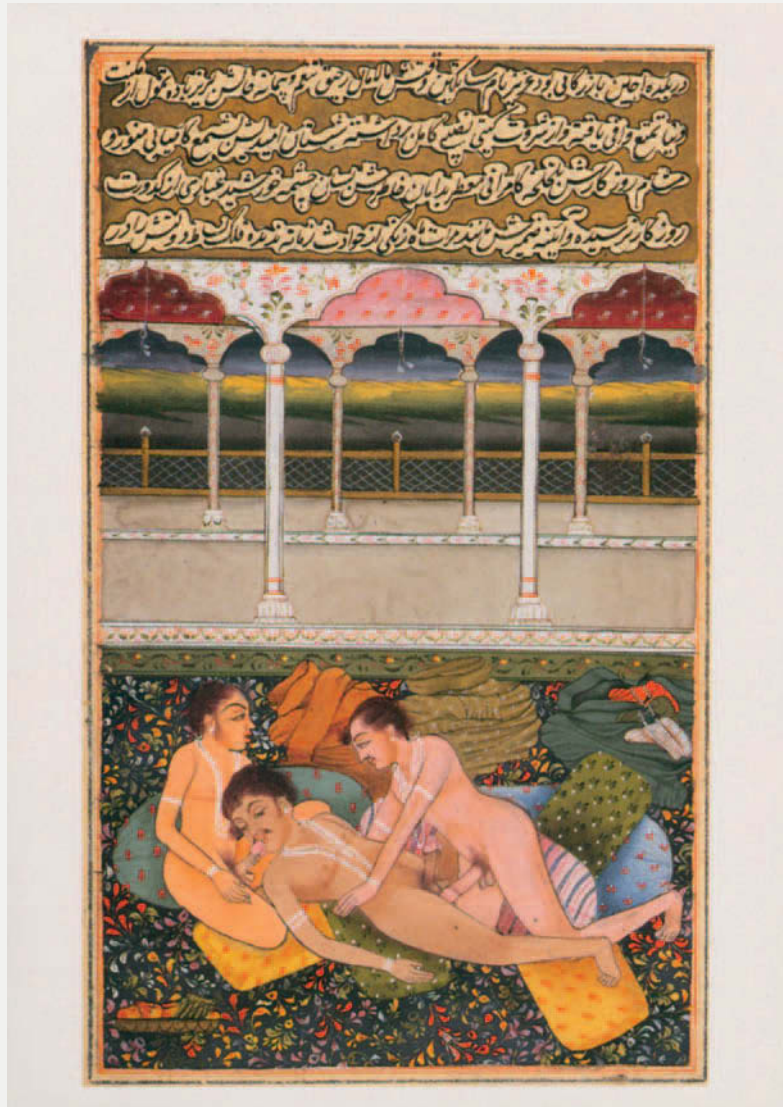
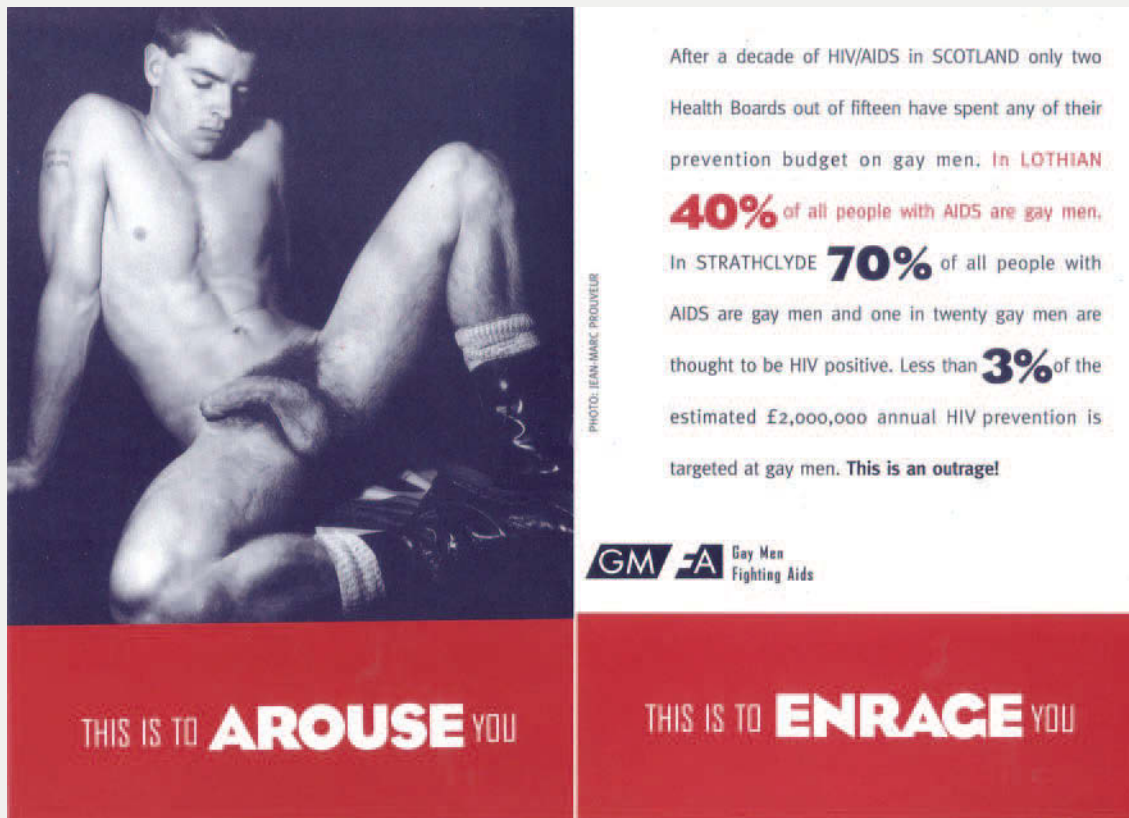


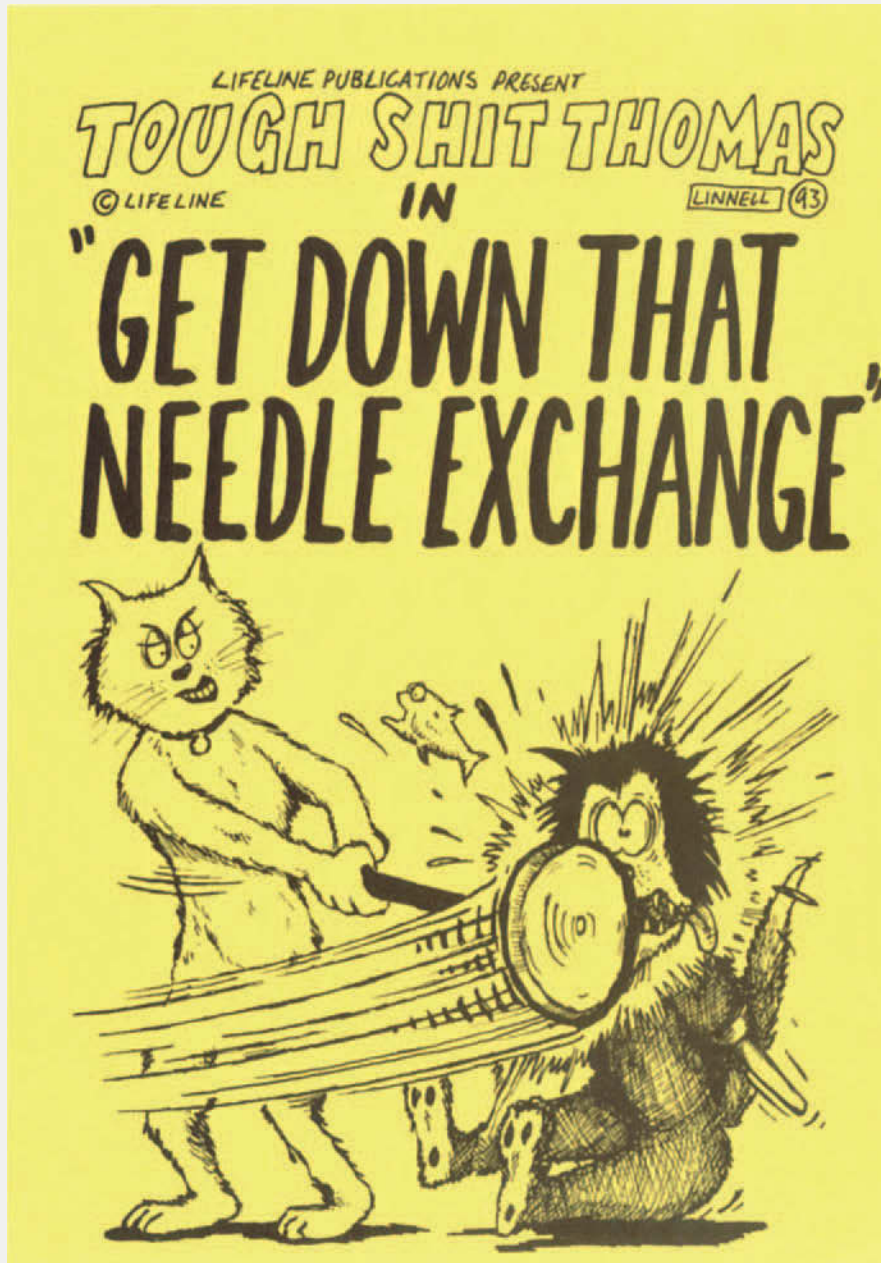
Fig 2. The Naz Project, Times Have Changed; it makes sense to use a condom, c.1995; one of an eight postcard set © The Naz Project. Reproduced with the kind permission of NAZ



GMFA, This is to Arouse You, 1994: postcard, front and back shown. Photograph by Jean-Marc Prouveur © GMFA.



Positively Women, 1. Prevention, 1994: Leaflet. Illustration by Jane Shepherd, Design by Néna Carney © Positively Women.



Lifeline, Get Down That Needle Exchange, 1993: Leaflet. Illustration by Michael Linnell © Lifeline. Image used courtesy of Michael Linnell, who also has an online archive of his drug-related work; <http://michaellinnell.org.uk/archive.html>

ACT UP Norwich (AIDS Coalition to Unleash Power) is a broad based organisation dedicated to fighting and exposing ignorance, fear and discrimination surrounding AIDS and HIV through non-violent direct action and resistance. We fight not only for the rights of those people living with AIDS or the HIV virus, but for the right of everyone regardless of gender, race, sexuality, age or known HIV anti-body status to appropriate, honest and accurate information about AIDS and HIV.

WHY ACT UP?

Because many have died worldwide and many millions more are HIV+ and **because** there is still no effective treatment for AIDS and **because** drug company profits come before lives and **because** government funding cuts mean less safer sex education, prevention and care and **because** people still think this can't happen to me and **because** women are still unable to gain equal access to treatment programmes, health care and drug trials and **because** there are no innocent or guilty victims and **because** people living with HIV on benefits can't afford to eat properly or keep warm and **because** people are being denied jobs and housing and **because** in prisons you can't get clean injecting equipment or condoms and **because** this government refuses to outlaw pre-employment HIV testing and **because** Section 28 and the gay age of consent deny gay men access to safer sex information and **because** sex workers are arrested for carrying condoms and **because** rights of parents come before rights of children to get HIV education in schools and **because** hysteria, homophobia, fear, racism and hatred sell newspapers and **because** health workers are more at risk than the patients they treat and **because** censorship kills and **because** us and our friends and lovers and relatives are dying now and **because** one more HIV+ person is too many and **because** after more than a decade of AIDS in this country there is still no cure...

Time to ACT UP!

ACT UP

ACT UP is lying in the road, telephone blockading, fax zapping, letter writing, informing, condom dropping, researching, lobbying, talking, shouting, screaming, stickering, misbehaving, lying in, dying in, painting, retaliating, creating and having fun!

ACT UP, PO BOX 73, NORWICH, NR3 1QD



THE AGENCIES AND ORGANISATIONS BELOW ARE HERE TO HELP! CONTACT THEM IF YOU WANT TO KNOW MORE!

HIV & SEXUAL HEALTH LINE 614314

Recorded information & details of helping agencies.

NORWICH AIDS HELPLINE 615816

Thurs 8-10pm Sat 11am-3pm

Confidential help, advice & information on safer sex, AIDS & HIV.

NATIONAL AIDS HELPLINE 0800 567 123

Free phone 24 hours.

GUM (Genito Urinary) CLINIC 286308

Advice on HIV testing & treatment of worries over STDs.

NORWICH GAY MEN'S HEALTH PROJECT 627514

Weds 3-7pm

Resources & information for gay men, including free condoms.

ACT UP NORWICH

PO Box 73, Norwich NR3 1QD

Direct action & research group fighting AIDS & HIV discrimination.

FERRY CROSS 619397

22/24 Colegate, Norwich NR3 1BQ

Advice on drug & alcohol use including needle exchange.

BURE CENTRE 667955

7 Unthank Rd, Norwich

Drug & alcohol advice & clean needles.

NORCAS 767093

Advice & help on alcohol issues.

FAMILY PLANNING CLINIC 621872

Free condoms, help & advice on contraception (including emergency contraception).

WOMEN'S CENTRE 628130

Information, advice & free pregnancy testing.

WOMEN'S HEALTH INFORMATION SERVICE 662280

Mon & Weds 11-4pm

Information, advice & free pregnancy testing.

RAPE CRISIS 667687

Tues 7-9pm

Free confidential advice for women.

UNION ADVICE UNIT 592505

LESBIAN & GAY LINE 592505

Mon 8-10pm termtime only



SM Gays, Rough Sex Safer Sex, 1997: Booklet. © SM Gays.

Notes

- 1** Janet Foster, *AIDS Archives in the UK* (London: London School of Hygiene and Tropical Medicine, 1990).
 - 2** The University of Reading, Centre for Ephemera Studies' validation for the study of ephemera; John Johnson, "...the ephemera of today becomes the evidential data of tomorrow...", accessed January 26, 2018, <https://www.reading.ac.uk/typography/research/typ-researchcentres.aspx>
 - 3** Kate Eichhorn, *The Archival Turn in Feminism: Outrage in Order* (Philadelphia: Temple University Press, 2013).
 - 4** Ibid.
 - 5** GMFA used the description, "By gay men, for gay men," and Positively Women stated "...written for women by the experts—women" on the front of their leaflets (fig. 4).
-

Siân Cook (MA, FRSA, FHEA) is a graphic designer and Senior Lecturer in Graphic and Media Design at London College of Communication, University of the Arts London. She has been involved with HIV/AIDS activism for 25 years and has designed for Terrence Higgins Trust, National AIDS Trust, Sigma Research, MeSH (Measurement & Surveillance of HIV Epidemics) and GMFA (the gay men's health project) where she was also a Trustee. Siân has built up a collection of graphic ephemera related to HIV/AIDS in the UK and is in the process of making this material available online at www.hivgraphiccommunication.com. She has given talks and authored articles about various aspects of the HIV/AIDS epidemic from a design and communication point of view. Siân has a background in design for the music industry, but has run her own design practice since 1994, working for a variety of charity and arts sector clients. She has extensive experience teaching in higher education and is also Co-Director of the Women's Design and Research Unit.

AIDS, Coca-Cola, and the Tompkins Square Park Riot

Avram Finkelstein

In 1981, there was a tempest on the horizon, and anyone with eyes could see it coming. In spite of its fiercely swirling vortex, the outlines of the cultural meanings of HIV/AIDS were immediately discernible, playing out as they did in the public sphere. So, our assumptions about HIV/AIDS formed quickly in our shared spaces, from policy to pop culture, and almost as quickly they began to crystallize into a canon, one that has enveloped us ever since.

Now, after decades of shell-shocked reflection, those who survived this moment appear ready to speak about it again, and new canons are springing up, canons that have become the subject of contemplation for a new generation of historians, archivists, artists, and activists, who were born in the midst of HIV/AIDS and are struggling to make sense of the worlds they both inherited and missed. A growing number of narrative films, documentaries, archival projects, theater revivals, books, and gallery exhibitions have already been devoted to the topic, and these were just the first to the gate. There are many more major undertakings in the pipeline. We are in a second vortex, something I call AIDS 2.0, and it is only just beginning.

For decades, academic consideration of our early responses to HIV/AIDS has been stacking into a very high wall, deepening our understanding of the cultural meanings of AIDS. On the other side of this wall, however, history is a process of generalization, and our new media landscape privileges the stories that are easier to tell. Within our public spaces, complexities are slipped beneath the shadows of our zeitgeists, and well-worn media tropes supplant more disorderly truths. As a consequence, AIDS 2.0 is not really the story of HIV/AIDS. It is its storytelling. Any scholarly understanding has been outpaced by how we talk about it in our cultural wilds.

In an effort to isolate certain aspects of the phenomenological penumbra of AIDS 2.0 in my book, *After Silence: A History of AIDS Through Its Images*,¹ I focused my investigation on a small sampling of the images we commonly use to represent it, the AIDS agitprop by two collectives I was a founding member of, the Silence=Death collective, and the art collective, Gran Fury. The output of these collectives is well-surveyed within curatorial circles, and as a result, inadvertently serves as a stand-in for the political engagement of that moment. But its meaning as cultural production is frequently detached from its function as activist work-product, hobbling the concomitant significance it might still have within grassroots organizing circles in the process.

In narrowing my attention to the Silence=Death and Gran Fury collectives, I chose *not* to explore another poster I had a hand in, *Enjoy AZT*.² It is the subject of this essay because I believe its unorthodox point of entry into curatorial canons is particularly germane to this issue of *On Curating*. As a wonky critique of the drug AZT (azidothymidine), the only pharmaceutical therapy approved at the time for People With AIDS (PWAs), this work was an unlikely candidate for the longevity it came to experience, and might have disappeared altogether if it hadn't been buoyed by an art practice beyond the collaborations it was born of and represented, the practice of an art

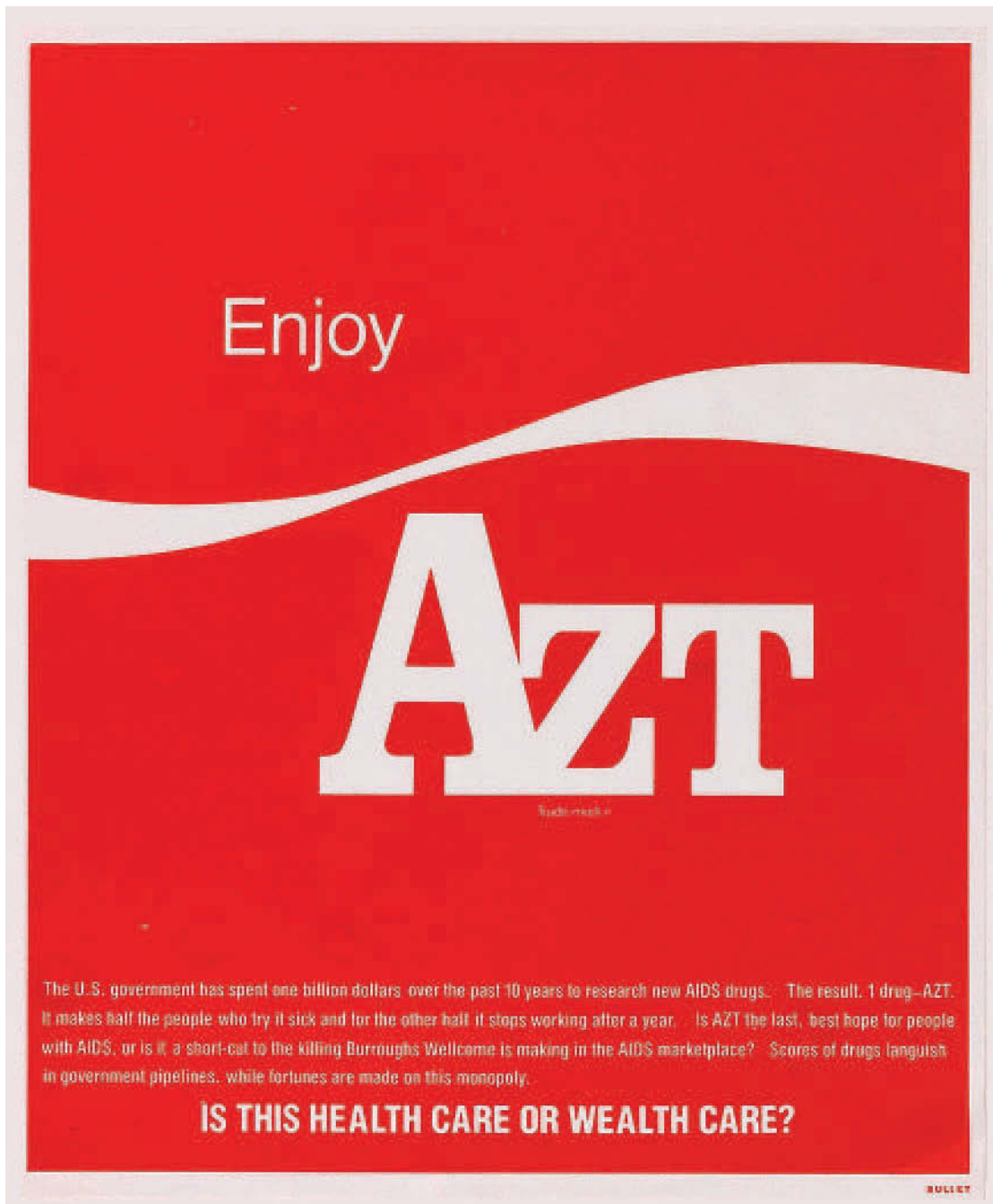


fig. 1: Avram Finkelstein and Vincent Gagliostro, *Enjoy AZT*, 1989. Silkscreen on Mohawk Vellum. 23 × 19 in. (58.4 × 48.3 cm). Courtesy of the artist.

collective entirely *outside* of the AIDS activist community, Bullet Space, whose anti-gentrification work captured the interest of curators and archivists. As a consequence *Enjoy AZT* “meandered” into international archives, and so, I believe this piece of AIDS agitprop remained closer to its activist roots—or at least, it did so for a longer period of time—and its journey may have distinct things to say about the machineries of meaning applied to our consideration of political art practices, as well as the intrinsic relationship between HIV/AIDS and gentrification, and about colonization and displacement more generally.

Collectivity, Bullet Space, and Enjoy AZT

The early sense of isolation AIDS created for individuals in Lower Manhattan was, at least in part, a catalyst for the vivid articulations of communal response that followed, and perhaps as a direct result, much of the cultural production associated with this political moment in New York involved collective output. So, it is important to note that when we privilege the cultural production of Silence=Death and Gran Fury to tell the story of how communities constituted themselves in response to the HIV/AIDS pandemic, it throws a cloak over the many other collectives working in ACT UP at the time, and the permeability of the borders between them: Zoe Leonard was in fierce pussy and Gang; Loring McAlpin was in Gang and Gran Fury; Carrie Moyer produced work for Queer Nation, Dyke Action Machine, and The Lesbian Avengers; Marlene McCarty from Gran Fury designed the *WAC Is Watching* poster for the Women's Action Coalition; Vincent Gagliostro produced work for ACT UP, Anonymous Queers, and Gran Fury. Focusing on Silence=Death and Gran Fury also overlooks the agitprop generated within ACT UP committees that were not centered on art practices, such as Majority Action, Wave Three, The Marys, the Women's Committee, the Housing Committee, the Treatment and Data Committee, and the Healthcare Committee; the local zines that spun off the sense of community ACT UP generated, like *My Comrade* and *Gay Action Heroes*; and the work coming out of other cities that experienced high pass-along within Lower Manhattan, like *On Our Backs*, *Diseased Pariah News*, and the work of the San Francisco collective, Boy With Arms Akimbo/Girl With Arms Akimbo. Focusing on Silence=Death and Gran Fury bypasses a generation of performance, theater, and musical output, and the work of other activist movements, such as anti-gentrification activists, who, like AIDS activists, placed their bodies on the line in conflicts that frequently escalated into urban warfare: it was not uncommon for police to use helicopters, armored vehicles and riot gear to battle squatters.³

One significant example of cultural production generated by anti-gentrification activism was the multi-year street art and publishing project, *Your House Is Mine*, which came out of the anti-gentrification work of the Bullet Space squat, originally founded in 1985 as the Six O'Clock Squat, and changed to Bullet Space in 1987, after the street name for the heroin local to the block on which the squat was founded. When Andrew Castrucci from Bullet Space saw the *Enjoy AZT* poster on the streets of New York, he asked if they could adapt it as part of *Your House Is Mine*, and through the self-generated archival practice of this urban artist collaborative, Bullet Space was responsible for reproducing this poster in various forms, posting it throughout the Lower East Side, and placing it within the curatorial circles responsible for sustaining it.

I originally proposed *Enjoy AZT* to Gran Fury during the early months of our formation in 1988, but it was rejected by the collective because they felt uncomfortable critiquing the only pharmaceutical intervention available to People Living With HIV/AIDS at the time. Instead, I used part of the poster's tagline, “Healthcare or Wealth-care?,” for the article I contributed to the 1989 Gran Fury *New York Crimes*⁴ collabora-

tion, and decided to further develop *Enjoy AZT* in its poster form over that summer with another collaborator, Vincent Gagliostro.

Enjoy AZT was intended as a street poster, and at the time of its making, direct-to-consumer pharmaceutical advertising in America had yet to be deregulated and was an unfamiliar form. After a century of branding work by Coca-Cola, squatting on this easily recognizable American commercial symbol represented a surgical visual code to explain how similar the mechanisms of delivering a drug to the marketplace were to those of any other consumer product, and it hinted at the processes through which pharmaceutical research can segue into commercial monopolies, a core activist critique of the drug approval process. The Coke logo did much of the heavy lifting in this complicated story, freeing us to focus on the didactic text to explain the underlying policy critiques of ACT UP's May 21, 1990 demonstration, Storm the NIH (National Institutes of Health), which *Enjoy AZT* helped announce. We produced this image as a 13½ x 11¼ inch newsprint demonstration poster, and wheat-pasted it around the city. Much of its data was drawn from ACT UP fact sheets.

AZT had been a target of ACT UP from the start: for its singularity, questionable efficacy and staggering price—it was the most expensive prescription drug in history at the time. This fact was made all the more galling by its long history of subsidization within the American government research establishment. When it was approved as the first AIDS therapy in 1987, the research and development costs of AZT had already been shouldered by a National Cancer Institute (NCI) grant to the laboratory that developed it in 1964. In 1984, the NCI helped dust off the failed cancer drug for the pharmaceutical company Burroughs Wellcome, who by then owned its UK patent, and went so far as to offer incentives that included a defraying of further testing costs and access to a key ingredient for the initial production, a synthesized form of thymidine that was produced by Pfizer. Drugs for the opportunistic infections associated with AIDS had been approved after AZT, and still others were available through Investigational New Drug (IND) protocols, but AZT had a healthy four-year run as the only HIV treatment before a competing drug, ddI, caused the domestic market for AZT to dip.

AZT also had a healthy run within the research protocols of the National Institute of Allergies and Infectious Diseases (NIAID), even as other therapies languished in the drug approval pipeline. Very soon after the Storm the NIH action, a controversial study began on women with AIDS, the 076 Trial⁵ at the AIDS Clinical Trial Group (ACTG), which set out to prove AZT's efficacy in preventing perinatal (mother-to-child) transmission of HIV. It was a large trial, conducted at 59 sites, and included a more representative sampling of women of color, unusual at the time. Unfortunately, the trial was also shot through with ethical sticking points, including the use of a placebo (there would be HIV+ women and infants who would not be receiving a potentially beneficial treatment); the fact that infants who were not HIV+ would be receiving a drug they did not need and which had acknowledged toxicity in adults; that participants were not guaranteed a continuation of treatment once the study concluded; that the trial treated the mothers as procreative vessels and bypassed their own medical needs; that the overall potential toxicities of AZT were still unclear; and finally that the informed consent clauses excluded the risk of vaginal tumors evidenced in animal studies.

Whether by coincidence or design, the 076 study phased in just as the American AZT market was in decline. The 076 study was successful, and the U.S. Department of Health and Human Services published encouraging results ahead of schedule in

February 1994, reinforcing the market for it in Africa, where heterosexual transmission remained undisputed, even amongst American policymakers who were loath to find the strong clinical evidence of it compelling domestically.

Reaganomics Was a Riot

This condensed history of this drug explains some of the intricate links between *Enjoy AZT* and AIDS activism. The reason this poster has entered into museum and academic archives, however, is because of a series of gestures indirectly connected to those critiques: *Enjoy AZT* also played a part in the anti-gentrification activism linked to the 1988 Tompkins Square Park riot.

On July 19, 1988, the New York City Commissioner of Health, Stephen Joseph, suddenly slashed the number of estimated AIDS cases in Manhattan, threatening to drastically reduce funding for AIDS services. ACT UP NY declared war on him. During a sit-in at Joseph's office, a copy of his itinerary was taken, and was circulated throughout ACT UP. We followed him, day and night, to public and private meetings, forums, lunches, and dinners, and even to his home. The commissioner was so unhappy about the ACT UP scrutiny that it led to a late-night visit to one activist's apartment by a New York Police intelligence case squad ordinarily tasked with police slayings. *The Village Voice* reported Joseph as having triggered the investigation, and it led several lawyers in ACT UP to conduct a teach-in on the history of the covert FBI surveillance, infiltration, and disruption of political organizations from 1956-1971, COINTELPRO (COunter INTELLigence PROgram), an operation aimed at destabilizing the American Communist Party, the civil rights and anti-war movements, and the Black Panthers.

The tense political shoving match between ACT UP and Stephen Joseph was further exacerbated by the Tompkins Square Park riot, which began within days of the harassment of Joseph. The skirmish was referred to in the *New York Times* as a "war zone,"⁶ which was not an exaggeration. The standoff, staged around the eviction of the homeless population living in the East Village park, involved mounted officers doing battle with bottle-hurling protesters, and low-flying helicopters combing the rooftops with searchlights. The protest over the gentrification threatening all of lower Manhattan was precipitated by the deregulation triggered by Reaganomics that led to tax incentives for real estate development, which was fanned into a bonfire by increased income inequality shifting middle and lower income properties into the hands of real estate speculators at the luxury end of the market.

It would be a misunderstanding of the activist topography that defined Lower Manhattan in the late 1980s to exclude the connections between the roiling AIDS activism centered in the already expensive West Village and the anti-gentrification struggles playing out across town on the Lower East Side. The energy that fueled ACT UP was due in no small part to an influx of younger queers from the East Village, who brought an enthusiastic, newly found activism with them. So, many ACT UP members lived near the park, and formed an obvious presence in their ACT UP T-shirts during the riots. One Gran Fury member lived a half block away from the park in a gutted squat, and we could see the police silhouetted in their helicopters from his window. If the protest was a spontaneous battle caused by hostile police actions, it had spun out of control within hours, impacting public sentiment, policy, and cultural production for years to come. Direct and indirect allusions to the tensions caused by gentrification in the East Village turned up several years later in the musical, *Rent*, and more recently in Tim Murphy's *Christodora*. It turned up the very next day, however, in a project by the urban artist collaborative, Bullet Space, in the form of their multi-year project, *Your House Is Mine*.



fig 2. *Your House Is Mine* poster and book project, on 8th St. Between Ave B and C, 1992. Photo by: Andrew Castrucci. Published by bullet space, 1988-92.

Your House Is Mine

During the period when ACT UP had declared war on Stephen Joseph, the FBI did, in fact, keep files on ACT UP.⁷ One file was directly related to ACT UP's pursuit of Joseph, explaining chain of command to Canada's FBI counterpart if an act of "terrorism" by ACT UP occurred at the Fifth International Conference on AIDS in Montreal, where Joseph was scheduled to speak. The New York FBI Field Office also sent correspondence to domestic terrorism units in DC and elsewhere in the U.S. detailing the Tompkins Square Park riot, claiming the conflict was triggered by an earlier demonstration on July 31, 1988, organized by "ACT UP" and "skinheads," which was a reference to the anarchist and performance collective, Missing Foundation, which was closely associated with the incident. Missing Foundation was already well-known throughout the city for their ubiquitous, graffitied pictogram, an upside-down martini glass with its contents spilling out, often with the accompanying slogan, "The party's over," a thinly veiled threat against the high-end real estate incursions swallowing the East Village. The title of Missing Foundation's 1988 studio album was *1933 Your House Is Mine*. *Your House Is Mine* perfectly described the political moment, and the topic of gentrification. It became the name of the Bullet Space project, and Missing Foundation contributed work to it.



fig. 3: Installation view of *An Incomplete History of Protest: Selections from the Whitney's Collection, 1940-2017* (Whitney Museum of American Art, New York, August 18, 2017–). From left to right, top to bottom: Vincent Gagliostro and Avram Finkelstein, *Enjoy AZT*, 1989; Joseph Wolin, Tom Starace, and Richard Deagle, *American Flag*, 1989; John Ahearn, Andrew Castrucci, John "Crash" Matos, Chris "Daze" Ellis, Jane Dickson, Jenny Holzer, Gary Simmons, and Martin Wong, *The Usual Suspects*, 1996; Barbara Kruger, (*Girl don't die for love*), 1992; John Giorno, *The world is getting empty...*, 1993; Donald Moffett, *He Kills Me*, 1987; Kay Rosen, *AIDS*, 1994; Frank Moore, trial proof and study for the poster *FACE IT—LICK IT*, 1992; Gran Fury, (*Men use condoms or beat it*), 1988; Glenn Ligon, (*Who will keep their dreams alive if we don't wake up to reality?*), 1992; Sue Coe, *Aids and the Federal Government*, 1990. Photograph by Ron Amstutz. Digital image © Whitney Museum of American Art, New York.

Gentrification created an unintended social ecology conducive to both street art and political resistance: the very same real estate tax abatements transforming Manhattan into the land grab that sparked the Tompkins Square Park riot ironically provided the Silence=Death collective, Gran Fury, ACT UP, and Queer Nation with the proliferation of boarded-up construction sites that served as potential spaces for posterizing, and we commandeered them as communication command centers for our resistance work. Anti-gentrification activists, however, went one step further, commandeering *the buildings themselves*, squatting in them before construction could even begin. Bullet Space had occupied one of those buildings, on 292 East Third Street, as their home and command center, and the day after the Tompkins Square Park riot they began using it as their base of operations for a sprawling street art and publishing project, *Your House Is Mine*, which they declared to be an “act of resistance.” When this artist collaborative saw the *Enjoy AZT* poster wheat-pasted in lower Manhattan, they hunted us down for its inclusion in their project. Bullet Space then became responsible for all further shepherding of *Enjoy AZT*.

As a project with multiple iterations, the organization, fabrication, and dissemination of *Your House Is Mine* spanned from 1988-1992. It started as 150 23-inch x 20-inch street posters on lightweight paper stock, to be wheat-pasted throughout lower Manhattan. Another 150 posters, in the same dimensions, were produced on Mohawk vellum paper, to be bolt-bound into an artist's book between wood covers cased in lead. The forty-page volume weighed sixteen pounds, and contained twenty-nine posters by local artists and activists that included David Wojnarowicz, Martin Wong, Seth Tobocman, Anton Von Dalen and Missing Foundation, the group linked to ACT UP in the FBI file. The book version is included in library and academic collections such as The Library of Congress, The Walker Art Center, Yale University, and The Getty Center Library, and is in the permanent collections of The Metropolitan Museum, MoMA, The Victoria and Albert Museum, The Whitney Museum of American Art, The Brooklyn Museum, The Cooper-Hewitt, The Fogg Museum, and The Guttenberg Museum. According to Andrew Castrucci, the driving force behind *Your House Is Mine*, “Print people are the misfits in the museum world,” and as a result of the relatively smaller institutional budgets for printed material, more intrinsically egalitarian. Curator David Kiehl at the Whitney was an early champion of the transformation of *Your House is Mine* from a street project into a bound book, and Castrucci credits him as having been instrumental in making the book version into a reality.

Apart from the accomplishments attached to this elaborate undertaking, Castrucci has also committed decades to what he considers to be a performative practice, which included the establishment of the squat, and its arduous renovation; the formation of the gallery space and artist collaborative, Bullet Space; the excavation of historical artifacts from the Bullet site; the construction and maintenance of a printing facility within Bullet (where many of the posters were printed); the exacting task of printing hundreds of acceptable copies of each serigraph; submitting grant applications to Art Matters, Artist Space, Northstar Fund, and the Andy Warhol Foundation to fund the project; the design, production, and distribution of 10,000 copies of a companion newsprint broadside; the placement of books within institutions; and, in the spirit of the organizing principles behind *Your House is Mine*, ongoing requests for museums with copies of the book to provide lifetime memberships for every artist collaborator.

Bullet squat is still owned by its original homesteaders, and Bullet Space has functioned as a community gallery since its inception. Unlike the New Museum, which moved from its original location on lower Broadway to the world-class museum space it constructed for itself on the Bowery, or the Whitney, which moved from Eighth Street

to Fifty-Fourth Street, to Madison Avenue, and now, to the Meatpacking District, Bullet Space still resides where the *Your House Is Mine* project originated, the day after the Tompkins Square Park riot made it clear that if the remaining vestiges of the Lower East Side were not documented, no one would remember the New York that existed before it was transformed into a theme park version of itself by gentrification. Bullet Space is social practice, long before we had that name for it. And *Your House Is Mine* is what archives look like, before they make their way into our temperature-controlled cloisters.

Had *Enjoy AZT* been a Gran Fury work, as I originally intended, it may have experienced similar institutional placement, but would have been delivered through a different set of trajectories, entering art institutions through the front door. Within the methodologies deployed by Bullet, however, it would be fair to say it came in the back way, using strategies closer to the activism it represents. I do not mean to falsify a dichotomy between *Enjoy AZT* and the work of Gran Fury, whose ongoing critique of capitalism threaded its way throughout the collective's entire output. In tone, *Enjoy AZT* might have been a more bald articulation of these critiques, but the back cover of Gran Fury's *New York Crimes* project—produced at the same time, and one might consider a companion piece borne of the same conversations—uses converse logic but applies an equally strident commentary on the profit motives of the pharmaceutical industry, also in the form of a fake ad. Its text is less didactic, yet equally damning by way of personal inflection, coming as it did in the form of a quote: “One million [People With AIDS] isn't a market that's exciting. Sure it's growing, but it's not asthma—Patrick Gage, Hoffman-La Roche, Inc.”⁸

Still, it cannot be denied that Gran Fury was given access to the institutional art world. We had no need to invade it. We were *invited* to infiltrate it. True to their practice, Bullet *squatted* within art institutions, occupying them, decades before the seizure of Zuccotti Park shifted the political meaning of occupation within the lexicon of resistance, and the intra-institutional political work of Occupy Museums and Occupy Wall Street's Arts & Labor Working Group permanently altered the way cultural producers and curators viewed our institutional dynamics.

Curatorially, there is a particular dilemma caused by exhibitions organized around the premise that the AIDS agitprop of ACT UP New York can be used as a model for how to mobilize communal responses during moments of crisis. It can be, but unlike the film and video from that period, which has context built into it, once these posters are isolated from the environment they were created for, they become oddly mute. When they are stripped of the native meanings that were activated in situ, their social proportion can't be approximated on a gallery wall with any degree of accuracy. Their “objectness” overtakes them, and no amount of didactic material adequately compensates for this effect. Work that easily sank its teeth into the scruff of your neck in a cluttered cityscape is immediately collared on a blank, white wall. It was never meant to have use in a gallery setting, and as a consequence, it doesn't.

AIDS 2.0 further complicates this curatorial dilemma, by implying that documenting HIV/AIDS is also somehow historiographical, even though any authentic history would be impossible to write while the ongoing pandemic still affects tens of millions of People Living With HIV/AIDS. Still, are there insights to be gotten here, within this example of the break in the chain of custody between the maker and the archive *Enjoy AZT* represents?

From first-hand experience, I am extremely aware of the scrupulousness with which archivists, curators, and historians approach the material they encounter, the reverence for the ethics behind the construction of archives, the many conversations about what sorts of curatorial gestures will sharpen archival practices as technology leapfrogs over them, the near-shamanistic challenges of archiving art practices that are fluid, performative, or intended to be ongoing, and I am fully attuned to the fine art of writing a finding aid, which serves as the tissue-thin line between a living archive and its becoming a crypt.

So, what manner of finding aid might connect the history of HIV/AIDS to the gentrification struggles in Reagan's America, as exemplified in the mediated journey of *Enjoy AZT* from the street to the museum wall? How do we link *Enjoy AZT*, curatorially, to *The New York Crimes*, or to the history of scientific research in America, in ways that enable a museum-goer to trace the intricacies of research protocols and international health policy as highlighted by the story of the drug AZT, now entering its fifth decade? With all the caution given to preserving intentionality within archival disciplines, how do we assure that archives remain dynamic organisms once the artifacts they contain are disconnected from their layers of hidden meaning, or their makers are gone and can no longer speak on their behalf? How do you cross-reference a history that can't be written until every last case of ongoing HIV/AIDS is history itself? How do we curate AIDS?

Notes

- 1 Avram Finkelstein, *After Silence: A History of AIDS through Its Images* (Berkeley: UC Press, 2017).
- 2 The poster text reads, "Enjoy AZT: The U.S. government has spent one billion dollars over the past 10 years to research new AIDS drugs. The result: 1 drug—AZT. It makes half the people who try it sick and for the other half it stops working after a year. Is AZT the last, best hope for people with AIDS, or is it a short-cut to the killing Burroughs Wellcome is making in the AIDS marketplace? Scores of drugs languish in government pipelines, while fortunes are made on this monopoly. IS THIS HEALTH CARE OR WEALTH CARE?"
- 3 Sean G. Kennedy, "Riot Police Remove 31 Squatters from Two East Village Buildings," *New York Times*, May 31, 1995, accessed February 13, 2018, <http://www.nytimes.com/1995/05/31/nyregion/riot-police-remove-31-squatters-from-two-east-village-buildings.html>.
- 4 Gran Fury, *Gran Fury: Read My Lips* (New York: 80wse Press, 2011), exhibition catalogue, 25-29.
- 5 United States Department of Health and Human Services, *ACTG 076 Questions and Answers*, accessed January 20, 2018, <https://aidsinfo.nih.gov/news/101/actg-076-questions-and-answers>
- 6 Robert D. McFadden, "Park Curfew Protest Erupts Into a Battle And 38 Are Injured," *New York Times*, August 8, 1988, accessed February 14, 2018, <http://www.nytimes.com/1988/08/08/nyregion/park-curfew-protest-erupts-into-a-battle-and-38-are-injured.html?pagewanted=all>.
- 7 Finkelstein, *After Silence*, 145-148.
- 8 The back cover of Gran Fury's *New York Crimes* is a fake pharmaceutical ad depicting a full-page close-up of a research scientist, holding a pipette to a petri dish, with the text caption "One million [People With AIDS] isn't a market that's exciting. Sure it's growing, but it's not asthma. — Patrick Gage, Hoffman-La Roche, Inc," with the tagline, "THIS IS TO ENRAGE YOU." The same graphic and quote (reformatted, in color, and

with a different tagline) appeared in a four-page Gran Fury intervention in the October 1989 issue of *Artforum*, titled *Control*.

Avram Finkelstein is a founding member of the Silence=Death and Gran Fury collectives. His work has shown at MoMA, The Whitney Museum, The Cooper Hewitt Museum, and Kunsthalle Wien, and is in the permanent collections of MoMA, The Whitney, The New Museum, The Metropolitan Museum, The Victoria and Albert Museum, and The Brooklyn Museum. He is featured in the artist oral history project at the Smithsonian's Archives of American Art, and his 2017 book for UC Press, *After Silence: A History of AIDS Through its Images* is available online and through local booksellers. He has been interviewed by *The New York Times*, NPR, *Slate*, *Frieze*, *Artforum*, and *Interview*, and has spoken about art, AIDS activism, LGBT cultural production, and the American Left at Harvard, Yale, Columbia, and NYU. Recent writing includes *NYU Flash Collective: An Art Intervention in the Public Sphere*, with Dipti Desai for *ART AS SOCIAL ACTION: An Introduction to the Principles & Practices of Teaching Social Practice Art*, Gregory Sholette, Chloë Bass, and Social Practice Queens, in 2018; *A Propagandist's Guide to Twenty-first Century Image Literacy*, *Visual Inquiry: Learning & Teaching Art*, Volume 6 No 2, *Intellect Journals*, 2017; and *FOUND: Queer Archaeology; Queer Abstraction*, for The Archive, Leslie-Lohman Museum of Gay and Lesbian Art, Spring 2017.

A Body of Work: Corporeal Materials, Presence, and Memory in Jerome Caja's Exhibition, *Remains of the Day* Kate Hallstead

Jerome Caja, legendary San Francisco drag performer and artist, dealt with the loss of his good friend, Charles Sexton, the way only a drag queen could—with guts, glitter, and a *damn good show*. After Charles' death from complications of AIDS in 1991, Jerome Caja created a body of works out of Charles' ashes, which was shown in an exhibition, *Remains of the Day* (curated by Amy Scholder and Rex Ray) the following year at San Francisco gallery, Southern Exposure. Caja's use of corporeal mediums was not simply an extension of his affinity for unconventional materials such as make-up and nail polish, but rather the result of a pact made with his late friend. Both artists being HIV positive, they said that whoever survived the other would have to make art from the other's remains. The show brought together the work of the two artists—something they never did in life. Caja's expansive body of work of and about Charles combines aestheticism and transformation. The small portraits demand close examination, pulling the viewer in to see not only Caja's rendering of Charles' visage, but also Charles himself, peppered into the ash and glitter-infused resin. This intimacy provides for a confrontation of his death, their own lives, and through his liminal presence, a sort of sacred conversation. The works were enclosed in glass cases, adorned with elaborate frames, and seated on black velvet recalling displays of saintly Christian relics.

Author and good friend of Caja, Adam Klein, remarked, "*The Remains of the Day* are reliquiae, though no longer protected or enshrined, but exposed to light and air, used, forced to work."¹ Unlike Christian reliquaries, the decay of Charles' body was not on display. The use of ash, rather than fingers, for example, in the reliquization of Charles provides a crucial distinction. Ash clearly demarcates death, but shows no sign of decay. This corporeal material navigates a space between life and death, creating presence from absence with a resistance to memory. The body of the dead is present, and cannot only exist in abstracted memory. When it comes to representing the dead, French intellectual Georges Bataille notes:

When someone dies, we, the survivors, expecting the life of a man now motionless beside us to go on, find that our expectation has suddenly come to nothing at all. A dead body cannot be called nothing at all, but that object, that corpse, is stamped...with the sign "nothing at all." For survivors, the corpse and its threat of imminent decay is no answer to any expectation like the one we nourished while that now prostrate man was still alive; it is the answer to that fear. This object, then is less than nothing and worse than nothing.²

Death is not complete absence, for a corpse remains, materializing the permanence of loss. The Aristotelian origin story of art is one born out of loss and a longing to recreate presence. Work with corporeal materials—blood, ashes, urine, etc.—is not simply

obscene or bold, but exemplary of the liminal body politics of the AIDS crisis for the dead, the living, and every state in between. Conceptually materializing remnants of a subject, literal or figural, brings a sense of spectral presence in its materiality, but with its presence, the fundamental immateriality of absence emerges with the recognition that the presence stands in for something lost. Corporeal materials, then, reverberate this vacillating conception of presence in their clear distinction between life and presence and death and absence. Acting almost as *memento mori*, these works force the viewer to confront not only the death of the person in the materials, but also their own. Especially in the context of the AIDS crisis prior to reliable treatment, viewing others' decline and death created a prophetic perspective of the human form in all states. They stand as a testament to visibility and presence in a society steeped in homophobia, mass death, and public funerals—openly countering the often hidden AIDS narrative in obituaries. They also stand as a consumable abstraction of death. Two works, Felix Gonzalez-Torres' *Untitled (Portrait of Ross in L.A.)* and Barton Lidice Beneš' *Brenda*, embody this well.



Jerome Caja, *Untitled (Portrait of Charles Sexton)*, 1992. Nail polish and Charles Sexton's ashes on bottle cap, approximately 2 inches diameter. Collection Amy Scholder. Photo credit: Christopher Burke Studios

Gonzalez-Torres' loss is manifested in his 1991 piece, *Untitled (Portrait of Ross in L.A.)*, in which 175 pounds of cellophane-wrapped candies, symbolizing the healthy weight of his newly deceased partner, Ross. Gonzales-Torres engages in an elegiac dialogue with Ross and longs for his returned presence. Removed directly from the cultural and viral plague that led to Ross' death, the space of contemplation created is more easily digestible than a work with corporeal mediums. Forced to confront ashes—and mingled within, the root of the death, the virus—wherein death is implied directly, the viewer cannot engage in any poetic abstraction from AIDS. A recent retrospective of Gonzalez-Torres' work sparked outrage over the erasure of the AIDS narrative so fundamental to his work in its curation.³ This ability to separate AIDS from his work is indicative of this indirect poetic narrative used in many works of the AIDS crisis. With the use of corporeal mediums, no such erasure can occur. Caja's explicit use of ash allows for no abstraction or reimagination of the virus as a foreign agent.

Beneš' piece, *Brenda*, c. 1991-2, incorporates the ashes of his late friend, Brenda, who died from complications of AIDS, into a multitude of ribbons, playing off the red awareness ribbon project. The uniform rows of stiff grey ribbons are reminiscent of tombstones in a cemetery. This funerary theme was solidified with the use of a central bronze plaque, acting not only as a gallery tombstone describing the work, but also as a resting place marker for Brenda, whose ashes—given her tough life and mostly invisible struggles—never had much attentive care prior to Beneš' work.⁴ Curator and Beneš aficionado, Kris Nuzzi, interestingly notes, "*Brenda* also must travel with a copy of Brenda's death certificate, as it is illegal to transport human remains without documentation."⁵ The ash-laden ribbons critique the ribbon project for being a hollow political statement. Beneš, who had a distaste for the ribbon project, commented, "If you want to do something about AIDS, contribute to research or make dinner for a sick friend. Don't wear one of those awful red ribbons."⁶ By adding Brenda's ashes, the ribbons take on a potency the simple red textile never had. Applying a product of death, paradoxically, endowed each one with an actionative energy. The fashionable red ribbon project brought awareness to AIDS, but *Brenda* plastered on the reality of the fatality of the virus and gave the epidemic scope. *Brenda* made her and many others' invisibilities visible despite the Academy Awards and Tonys being littered with red ribbons. If the reality of the epidemic was present in the ribbon itself, like with *Brenda*, would so many stars be wearing them on the red carpet? The ease of pinning a simple symbolic red ribbon onto a lapel is disrupted by the direct contact with Brenda's ashes. The activist critique to Beneš's grieving gave depth to the hollow, consumable symbol. Here, with the use of ash, there is no angle for the abstraction of not only the fatality of the virus, but also generally tepid attitude of AIDS awareness by those not directly affected.

Considering the work of Gonzalez-Torres, Beneš, and Caja, the museum, then, becomes a space wherein absence can be given form; where morbidity, mortality, and memory can coexist. The ritualistic practices of mourning, with stages of grief and customary practices, produce an altered state of reality. Quiet galleries with white walls transport the audience to a liminal space where—removed from the everyday, but also not quite a heavenly, atmospheric transcendence—they can contemplate the past, present, and future. We see this with Caja's portraits of Charles, who in the work is conjured at every stage of his being, including in his late-stage disability. Charles, losing his eyesight due to the common AIDS-related opportunistic infection, cytomegalovirus (CMV), chose to die by assisted suicide. With vivid colors so integral to his life as an artist, he could not bear the slow, muted, and colorless march toward death. Caja's portraits preserved him in color: a vibrant, glittering phoenix rising from the

grey ash. His absence was cultivated into a new presence. Charles, in his complex relationship with Catholicism, wished for his remains to be transformed into quasi-reliquary artworks by Caja to find a more positive, almost spiritual relationship with his body; transfiguring the ugliness of disease and death into an immortal reinterpretation of Charles and also a coping mechanism for Caja's own imminent confrontation with mortality.

The AIDS crisis and its advocacy, during the plague years as well as today, is centered around the body—its decline, death, and its resilience. Corporeal mediums become a fundamental tool for creating presence from absence, and visibility from invisibility—not only central to AIDS, but also to larger queer culture and others marked by this kind of loss. With remnants of Charles in every piece, his presence is multiplicitous. His portraits litter the walls, and after the exhibition, many were gifted to friends and family around the globe as personal relics. The others make their way around galleries, allowing the San Francisco queen to work for eternity.

Notes

- 1 Adam Klein, from his essay, "The New Eyes," in *Life Sentences: Writers, Artists, and AIDS*, ed. Thomas Avena (San Francisco: Mercury House, 1994).
 - 2 Georges Bataille, *Eroticism: Death and Sensuality*, trans. Mary Dalwood (San Francisco: City Lights, 1986).
 - 3 Darren Jones, "Galleries Representing Felix Gonzalez-Torres Are Editing HIV/AIDS From His Legacy: It Needs to Stop," *POZ*, June 9, 2017, accessed February 20, 2018, <https://www.poz.com/article/galleries-representing-felix-gonzalez-torres-editing-hiv-aids-from-his-legacy>.
 - 4 Laurel Reuter, "In the permanent collection, gift from Barton Benes," North Dakota Museum Of Art | Barton Benes, accessed February 11, 2018, <http://www.ndmoa.com/barton-benes>.
 - 5 E-mail to Kris Nuzzi, March 15, 2018.
 - 6 Reuter, "In the permanent collection, gift from Barton Benes."
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Kate Hallstead is an art historian and artist. She obtained her B.A. from University of Washington in art history and political science in 2018. Since 2017, she has been a curatorial intern at Seattle's Center on Contemporary Art (CoCA). She serves as a freelance arts writer in Seattle, often commenting on the detritus and spectral remnants left in the wake of hyper-urbanization. Her background in dance has influenced her studies in art, focusing on the body and concepts of presence. She currently serves on the Content and Experience Committee for the Seattle AIDS Memorial Pathway public art project. In the fall of 2019, she will attend City College of New York for her Masters in art history with a concentration in museum and curatorial studies.

In Case You Forgot How I Looked

Dudu Quintanilha

– *Artist Project*

Dudu Quintanilha is an artist who uses video, performance, collaboration and research to study expanded experiences of art engagement and social vulnerabilities. Along with Anita Silvia Lima Miranda, he is a founding member of Grupo Mexa, which uses artistic practices such as writing and performance to develop articulations of social issues in São Paulo. He is also a founder of Eterno Work In Progress, with Luisa Cavanagh, a film club that works to deconstruct ways of showing audiovisual works. His main individual exhibitions are: *XX.XX.XXXX* (2019, Mite Galería, Buenos Aires), *Cancioneiro Terminal* with Grupo Mexa (2019, Museu da Cidade, Bienal Sesc de Dança, Campinas, 2019), *Peup-* (2018, Kunstenfestivaldesarts,

Kanal Centre Pompidou, Kunstenfestivaldesarts, Brussels), *Fantasia casi soneto después de una lectura de dan(c)e* (2017, Universidad DiTella, Bienal de Performance, Buenos Aires), *Passinho* (2016, DotFiftyOne Gallery, Miami), *Ingovernables* (2015, Mite Galería, Buenos Aires), *Young at Heart* (2014, Solo Proyecto Arco Madrid, Madrid), *Coragem* (2012, Museo de Arte Contemporáneo de Rosario, Rosario), *Después de todo lo anterior* (2012, Galería Garash, México DF), *Selfcleptomano* (2011 Mite Galería, Buenos Aires). He was part of the following residencies: Q21 MuseumsQuartier (Vienna), Casa das Caldeiras (São Paulo), Red Bull Station (São Paulo), and LEA Faena Arts Center (Buenos Aires).

In case you forgot how I looked



these photos were taken before I had you.

So sad today, suddenly missing him a lot.

He was handsome and
always loved me so much,
even though he mixed his love with violence.

He was like us,
a person of great intensity, half hostage to the brute force of emotion.

How can I be the best me, with someone I do not know, without risk?
A risk, enduring an inevitable future.

I had a daughter 19 years ago.

I got HIV about 7 years ago.

She lives and works.

I still work on what I believe
it is the only thing I can do.



I decided not to deny what was given to me.
I decided to be alive,
alone, weeping in the brambles.

The strength I made to have her I never have found for anything else.
Sometimes I think the only way you could see me,
then, or now,
is if you saw me get hit by a van, a motorcycle, and a car
and you witnessed how
I stood up and kept walking.

Sad, only because watching, everyone took my power as their relief.

It was maybe during Carnival.
We had sex on a bed in a hotel room in Copacabana.
There was that friend of yours sleeping in the single bed beside you.
We started fucking.
You behind me, imitating the shell that we were wanting you to be.
But we didn't stay there long.

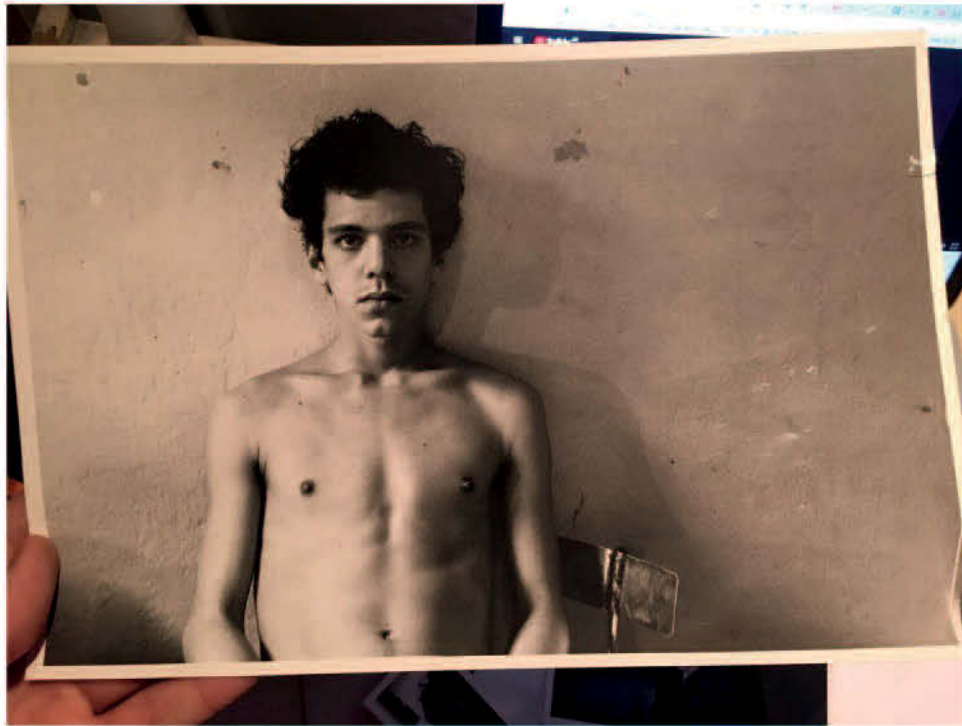
We moved to the bathroom
so you had the room you needed to enter me
and I could try to say something in your ear.
We did not use condoms and we did not worry.
I remember several positions in which we had sex.

I remember two beds. The pair of white sheets.

You had a drug problem that you hid with those loud shirts you wear.

Maybe it was that night
we thought we would be together forever,

How things turned out,
my wish coming true.



This may not be the first memory of a risk.

Maybe the scar I have on my upper lip,
on the right side, is the first one.

The one I've had since I was a baby.

19 years later I still have this feeling.

You, baby, are the thing that scares me most in life, imagining
something I could do could leave a scar on you.

We,

perhaps not all of us

live with this feeling
that we can kill unwittingly
and suffer for the rest of our lives.

I never accused or accuse you. Never.

But I've already been accused.
I've thought that any boy who finds out that my lip is
bleeding would think that if I kissed him I could infect him.
Spread it.

Dangerous kisses.

Only sometimes I can I let myself go out on the street
thinking that I could kiss anyone who wanted to with a cut on my lip.
It would feel so good that you would not even want to accuse me.

I believe in pain.

Like the pain I felt when your head started to flow through my vagina.
Those hands helping us. And only a few years later that face without scars...

Someone forced you, made you ache,
marked you and made you feel this guilt I feel.
The guilt of wanting to explain something that cannot be explained.
Guilt that hurts.
Guilt imposed on us by others,
the fears and shame of others.



Scratches.

I do not know if we all feel like people are taking enough risks
I like being that man who can kiss you with blood.
Being a mother, I decided to take care of you.

Our lives through camera-caught fictions, proof that anything can happen.
Is that why we do what we do? Is that why we love?

That's why I bother with several people.

I could try to make a movie that recounts the past
where we lived together in that city that floods.
Filmed in the years before meeting you.

Make a story of having a disease that weighs
as much as a stigma.

But in the movie, we will tell of the force that hurts the body
but that makes us feel the body.

The privilege of that pain
that still allows me to walk down the street imagining
white sheets,
my daughter,

with blood.

To imagine lovers who
could feel the same thing,

a common risk. With years of difference
we all meet.

I wish I could tell you how we knew each other.

If you wanted to make a movie about HIV I recommend that you try to do it
not set in the past, but in that city that floods.

Make a movie about the future,
where we would all be infected and positive;
and no one would suffer from abuse,
guilt would be given back to God (that in the future still exists),

And we still get pregnant
and having a daughter is an act of courage and risk.

And God kisses lips, with blood
and if you do not have enough courage to kiss while the movie is playing
you lose the chance to feel how soft and warm kisses can be.



Legacy: A Timeline of HIV/AIDS

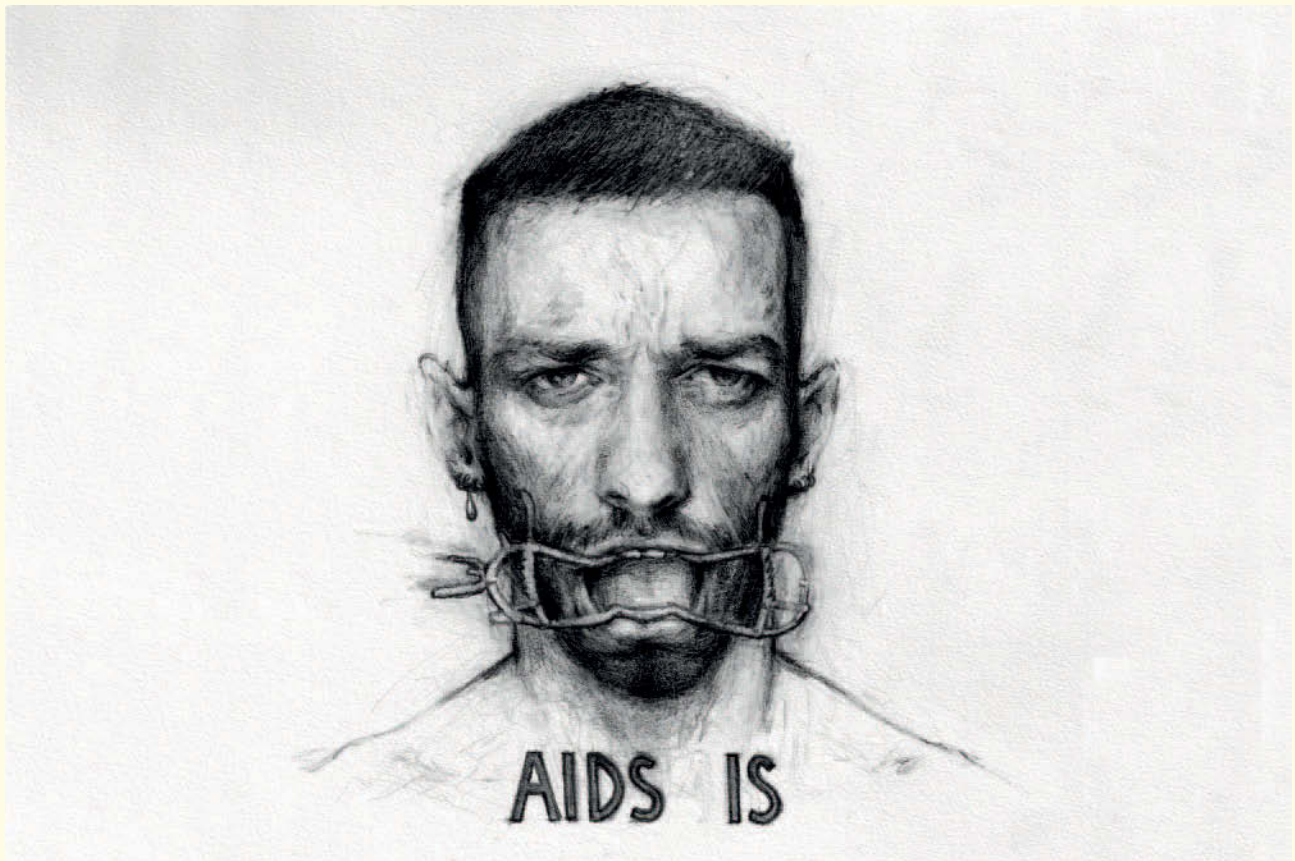
Carlos Motta

– Reprint

For an endurance performance video entitled *Legacy*, artist Carlos Motta worked with issue editor Theodore (ted) Kerr to create a timeline that he then performed along with journalist Ari Shapiro, with support from Tyler Haft. The text from the video was also created into a broadside that includes a drawing by Motta and Luca Cruz Salvati. The video

and the broadside are presented in *United by AIDS — An Exhibition About Loss, Remembrance, Activism and Art in Response to HIV/AIDS* at the Migros Museum, curated by Raphael Gyax. Below is the image and the timeline text.

– Theodore (ted) Kerr



Carlos Motta and Luca Cruz Salvati, *AIDS IS*, 2019. Courtesy of the Artists.

Legacy: A Timeline of HIV/AIDS

1908 — Scientists suggest that yet unnamed Human Immunodeficiency Virus (HIV) was first transmitted, from one chimpanzee to one human, as early as 1908 in the southeastern corner of Cameroon.

1960s — An HIV viral variant known as HIV-2 is found in West Africa and alleged to have transferred to humans from sooty mangabey monkeys in Guinea-Bissau.

1964 — Jerome Horwitz of The Barbara Ann Karmanos Cancer Institute and Wayne State University School of Medicine synthesized Zidovudine (AZT), a drug originally intended to treat cancer.

1966 — Genetic studies of the HIV virus indicate that it first arrived in the Americas in 1966, infecting a person in Haiti.

1969 — Robert R., a teenager from St. Louis, Missouri, dies of an illness that baffles his doctors. 18 years later, molecular biologists at Tulane University would test samples of his remains and find evidence of HIV.

1970 — Bayesian phylogenetic analyses estimate the jump of the HIV virus to the U.S. at around 1970, suggesting a crucial hub of early U.S. HIV/AIDS diversification.

1975 — The first reports of wasting and other symptoms, later associated with HIV/AIDS, are reported in Africa.

1976 — Arvid Noe, a Norwegian sailor, and daughter Bente Viviann Røed, die. It is later determined that Noe contracted HIV/AIDS in Africa during the early 1960s, transmitted the virus to his wife Solveig Oline Røed, who shared it with her daughter in utero.

1977 — A San Francisco sex worker gives birth to the first of 3 children who would later be diagnosed with HIV/AIDS. The mother would die of AIDS-related complications in 1987.

1978 — Senhor José, a Portuguese man, dies. He would be later confirmed as the first known case of HIV-2 infection and believed to have been exposed to the virus in Guinea-Bissau in 1966.

1980 — Ken Horne, a San Francisco resident, the first recognized case of HIV/AIDS in the U.S., is reported to The Centers for Disease Control (CDC) with Kaposi sarcoma.

1981 — The New York Times publishes its first article about HIV/AIDS.

— Morbidity and Mortality Weekly Report (MMWR), the weekly epidemiological digest published by the CDC, reports of five cases of Pneumocystis carinii pneumonia (PCP) among previously healthy young men in Los Angeles. All of the men were described as “homosexuals.”

1982 — The term Gay-Related Immune Deficiency (GRID) is mentioned by the media and health care professionals, suggesting an inherent link between homosexuality and HIV/AIDS.

— The term Acquired Immunodeficiency Syndrome (AIDS) is proposed at a meeting of gay community leaders, federal bureaucrats, and the CDC to replace GRID, as evidence showed the illness was not specific to homosexual populations.

1983 — French virologist Dr. Barré-Sinoussi isolates a retrovirus that kills T cells from the lymphatic system of an HIV-positive homosexual patient.

— The CDC reports 3,153 cases of HIV/AIDS in the U.S. and 1,512 deaths.

1984 — Gaëtan Dugas, a Canadian flight attendant who was unjustly linked by the CDC with several of the first reported cases of HIV/AIDS in the U.S., dies. His name has been exonerated since.

— The U.S. Department of Health and Human Services (HSS) announces that scientist Dr. Robert Gallo has discovered the probable cause of AIDS: the retrovirus Human Immunodeficiency Virus (HIV).

1985 — Rock Hudson, the first American celebrity to publicly admit having HIV/AIDS, dies.

— The first HIV antibody test is approved in the U.S. HIV testing of blood products begins.

— 91% of all U.S. health insurance companies deny coverage to people living with HIV/AIDS.

1986 — HIV is formally adopted as the name of the retrovirus that causes AIDS.

— The New York Times reports that “one million Americans have already been infected with the virus and this number will jump to at least 2 or 3 million within 5 to 10 years.”

1987 — AZT, the first antiretroviral drug, becomes available to treat the HIV virus.

— The AIDS Coalition to Unleash Power (ACT UP) is founded in New York City, a day after a stirring speech by activist and Gay Men's Health Crisis (GMHC) founder Larry Kramer.

— The "Silence = Death" project begins to appear on the streets of New York City.

— U.S. President Ronald Reagan says the word "AIDS" in public for the first time.

1988 — December 1st is declared as World AIDS Day by The World Health Organization (WHO).

— The U.S. FDA accelerates the drug approval process in response to demands by HIV/AIDS activists.

— American art critic Douglas Crimp edits *AIDS: Cultural Analysis/Cultural Activism* for the influential journal *October*.

1989 — New York arts organization Visual AIDS initiates the first Day With (out) Art, an event where educators and arts administrators work in partnerships to program art projects that raise awareness of HIV/AIDS and demonstrate support for people living with the disease and their caregivers.

1990 — Artist Keith Haring dies from AIDS-related complications.

— U.S. Congress enacts The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

— U.S. Congress enacts the Americans with Disabilities Act (ADA), which prohibits discrimination against persons living with HIV.

1991 — The red ribbon becomes an international symbol of HIV/AIDS awareness.

— The National Basketball Association (NBA) all-star Magic Johnson publicly announces that he is HIV-positive.

— Singer Freddie Mercury dies on November 24th, shortly after publicly disclosing his HIV-positive status.

1992 — The first combination drug therapies for HIV/AIDS are introduced. These "cocktails" prove to be more effective than AZT and slow down the development of drug resistance to the virus.

1993 — The CDC expands the definition of AIDS in response to criticism that the existing definition under-counts women and other populations living with the virus.

1994 — U.S. actor Tom Hanks wins an Oscar for his portrayal of a man living with HIV/AIDS in *Philadelphia*, America's first mainstream movie dealing with HIV/AIDS.

— Invirase, the first HIV protease inhibitor is approved in the U.S.

1995 — Saquinavir, a new protease inhibitor, becomes available to treat HIV. Highly Active Antiretroviral Therapy (HAART) also becomes available. Within two years, death rates due to HIV/AIDS would plummet in the developed world.

— AIDS activist and patient Jeff Getty becomes the first person to receive a bone-marrow transplant from a baboon, as an experimental procedure to treat HIV infection.

— HIV/AIDS becomes the leading cause of death for Americans between 25 and 44 years old.

1996 — The Joint United Nations Programme on HIV/AIDS (UNAIDS) is established to coordinate a global response to the pandemic.

— The first home HIV test is approved by the U.S. FDA.

1997 — French President Jacques Chirac invites other countries to create a fund that would help increase the number of HIV/AIDS studies and experiments.

1998 — The Treatment Action Campaign (TAC) is founded by Zackie Achmat to campaign for greater access to HIV/AIDS treatments in South Africa.

— Gugu Dlamini is stoned to death in Durban after bravely revealing her HIV-positive status on the radio, inspiring protests in South Africa and around the world.

1999 — First HIV human vaccine trial begins in Thailand.

— Zackie Achmat announces the world's first drug strike stating, "I will not take extensive treatment until all ordinary South Africans can get in on the public health system."

2000 — The WHO estimates that 15 to 20% of new HIV infections are the result of blood transfusions.

— The U.S. pledges \$200 million dollars for HIV/AIDS relief in Africa.

2001 — The U.S. FDA licenses the first nucleic acid test (NAT) systems intended for the screening of blood and plasma donations.

— South African President Thabo Mbeki rejects calls to declare HIV/AIDS a national emergency.

2002 — Data shows that the HIV/AIDS epidemic's shift into poorer and marginalized sections of society continues.

2003 — The Clinton Foundation secures price reductions for generic HIV/AIDS drugs to benefit developing nations.

2004 — The United Nations (UN) Secretary General Kofi Annan compares the "War on Terror" with the "War on AIDS."

2005 — The CDC recommends anti-retroviral Post-exposure prophylaxis (PEP) for people exposed to HIV through rape, accidents, or occasional unsafe sex or drug use.

2006 — June 5th marks a quarter century since HIV/AIDS's first official case was reported.

2007 — "The Berlin Patient," Timothy Ray Brown who was co-infected with myeloid leukemia and HIV, undergoes stem cell transplantation and is cured from HIV.

— The WHO and UNAIDS recommend male circumcision to be considered as part of a comprehensive HIV prevention strategy.

2008 — The Swiss National AIDS Commission issues a statement for doctors in Switzerland about the safety of HIV treatment to reduce transmission, stating that an HIV-positive person on effective HIV treatment (ART) cannot transmit HIV through sexual contact.

— For the first time in Latin America, The 7th International AIDS Conference is held in Mexico City.

2009 — The Obama Administration lifts the HIV Travel Ban.

2010 — U.S. President Obama signs a comprehensive health reform, the Patient Protection and Affordable Care Act (PPACA) into law providing new health insurance coverage opportunities for millions of individuals in the U.S., including people living with HIV/AIDS.

2011 — U.S. Congress reinstates a decades-long ban on federal funding for needle exchanges only two years after eliminating the same ban.

2012 — The Oslo Declaration on HIV Criminalization, a ten-point declaration calling for the end of criminal prosecutions for HIV non-disclosure, exposure, and unintentional transmission is drafted by activists and academics in Oslo.

2013 — UNAIDS reports that since 2005 deaths related to HIV/AIDS have declined by almost 30%.

2014 — A child thought to have cleared HIV with treatment, tests positive for HIV, a disappointing setback in the quest for a cure.

2015 — Findings from IPERGAY and PROUD studies show Pre-exposure prophylaxis (PrEP) to be effective in reducing HIV transmission.

2016 — First organ transplant from HIV-positive donor to HIV-positive recipient conducted in the U.S.

2017 — The U.N. and partners announce pricing agreement to accelerate the availability of an affordable, generic, single-pill HIV treatment regimen in low and middle income countries.

2018 — There are approximately 37.9 million people living with HIV and 1.7 million people newly infected globally.

2019 — President Donald Trump announces his Administration's goal to end the HIV/AIDS epidemic in the United States within 10 years.

— In a medical breakthrough, the kidney of Nina Martinez, a 35-year-old HIV-positive woman is transplanted into another patient with the HIV virus.

— U.S. Congresswoman Democratic Representative Alexandria Ocasio-Cortez of New York, confronts drug company Gilead's CEO about the high cost of HIV-prevention drug Truvada, advised by prominent HIV/AIDS activists.

— HIV/AIDS key populations continue to include men who have sex with men, people who inject drugs, people in prisons, sex workers and their clients, and transgender people.

Co-produced by Migros Museum für Gegenwartskunst for United by AIDS — An Exhibition About Loss, Remembrance, Activism and Art in Response to HIV/AIDS, curated by Raphael Gyax. 1st edition: 2500. August 2019.

Seeing

HIV Ambivalence and Game-Playing Influence

Artist Kelvin Atmadibrata in Conversation with Oral Historian Benji de la Piedra

Growing up, artist Kelvin Atmadibrata played a lot of RPGs (Role-Playing Games). As an adult, he often creates images and experiences in which he destabilizes ideas of identity, power, audience, and play. In the conversation below, I use my skills as an oral historian to guide Atmadibrata to consider the connections between his playing and his creating. During the conversation, what emerges is a map of influence, in which games and geography seem to play a bigger role in the work he makes than other possible factors, such as his HIV status. The interview begins with me getting up to speed on role-playing games.

- Benji de la Piera

Benji de la Piedra: Since I'm an oral historian, I'm going to ask you to start briefly at the beginning. When and where were you born and raised?

Kelvin Atmadibrata: I was born in 1988, in Jakarta. I was born into a Chinese-Indonesian family, which is a kind of minority in Indonesia. I moved to Singapore when I was 13-ish, and prior to that was in Kuala Lumpur for three years. So, I spent most of my growing-up years overseas, and I only came back to Indonesia about four years ago. That was because I was diagnosed with HIV, and Singapore does not allow foreigners to stay in the country if they get the diagnosis.

BD: In terms of your work, I know video games are a major influence for you. I'm wondering if you can take me back to when you were, like, nine years old: What games did you play? What captured your imagination?

KA: Most of the games I played were Japanese Role-Playing Games (RPGs), like *Final Fantasy*, for example. I'm not sure if you're familiar with it.

BD: I'm not specifically familiar with *Final Fantasy*, but I used to spend a lot of time playing other video games, so tell me.

KA: Japanese RPGs are much more focused on story and characters and the development of narrative. They're very different from first-person shooters or *The Sims*, for example. I found that playing Japanese RPGs is more like reading novels. There are a lot of influences from folklore. Some people consider these games to be really boring, because they are very easy to play. You can usually finish them in ten to twenty hours of gameplay. But somehow the story gets really, really complex. I think most of the fan base is attracted because of the storylines.

BD: You mention these games are infused with folkloric elements, which is super interesting to me. Would you be able to talk to, say, your grandparents about video games?

KA: When I was growing up, video games were considered a children's thing. And they still are, so adults don't really talk about them. But now that you mention it, I think in terms of the narratives—and I'm talking specifically about the narratives—you might actually be able to talk to someone who is much older about them. But when you try relating it back to the gameplay, then you would lose their interest. So, it's a distinct approach you would have to take with someone of the older generation.

BD: As an artist, why pick video games to be in conversation with? What about the video game as a place of narrative is exciting to you?

KA: To be honest, I've never really thought much about it. I think it's a natural response. Only recently I found out that it's very common for Indonesians who grew up in the '80s and '90s to play a lot of video games. The games are quite expensive, but the pirated versions made it very accessible for almost everyone. So that was a natural growing-up experience, playing a lot of video games, especially Japanese RPGs.

BD: This may sound like too much, but I sense almost a pan-Asian-ness to what we're talking about: You're Indonesian, but part of a Chinese minority, you grew up in Singapore, and your greatest inspiration is Japanese. We Americans easily forget how much diversity there is on your side of the world, and that you may not identify yourself as "Asian" first, or even at all. So, I'm wondering how, if at all, some of these more precise cultural markers show up and intersect in your work.

KA: I'm thinking of my childhood in Indonesia. The majority of people in the area I grew up in were of Chinese descent. Economically, we tended to have more than other racial groups, so I think that actually gave us more flexibility in terms of video game consoles. Most of my classmates in primary school had at least two consoles at home. Whereas people not living in the city might have to share one console for a whole village. So that made games like Japanese RPGs more accessible.

Most Indonesian kids grow up with Japanese pop culture, even today, especially anime and manga comics. Again, it's very affordable, because the local publishers actually translate the comics, so it becomes very cheap for us to consume them. And because of all these cartoons that you watch every weekend, and the comics that you read every day, and the video games, I guess that "Asian-ness" just becomes commonplace.

That's kind of interesting, too, because it's only quite recently that Western or American cartoons and pop culture have been getting more popular here. If I remember correctly, Marvel superheroes, for example, were not popular back when I was a kid. But we watched a lot of *Power Rangers*, *Sailor Moon*—which are basically Japanese products. Maybe it has to do with the diplomacy that these two countries had in the past, though I'm not sure.

BD: That's fascinating. I know that Shogun and Harakawi are important influences for your work, so I'm also wondering if you can walk me through your early exposure to these visual languages. Did you notice a homoeroticism in them right away? Or did you develop a view of it over time and start to inject more homoeroticism into these languages through your work?

KA: I guess subconsciously I realized it all along, just from reading these comics and watching these movies and playing these games. But it's only recently that I have purposely injected these elements into my work, after having studied in greater detail the particular Japanese obsessions with things that are considered erotica, how acceptable it is in their social climate.

Two or three years ago, I had this idea that I wanted to try out in my work, about the different perception of Japanese superheroes versus American or Western superheroes. It was something I experienced back in Singapore, where there is a wider range of popular culture to be influenced by. There was a whole group of kids who grew up with Spiderman and all the Marvel superheroes. On the other hand, there was another set of kids who were anime maniacs. I noticed two very distinct personalities resulting from these attractions. The kids who are into American superheroes tend to grow up more what we perceive as masculine. Those who are into more Asian or Japanese comics and animes are more feminine, more bookwormish and nerdy. For me, this was an interesting opportunity to consider gender and the influence of popular culture on how we grow up.

BD: Has that influenced the way you go about putting on your work, your installations, your performances?

KA: I don't know. Maybe not so much. It's an observation I had a couple years ago. My works tend to fix on narrative, which is still very heavily based on the Japanese RPG that we talked about earlier.

BD: Right. Let's talk about your development as an artist. When did you start making art, or putting on performances?

KA: I started drawing when I was a kid, but I wasn't really allowed to grow up as an artist. Only when I was in Singapore, when I was away from my family with a lot of personal freedom, did I start to make my decision that I wanted to become an artist. That was 2006. And even then, I've never considered myself a painter, or someone who draws. I'm more excited by works which are not that conventional, or works that are really, really weird. I guess it's one of the reasons I started making installation work, and gradually developed into performances.

BD: So, Singapore was the place that you decided to become an artist. Can you talk about the contrast between Indonesia and Singapore? Was it because Singapore itself had some kind of effect on you, like the culture or the space there?

KA: Culturally speaking, they're very similar. But Indonesia is still considered to be a developing country, while Singapore is pretty much like New York. There's a lot of tall buildings and central business districts, etc. But when it comes to my personal experience, it was more about how far I was from my family. My family stayed in Indonesia, and I think that gave me a lot of personal freedom to try things out. I tried out different phases of sexuality and experimented a lot with my career path.

BD: Makes sense. Is there a strong artist community in Singapore? Did you find it incubated you there?

KA: Yeah, definitely. I started out my practice being really, really close with some of the more senior artists there. They gave me my first few opportunities to show my work.

The artistic community in Jakarta is pretty similar, but more politically inclined compared to Singapore.

BD: I want to ask about a couple of your pieces. I was hoping we could talk about *Death Saves the Strawberry* first. Can you walk me through its development?

KA: That work is more of an exploration than a strong piece. It was a time when I was trying to create new narratives from existing ones. Growing up in Singapore, all of the boys have to serve in the army for two years once they reach 18. But I did not have to, or was not allowed to, because I was not Singaporean. Being in the army was one of my aspirations as a kid, so it felt like a missed opportunity, though it's not something I regret. So, the work is, in a way, a playful recollection of that memory alongside all these stories, all these movies, all these characters, which I managed to compile.

BD: What was the audience response?

KA: That particular work did not require an audience, because it was meant to be performed for the camera. That is why the choice of the site was specific. It had to be performed in a place that used to have barracks. We have a lot of those in Singapore. At that same time, I was also having to fly back to Indonesia, because of a visa issue and possible deportation. I came across some strawberry fields in a city near Jakarta, which are pretty common, so I found it quite interesting to implement these contrasting sites and make a new narrative out of it.



Death Saves the Strawberry, 2013. Performance images courtesy of artist.

BD: In the description of the work you write, “Growing up as an urban kid did not give me a lot of spaces to be physically free and playful.” But in the next paragraph, you write, “The performer takes the role of an adolescent character.” So, it starts off personal, but then it’s almost like a set of instructions for someone to replicate it on their own. Is that something you envisioned when creating the performance, that others might do it themselves later?

KA: I never thought about that for this particular work. But for some of my other works, yes. I’m interested in the relationships that adults can have with video games. I played a lot of video games growing up, and I absorbed a lot of video game narratives during those years, but unfortunately I have completely stopped playing Japanese RPGs now. So, those narratives are contained within a short period of my life, maybe ten years.

So, now I’m interested in that attraction in the context of being an adult. There’s a period where people generally change from being innocent to being teenagers. It’s quite interesting because that’s very much reflected in the development of the main characters in most Japanese RPGs. You start with a character who is extremely weak, level one, without good equipment, no skills, nothing. But as the story goes, and you’re being told a lot of different storylines, the character grows up. So, it becomes a kind of parallel to how the players are growing up.

And now that I’ve been reflecting about it, I realize that some of the games I played were fifteen years ago. It’s almost as if I’m the character, in a metaphorical and physical way. That idea of adolescence was immortalized in a way. I think that’s one of my attractions to it. Those adolescent years are when people begin to question their sexuality and think about gender and sexual politics.

I think I have not really answered the question directly in terms of performances that are personal vs performance as instructions. It really depends—my practice has shifted—not necessarily better or worse, but I guess artists who create performances (in fact, artworks in general) started off with what is considered personal. Whether or not it eventually sustains one throughout one’s practice, I cannot say for sure, but in my case the personal perspective is important—but likewise, how they can be relevant to audiences who are foreign to my memories. So, in the process of making recent works, I try to start from what is personal and then seek potential unexplored spaces in which the work can still be presented by others—hence (maybe) universally more inclusive.

Ultimately, I do not think my works (which in themselves are often considered fan-fiction of existing narratives) are entirely mine *per se*. I always seek opportunities for others to be involved, in forms of following instructions (delegate performances) or collaborations.

BD: That makes me think of your work *Deep Throat*. How did it come to be?

KA: I did that in 2017, at the invitation of a festival in India. By then I was already back living in Jakarta. Making work with strong elements of erotica is not really possible here, because of the social climate. The festival gave us a theme to work with, which was “Silence.” So, I took that as an opportunity to perform something with more freedom to explore. Since it was abroad, I decided to create with more homoerotic elements.

BD: What was the audience like and how did they respond?

KA: The response was positive. The artist community there tends to support each other, so they don't really give negative criticism. But that was in India. I managed to re-perform this piece in November for a competition in Indonesia. When I was selected as a finalist, the response was pretty positive. I guess they were accepting, but there were rumors going around that I wouldn't advance further because of the subject I chose to discuss. Erotica, especially homoeroticism, is still quite questionable in Indonesia.

BD: Can you tell me about your decision to sign up with the Visual AIDS Registry?

KA: I knew about the site when I was in Singapore. I was part of a small group of artists that had come upon it. I can't remember when I made the decision to put myself on it. But I remember that shortly after I did, I put the link onto my website. It's just a one-line link, but it's there so my audience can discover something. It's like an Easter egg.

BD: I like that. Has anything changed for you since you listed yourself on the registry?

KA: Not significantly.



Depthroat, 2017, Performance images courtesy of artist.

BD: Is there's a way in which being an HIV-positive artist affects the work you make? Are you addressing a certain audience or trying to get a certain point across related to being positive? Or is your status just another fact that is part of the mix?

KA: I don't think too much about it when making my work. Now that you mention it, maybe I should be involving it more actively in my thinking process. But in terms of how and when and what, that's something I still need to experiment with.

BD: Is there a community in Jakarta of people that are positive? Are you able to have conversations about HIV?

KA: There are communities, but I'm not really having these kinds of conversations with them. But then again, it's just not that big a deal to me personally. So maybe that's why I'm not having those conversations, because it's never been a big part of who I am.

BD: What is next for you? Is there anything you want to tackle? Confront?

KA: Because of the political climate here in Indonesia, a lot of artists, myself included, have barriers towards making and showcasing our own work. We have to be extra careful. That said, I feel I will always inject elements of eroticism into my work, whether it's very, very vulgar or just beneath the surface. It will always be present in my work.

Kelvin Atmadibrata is a visual artist living in Jakarta, Indonesia. He works primarily with performances, often accompanied by and translated to drawings, mixed media and objects compiled as installations.

Benji de la Piedra is an oral historian and writer based in Little Rock, Arkansas. Among other projects, he is at work on a biography of Herbert Denton, Jr., an African American journalist at the *Washington Post* who died of AIDS in 1989.

Looking for the Faces of Our Friends

Emily Bass and Yvette Raphael

Zadie Smith has written, “In the history of photography that has concerned itself with Africa and its diaspora, the concept of the portal has been central. In a newspaper, say, a photograph of a black subject is usually conceived as a window onto another world.” For the past thirty years, AIDS in Africa has been on view through this portal. For those of us that work in the field, what is striking is how consistent the images seen on the covers of reports, accompanying media articles, and online have remained.

We have both been working on and been affected by HIV for more than two decades. In different countries, contexts and communities. We have, in this time, undergone our own changes. We have gotten older; so has the fight to address AIDS in Africa and the US and everywhere else in the world. There have been changes in access to medicine, in discourses about women’s rights, human rights, queer rights, the collision of the biomedical solution, and the basic realities that complicate use of medical tools—PrEP, antiretrovirals, and more.

So, we have changed, the epidemic has changed. And yet a peep through the portal that the media still periodically opens, via photo essays and articles, onto AIDS in Africa suggests that nothing has changed at all. We look through the portal and see the same images that we saw five, ten, and fifteen years ago: packed benches of women holding babies in swathes of colorful wax cloth; children in used t-shirts; men, wearing coveralls or construction helmets signifying migrant labor; adolescents in flip flops on dusty roads; crowds of young people grinning for the camera, leaping upwards, looking for all the world like contestants on a game show. What is the prize? Who is winning?

This sameness seems specifically true as it applies to HIV and women in Africa, where the most common image that we see is a sad but determined looking mother, available to be helped. She exists. This story is important. But it is not the whole story; the image is not the only one that’s available today. We miss, when we look at depictions of African women in the context of HIV, glimpses of changing realities: professional Africa AIDS activist women exhausted after another panel where they stood in for all women everywhere; economically stable men and women looking sharp, raising families, remembering to take their meds after a long day at work; and so much more.

Of course, like the epidemic, technology and media have also changed. Newspapers, NGO reports and television news segments are not the only way in. There are now portals on our phones. The perfect circle of the Whatsapp profile picture, so small it’s like looking through the wrong end of the binoculars. Tap it, and it flies up to fill the screen. There are long nails and short hair, new dresses, fierce faces and romances, children on the first day of school, images from professional photo shoots, little love stories.

We—Yvette and Emily—exchange pictures all the time. We call each other “ninja,” we can’t tell you when it started, but it works. Whatever outfit we’re in, we’re prepared to fight. We see each other infrequently. We peer at each other through our social media portals in the meantime. Yvette goes to Winnie Mandela’s funeral and posts real-time pictures on Facebook. In one, she’s spreading the shawl she’s wearing like wings and

turning her face to the sun. Here is Emily in front of a statue of lions in New York City. Yvette in a black beret. What does it mean, today, to be fierce?

Yvette is a curator and she is also one of the curated. She is a South African woman living with HIV. Emily writes about and works within the world of Americans engaged with AIDS in Africa. To do this work, you need to remember, every day, what you can and cannot see, what you do and do not know.

Earlier this year, we walked through the halls of the Smithsonian Museum of Natural History in Washington, DC, through an exhibition about “outbreaks.” There was a cage of taxidermized guinea pigs and hamsters: hanta virus. A spiky virus design in the carpet on the floor. We knew what we were looking for. There, in the middle of the room: a portrait of Yvette under a quote, banner size, above them all. Her words: “Where the governments see statistics, I see the faces of my friends.”



Emily Bass, *Yvette Raphael in DC*, 2019. Yvette Raphael, *Emily Bass in DC*, 2019.

Emily photographed Yvette there, beside her picture. The kind of picture we don't see enough, the kind of picture that we need to see when it comes to the ongoing response to HIV/AIDS: the picture that shows us the faces of our friends. Yvette also photographed Emily there.

Our trip to the Smithsonian to see Yvette's portrait came after we'd begun our own conversation about images, curation, the view of African women with HIV. We structured our conversation around specific images, a way to say more clearly to each other what we saw and what we knew.

The exhibition we'd talked about opened on World AIDS Day 2017. It was called *Umema Omesibindi, Mother of Courage*, and it hung in Constitution Hill in Johannesburg. It is a former prison and the site of the current Constitutional Court. The photos are of African women living with HIV, taken by a white woman who embedded herself with UNICEF for over a decade. The Bill & Melinda Gates Foundation pays for select images from the show to be available on *The Guardian* website to anyone who clicks a link.

Constitution Hill describes itself as a "living museum" and also posits on its website that, "There is perhaps no other site of incarceration in South Africa that imprisoned the sheer number of world-renowned men and women as those held within the walls of the Old Fort, the Women's Jail and Number Four." We think again of Winnie Mandela, who was imprisoned there. Constitution Hill is a place to remember women kept behind bars: women of courage. What happens when confinement becomes the condition for courage, when that same woman, once free, is vilified and smeared for her foibles, her violence, her rage when she gets out? What happens to women when they step outside the role set for them? How do we capture them? How do we fit them into the confines of narrow portals?

These are the questions that face us every day. They are the questions we think about when we choose our clothes, our images. And they are the queries that we brought to a conversation, reproduced here, about the *Mother of Courage* exhibition.



Screenshot, *Mother Of Courage / The Guardian 1*, 2019.

Yvette Raphael: I just think it gives a picture of a very poor Africa. For me, the missing part here is most of it depicts women alone in a struggle, right? Example, the photo of the woman feeding the baby, has a picture of a man, but it's so distant it doesn't show as a family unit. So, what is he doing in the corner? And he's so old.

Emily Bass: He's the only man, I think, in this whole series. And it's the only time that we see these women surrounded by, or not surrounded but even close to, anybody that either might be a source of support or a source of risk or a source of violence or anything.

YR: Yes.

EB: So, I noticed that as well. Do you feel like that's a pattern? Do you feel like these are absences that you see a lot?

YR: So, what I think we're perpetuating with these images is that African men are always absent. So if we have to talk about why are they absent, it can be a whole political thing. Why are men this absent? I feel this exhibit specifically feeds on the weaknesses of African men, of their inability to be fathers in a unit, right? It also feeds into a certain narrative that says African men don't care. However, if we look at it politically, we will also realize that patriarchy and capitalism brought into the fact that the husband always has to be away. So, some of them are just absent fathers—but also that's the narrative that's been pushed. That the husband has to go out and go and work, and the woman has to stay at home.

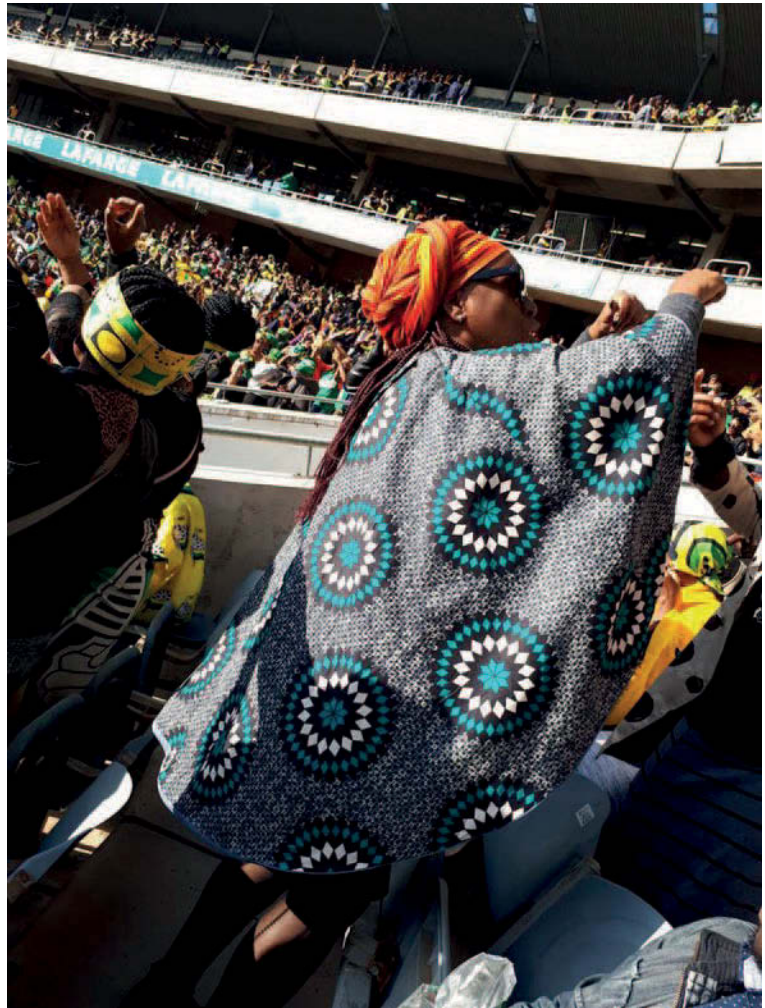
EB: What I wanted to ask you about was the young women that you work with—how likely is it that they would see and exhibit like this and what do you think their reaction is? What does it feel like to see these images?

YR: I think first of all it would shock. They would not even think these women are in South Africa, for one. And it will also be to some extent disgusting and painful for them. I use the word disgusting because they would feel like these women are selling out. You know by portraying an image of poverty. "You knew you were coming to do some event, why didn't you dress up, why didn't you wear Sunday shoes, why didn't you put on your cloak that is for meetings like those?" You know what I'm saying? "Are you posing, are you asked to pose?" Those would be some of the questions.

I would also want to say some of these images can be empowering—for instance, the women in the fields. That's very empowering; it shows that we can work either way. But it brings back a certain extent of our vulnerability and also of our oppression because whose land are we working right now? We're working the land of somebody who owns the land. But in other countries like Malawi and Zambia, say, women are really working their own land.

EB: There is a way that the pictures are seeking to be beautiful in a certain way. And what I noticed particularly is this photographer really likes this kind of golden light rays, it almost feels religious in a way. Should these exhibits be aiming for beauty and what kind of beauty?

YR: What we see as beautiful entirely depends on who is looking at it. So, I would look at it as depressing me, because it doesn't depict the Africa I live in, the Africa that I want, the Africa that I would want to see. You know what I'm saying? However, some



Yvette Raphael, *Winnie Mandela's Funeral*, 2018.

people can look at it and say, "Wow, what a beautiful black baby!" For me it was, why was this woman... my biggest pet peeve is women exhibiting their children.

It took a very long time for me to start showing my kids publicly as a mother living with HIV. I didn't show my kids for a long time. I don't exhibit that part; I exhibit the better picture of a strong woman living with HIV, making it against all odds. So, when I look at [the exhibit], it's not beautiful. Why are these women making their children vulnerable? What happens if this young child does not want that part of her life exposed, ten years after her mother died?

EB: You regularly put up these beautiful series of images of yourself. Sometimes it's sets of a day of seriousness but also realness. I wanted to ask you about the choices you're making when you do that and who you think your audience is?

YR: First of all, like I say, my Facebook is to teach, to laugh and to learn. It's not just to show off; I use my social media to talk about my struggles of being a women living with HIV, being an activist but my work is very political, right? This an old coping mechanism that we've learnt as activists. So a lot of our humor is also a coping mechanism. When we are afraid, we laugh. I'm afraid of the realities of living with HIV, I'm afraid of the reality of being a single mother and raising my kids on my own. I make a lot of jokes around that I take care of eight kids that are not mine, that are my friends' children, that I made a "stupid agreement." I always call it a stupid agreement because ... I don't think it's humanly possible what I'm trying to do, it's to raise eight other children that are not kids. To say, "I'll take you through school, I will help you, I will be your mother." I actually laugh through that, I call it my stupid commitment to my friends because: how did I think I would be able to possibly do that? But when I was faced with the challenges of my friends dying, I needed to make a commitment to them, to say, "Listen don't worry."

So, I take care of their school uniform, making sure they don't go to school with torn and tattered clothes. At times I do not have money to literally go and buy a cake, but I have a brother who bakes. I want to move forward, that's what I want to do. That's the picture I want to paint.

I am able to get a new phone because I have a contract on that, right? So I give my daughter my phone, she gives it to the next one in line, and they all hand the phones down to each other like that.

But here's the trick, the one who has the last phone must give it to somebody outside the family that they know would appreciate it—they move forward. So, I'm teaching my kids to share. You know what I'm saying?

EB: I'm thinking about how most of us make our images of ourselves with our phones, right? So, when you're passing along a phone, that's also sort of putting into people's hands their ability to curate and their ability to make images and their ability to represent themselves and share that. None of the women in their photo exhibit is laughing; I just went back and checked, none of them are even showing their teeth. So if they have a sense of humor, they weren't asked to show it.

YR: Yes. Most of the time when you go into communities, we don't think these people actually have a creative side to them. So we need to tell them how to stand, we need to tell them how to walk, we need to tell them how to jump, you know what I'm saying?

Unless you listen to them, will you hear? I don't think most of the time we listen to them because if you listen to them, you will hear, if you watch them, you will see.

EB: What era do you want to see pictures from, or do you not want to see pictures anymore?

YR: I would love to see pictures from the whole HIV era, right? I want to see pictures of what women want to be taken, right? I have friends who survived AIDS and are coming back and are looking at these pictures and don't want to see those pictures. However, these pictures are all over the world. So, if you come to me in my most vulnerable state, and I allow you to take a picture because I think my picture of me being sick and dying is going to help make government or in our case a government changes their mind about how to keep people living with HIV and actually give them treatment. Yes, I'm going to do that, if my vulnerability is going to serve a purpose.

EB: That's a powerful thing you just said, that of using our vulnerability to serve a purpose.

YR: I'm saying, I just felt you had a moment there.

EB: I'm having such a moment. We can have power when we share images of ourselves in vulnerability. But it's when we make that choice ourselves, I think, right?

YR: Yeah. That happened ... But also what happened is I survived it.



Emily Bass, *Yvette and Emily*.

Yvette Alta Raphael is a consummate leader in the fight against HIV. As a woman who has been living with the virus for over 15 years, she has experienced first-hand what HIV stigma, insufficient prevention education, and reduced access to healthcare can do. She utilized her natural leadership abilities to co-found the Tshwaranang Care Center for People Living with HIV and AIDS (PLWHA). Ms. Raphael has spoken around the globe, including several International AIDS Conferences to advise researchers, advocates, and policy makers on how to best win the war against HIV and AIDS. Her passion has been to improve the health outcomes for young women and girls, but her trusted expertise has also been lent to developing policies in the workplace and to create better, more efficient structures to utilize the available governmental resources to End AIDS. Furthermore, Ms. Raphael is a trusted globally renown advocate on effective and efficient education to the general community regarding new and developing research for medications that treat and/or prevent HIV.

Emily Bass has spent more than twenty years writing about and working on HIV/AIDS in America and East and Southern Africa. Her writing has appeared numerous publications, including *Esquire*, *The Lancet*, *Ms.*, *n+1*, *Out*, *POZ*, and *Slice*, and she received a notable mention in *Best American Essays*. For the past thirteen years, she has worked at AVAC, a New York-based advocacy organization where, as Director of Strategy and Content, she helps build powerful, transnational activist coalitions that use data to campaign for AIDS accountability and change. A lifelong social justice activist, she has served as an expert advisor to the World Health Organization and is a member of the What Would an HIV Doula Do Collective. *The Plague War*, her book on America's war on AIDS in Africa, is forthcoming from PublicAffairs Press in 2020. She has been a Fulbright journalism scholar in Uganda and received scholarships from the Norman Mailer Writer's Colony and the Vermont Studio Center. She is the 2018-2019 Martin Duberman Visiting Research Fellow at the New York Public Library. A Manhattan native, Emily lives in Brooklyn with her family.

Stones and Water Weight: Working Out Past and Future with Mykki Blanco Edward Belleville

At the German premiere of *120 battements par minute*, director Robin Campillo recalled helping dress the body of a friend's dead lover. From the audience, veteran activists were impatient to share their own anecdotes about the Paris and Berlin and New York chapters of ACT UP. They tutted when they grew bored. I took notes.

Much early AIDS activism was intended to be memorable. Shocking, disruptive, and effective, the interventions of ACT UP and other activist communities have been popping up again in recent years, on screens and in galleries: part of what Theodore "Ted" Kerr, editor of this issue of *On Curating*, and Alexandra Juhasz call the AIDS Crisis Revisitation. According to Kerr¹, this representational trend began around 2008 and has undertaken valuable work in commemorating the early crisis response of the '80s and '90s. Nonetheless, his critique also draws attention to how exclusions of race, gender, and class continue to structure these discourses of memory, in such a way that gay white cisgender men in urban settings tend to emerge as lone protagonists of the AIDS narrative. Juhasz has discussed how a focus on certain forms of activism have privileged those who were "more photogenic, wealthier, more powerful, and simply sexier (in the eyes of dominant culture)²." These are typically the AIDS stories that have been recorded in archives, discussed by researchers like myself, and even now made object of a certain nostalgia for community-based action. To combat this narrowing of AIDS narratives, artists and organizers are increasingly working to reflect the diversity of experiences and responses to the epidemic.

It was snowing a week later as I walked to the screening of the 2017 Day With(out) Art film project, "Alternate Endings, Radical Beginnings." Visual AIDS inaugurated the first Day With(out) Art on December 1, 1988, calling on the art world to contribute its resources and participate actively in the AIDS response. More recently, Visual AIDS has been marking December 1 by distributing audiovisual works (such as the ACT UP documentary *United in Anger* in 2012) or commissioning short films. For the 2017 edition, Visual AIDS commissioned black filmmakers to create new work about their experiences of HIV, to be projected both locally and internationally on December 1, from the Whitney Museum in Manhattan to my corner of Neukölln in Berlin. The project's title references 2014's film *Alternate Endings* with that extra clause, as a finger pointing in the direction of the future. Making black HIV experience the explicit focus of these seven short films, in the words of curators Erin Christovale and Vivian Crockett, is "a reclamation and affirmation of what has always been there"³ but till now marginalized or overlooked.

In the snowfall, a song lyric was bouncing around my head: "If you wanna see me..." the chorus looped. Back when I was newly arrived in Berlin, disembarking from my own terrible year, I saw Mykki Blanco perform at Club Gretchen. His first album had just come out and it insinuated its way into the rhythm of my nights and days. The alter-ego of Michael Quattlebaum Jr., Blanco's crossover success has marked new

space for socially conscious, queer-identifying rappers in the mainstream. He has also spoken candidly about the challenges of living with HIV since disclosing his status via Facebook in 2015. His openness and his global visibility as an artist (surpassing that of earlier HIV+ gay rappers like Tim'm T. West of Deep Dickollective⁴) have made Blanco's a powerful and arguably unprecedented voice for seropositivity in the 21st century. This is especially true for the younger generation that largely constitutes his audience, who did not experience the AIDS crisis first-hand, and whose knowledge of HIV bodies is shaped by the representations and collective remembering undertaken on days such as the Day With(out) Art.

Among a roster of renowned and talented artists who contributed to "Alternate Endings, Radical Beginnings," Blanco is one of the headliners. In the statement for his short film, *Stones and Water Weight*, Blanco speaks about HIV renewing the sense of how he produces his work and artistic persona: "I physically have to be somewhere, in a location moving my body."⁵ The doing and becoming of physical performance is how Blanco has learned to "intrinsically survive," how to pay his bills but also make a living artistically—a form of representational survival that, by performing the body of his own continuation, resists hegemonic narratives. He has explored issues of visibility, gender identity, shame, and empowerment in his previous work, such as the video for 2017 track "Hideaway," which was released to mark National Youth HIV & AIDS Awareness Day (and from which that lyric, "If you wanna see me..." loops). In *Stones and Water Weight*, Blanco further thinks about how certain bodies are made to 'fit' a cultural view of health and wellness that rewards self-perfection and erases otherness.



Mykki Blanco, *Stones & Water Weight* (video still), 2017. Courtesy of Visual AIDS.

The film consists of a single shot of a rocky landscape. It bears no marks of time or place, no horizon or sense of scale in which to situate the frame. For a full minute, its emptiness is all we have to gaze at before the figure of Blanco emerges into the upper right corner and proceeds cautiously to the center of the shot. He seems small, easily lost against the jagged stones, as he carries with him a Judy-Garland-as-Dorothy-style basket. This scene offers a visual representation of marginalized space where bodies like Blanco's are made precarious. Judith Butler theorizes precariousness as the "politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence, and death."⁶ Strongly concerned with how racialization produces such relations of inequality, enacted onto bodies, Blanco has in the past spoken about the "nutritional racism" that deprives non-white communities of affordable food. These racial divisions are furthermore central to recognizing the ongoing effects of the epidemic in the US, which disproportionately affects non-white groups (particularly men but not exclusively) living away from coastal urban centers. Blanco's careful movements across the jagged rocks, then, can be read as part of a wider intervention to represent and counter these trends. By materializing and positioning his Black seropositivity for the camera lens, Blanco undertakes what he calls in his statement "a show, a ceremony"⁷ of making a living visible.

We cannot, of course, represent whatever we want. As Butler makes clear in her reading of Foucault, "There is no body outside of power, for the materiality of the body—indeed, materiality itself—is produced by and in direct relation to the investment of power."⁸ The body is produced through the subjection of identity, by which power makes us (momentarily, imperfectly) visible as *a particular kind of* someone. Blanco's body remains undisclosed throughout the performance, beyond the baggy green outfit he wears, but as he reaches the center of the shot he puts down his basket and begins to pull out pink clothing, which he lays in a circle around him. The pink materials suggest hidden or forbidden significations: the feminine and the sexual, readings that Blanco's body (marked as male and as HIV+) exists in tension with. This is suggestive perhaps of Blanco's own fluid gender identity, which has moved from trans-identifying to gay male in recent years.⁹ However, he does not inhabit the embodiments that each pink garment suggests but arranges them and seems to highlight the split between body and potential body markers.

As he does so, two off-camera voices speak up, both voiced by Blanco. Their incoherent and overlapping speech seems to describe different mental states: the deeper voice speaks of paranoia and shame, while the other is earnest about the need for inner cleansing and a restored connection to Gaia. They speculate about the goal of wellbeing without reaching any outcomes, and in this way their repeated and distorted monologues give voice to the loops of self-scrutiny that determine how we present our bodies. Though the circle of pink material contains and protects Blanco, marking a new locus for action from abject space, yet in these off-screen voices we hear underlying narratives of anxiety and self-estrangement. We are confronted with what our own gaze, as the camera's, seeks to project and affirm of Blanco's body: whom do we have to satisfy, to look and feel well? Whose bodies are seen 'fit' for inclusion in regimes of value?

I read the rest of the performance as Blanco's response to this central question, through a complex repositioning of signifying practices that situates his bodily ceremony in relation to discourses of fitness and self-improvement. The pink circle complete, Blanco picks up a rock and holds it out in front of him. In silence we watch

him strain and tremble under this new weight, his eyes shut and lips pressed together. This posture puts him in a tradition of classical strongmen, whose taut bodies stand on podiums and perform extraordinary feats of strength, coded from Atlas to Arnold Schwarzenegger as the pinnacle of masculine power. I suggest that Blanco is also commenting, however, on contemporary obsessions with fitness imperatives, as part of wider shifts in how we think about our bodies *ethically*, as subjects of biopolitical and neoliberal regimes of power.

Shelley McKenzie suggests it was in the fitness culture of the 1980s that buff male gym bodies went mainstream¹⁰. Previously, exercise trends emphasized health benefits, like the rise of jogging in the 1970s. Exercising for looks had been viewed as suspiciously homoerotic and limited to bodybuilding subculture, but as the male body became more visible and commercialized (iconically packaged in Calvin Klein briefs) so too was a new habitus forming through the gentrification of gyms. Young and ambitious corporate athletes flocked to these sanitized spaces, wearing branded sportswear and getting to grips with user-friendly equipment like the Nautilus, to work out the new fitness imperative and build a gym body.

Reclaiming the podium for a different sort of workout, Blanco uses the central image of weight to challenge fitness outcomes of gaining and displaying muscle mass. By holding onto the stone, he grips the burden of trauma in an act of *épreuve* that resignifies the 'strength' of muscle men with the pain and resilience of culturally 'unfit' bodies like his own. Encompassing these exclusions, Blanco ultimately produces a queer form of self-knowledge that again plays on questions of visibility and value. Of the two elements in the film's title, *Stone and Water Weight*, only the first is apparent in the scene. Stones surround Blanco and provide an image of fixed weight and body measurement on which fitness practices are founded. Of water, there is not a drop in sight: the expression 'water weight' in fact plays on a term from fitness discourse. One *Muscle and Fitness* article describes water weight as the "subcutaneous fluid stored in your cells, causing your skin to have a puffy, inflated look, and ultimately covering any muscle definition you may have earned."¹¹ In other words, this retained water weight disrupts the making *visible* of fitness.

As he comments in his statement, though, Blanco's water weight has another symbolic function: as "the easiest to shed," water weight signifies the need for "release" of physical and mental trauma¹². Blanco plays with the language of fitness as well as its practices, then, to suggest an alternative to the visible heaviness in kilos and pounds of the stone in his hands. His performance invites us to consider a weight of remove that is traced through the body's displacement of itself, as working through and exorcising the obstructive past. We do not see the water Blanco sheds as sweat during his work-out but imagine the crossing over that transpires, undetectably, through his skin in its exchange with inert rock. Here in the precarious space of unrepresented bodies, working out such alternative queer forms of weight offers a personal ritual and practice of embodied memory that addresses itself not to the stringent regard of culture but to personal and collective survival.

These concerns challenge us to engage furthermore with how certain bodies (dis) appear in discourses of health and fitness. As a black person, Blanco's body is subject to racial discourses of hyper-sexuality and hyper-masculinity that, as discussed in a recent collection by Brittany Slatton and Kamesha Spates, produce black male bodies in terms of threatening criminal physicality.¹³ In these discourses, muscular black male bodies are not typically 'fit' for the same aspirational narratives as white ones,

rather they are imagined within abiding racist logics as dangerous and poor, an unruly element against which social violence is justified.

When gay male bodies work out, they too mean something else than the white heteronormative ideal. Tim Dean argues that, in health discourses of risk, keeping a fit body is the sign of being a self-disciplined, productive member of society.¹⁴ In the context of the AIDS crisis, gay bodies came under enormous pressure to distinguish themselves from 'unethical' (uncontrolled, polluting, HIV-transmitting) sexual desire and the dread potential to conceal illness. The fit gay body has thus been produced in tandem with the stigma of AIDS, which emerged in the public imagination through educational campaigns and media images of sarcoma, muscle wastage, and grieving bedside relatives. Having the right musculature presents an ethical gay subject under the control of a fitness regime, contained by the duty to enhance and display the body. Originating with '80s "clone culture," muscled gay bodies can also be seen as part of cultivating and idealizing classically male attributes, which reinforce a fantasy of coherent and normative gender: a rugged and unambiguously 'male' body that resists maligned and improper femininization.

The pervasive demands on gay bodies to embrace fitness—as the required signifier of ethical self-control and gendered desirability—have produced a commercialization of gay muscles that continues to sell not just memberships at gay gyms but underwear, cruises, and Pride parties: part of the apolitical consumerist gay lifestyle that Lisa Duggan has critiqued as the homonormative.¹⁵ A glance at apps like Grindr underscores the dominance of this form of embodied fitness: the gallery of headless torsos is like the wing of a museum packed with antique sculptures, all variations of the same "highly athletic, toned, lean, hairless, Caucasian body ideal."¹⁶ Of course, such accounts need to be wary of reproducing a discourse of over-sexed and body-obsessed gay narcissists. Recent scientific research has been criticized for producing "a gay male body dissatisfaction imperative"¹⁷ that over-determines gay men as endlessly *desiring* their own bodies (harder abs, tighter glutes) to pathological excess, an inversion of eroticism turned inwards rather than out, unlike their fit straight counterparts.

I would suggest that, taking the intersection of black and gay readings into account, Blanco uses the significations of fitness practice to present a wider challenge as an HIV+ subject to the imperatives and restrictions of health. Though increasingly critical of being asked about his own health, Blanco has identified in the past as a "health nut" who avoids institutionalized healthcare by following a rigorously individual approach: "I honestly think it just comes down to how I personally take care of my body [...] I literally do everything that I can to keep my body and my mind healthy."¹⁸ He furthermore speaks in his statement of his frustration that fans compliment him on how well he looks, their assumption being that he is "somehow ill or incapable."¹⁹ He calls for "new interpretations of the HIV+ person"²⁰ that will no longer treat seropositivity as a position of compromised health.

It is an understandable desire to break with past assumptions about HIV bodies. Since being developed in the late 1990s, antiretroviral therapy has made it possible to suppress HIV and reduce the virus to 'undetectable' levels in the blood, which prevents transmission and makes HIV a manageable condition for those with access to daily medications. This shift in medical technology has reconfigured the most stigmatizing effects of illness—physical decline and risk of communicability—which raises the paradox of an HIV+ body that is irrevocably 'ill' at the same time as being

fit and undetectable. Does this count as health? I would say that Blanco's seropositive workout encourages us to dismantle the categorization of 'health' as an essential and an absolute, and to think instead about an unstable relation we move in and out of over the course of our lives.

Yet is it enough to resist being called 'ill'? I would suggest that our ongoing resistance to silencing and assimilation calls for us to consider occupying and resignifying the marginality of illness, towards an analysis that might also accommodate intersections with discourses of disability and mental health among others. If we are less prone to recoil from being identified as 'ill' in the eyes of culture, even as HIV is becoming manageable medically, we might avoid reproducing the exclusionary binary of health that stigmatizes particular bodies. Furthermore, the potential for HIV+ bodies to achieve viral suppression through antiretroviral therapy should prompt us to interrogate current and future conditions of seropositivity. Who has access to these treatments, both nationally and internationally? Who, through their exclusion from the discourse of medical undetectability, just as much as from that of AIDS memory, continues to be forgotten or ignored by our HIV narratives?

Nonetheless, within a context of racial discrimination and historical effacement, contesting the illness of HIV bodies is for me a radical enough beginning for a gay rapper lifting a stone. Dropping it again, Blanco lifts his face and eyes to the sky as the screen fades to black. We might read lament or redemption into this final gesture, or just grit. Redefining things involves more than the will to transcend them, and while the option to become undetectable is still unavailable to so many, the visibility of art such as Blanco's is a political necessity. It restores imagery of what has been left out, experiences that must be struggled with and against in the difficult processes of working out and fitting into seropositivity. This difficulty should also prevent us from simple narratives of overcoming. A recent survey on poz.com posed the question of whether respondents felt their HIV diagnosis had made them "ultimately stronger." Results were inconclusive: at the time of writing, 39% said yes, 27% no, and 34% did not have the virus.²¹

The crowd in the bar in Neukölln was smaller than I had expected, and nobody said very much in the post-screening discussion—not till after the projector was turned off and the music back on. As the snow continued to drift outside, there was no hurry to leave. We chatted about what we had seen: Blanco, and the other short films by Cheryl Dunye and Ellen Spiro, Reina Gossett, and Thomas Allen Harris, among others. We shared what we were doing in our different cities, and how these efforts were part of the outpourings and commemoration, the ongoing discussion of how to work out the past and the future—Blanco and I and the millions of others who were not around while ACT UP was on the rampage.

A flake at a time, it falls on us.

Notes

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The Denver Principles

People with AIDS advisory committee

– *Reprint*

In June of 1983, at the Fifth Annual Gay and Lesbian Health Conference in Denver, Colorado, a group of about a dozen gay men with AIDS from around the U.S. gathered to share their experiences combating stigma and advocating on behalf of people with AIDS.

Until that point, “AIDS activism” was mostly a local or neighborhood phenomenon in the West Village and Chelsea in New York, in the Castro district in San Francisco, in West Hollywood and a handful of other places around the country. The men gathered at the Denver conference were meeting for the first time, comparing notes and strategizing how to move forward to ensure their voices were heard and their expertise, as individuals living with the disease, respected.

They wrote out a manifesto, now known as The Denver Principles, outlining a series of rights and responsibilities for healthcare professionals, people with AIDS, and all who were concerned about the epidemic.

This was the first time in the history of humanity that people who shared a disease organized to assert their right to a political voice in the decision-making that would so profoundly affect their lives. Yet, the concepts codified in that document were not original; they were informed and inspired by the women’s health movement that arose in the 1960s. They reinforced the message that the personal is political and that women—and those facing a stigmatizing, life-threatening illness—needed to become agents for change, for themselves and for their communities.

In the months and years that followed, The Denver Principles spawned a self-empowerment movement that launched thousands of organizations and

became a lifeline for people with HIV around the world. While a few points in the document are dated, like the point advising health care professionals to “identify and discuss the theory they favor as to the cause of AIDS,” which was written before HIV was discovered, the underlying ideals remain unchanged. In 1994, those ideals were also reflected in the GIPA Principles (Greater Involvement of People with AIDS), later amended to become GIPA/MIPA (Greater and Meaningful Involvement of People with AIDS). Below is the text from the original Denver Principles document: a few words, urgently written with passion, vision and love, that launched a global movement that continues to grow.

Part of that growth is the Sero Project, a network of people living with HIV and their allies that continues to uphold and promote the enduring message written in Denver more than 35 years ago.

While much about HIV has changed since then, including dramatic treatment advances, HIV stigma has remained as dehumanizing, stubborn and damaging as ever. Sero believes that to combat stigma, we need to focus less on the stigmatizers—there is little defense against those who are willfully ignorant, cruel or hateful—but to focus more on the empowerment of the stigmatized. The Denver Principles remains our North Star, guiding not just people living with HIV, but all who face stigma and institutional disempowerment, toward a more enlightened and just future.

– Sean Strub, The Sero Project



Steph J Kim, *untitled (Denver Principle / PWA Self Empowerment group)*, 2019 (inspired by a 1983 photograph). Courtesy of the artist.

THE DENVER PRINCIPLES

Statement from the People with AIDS advisory committee (1983)

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

Recommendations for All People

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.

2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

Recommendations for People with AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.

2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.

3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

Rights of People with AIDS

1. To as full and satisfying sexual and emotional lives as anyone else.

2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.

3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.

4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.

5. To die – and to LIVE – in dignity.

The Denver Principles were drafted by Richard Berkowitz, Bill Burke, Michael Callen, Bobbi Campbell, Bob Cecchi, Artie Felson, Michael Helquist representing his recently-deceased partner Mark Feldman, Phil Lanzaratta, Tom Nasrallah, Bobby Reynolds, Matthew Sarner, Gar Traynor, Dan Turner, Elbert from Kansas City by way of Houston; and a PWA from Denver whose name has been lost to history. In the years since the Principles were drafted many of these men have died. This list was reviewed by Richard Berkowitz who remarks that it is hard to remember who did what when it came to the labor of producing The Denver Principles, indicating that some people were present and active during the entire process, while others showed up, and left.

The Sero Project is a network of people with HIV and allies fighting for freedom from stigma and injustice. Sero is particularly focused on ending inappropriate criminal prosecutions of people with HIV, including for non-disclosure of their HIV status, potential or perceived HIV exposure or HIV transmission.

Poland and AIDS

A Conversation Between Szymon Adamczak, Luiza Kempieńska, and Hubert Zięba.

In the spring of 2018, I was in the USA on a research trip looking at AIDS cultural production, with a focus on independently produced activist film and video. As I was finishing up the trip, a mentor, scholar Alexandra Juhasz, mentioned that I should speak with her friend and often collaborator, Theodore (ted) Kerr. Through Alex's work I had come across his name, and so I was somewhat familiar with his work. However, it was not until we had a chance to meet that I was reminded that much of the joy of research and being in the academy is not only the process of thinking and theorizing, but the opportunity to make connections, and community, to both witness and feel seen.

I met Ted in a coffee shop near his home in Brooklyn. Beyond some shared sense of media theory and AIDS analysis, what I was excited about within our conversation was the realization that someone else has already faced the problems I had been encountering in the course of my research. Those included doubts about the legitimacy of my interest in AIDS as someone with a seronegative status, the urge to prioritize my interest in minoritarian social groups excluding white gay men (while trying to focus on the cultural production within the so-called mainstream media), and the emergent reluctance to acknowledge the role some gay men played in the struggle for survival not only of themselves, but all the affected. Of course, that is not to say that over one cup of coffee, or even subsequent encounters, either of us resolved these topics. However, from then on, I have been better able to communicate my thoughts, and I have known that at least one other person would understand.

A few months after my trip to the USA, I got an email from Ted asking if I would like to be in conversation with two other academics, doing work about AIDS in Poland. At first, I was quite naively astonished by the fact that there were other Poles involved with the subject, but before long my initial disbelief was displaced by feelings of community and pride. Within a month, I had a chance to virtually meet Luiza Kempieńska, an art historian and graphic designer, and Szymon Adamczak, a theatre artist, writer, and culture field worker. Together, we had intersecting yet somewhat disparate interests, regarding HIV/AIDS, culture, and Poland. What was interesting was that all three of us experienced growing up in the post-Soviet Poland, working on our AIDS-related projects independently and virtually unaware of each other's work. It took an outsider, a world away, to bring us together.

In the conversation below, Luiza, Szymon, and I discuss our relations with HIV/AIDS and our homeland, education, and upbringing, our hopes and expectations about our professional and academic activities, our goals, and primary motivations behind the practices we have been developing for the last few years. Thanks to Alex and Ted, and Luiza and Szymon, not only did I begin to understand that I was not alone in my analysis, but I have also finally been provided with a sense of

belonging. And although I can only speak on my own behalf, knowing that as a researcher I have peers and readers is significantly stimulating despite the fact that we might be small in number.

– Hubert Zięba



Marek Sobczyk, *Me and AIDS*, 1996. Courtesy of the artist.

Theodore (ted) Kerr: Tell us a bit about yourself and your relationship to HIV and Poland.

Luiza Kempieńska: I am an art historian, a graphic designer, and a PhD student, based in Poznań. I was born in 1990, so I grew up in a time of political transformation in Poland; between the social and political remnants of the previous system and the focus on development, capital accumulation, and discourse of success that the country is struggling with now.

Szymon Adamczak: I am a theatre artist, writer, and culture field worker based in Amsterdam. Born in 1991, my everyday life is now anchored in the Netherlands, where I recently finished an MA course in theatre-making. Nonetheless, I maintain a vital relationship to the Polish art scene and to my peers who are largely operating from Warsaw.

Hubert Zięba: I was born in 1987, two years before the fall of communism, but I have no recollection of what was happening in Poland back then. One could say I am Polish and a researcher, but I'd rather focus on the behavioral aspect of my life and say that I can speak Polish and that I am doing research on HIV/AIDS, because I can't ignore the processive nature of being the same way I would like to call myself queer in the

performative sense that transgresses the boundaries of gender and sexual orientation. However, identifying as queer in Poland on most occasions requires an explanation and usually leads to being labelled in binary terms as gay anyway (as opposed to heterosexual).

LK: For me, identity informs my work. Or maybe I should say, from early on, I considered subjectivity in the context of presence and absence, the affective experience of art, illness, and mourning as part of my research. Maybe this was informed by my gender, related to my personal experiences. With a supervisor, I spoke about my participation in a research grant, concerning all-women Polish exhibitions, considered as a form of strategies and tactics of gaining space in the field of art, strongly taking into account the socio-political context. From there, at some point I became interested in HIV/AIDS in the US. In doing that work, I soon came to feel that I needed to change my location, for my research and myself. So, after some time, here I am in the US, looking at HIV/AIDS in the US as someone who has a Central European background. This shift in location was important to me. I thought I could say something more about HIV/AIDS, from here, that has been ignored so far and actually give these neglected issues a voice, restore their agency.

SA: My approach to HIV completely shifted after my diagnosis in 2017. It has been a turbulent year, as I have already resigned from a job at National Stary Theatre in Kraków, which happened to be one of the first institutions in Poland altered by the cultural war that the right-wing government has incited. Diagnosis found me right afterward in Amsterdam, when I was entering graduation year at DAS Theatre with no funding and with no insurance.

Without further ado, I aligned my artistic development with a new health condition and started to work and to reorient myself from there. Following Boris Groys' observations in his article called "Education as Infection," the body of an artist within art education undergoes an intrusion of bacteria new to the organism. He points to a five-step trajectory of such an event: shock to the system, weakness, resistance, adaptation, renewal. Constant (self)infection is perceived then as a chance of preserving the spirit of artistic development by embodying it, thus transmitting what is digested as a response from-within-to the outside world. I was not initially trained to be an artist. But thankfully the greenhouse-like conditions of an art school let me practice what it means and what it takes to be one, and I am talking about one infected with HIV and transformed in the consequence of it.

HZ: I did my first degree in English philology at a local university in the town of Rzeszow, my hometown, the very capital of Polish Catholic conservatism. While I was preparing my dissertation, which turned out to be a comparative study of gay movements in Poland and the United States, I was also involved in organizing integration parties for the LGBT communities from my region. It was a pretty exhilarating experience at times, especially when a mob of skinheads lined up in front of the disco club we rented. Having received my bachelor's degree, I left Poland and began a master's degree in gender, sexuality, and culture at the University of Manchester. Although I try to remember only the positive aspects of my stay in the United Kingdom, such as the level of higher education, friends I made there, and feeling secure against discrimination on the grounds of sexual orientation, I will probably never forget being treated unfairly for my ethnic origin. However, it was in the UK where I first met people open about their seropositive status.

SA: I find it quite striking, but can't help to notice, that I entered the HIV/AIDS field with quite a typical *Polish* mindset. I come from a Catholic, lower middle-class family. Being openly gay was already a lot to my environment. HIV was just not part of my lived experience apart from the virtual, yet quite tangible, fear of catching it whenever I went to get tested. I mostly took a free test at a local NGO, located in a shady hospital corridor that was filled with shame and "let's pretend that we have never seen each other here" faces.

I had been aware only to a certain extent about the legacy of AIDS. I am thinking here of groundbreaking version of *Angels in America* directed by Krzysztof Warlikowski, which I saw when I was 18. It had premiered while the ruling right-wing populist party Law and Justice was in power for the first time. Reagan's America was an apt metaphor for a political climate in Poland. Still, the AIDS epidemic felt like a foreign phenomenon, somebody else's story. I learned more about it when I was a student of liberal arts program at the University of Poznań. I could point here to Paweł Leszkowicz in the history of art department whose classes on the male body were rich with context from queer theories and from the development of queer rights worldwide, including HIV/AIDS activism in the USA.

I also barely knew anyone who was open about their status at the time. Not in Poland, for sure. At least in the context of the Netherlands, where I started to forge relationships with HIV positive people, I understood that for many it was not necessary to make HIV a crucial part of their identity or/and their public persona. With welfare, accessible medication, and a progressive neoliberal society, the stigma has become rather an individual than collective issue. I mean here especially the observed attitude indicated in the phrase "one pill a day makes a problem go away." It was not possible for me to just move on and to live with HIV as if it's just a chronic disease. Even if it is, then it maintains to be a very charged one.

I am aware of the very low and mostly controversial presence of HIV/AIDS coverage in Polish media and in the public discourse over the last decade. For example, the public viewed the issue of HIV through stories like this one about a persecuted black man, held responsible for infecting more than a dozen women. HIV is still rarely addressed as a public health issue; it is doomed to be framed as sensational and is often captured with an underlying moral judgment. I am convinced nevertheless, recently observing efforts of many people in the field, like the three of us in this conversation, that it is possible to change the discourse.

HZ: I remember the story. It dates back to 2008, when I wasn't really concerned with AIDS. The black man in question, a Cameroon-born journalist, was known in Poland under the name of Simon Mol. He died in custody a few weeks after being arrested. His serostatus had been known to the authorities, but apparently, he refused to go into antiretroviral therapy. At least that is the official version of events presented in the media.

For myself, having returned to Poland in 2010, I knew I wanted to continue pursuing my academic career, and I knew wanted to focus on AIDS. However, it took four years until I finally applied for a PhD. And as I was in the middle of the recruitment process, a very dear person to me came out to me saying that they had contracted the virus. I cannot deny that they have been a motivation for me ever since. I do not want to disclose how close this person is to me because of deep-rooted prejudice about HIV and AIDS in Poland.

Now, as I am finalizing my doctoral studies, I decided to emigrate to Ireland, because I have grown tired of facing homophobia in my workplace, neighborhood, and family.

TK: Tell us about projects you are working on. What do you want people to know about your work? What are some hopes/goals that you have?

LK: I am focusing on the as yet unexamined exhibitions of art relating to HIV/AIDS, organized in the second half of the 1980s and in the 1990s in Central Europe. I am paying particular attention to Poland, the Czech Republic, and Germany. I am analyzing these exhibitions in connection with contexts of transformation, the fall of the Eastern Bloc, and the processes of rebuilding the existing order, as well as the emergence of various particularisms. I view transformation as the process occurring on many levels, comprised not only of the political system and the economy, but also society in its various dimensions, including culture and identity.

HZ: I am currently working on my doctoral dissertation, on the variety of ways of reacting to the epidemic in the US through the use of audiovisual media. My first goal was to explore popular ways of portraying the disease and those affected by it, because of—as I used to think—the lack of the source material in Polish cinema and television. The choice of the subject was also influenced by the fact that popular imagery usually permeates from the dominant American culture into the Polish culture, and not the other way around. This, however, does not mean that Polish visual culture has been completely ignorant of the local aspect of the pandemic.

To the best of my knowledge, there are two feature films related to problem of AIDS, which are: *Pora na czarownice* (1993, dir. Piotr Łazarkiewicz) and *Kto nigdy nie żył* (2006, dir. Andrzej Seweryn). Moreover, for over two decades the theme of seroconversion or the risk of it have also been the themes of a considerable number of episodes of Polish soap operas (including *Klan*, *Pierwsza miłość*, and *Samo życie*) and—more recently—docu-soaps. What is more is the fact that apart from Warlikowski's adaptation of *Angels in America*, there is another play addressing the disease and stigma related to HIV/AIDS. It is entitled *Miss HIV*, and it was written by Maciej Kowalewski and adapted into a teleplay by Krzysztof Czczot.

Although in my academic work I focus mainly on the films made in the United States, what is striking about the contemporary portrayals of HIV-positive characters in Polish mass media is that most of them represent social groups which have hardly been affected by the disease, mostly white straight men, including a Catholic priest, and highlight the types of behavior which pose a substantially low risk of contracting the virus. While such a universalizing approach prevents Polish gay men from being scapegoated for spreading the disease, it leads to the erasure of their narratives.

As far as my doctoral project is concerned, having discovered that the images of the virus in the so-called mainstream US cinema and television are rather invariable and focus mainly on white middle-class homosexual cisgender men and—to a lesser extent—on white middle-class heterosexual cisgender women, I shifted my attention from popular imagery to representations of the struggle with the disease from independently produced alternative film and video. If it was not for the Tokyo Foundation, I would have not been able to complete the project, because due to copyright protection laws and the fact that many of the videotapes have not been digitized yet, I could not access the research material in question from the other side of the Atlantic Ocean.

SA: I have created a performance called “An Ongoing Song” and I released a zine contextualizing this work as my graduation project at the DAS Theatre in Amsterdam. It is a piece of visual theatre in a form of a duet between myself and American performer Billy Mullaney whom I invited to operate or to embody the metaphor of the HIV virus as I perceive it.

What I wanted to capture is the poetics of living with the virus which I understand as coming to terms with a non-human agent inside your body. In fact, it is a daily negotiated symbiosis:

I won't kill you, you won't kill me, here we are together, and let's make sense out of it. I think this process required a strong sense of solidarity and friendship. Billy who was a fellow student, in a way a perfect stranger to me, became an engaged and patient collaborator. I find it worth mentioning that with him being cis heteronormative and HIV negative, we constantly needed to work out our differences while maintaining a sense of separateness.

With this performance, I make my claim to become part of the heritage of HIV. I realized this on a study trip to New York, where I spent many hours reading up on the collection at Visual AIDS. I was studying the work of the artists relating to the virus over decades, and I was viewing it as a lineage that I would like to acknowledge and broadcast to the public.

However, the word “HIV” is never uttered in “An Ongoing Song.” I preferred to subtly mark it only with the medication bottles present in the space in which I potted hyacinths, a reference to Polish secret services gathering up files on homosexuals during the Communist regime. In this way, I am rather hoping to invite the audience to relate on their own to things that each is individually infected by, to transformations we've had, to all sorts of medications we take.

My performance is going to tour across Poland, and this is a new chapter for me. I will also present a video from my personal archive of me taking a Genvoya pill for the first time. It will be presented within the exhibition *Creative Sick States* at a public art gallery, Arsenal, in my hometown of Poznań. There hasn't yet been a Polish artist vocal about their seropositive status. I hope that my de-dramatized approach to HIV will offer an inviting, human-scaled tone to the conversation about HIV/AIDS in Poland.

LK: In the early 1990s, in Poland HIV/AIDS was associated with a very strong stigmatization, which resulted from the lack of social awareness. Educational activities and social campaigns did not reinforce the basic knowledge about the disease immediately. Numerous public controversies arose over actions taken by the state and non-governmental organizations. For example, establishing centers for people living with HIV/AIDS often triggered protest actions of local communities.

HZ: Łazarkiewicz's *Pora na czarownice* is a fictionalized account of an attempt to burn such a facility. And although such an arson has never been successful, the very efforts, which must have inspired the filmmaker, indicate deep stigma associated with AIDS in Poland in the 1990s.

LK: In this political and cultural atmosphere, opening art exhibitions related to HIV/AIDS was not an easy task. The first exhibition of art related to HIV/AIDS in Poland, organized, what is important, in the lobby of the Warsaw cinema, was closed after a few days, which was justified by the presence of works that were shocking to younger

audiences. I think then it makes sense to me that my research interests are rooted in analyzing exhibitions related to HIV/AIDS as emancipatory practices of the queer subject. I view these practices as activities carried out within the dominant system by its users, in a completely different way than it was intended. This approach does not assume the overthrow of the current order by its rejection or negation, but by such ways of operating that are foreign to this order. It makes use of a system that undermines power and escapes it, a response to procedures that create a socio-political order. At the same time, practices are not undertaken as part of a deliberate plan, but they rather are a kind of countless and scattered transformations of law.

SA: When I was diagnosed, I could not initially find satisfactory material about experiences of seropositivity that would speak to my heart. I was mostly exposed to more lifestyle-like brochures released by the big pharma companies and the cinematography aimed at revisiting the AIDS epidemic, like *120 BPM*. By making the historicized perspective prevail in the cultural production, it might in my opinion turn public opinion away from such phenomena as PrEP and from the obvious fact that the HIV/AIDS story is an ongoing story, with many new chapters and blank spots to discover. It is, still and most of all, a profound human experience to face and to bear with this illness. Eventually, I found this kind of guidance and depth in the writings of Gregg Bordowitz and Hervé Guibert.

Today, I find it necessary to speak from a perspective of a seropositive yet undetectable body, and to engage with the communities affected by HIV. For example, I am collaborating with the team of the Dutch magazine *Hello Gorgeous*, which is dedicated to HIV-positive people in the container installation performance for the AIDS Conference in Amsterdam, called *Stigma Experience*. It is envisioned to offer an experience of going through and past the stigma, tailored for a one person at the time. Soon the installation will be turned into a VR project.

HZ: I am pretty sure that it is necessary to first bring public attention to such therapies as PrEP and PEP before worrying about them being forgotten. Did you know that the latter is free only if you declare, for instance, that you have been a rape victim or have been assaulted by a lunatic with a syringe? Otherwise, you'll get a prescription which costs approximately €1000. I have recently been asked by a friend of a friend, why did I decide to do research on a problem that has already been tackled. That reminded me of an attempt to secure funding for my research. I applied for a scholarship from an institution named after a Polish and American war hero, Tadeusz Kościuszko. While I was pitching my project, I was accused of focusing on an outdated issue, no longer of any interest to anyone since the development of increasingly effective pharmaceutical therapies.

I am mentioning this not only to expose bigotry in the philanthropic institutions, but mainly to use the opportunity to debunk the myth of the patron of this particular foundation. Kosciuszko is believed to have embodied such virtues essential to Polish national identity as courage, patriotism, and unimpeachable (sexual) morality. While some traditional accounts of his love life focus on a failed relationship with a gentlewoman, other historiographers emphasize his sexual appeal to young men. The latter is very unlikely to be soon included in the official syllabus for teaching history in Polish primary and secondary schools. What is more, he is not the only figure whose homosexuality is left unsaid, and I am not very optimistic about when—if ever—this is going to change. Non-heterosexual gender identities are still taboo in Poland. While male members of the ruling party are being photographed caressing and kissing other

men, deny being gay, and threaten to sue anyone who claims otherwise, the opposition aligns itself with politicians known for openly homophobic remarks and persecute people for replacing the background of the Polish coat of arms with a rainbow. This does not create a positive aura for HIV/AIDS education and prevention in Poland.

SA: I am actively mapping the present practices and emerging projects in the field of HIV/AIDS in Poland. There are social scientists who recently started to build an oral history project in order to tell a story of HIV in Poland (within a larger scale project called EUROPACH). The theory that being part of Soviet Union “saved” Poland from epidemics does not mean that there is nothing to tell. There is also a collective of Polish academic researchers that includes artist Karol Radziszewski and his Queer Archives Institute, and they are busy with unfolding the pre-AIDS era in the framework of the international Cruising the Seventies program. There is a theatre critic working on a book about a Polish theatre director who died of AIDS in the '90s and obviously is not at all remembered as “our” Reza Abdoh. There is a foundation for a social education in Warsaw run by Agata Kwiatkowska, a leader in harm reduction, that offers therapies empowering HIV-positive men and those who are addicted to chemsex. She told me that there is a correlation specific to Poland of being infected with HIV and entering the chemsex scene afterwards. I also recently met Tomasz Siara, a new important voice from within the gay community, whose activist portfolio just started with a remarkable, grassroots platform aimed at promoting and popularizing the undetectable=untransmittable agenda.

What I feel is missing is the isolation of those many initiatives within confined and selective spaces of academia, art institutions, or the public health work scene. At times, I find many Polish peers very well aware of the current worldwide discourses on HIV/AIDS. I would say here that we blossom as individuals, our projects grow, but we fail to translate what we do to the average Polish citizen.

As an artist, I try to navigate between the aforementioned perspectives, so I guess I would say my goal, or rather, my role is to dedicate my time to facilitating new conversations and being as generous and helpful as I can to anyone who is trying to advance awareness of HIV in the Polish context. In the coming time I am going to pay the most attention to the archives gathered at Warsaw's Lambda Association and at Amsterdam's IHLIA Queer Library in order to grasp the AIDS epidemics in Polish and Eastern European contexts from the historical scope to the present manifestations, voices, and practices.

LK: My goal is to examine and restore awareness of these exhibitions, often overlooked in the historical-artistic discourse. The socio-political context in times of the political transformation in Poland is specifically reflected in the dynamics of the discourse accompanying exhibitions related to HIV/AIDS: from emphasizing a strong distance, fear of infection, and considering HIV/AIDS as a distant problem of Western provenance, towards emphasizing the full, direct involvement of artists and curators and the presence of HIV/AIDS in everyday life.

HZ: One of my goals is to expose state-funded inertia in terms of HIV prevention in the Polish gay community. Since the outburst of the epidemic, the number of HIV infections has been growing increasingly, year by year. Polish gay men invariably remain at the greatest risk of contracting the virus. Since the very beginning of the epidemic in Poland, men-having-sex-with-men constitute the majority of all HIV and AIDS cases. But despite that fact, and despite the fact that both independent and state

auditors have been calling on the officials responsible for fighting the disease to address the problem in the gay community, money is still being wasted mostly on campaigns targeted at the indefinite general public, no one in particular, or groups at relatively low risk of contracting HIV. To make the matter worse, the annual number of new infections has been soaring in the last few years.

TK: Where has your knowledge of HIV come from? How has the age you live in and the countries you have lived in impacted your awareness/knowledge?

LK: At the beginning, my knowledge about HIV/AIDS came mainly from school, but I remember that these educational activities mostly concerned the prevention of drug use, while HIV/AIDS itself was a side-related, accompanying topic. I have also talked about it with my friends. Regarding media campaigns, by the end of the 1990s in Poland, due to the limited financial resources, quite modest means of propagating information related to HIV/AIDS prevention were used; most of them were leaflets, posters and stickers. It was not until the year 2000 that planned and comprehensive activities were undertaken, and various media techniques began to be used.

HZ: I can recall one TV spot from a media campaign launched in 2007. It featured a few allegedly heterosexual couples dancing to a Leonard Cohen song. The punchline was: life is a dance—every step matters. I remember it was not long until one of the dancers from the clip actually came out as gay. However, at the time of the campaign, AIDS was not an issue to me. I also remember my mum watching a film about a white gay man throwing a farewell party before his death, apparently from AIDS. It must have been the late 1990s. I was too young to watch it with her. Twenty years later, I discovered that I was *It's My Party*. I have also seen some fragments of *Philadelphia...* with my mum. My dad, on the contrary, would joke about Freddie Mercury contracting AIDS, by calling the disease Adidas. Also, I will never forget his homophobic remarks about Elton John marrying his partner. He entered the kitchen where I was sitting having tea and said: “The world's ending - faggots marry.” I few years later, I came out to him as gay. Having said that, I have to admit that he has changed since then and that recently he has been very supportive.

SA: My awareness of HIV grew exponentially thanks to the emergence of the Internet, and when I started to travel and work internationally. The sexual education I received in the school was rather brief, except for a truly passionate biology teacher who made sure that we understood what HIV was. But nobody told me how a person actually does live with HIV.

Because I live in the Netherlands, I am renegotiating my relationship to Poland, and subsequently to HIV. I am in a place where I don't have to live with fear. I have easy access to medication, an understanding partner, a friendly and experienced doctor, and a queer-minded therapist. This kind of comfort protects me against the pessimism, hopelessness, and negativity, which I often encounter while visiting Poland and talking to my friends. For many of them, I am the first person they know who is living with HIV. Some would occasionally tell me that I am brave, but I would always disagree. Why? Millions of people live with HIV today. It is *brave* not to see it.

HZ: I can easily relate to that. Having virtually no sex education until the age of eighteen when I started coming to terms with my non-normative sexual preferences, I had never considered AIDS an issue. I knew the pronunciation, but I didn't know the spelling. I didn't know what it was. It was apparently the worst disease ever, but it

didn't endanger me. It wasn't my problem. Or I thought it wasn't. Then, as I began exploring my sexuality, I slowly started learning about this incurable fatal disease from films and TV dramas, books, the press, the Internet, and gay people I met.

LK: The biggest impact on me in terms of learning about HIV was the artistic creativity associated with HIV/AIDS, because the works began to show me specific, lived experiences.

TK: How would you describe the political climate in Poland right now, and how does that impact your HIV-related work and projects?

HZ: The political climate in Poland does not differ dramatically from the situation in other places of the world, including the US. The ruling party has been elected by people disillusioned by the liberal free market politics. Since the political and economic transformation, which took place in Poland as a result of the first partially free elections since the end of the Second World War, in 1989, the social situation of hundreds of thousands of Poles has hardly improved, while the elite has been thriving. I was not surprised with the result of the last parliamentary elections, although I am far from supporting the ruling party. I wasn't surprised, but I have been hopeless ever since. They won by handing over a symbolic amount of money to people for raising children, and they are unlikely to lose the elections any time soon. They also won by threatening Poles with the refugees and immigrants from Africa by identifying them with terrorism and the infectious diseases they might bring along, if the Polish authorities comply with the EU regulations on the relocation of Africans kept in refugee camps established in the southern parts of Europe. I cannot put all the blame on the current government. The previous authorities had the opportunity to grant same-sex relationships legal recognition and to criminalize hate speech on the grounds of sexual orientation. Now, they have a big mouth when it comes to criticizing those in power, but when they had a chance to make a difference, they failed.

And quite recently African refugees have been replaced by the LGBT community as the worst political enemy of the ruling party. Prominent right-wing politicians equate gay people with pedophiles, while calling journalists revealing scandals involving Catholic priests actually sexually harassing minors enemies not of the church, but of the state.

SA: Resentment, elitism, bigotry, and culture wars between the left and the right of the political spectrum make Poland quite a frustrating place to live. Democracy seems to be just a fictive framework. Massive protests are mocked with almost no answers. The urgency of climate change is barely treated seriously. Economically speaking, it feels like the process of transformation came to an end, too. Poland has become the West, especially from the perspective of Ukrainian citizens and other newcomers who migrated here in recent years.

Earlier in the conversation, I mentioned *Angels in America* premiering in Warsaw more than a decade ago. Ever since, none of the bills in favor of equality has passed except for the LGBTQ rights declaration signed by the president of Warsaw. The conservative party Law and Justice has learned its lessons and now dominates the political landscape, and the artistic field seems from my semi-foreign perspective to be paralyzed by these politics and its own ambitions.

HZ: ...And the prospects are rather gloomy. As far as the impending AIDS crisis in Poland is concerned, the activities of the national AIDS agency, under the rule of

previous governments, have been audited at least twice, in 2004 and 2015. The need for shifting the focus of educational campaigns to sexual minorities most severely affected by the disease is expressed in both documents very clearly. It seems no one in charge of the agency has read and/or taken the reports seriously. What is continuously being promoted in the state-funded educational campaigns about HIV and AIDS are highly enigmatic symbols, such as the red ribbon, the promotion of which is an official part of the agency's policy. Yes, the promotion of a symbol, which in combination with a three- or four-letter acronym, can be considered an example of prison slang rather than a message about safer sex practices.

SA: It is hard for me to say in what way specifically this atmosphere impacts my HIV-related work. I will be exploring this in the upcoming period. The native artistic scene in Poland is definitely, gradually opening up for non-normative voices and practices. When it comes to HIV *per se*, there is lots of work to be done even among us, the culture field workers. From the many conversations I have had, I can report that for a surprising number of people the notions of HIV/AIDS matter little or nothing.

Imagine—a privileged middle-aged professional from a renowned theatre in a private conversation hinted that I am doing the work about HIV so I could capitalize on it. Then he admitted that he takes PrEP, and that he gets it from Sweden. I was speechless. I had just received my first undetectable result at that time. By sharing this example, I would like to stress how very important it is to work towards de-stigmatizing people living with HIV in Poland. We need not only to know who has HIV in Poland, as Jakub Janiszewski's book states, but also who has died of AIDS in Poland to break the spell. HIV-related work is about empathy, intersectional attitude, intergenerational dialogue, and solidarity despite accumulated wealth and achieved social status. Poland was never more ready for this.

LK: The current political climate in Poland is worrying. I am particularly critical of the lack of sex education in schools, the discrimination of LGBTQ people in society, the atmosphere of exclusion, the stigmatization by the Polish church, the promotion of the traditional family model by the state, and the declining freedom, even to decide about your own body. I would like to stress that it is important to talk about it, especially in the context of such politically embedded research that we are conducting—related to HIV/AIDS. Such an atmosphere is not conducive to increasing awareness and knowledge; it does not build understanding and does not encourage cooperation. Actually, the political climate impacts my HIV/AIDS-related project, because I feel that my work is needed and its character in this context becomes more emancipatory and involved.

Szymon Adamczak is a Polish artist, writer, and dramaturg, working with theatre and performance, based in Amsterdam, the Netherlands. Member and co-founder of Kolektyw 1a Association in Poznań, he studied art history and philosophy at the University of Poznań and graduated from DAS Theatre in Amsterdam, a post-disciplinary research master for theatre practitioners. Previously, he served as the dramaturg and programmer of the National Stary Theatre in Kraków under the artistic direction of Jan Klata (2015-2017). He advocates for ambiguity, sincerity, and poetry in proposing projects that serve as means of reflection on the complexity of contemporary living. He has been working both in state theatres and on independent projects in Poland and internationally (Romania, Israel, Bulgaria, the Netherlands, the Czech Republic).

Awarded for performances devised with Magda Szpecht: *Dolphin_who_loved_me* at the 100° Berlin Festival (2015, Hebbel am Ufer) and *Schubert. A Romantic Composition for Twelve Performers and String Quartet* at the International Divine Comedy Festival (2016), both presented at several performing arts festivals in Europe. He was the recipient of a Młoda Polska/Young Poland Scholarship in the field of theatre (2017). Currently, he is preoccupied with forging an artistic practice within the HIV/AIDS field and its cultural, artistic, and social-political legacy of the past decades.

Luiza Kempieńska is an art historian and graphic designer. A graduate in graphic design at the University of Arts in Poznań, Poland, she is currently a Ph.D. candidate at the Department of Art History at the Adam Mickiewicz University in Poznań, Poland, writing her thesis under the supervision of Professor Agata Jakubowska. Kempieńska is interested in contemporary art, mostly related to HIV/AIDS and is currently working on a project devoted to HIV/AIDS art exhibitions organized in Poland in the second half of 1980s and in the 1990s during the political transformations. She participated in a project financed by the Polish National Science Centre (directed by Professor Agata Jakubowska), regarding all-women exhibitions organized in Poland. She also was co-organizer of the conference, “Theorizing the Geography of East-Central European Art” (2018, Poznań), associated with the “Piotr Piotrowski Center for Research on East-Central European Art” and is a teaching assistant in a travelling research seminar, “Gender Politics and the Art of European Socialist States” (2019-2020, Poznań, Zagreb, Timișoara) launched with the support of the Getty Foundation. She is also co-curator and researcher in the project *Creative Sick States* organized at the Arsenal Gallery in Poznań.

Hubert Zieba is a PhD candidate at the Institute of Audio-Visual Arts at the Jagiellonian University in Krakow. The main aims of his doctoral research are to identify past and present trends of representations of HIV/AIDS in the visual culture and to explore the non-uniformity of ways of responding to the problem. He received his Master's degree in gender, sexuality and culture from the University of Manchester in 2010. Since 2014, he has been conducting seminars on the history of culture and the history of New Wave cinema, and giving guest lectures on the cultural representations of HIV and AIDS. He also studied in London and—thanks to a grant from the Ryoichi Sasakawa Young Leaders Fellowship Fund—in New York and San Francisco. He is an active member of both local and international communities. In 2005, he represented his country at the International Session of the European Youth Parliament. Four years later, he organized events for the LGBT community in Rzeszow and worked to establish a local branch of KPH (Campaign Against Homophobia), a non-governmental organization dedicated to representing queer communities in Poland. In June 2019, he decided to emigrate from Poland to Ireland.

From Tactic to Demand: HIV Visibility Within a Culture of Criminalization

Theodore (ted) Kerr – *Reprint*

I wrote this text as a commission from Risa Puleo for the catalog of her 2019 exhibition *Walls Turned Sideways: Artists Confront the Justice System* at the Contemporary Arts Museum Houston. It was edited with great care by Jillian Steinhauer, and published by the Miami-based non-profit [NAME] Publications, under the editorial direction of Natalia Zuluaga, Lucie Steinberg, and Gean Moreno. *Walls Turned Sideways* “featured work by artists from across the nation that addresses the criminal justice system, mass incarceration, and the prison-industrial complex.” I was to consider the relationship between HIV, incarceration, and art. I had worked with Risa before, on “Curation will not save us: Wrestling with the spaces between analysis and action,” a published conversation for the exhibition *Cell Count*, curated by Kyle Croft and Asher Mones for Visual AIDS. Risa and I built upon her curatorial thesis, which explores connections between prisons and museums. Additionally, this text was also part of *A Structural Crisis in an Emotional Landscape*, a work by artist Kenneth Pietrobono, in which the artist commissioned writers to create with great political care. See the bottom of the article for more information.

– Theodore (ted) Kerr

In 2017, Brooklyn-born, Atlanta-based activist Shyronn Jones worked with the Georgia Coalition to End HIV Criminalization to create one of six postcards. On the front is a photo collage by Jones, the foreground of which shows a single light bulb on a string—an image that evokes the work of Félix González-Torres, ideas around “shedding light” on an issue, and as Jones puts it, a scene all too easy to imagine in which “detectives aggressively interrogating people living with HIV based on a mixture of false accusations, propaganda, speculations and stigma.”¹ The background features Jones, who is the founder of the HIV/AIDS awareness firm *iknowAwareness*, wearing a red T-shirt that declares: “HIV IS NOT A CRIME.”



Shyronn Jones, *HIV IS NOT A CRIME*, 2017.

Photograph by: Shymere Jones. Courtesy of the artist.

Produced by: GEORGIA COALITION TO END HIV CRIMINALIZATION

The text of the T-shirt is, of course, wrong—at least for now. Having HIV is a crime, especially if you are also a sex worker, a drug user, black or brown or queer, living in poverty, homeless, experiencing mental health issues, or at the intersection of any of these ways of being alive.² Depending on how and where you live, having the virus can land you in jail, solitary confinement, on a sex offender registry, outed on the nightly news, or with your kids, job, housing, and support system taken away.

Across the U.S., 34 states have laws that are used to punish people living with HIV, with prosecutors positioning positive folks as deadly weapons due to their status and as murderously inclined if they are unable to prove that HIV disclosure occurred before a consensual intimate encounter.³

In response to these laws, people living with HIV have been building organizations and a movement to turn the spirit of the “HIV IS NOT A CRIME” T-shirt into a reality.⁴ They have been working within their own communities and with the media to generate awareness about criminalization.⁵ They have also been working with state politicians to abolish or modernize HIV-specific laws.⁶ Many of those laws were put into place in the late 1980s and amended or intensified throughout the 1990s.⁷

Having HIV today means that, on top of addressing the ramifications of an incurable virus living in one's body, one must negotiate how to be seen as positive in order to stay out of jail, while also dealing with the stigma that comes with disclosure. But within the history of the epidemic, navigating optics to stay alive is nothing new. Before 1983, when the virus did not even have a name, people dealing with a then mysterious illness began using visibility as a tactic to combat silence, neglect, apathy, and the unknown. Since criminalization laws were passed, visibility has become a state-enforced demand.

Becoming Visible Against the Silence

With her postcard, Jones joins a long tradition of people who have lived with the virus and centered themselves in a blend of art and propaganda, working to be seen while also asking for help, sharing available information, and creating community in a call for care and justice. One of the first AIDS awareness posters was put up in the fall of 1981 in the window of the Star Pharmacy in the Castro in San Francisco. Nurse and activist Bobbi Campbell (1952–1984) created a flyer using photos of the Kaposi's sarcoma (KS) lesions on his body under text that read “GAY CANCER.” At the bottom, Campbell called on people with similar-looking marks to see a doctor.⁸ Five years later and across the country, a group of men in New York City formed a consciousness-raising group to deal with life in the dawning age of AIDS. The guys did not know what would come of their time together, but over the course of the gray winter and spring of 1986–87, they created the iconic “SILENCE = DEATH” poster.⁹ With loss all around them, they understood that the lack of public dialogue was making

the crisis worse. People were not getting the information they needed. The collective hoped the poster would send the message that no one should feel alone in the epidemic, that AIDS was an emergency, and that action must be taken.

Several years later, Alexandra Juhasz, a student in the Whitney Independent Study Program, brought together a group of women who were caring for people living with HIV. They gathered for months to talk about the challenges of the epidemic, exasperated by the culture's bias against black women and women of color. The group named itself the Women's AIDS Video Enterprise (WAVE), with a goal of creating activist videos dealing with HIV. In 1991, they released *We Care* (1991), a thirty-minute resource aimed at women and other caregivers. Thanks to a distribution grant from the New York State Council on the Arts, WAVE members were given \$50 for each *We Care* screening they hosted within their own communities, followed by frank and vulnerable conversations about health and sexuality.¹⁰

In our age of social media, it can be hard to imagine that the work of Campbell, the Silence = Death collective, and WAVE was created not for online likes or shares, nor for influencers, patrons, critics, or curators, but rather for people in need, in the hopes of creating communities. These activists aimed to reach the public wherever its attention could be grabbed: in the streets, store windows, church basements, neighbors' living rooms, and community centers. In a matter of years, information started to go viral, circulating in magazines and newspapers, on flyers in health centers, on the nightly news, and, in time, within classrooms and even via sitcoms and the movies. This visibility brought with it treatment and care, but also stigma and discrimination.

For communities deeply impacted by HIV and AIDS, such as the activist and art worlds of New York City in the 1980s and '90s, the urgency that had manifested in early posters and videos turned into a deep consideration of the power and purpose of art and culture in the face of suffering, apathy and death. Gregg Bordowitz, a member of the advocacy group ACT UP, a chronicler of the beginnings of the epidemic, and the director of many films exploring personal and systemic dimensions of the crisis, recently revisited these questions and the contexts in which they were originally considered. His 2011 book explores the Canadian collaborative General Idea's *Imagevirus*, a multiform project that generated much controversy among the AIDS and artist communities in its time. A generation older than most of the

ACT UP members, General Idea (AA Bronson, Felix Partz [1945–1994], Jorge Zontal [1944–1994]) took Robert Indiana's iconic *LOVE* image and reimagined it to read "AIDS." The group made a 1987 painting for a benefit in support of amfAR, the Foundation for AIDS Research, and would soon after circulate the updated image on billboards, subway ads, screens, and in sculpture.

For Bordowitz and others involved with ACT UP, *Imagevirus* was a logo that failed to give direction for action—a wasted opportunity that undermined the power of what they thought art about HIV should do. What Bordowitz and others didn't see in the moment was that, while *Imagevirus* may have seemed empty in the activist enclaves of New York, for others in mainstream places where denial of the existence of AIDS dominated the discourse, the work was a much-needed intervention. *Imagevirus* addressed populations across a spectrum of Western countries, each with their own distinct yet related issues. Rooted in replication, the transmission of the image crossed language barriers. "Indiana's *LOVE* logo is what communicates in the end," said Bronson recently. "Even teenagers in small German towns knew that AIDS should have read *LOVE*."¹¹

In the first decade of the epidemic, the visibility of the virus was propelled primarily by an urgency caused by desperation and death. Getting AIDS on people's agenda—cutting past hatred and fear to care and action—was a core goal that was achieved with profound success. In the years to follow, with the introduction of life-saving medication in 1996 and the newfound ubiquity of the disease, one might have assumed that visibility for a person living with HIV would become less fraught. But, as the ongoing story of AIDS reminds us, that has not been the case.

Dealing with the Dis-ease of Disease

At the turn of the millennium, Jones moved to Atlanta from Albany, where she had lived for ten years after leaving Brooklyn, the place where she was born and raised. She had recently been diagnosed with HIV and needed a change of scenery to figure out her new reality. Since moving, she has been able to make a home for herself and her daughter. She stays busy with a social life, work, and commitments to the Georgia Coalition and the local chapter of the Positive Women's Network – USA. Yet even in a city where she has lived for more than 15 years, she never feels entirely at ease. "The concrete wall in front of my apartment building for low to moderate income people looks like a prison cell

block, a reminder of both criminalization and my entrapment in housing inequality," she says. "I look at it and I just know that prison is the worst place for people living with HIV, because treatment, prevention, and support are limited on the inside. We deserve health-care, not incarceration."¹²

Jones is aware that her life would be much different had she been diagnosed a few years earlier. In 1996, highly active antiretroviral treatment (HAART) was released, and it meant that being told you had HIV was no longer a notice of impending death. With medication and access to housing and care, people now have the chance to live long and happy lives with the virus.

In addition to saving millions of lives, HAART has introduced methods of curbing new cases of HIV. Treatment as prevention (TasP) is a strategy that uses antiretrovirals to reduce the risk of transmission by medicating people with and without the virus.¹³ For HIV-negative people, TasP consists of post-exposure prophylaxis (PEP) or pre-exposure prophylaxis (PrEP), a regimen of meds taken before or after possible exposure that works to prevent the virus from taking hold in the body.¹⁴ For HIV-positive people, TasP refers to HAART's ability to suppress someone's viral load to an undetectable level, making transmission impossible. With this big change has come a host of questions, including: Who is and isn't seen as the "public" in public health?

Before TasP, people with the virus and their doctors spoke of T cells and CD4 counts, measurements of the body's capacity to fight infection. Now those numbers often take a backseat to viral load, a metric that indicates the amount of virus in the blood and thus the potential for transmission. A patient's adherence to their medication is tracked—a form of surveillance—to the point where their ability to suppress the virus becomes as much about self-care as it is about public health. The contours of visibility for people living with HIV changed under TasP. They're now held to a higher standard of responsibility than any other group with an illness in our culture. Managing the risk of contact, the labor of achieving good health, and the burden of disclosure all fall on their shoulders. And even though this work by HIV-positive people serves to reduce an HIV-negative person's chances of getting the virus, it may do little to convince someone not to press charges after the fact if something goes awry. As activists have pointed out, talk of viral load sometimes never enters the court, since it's beyond the understanding of many lawyers and often deemed inadmissible by judges who, like the laws themselves, are not up to date on the

science.¹⁵ Others, question whether it should be used at all, since medical access issues prevent many people from reaching an undetectable viral load, thus putting them at further risk for criminalization.¹⁶

In the face of all this, people scramble to furnish evidence of their disclosure. Some women freeze condoms to prove that protection was used; others bring potential partners to the doctor's office or have them sign a form acknowledging that a conversation occurred. Still others screenshot text messages in which personal HIV information is shared. People must go to great lengths to appease out-of-touch lawmakers who make assumptions and regard them with mistrust. "Disclosure happens more than lawmakers and/or the general public would like to admit," says Jones, "and it should be no surprise that disclosure happens more often in safe, empathetic and educated environments."¹⁷

The extraordinary burden of living with HIV is often keenly felt when the opportunity arises for intimacy with someone new. Artist and writer Jordan Arseneault explored this in a 2012 work titled *The New Equation*, created for the public art campaign *PosterVirus* by AIDS ACTION NOW. Arseneault's project riffs on the aforementioned "SILENCE = DEATH" poster, but with a new mutation: "SILENCE = SEX." Arseneault created his poster, text, and performance to work through the pitfalls of making oneself visible as living with HIV and to probe the questions and feelings that come up when the possibility of sex is on the horizon:

It's that awkward moment where you look up at the
SILENCE = DEATH poster
On his cluttered bedroom wall
And say the words
I AM HIV POSITIVE
Only to see him freeze, lose his boner, sigh,
And explain trippingly that he has an anxiety disorder
And "just can't take it right now."¹⁸

In the face of rejection after disclosure, Arseneault contemplates how, in the future, maybe silence could be an option. He takes the iconic poster and swaps out the old equation for his new one. But he doesn't stop there. At the bottom of the original work, a set of lines questioned the lack of structural response to the crisis and encouraged lesbian and gay viewers to act, ending with: "Turn anger, fear, grief into action." For his update, Arseneault writes: "The criminalization of HIV+ people perpetuates stigma and prevents preventions. HIV+ people are often caught in a 'Catch 22,' wherein

disclosure is required by law but often leads to immediate rejection. Inform yourself: overcome stigma and get laid!"¹⁹

Because of the law and prevailing stigma, even in the face of treatment as prevention, intimate encounters are fraught. Arseneault's poster highlights how, when the possibility of pleasure arises, people living with HIV are forced to decide between intimacy and the threat of Jones's bright light bulb of visibility. With shunning, isolation, false accusations, and jail sentences as possible outcomes, is there space for nuance? How can sharing something about oneself move from obligation to mutual discovery? How can the person living with illness be situated in a place of care, protection, and consideration rather than one of suspicion?

Artist Camilo Godoy, who is HIV-negative, is also grappling with the inequality of criminalization. For the 2013 Visual AIDS exhibition *Not Over*, he collaborated with people living with HIV on a series of performances in which criminalization statutes and punishments were written in a book using blood containing HIV instead of ink.²⁰ That same year he made a print that reads, "HIV: no longer a death sentence, today it is a prison sentence." The text appears on a piece of 8.5" x 11" newsprint and is hung using only two pins at the top, making it vulnerable. It flutters, shivers, and is always at risk of falling or being torn as people move through the space and building systems impact the flow of air. Art historian Kate Hallstead sees the work as a success for the clarity of its message and its connection to the world when on view: "It is obvious that HIV criminalization cannot be abstracted into anything but pure, simple discrimination. The piece pins the options of death and prison against each other in public."²¹

In Arseneault's and Godoy's art, as with Jones's postcard, the physical surface plays an important role, becoming a stand-in for some notion of neutral ground where facts about HIV disclosure and criminalization can be exchanged. The works trouble ideas of impartiality, highlighting the fraught nature of any discussion platform when inequality is present and exposing the fragility of reason and visibility when it comes to HIV.

The Demands of Being Undetectable yet Seen

In 1983, a group of people living with HIV came together at a health conference to draft and then release the Denver Principles, a document that called on news outlets to cease using the word "victim" and instead

employ the phrase “People With AIDS.”²² Decades later, a group of people living with HIV also came together, this time to create something less directed at the media and more aimed at educating each other and the public. In 2016, the Prevention Access Campaign published its Consensus Statement, an attempt to eliminate ignorance of what TaSP means for transmission. In the process, the slogan “U = U” was born, a meme-friendly way to convey that if someone is “undetectable,” then their virus is “untransmittable.”²³ Activists and advocates began to use it, and soon enough it caught on, resulting in everything from a Housing Works comic book series based on the idea to people posting it on social media as a status. Log into Scruff or Grindr and, along with barebacker, bear, and bottom, you'll find someone self-identifying as undetectable. Check out enough Facebook profiles and you'll come across someone whose avatar includes the U = U logo.

Even the CDC has been getting into the identity game. Since 2000 the agency has been running a campaign rooted in the message that TaSP and personal responsibility on the part of people with the virus can end the crisis. A 2014 set of ads features portraits of people living with HIV cut in half: On one side, under the label “DETECTABLE,” they're black and white; on the other, under the label “UNDETECTABLE,” they're in color. Beneath the picture on the color side is the person's name and the year they were diagnosed. Bridging the halves is the campaign slogan, “HIV Stops With Me.”²⁴ The message is clear: Take on the individual work of ending the crisis by choosing to become undetectable, and your life will be more vibrant, your identity legible. Be detectable, and not only will you not end the crisis; your life will be drab, and your sense of self will be disconnected from who you are. Nowhere on the images is there mention of what the CDC itself calls “social determinants of health,” that is, the ways in which economic stability, education, community context, access to care, and the built environment impact a person's health.

Since the Denver Principles, a lot of work has been done to encourage people to embrace their positive HIV status. And at first glance, this reclamation of a stigmatized body seems to be on view in the “HIV Stops With Me” campaign. The people in the posters are spokesmodels living with the virus, carrying on the tradition started by Bobbi Campbell of sharing a part of themselves with the hope of shaping the public's attitude toward HIV. But what else is going on? Who is behind the camera? “HIV Stops With Me” traffics in

self-representation yet is mediated by a state-funded PR agency that does not help promote a holistic or systemic understanding of the virus, putting the burden of the epidemic instead on the people who are already most affected by it. In this way, the optics of self-representation are being used as a form of self-incrimination.

In 2015, artist Kia LaBeija brought her voice to the undetectable conversation with a contribution to *PosterVirus*. In her work, multiple images of LaBeija as a sexy, 1950s-inspired siren with green hair fill the frame as the hashtag #undetectable fades in repetition. Voguing is central to LaBeija's art—she is the mother for an iconic house in the ball scene—and with this poster she serves reclaimed jezebel and bombshell realness. The result is LaBeija as a familiar yet alien femme fatale, haloed by a ring of Day-Glo curls—a woman visible in her difference.

In the poster, LaBeija imbues the word *undetectable* with a lot of meaning, not only linking it to a status available for people living with HIV, but also using it to signal the ways in which black women go unseen except through tropes. Most subtly yet powerfully, the word refers to the history of when women *were* undetectable within the AIDS response. Not until 1993 did the CDC expand its definition of AIDS beyond men, a process started by Katrina Haslip (1952–1993), a black woman who was incarcerated at the time.²⁵ Before the change, women living with HIV could not get treatment or qualify for state support. Gran Fury made a poster that read, “Women Don't Get AIDS. They Just Die from It.” LaBeija continues the conversation. *Undetectable* is a sharp piece of social navigation, at once an awareness poster and a means of highlighting history, as well as the ongoing impacts of erasure. What does *undetectable* mean for people who have already experienced being illegible, discarded, unnoticed, and underserved by society? What can laying claim to an identity, idea, or goal do when uncertainty or worse might be the only thing one can count on?

In thinking about her “HIV IS NOT A CRIME” postcard, Jones was well aware of the gulf between the message and reality. Her work is the bell hooks quote in practice: “The function of art is to do more than tell it like it is—it's to imagine what is *possible*.”²⁶ Like LaBeija, she is using her self-image to generate conversation, while also drawing a connection between the criminalization of those with HIV and of black people. On Jones's T-shirt, the *V* in HIV is replaced by a black silhouette seen from behind, with hands raised in a posture often

accompanied by the chant, “Hands up, don’t shoot!” and made famous by activists protesting the police murder of Michael Brown (1996–2014) in Ferguson, Missouri. Jones echoes the stance in her own image: Her legs are grounded, with one hip popped out in defiance and her arms up, reaching beyond obstacles, past the threat of prison and over the limitations put on her body. The only difference between her and the silhouette is that Jones faces the viewer. As a black cis straight woman living with HIV in the southern United States, Jones invites the viewer to see her, consider her life, and understand that she will not be disappeared into systems of incarceration or turned into another faceless statistic. She will be seen on her own terms. The text she wrote for the back of the postcard reads: “I’m not armed or dangerous. I RESIST the unjust criminalization of people living with HIV who know their status and are proactively taking action to not transmit HIV to others!”²⁷

Jones and LaBeija refuse to decry who they are or their status. This is in direct opposition to the intention of HIV criminalization, in which the state tells HIV-positive people to both announce and denounce their bodies. Whether through the promotion of undetectability or through laws that imprison, the state positions people living with HIV as the sole problem and puts the bulk of the burden of solving the crisis on them, rather than addressing the systemic and social determinants of health. Jones and LaBeija take on the specter of threat that surrounds them in a culture afraid, dismissive, hateful, and ignorant of black women living with HIV, and they turn it into strength. Jones claims her role as a powerhouse who will live to end HIV criminalization, and LaBeija dismisses any easy narrative of what it means to be undetectable. They use their visibility as a tactic to push back against the demands placed upon them.

Navigating Visibility in the Museum

In the earliest days of what would become an epidemic, there were people suffering, questions, and fear. There weren’t tests, treatment, or even a known cause (HIV was not identified until 1983). In the face of silence, the unknown, and a mix of apathy and discrimination, images and words about living with the illness started to be shared, serving as a way forward. This legendary activist response led the public and politicians to take the fate of people living with HIV/AIDS seriously. Personal visibility was marshaled to damn premature death. But being visible as someone living with the virus is no longer a strategic choice, as it was for a brief

period. Instead, because of criminalization, announcing oneself as HIV-positive is now a state-enforced expectation. Activists and artists have always been at the forefront of navigating these shifts of being seen—from activist survival tactic to government demand—exploring them in explicit and nuanced ways.

In his book *After Silence*, Gran Fury and Silence = Death collective member Avram Finkelstein considers the impact of visual culture made in the face of death and despair. In talking about *The Government Has Blood on Its Hands*, a poster created by Gran Fury, he writes, “Posters such as this one, made during times of crisis, are a call to action. They are an advertisement for individual agency and have a completely different set of goals. Activism is not necessary culture production. A community in crisis is not art.” There is a danger, Finkelstein argues, of works made for activist purposes being understood primarily as art, thus missing the totality of their visual reach and impact. This type of reading, Finkelstein says,

strips them of their potential as gestures of resistance, deactivating an entire set of functions. That’s not to say their only meaning is political and they may never be explored as artifacts. I am saying that once the echo of the movement dissipates, all that remains is how we talk about this work, and any canon that elevates the “art of dissent” simultaneously domesticates it by privileging its contribution as cultural production over the critiques that generated it.²⁸

What he’s talking about here is how, as illness became epidemic, activists claimed materials and public space and deployed them to expose the storm hanging overhead. Visibility was less of an option and more of an imperative, a shedding of powerlessness using whatever means were available. Decades later, however, WAVE’s videos, General Idea’s images, and the posters by Campbell and the Silence = Death collective have ended up circulating in the art world, through exhibitions, scholarship, and even this essay. This poses a danger to the works—the possibility of erasing the social conditions under which they were made. If these objects are visible only in an art context, they run the risk of becoming related more to ideas of collection, obsession, and nostalgia than to fear, emergency, and death. What does it mean for such objects to be seen, but to have the urgent circumstances of their creation become undetectable?

Art-only visibility also impacts how we read the work that follows in a similar vein. If our understanding of “SILENCE = DEATH” comes primarily from a museum or gallery, we may miss the impetus of Jones’s work and the way her choices about representation and disclosure represent a tactical shift. Seeing the poster and postcard in connection with each other reminds us that neither was created for the museum, nor for passive engagement. They are rebel yells made to echo in public, addressing life and death, intimacy and desire. While they may be viewed on white walls or pages, it is not necessarily there that their visibility is best understood. Jones’s postcard, like the “SILENCE = DEATH” poster, is a gesture of pushback, as well as an invitation. It is not an artwork to be collected or contained. She wants it addressed, stamped, and activated. She has already spent so much of herself in making it. The least we can pay for her visibility is our action.

The text is part of an artwork, *A Structural Crisis in an Emotional Landscape*, by Kenneth Pietrobono, in which its author, Theodore (ted) Kerr, agreed, for compensation, to refrain from using the following words: capital/capitalist/capitalism, Fascist/Fascism, neoliberal/neoliberalism, populist/populism, political/politician/politics, divide/division/divisive, establishment, global/globalizing/globalization, nation/national/nationalism, government, conservative/conservatism, liberal/liberalism, party/partisan/partisanship, country/countries, Right, Left/leftist, progressive, -phobic, Republican/republic, Democrat/democratic/democracy, America/American, colonial/colonialism, corporate/corporation/corporatism, racist, elite/elitism, sexist, resist/resistance. At the discretion of the author, the quotes of others were unaffected.

Notes

- 1 Shyronn Jones, email to author, February 14, 2018.
- 2 To read more about the intersection of identity and HIV criminalization, see the forum edited by Ryan Conrad that brings together text and images to further explore the issue in the present. Included is a letter by Michael Johnson, who was initially sentenced to thirty-plus years on HIV criminalization felony charges in Missouri and now, due to advocacy and a plea deal, will be out in 2019. Ryan Conrad, ed., “HIV Criminalization Forum,” *QED: A Journal in GLBTQ Worldmaking* 3, no. 3 (Fall 2016): 174–200, https://www.academia.edu/31266635/HIV_Criminalization_Forum.

3 For a detailed list of different states’ related laws, see the Center for HIV Law and Policy’s “Chart: State-by-State Criminal Laws Used to Prosecute People with HIV,” August 2017, <https://www.hivlawandpolicy.org/resources/chart-state-state-criminal-laws-used-prosecute-people-hiv-center-hiv-law-and-policy-2012>.

4 The Sero Project was founded in 2011 with the goal of building a broad network of activists living with HIV and their allies to end HIV criminalization. One of the group’s largest undertakings is the biennial HIV Is Not a Crime conference and training academy. Along with the Georgia Coalition, other organizations doing work on this issue on the state and federal levels include (but are not limited to) the Center for HIV Law and Policy, Positive Women’s Network USA, Empower Missouri, and Texans Living with HIV.

5 See *Making Media Work for HIV Justice: An Introduction to Media Engagement for Advocates Opposing HIV Criminalization*, HIV Justice Worldwide, accessed May 16, 2018, <https://drive.google.com/file/d/1nBPqa90C5DQjKSpwE-cp9nU5qEDxyXRJ/view>.

6 While stigma and discrimination seem to make it impossible to abolish HIV criminalization laws altogether, modernization is a tactic by which some activists work with politicians to update existing laws to better reflect scientific and medical advances. In 2016, Colorado passed a law that repealed two HIV criminalization statutes and reformed another, while also updating language about HIV and other sexually transmitted infections. The passage of the bill was achieved through the collaboration of activists living with and impacted by HIV with a state representative and his office. Since then, similar modernization efforts have been introduced in Florida and California, with the latter’s assembly passing a bill in September 2017 that, if made into law, will reduce HIV criminalization from a felony to a misdemeanor.

7 Many have suggested that the introduction of the Ryan White CARE Act in 1990 intensified the call for criminalization, but sociologist Trevor Hoppe argues that this logic is overplayed, since so many legislatures were already drafting and considering such bills. Kenyon Farrow, “What’s the Future of HIV Criminalization Activism? An Interview with Trevor Hoppe,” *The Body*, December 12, 2017, <http://www.thebody.com/content/80680/whats-the-future-of-hiv-criminalization-activism-a.html>.

8 In his book *Victory Deferred: How AIDS Changed Gay Life in America*, John-Manuel Andriote suggests that Campbell’s was the first AIDS awareness poster. In 1982, the San Francisco-based Sisters of Perpetual Indulgence put out a brochure called *Play Fair*, which

addressed growing concerns about “unusual incidents” of illness within the community. A year later, Richard Berkowitz and Michael Callen, with the help of Dr. Joseph Sonnabend, published *How to Have Sex in an Epidemic: One Approach*, a brochure that suggested condom use and other methods to reduce the transmission of what would come to be known as HIV.

9 The Silence = Death collective members were Avram Finkelstein, Brian Howard, Oliver Johnston (1952–1990), Charles Kreloff, Chris Lione, and Jorge Socarrás. For more on Silence = Death, see Finkelstein’s *After Silence: A History of AIDS through Its Images* (Oakland, CA: University of California Press, 2017), 27–57.

10 A more in-depth account of WAVE and its activities can be found in Alexandra Juhasz’s *AIDS TV: Identity, Community, and Alternative Video* (Durham, NC: Duke University Press, 1995), which discusses how the group grew out of her PhD dissertation work. WAVE participants included Marcia Edwards, Alexandra Juhasz, Aida Matta, Juanita Mohammed, Sharon Penceal, Glenda Smith, Carmen Velasquez.

11 AA Bronson, email to author, February 19, 2018.

12 Shyronn Jones, email to author, February 13, 2018.

13 According to UNAIDS, 47 percent of people living with HIV were not receiving antiretroviral treatment in 2016. “Fact sheet - Latest statistics on the status of the AIDS epidemic,” UNAIDS, accessed May 16, 2018, <http://www.unaids.org/en/resources/fact-sheet>.

14 The CDC states that “PEP (post-exposure prophylaxis) means taking antiretroviral medicines (ART) after being potentially exposed to HIV to prevent becoming infected. PEP should be used only in emergency situations and must be started within 72 hours after a recent possible exposure to HIV.” See “HIV Basics: PEP,” Centers for Disease Control and Prevention, accessed May 16, 2018, <https://www.cdc.gov/hiv/basics/pep.html>. In 2012, the CDC approved Truvada for “daily use as PrEP to help prevent an HIV-negative person from getting HIV from a sexual or injection-drug-using partner who’s positive.” See “HIV Basics: PrEP,” Centers for Disease Control and Prevention, accessed May 16, 2018, <https://www.cdc.gov/hiv/basics/prep.html>.

15 JD Davids, “Undetectable Viral Load and HIV Prevention: What Do Gay and Bi Men Need to Know?” *The Body*, October 10, 2017, <http://www.thebody.com/content/78721/undetectable-viral-load-and-hiv-prevention-what-do.html>.

16 See “What is the *Consensus Statement on HIV ‘Treatment as Prevention’ in Criminal Law Reform?*” The Consensus Statement on HIV “Treatment as Prevention” in Criminal Law Reform, accessed May 16, 2018, <https://www.hivtaspcrimlaw.org/>.

17 Shyronn Jones, “Georgia’s Fight to Modernize HIV Criminalization Laws,” Positive Women’s Network, March 29, 2017, <https://www.pwn-usa.org/georgias-fight-to-modernize-hiv-criminalization-laws/>.

18 Jordan Arseneault, *The New Equation*, PosterVirus, November 18, 2012, <http://postervirus.tumblr.com/post/35974194219/silence-sex-the-new-equation-by-jordan>.

19 Arseneault, *The New Equation*.

20 *Not Over: 25 Years of Visual AIDS*, curated by Kris Nuzzi and Sur Rodney (Sur) for Visual AIDS, at La MaMa La Galleria, June 1–30, 2013.

21 Kate Hallstead, email to author, February 12, 2018.

22 “The Denver Principles,” ACT UP New York, 1983, <http://www.actupny.org/documents/Denver.html>.

23 “Consensus Statement,” Prevention Access Campaign, issued July 21, 2016, updated January 28, 2018, <https://www.preventionaccess.org/consensus>.

24 For an in-depth read of the “HIV Stops With Me” campaign, see chapter two in Trevor Hoppe, *Punishing Disease: HIV and the Criminalization of Sickness* (Oakland, CA: University of California Press, 2017).

25 Two helpful resources offering more information on the role of women in AIDS activism are “Women of ACT UP NY History,” panel at the New York Public Library, April 1, 2014, video, posted by John Riley, 1:48:32, April 19, 2014, <https://www.youtube.com/watch?v=SL-NrFy982vQ>; and *Nothing Without Us: The Women Who Will End AIDS*, directed by Harriet Hirshorn (2017), <http://womanatthereel.com/the-film/>.

26 bell hooks, *Outlaw Culture: Resisting Representations*, (New York: Routledge, 1994), 281.

27 Shyronn Jones, postcard for #HIVIsNotACrime Georgia Postcard Project, 2017, Georgia HIV Justice Coalition.

28 Finkelstein, *After Silence*, 136.

HIV Affects Indigenous Communities

Demian DinéYazhi' + R.I.S.E.

– *Reprint*

R.I.S.E. is an Indigenous founded artist/activist/warrior initiative, dedicated to the education, dissemination, & evolution of Indigenous art & culture. In 2014, for World AIDS Day / Day With(out) Art, artist and R.I.S.E founder Demian DinéYazhi' began creating downloadable posters to raise awareness of HIV within Indigenous communities. He posted them on social media with permission to share, along with facts from the USA's Centers for Disease Control about HIV and indigenous commu-

nities. Two of the posters are below, along with updated CDC statistics.

– Theodore (ted) Kerr

These poster coincides with #WORLDIDAIDSDAY and #DAYWITHOUTART. As with all our posters, feel liberated to, share, print out, wheatpaste, and disseminate at will!

– R.I.S.E.



NDN AIDS flag, 2015

HIV/AIDS AFFECTS INDIGENOUS COMMUNITIES
BECAUSE STIGMA OUTSIDE OF INDIAN RESERVATIONS EXISTS
BECAUSE COLONIZATION BEGETS GOVERNMENT MISTRUST
BECAUSE **HIV/AIDS** AFFECTS INDIGENOUS TRANS & 2SPIRITS
BECAUSE **HIV/AIDS** AFFECTS INDIGENOUS MEN & WOMEN
BECAUSE SUBSTANCE ABUSE AFFECTS INFECTION RATES
BECAUSE PREVENTION SPEAKS MANY LANGUAGES
BECAUSE POVERTY AFFECTS ACCESS TO HEALTH CARE
BECAUSE SEX EDUCATION IS INSUFFICIENT
BECAUSE INDIGENOUS SUICIDE RATES ARE HIGH
BECAUSE RESISTANCE IS AWARENESS
BECAUSE AWARENESS IS SURVIVAL
BECAUSE WE ARE WARRIORS
BECAUSE OUR HEALTH MATTERS
BECAUSE WE HAVE A RIGHT TO SURVIVE
BECAUSE STIGMA ON INDIAN RESERVATIONS EXISTS

R.I.S.E.: Radical Indigenous Survivance & Empowerment

HIV/AIDS Among American Indians and Alaska Natives (CDC website)

Fast Facts

HIV affects AIs/ANs in ways that are not always obvious because of their small population sizes.

Over the last decade, annual diagnoses increased 63% among AI/AN gay and bisexual men.

AIs/ANs face HIV prevention challenges, including poverty, high rates of STIs, and stigma.

HIV is a public health issue among American Indians and Alaska Natives (AIs/ANs), who represent about 1.3% of the U.S. population. Overall, diagnosed HIV infections among AIs/ANs are proportional to their population size.

Compared with other racial/ethnic groups, AIs/ANs ranked fifth in rates of HIV diagnoses in 2015, with a lower rate than blacks/African Americans, Hispanics/Latinos,^b Native Hawaiians/Other Pacific Islanders, and people reporting multiple races, but a higher rate than Asians and whites.

The Numbers

Of the 38,739 HIV diagnoses in the United States in 2017, 1% (212) were among AI/AN.

From 2010 to 2016, the annual number of HIV diagnoses increased 46% (from 157 to 230) among AI/AN overall and 81% (from 90 to 163) among AI/AN gay and bisexual men.^d

Living With HIV and Deaths

In the 50 states and the District of Columbia: An estimated 3,600 AI/AN had HIV in 2016 and 82% of them had received a diagnosis.

Of AI/AN with HIV in 2015, 60% received HIV care, 43% were retained in care, and 48% had achieved viral suppression.

During 2016, 46 AI/AN with diagnosed HIV died in the US. These deaths may be due to any cause.

Prevention Challenges

Sexually transmitted diseases (STDs). From 2013 to 2017, AI/AN had the second highest rates of chlamydia and gonorrhea among all racial/ethnic groups. Having another STD increases a person's risk for getting or transmitting HIV.

Awareness of HIV status. An estimated 8 in 10 AI/AN with HIV in 2016 had received a diagnosis. It is important for everyone to know their HIV status. People who do not know they have HIV cannot take advantage of HIV care and treatment and may unknowingly pass HIV to others.

Cultural stigma and confidentiality concerns. AI/AN gay and bisexual men may face culturally based stigma and confidentiality concerns that could limit opportunities for education and HIV testing, especially among those who live in rural communities or on reservations.

Cultural diversity. There are over 560 federally recognized AI/AN tribes, whose members speak over 170 languages. Because each tribe has its own culture, beliefs, and practices, creating culturally appropriate prevention programs for each group can be challenging.

Socioeconomic issues. Poverty, including limited access to high-quality housing, directly and indirectly increases the risk for HIV infection and affects the health of people who have and are at risk for HIV infection. Compared with other racial/ethnic groups, AI/AN have higher poverty rates, have completed fewer years of education, are younger, are less likely to be employed, and have lower rates of health insurance coverage.

Alcohol and illicit drug use. Alcohol and substance use can impair judgment and lead to behaviors that increase the risk of HIV. Injection drug use can directly increase the risk of HIV through sharing contaminated needles, syringes, and other equipment. Compared with other racial/ethnic groups, AI/AN tend to use alcohol and drugs at a younger age and use them more often and in higher quantities.

Data limitations. Racial misidentification of AI/AN may lead to the undercounting of this population in HIV surveillance systems and may contribute to the underfunding of targeted services for AI/AN.

Demian DinéYazhi's artwork is materialized through the lens of art production, site-specific installation, poetic expression, social engagement, and curatorial inquiry. DinéYazhi' was raised in a matrilineal household and their maternal grandfather served in the U.S. Marine Corps as a Navajo Code Talker. The undercurrents of DinéYazhi's work include a reverence toward traditional Diné practices, storytelling, traditional ceremonies, and acknowledging the criticality and sacredness of land, while simultaneously challenging contemporary archetypes of authenticity and jurisdiction. They received their BFA in Intermedia Arts from Pacific Northwest College of Art in 2014. DinéYazhi' is the founder of the artist/activist initiative R.I.S.E.: Radical Indigenous Survivance & Empowerment. DinéYazhi' also serves as co-editor of the zine *Locusts: A Post-Queer Nation Zine*. DinéYazhi' is a recipient of a 2015 Art Matters Foundation grant as well as the Henry Art Museum's 2017 Brink Award. Currently, he has a solo exhibition at the Henry Art Gallery, Seattle, WA, and is in the group exhibition *Between the Waters* at the Whitney Museum of American Art, NY.

Because PrEP is Not About AIDS

An Exchange to Expand on the *PrEP Manifesto* between Carlos Motta and John Arthur Peetz

In 2017, SPIT! (Sodomites, Perverts, Inverts Together!)—comprised of Carlos Maria Romero, Carlos Motta, and John Arthur Peetz—produced *The SPIT! Manifesto Reader*, an anthology of queer manifestos, dating from the 1970s to the present. The reader brought together key manifestos and other texts produced by queer activists and artists about sexual and gender politics. In addition to the historical texts, SPIT! wrote five new manifestos to address urgent contemporary queer issues. Amongst these manifestos is *PrEP Manifesto* (2017), a text that challenges, problematizes, and valorizes PrEP use by positioning it within a larger cultural, social, and political context. Below is a discussion between SPIT! members Carlos Motta and John Arthur Peetz to further elaborate on some of the statements put forth in the manifesto.

Carlos Motta: Last night, at R's, a sex party in a New York City midtown loft that has been running since 1996 and that advertises a policy of “sex with condoms enforced, zero tolerance for barebacking,” I was fully engaged with a cute and presumably very young top who wanted to fuck me. We clumsily dragged our aroused bodies to a couch where he turned me around to slip his cock inside me, followed by saying: “We are OK, I am on PrEP, I am clean.” What did he mean? *What is OK? Are WE OK? What does he mean “CLEAN?”* At “Gender Talents: A Special Address,” a symposium I organized at TATE Modern in 2013 (in collaboration with Electra), theorist and philosopher Paul B. Preciado made a critical exposé of regimes of power, from the 19th-century clinic, to the death of biopolitics, to what he's termed the “pharmacopornographic” regime. At the end of his address, Preciado jokingly said: “When I see people that tell me, ‘Oh I am not going well,’ I say, ‘how can you go well? You have three regimes of power that are completely working against each other within your body!’” At the risk of being a boner killer—even with Paul B.'s words rapidly flashing through my mind—I opted not to get into it with my top and instead told him, “Use a condom, I am here with my boyfriend and I don't want to give him anything.”

I am on PrEP, too; in fact, I was patient number twenty-one at Callen-Lorde's initial PrEP study back in 2013 and have taken Truvada 200/300 mg, as treatment as prevention, daily since. I have had five years to consider the effects that the PrEP regime has had on my psyche, my social body and sexual relations, and my relationship to the HIV/AIDS infection. I was a teenager in the 1990s, and until 2013 the specter of infection haunted my sex life. An orgasm was always followed by an imminent image of death. Did the condom break, did he come in my mouth? In the last five years, as I take Truvada, this paranoid equivalence of sex and threat has disappeared. There is an undeniable beauty to fucking without condoms and to surrendering to my uncensored desires, yet PrEP is about so much more than my sexual enjoyment: PrEP represents a medical, social, cultural, and political shift that defines sexual subjectivities in a profoundly unequal neoliberal world economy where financial profit precedes pretty much anything else.

Last year, a year into us dating, you and I wrote *PrEP Manifesto*, a manifesto where we laid out a set of thoughtful statements about PrEP. For this exchange, I propose we dissect together some of the lines we wrote, to reflect on this new landscape of pharmaco-mediated subjectivities and how, in fact, one could argue that PrEP, today, *is not about AIDS*:

**Because PrEP has been hailed as a victory
for the assumed “end” of the AIDS epidemic**



NIAID, *Pre-Exposure Prophylaxis (PrEP)*, 2016. Wikimedia Commons, the free media repository.

John Arthur Peetz: I wouldn't just support the argument that the discourse around PrEP is no longer about AIDS for those who take it, as well as those who market, distribute, and manufacture it. I would go as far as to say that the modern “pharmaco-pornographic” regime (borrowing from Paul B. Preciado) and its miracle pill, which I also take daily, is actively contributing to an erasure of the legacy of AIDS activism as well as an erasure of the concerns that affect the people who are still most disproportionately affected by the virus. I think we can look at this perceived “victory for the assumed ‘end’ of the AIDS epidemic” as creating the conditions necessary for a vulnerable, and at one point radically politically engaged community, to distance ourselves from the struggles of those without health care or who live in regions where the PrEP regime hasn't been made available. Looking at this preventative regime of medication as a “victory” distracts us from the actual reality of the rates of infection in marginalized populations who can't participate in medical trials and testing. One of the most undeniably fascinating strategies of resistance born from the legacy of HIV/AIDS activism was the shift from accepting assumed scientific truths about diseased bodies to an active re-engagement with the construction of subjectivities via direct action and the changing methodologies of self-administration and self-care. As your sex party anecdote demonstrates, what we seem to have now is a community of bodies

on AIDS medications, some living with the virus in their bodies, some not, whose active engagement consists in the consumption of pharmacology and a willful disengagement with the hard-won agency that AIDS activists fought to secure.

**Because we are the survivors
and the inheritors of a plague that has killed millions**

CM: There are profound differences between those who died of AIDS-related complications in the 1980s and 1990s and those who survived those initial years, those who came of age after the AIDS Cocktail was introduced in 1996, and those who have access to PrEP today. For each of these groups, the stakes are so high, so different, so layered, and so fraught with contradictions. Yet we are all, as we say in the manifesto, the survivors and as such, we are all responsible to the dead and to the activists and caretakers who put their bodies and livelihoods on the line to save our lives, to fight government inefficacy and cultural stigma, and to reject all the other forms of abhorrent discriminatory and ignorant behaviors in regard to the HIV/AIDS crisis. Yet, we can't expect people today to carry the burden of the past generation on their shoulders and to live in a perpetual state of mourning. While there is a part of me who wants new generations of queers to know the history that has made it possible to *forget*, there is another part of me that thinks this naïveté is a form of liberation they are indeed entitled to. In regard to this, I often think of Walter Benjamin's beautiful "the angel of history" in *On the Concept of History* (1940):

An angel is depicted there who looks as though he were about to distance himself from something which he is staring at. His eyes are opened wide, his mouth stands open and his wings are outstretched. The Angel of History must look just so. His face is turned towards the past. Where we see the appearance of a chain of events, he sees one single catastrophe, which unceasingly piles rubble on top of rubble and hurls it before his feet. He would like to pause for a moment, to awaken the dead and to piece together what has been smashed. But a storm is blowing from Paradise, it has caught itself up in his wings and is so strong that the Angel can no longer close them. The storm drives him irresistibly into the future, to which his back is turned, while the rubble-heap before him grows sky-high. That which we call progress, is this storm.

But if "progress" is an ever-present storm of inequality, classism, racism, and patriarchy, political neoliberalism, market capitalism, pharmaceutical control, patents, and greed, how do we continue to resist in the midst of an illusion of progress? How do we honor the dead, fight back, and live freely in the present while facing these destabilizing contradictions?

**Because PrEP is the product
of the years of labor of AIDS activism**

JAP: It is *foolish* and perhaps even draconian to think that the PrEP generation should fuck with the specter of an epidemic hanging above their heads. But there is a troubling compliance and unexamined consumption that goes along with not understanding the historical labor of resistance and activism that brought us to this

current medicated state. Let's consider that HIV/AIDS activism was not only important because of the lives that it saved, but also because it represented an epistemological shift in redefining the engagement with the micropolitics of identity and dissent. Now let's examine the fruits of two decades of activist labor. On one hand, we have an empirical and scientific product: an effective drug cocktail, the reallocation of state funding, and PrEP. On the other hand, we have the genesis of treatment activism: an engaged population that successfully and in a self-directed manner transformed themselves from "victims" to chemists, administrators, and propagandists, forming new political subjectivities. Campaigns such as the "Open The Pill" call to action, asking patients to examine and know the content of the medication they were ingesting, exerted a double pressure to stop the bureaucracy of scientific truth trials through placebo studies and asserted an active role in the decision-making process around HIV/AIDS medication and treatment. I would argue that part of the reason why PrEP is not about AIDS, is precisely because of a lack of engagement in that consumptive process. We are no longer asking to be in charge of constructing ourselves as active pharmaceutical subjects, rather we are passively allowing ourselves to be constructed as consumers and test-subjects.

**Because PrEP embodies at once the liberatory sexual ethos
of the pre-AIDS crisis while retaining HIV/AIDS stigmatization
of the '80s, '90s and 2000s**



Britney Spears. *untitled*, 2017. from Instagram

CM: It is important to keep in mind the immensely positive effects the PrEP regime has brought around, like making sexual relationships between zero-discordant people less risky, enabling sex workers with access to PrEP less vulnerable to recurrent exposure to the virus and infection, and encouraging a more open conversation about

HIV status between HIV-conscious sexual partners. Because of its unprecedentedly high success rates, one could argue that PrEP has also liberated sex from fear, producing a kind of renaissance of sexual freedom similar to the mythical 1970s. In countries where PrEP has been regulated by government health systems, subsidized by health insurance, or where Truvada as PrEP is available for purchase with a medical prescription, I have experienced a complete shift in sexual behaviors, where for example, barebacking, getting loaded, and swallowing cum are now unexamined and completely accepted practices. I have had many conversations with sex partners, friends, and random hook-ups about the ways in which our relationship to HIV/AIDS changed so fast, from a constant meditation on mortality to an emancipatory, if somewhat careless, freedom to fuck whoever and as many people we want. In this regard, PrEP is also not about AIDS; it is about a change of attitude towards sex in general, where HIV infection isn't a point of contestation or even something people think about often. This is rather paradoxical: How is it that people take an HIV medication daily and never consider HIV? Voluntarily taking a pill everyday as a preventative measure has dissociated the virus from the medication in people's imagination. Perhaps the distance between a medicated body and a diseased body is the new condition of our time. HIV-positive friends, however, continuously tell me chilling stories of discrimination, where upon disclosing their status to sexual partners, they are rejected and ostracized. While HIV-undetectability and PrEP have given HIV-negative people more tools to prevent infection, HIV-positivity continues to produce a fear that is deeply rooted in the media-medical discourse of the 1980s, 1990s, and 2000s. The socially constructed fear of what Larry Kramer famously referred to as "a plague," manifests itself as an acute stigma that even a medical breakthrough such as a preventative treatment like PrEP doesn't seem to eradicate.

**Because PrEP is a deal with the devil of capitalism
and the devil likes to barter with the privileged and affluent first**

JAP: I have been thinking a lot about stigma and its pervasive staining presence in the social mind in terms of the continual criminalization of people who spread HIV or self-define as bug chasers. Recently, within our larger friend group, we learned that someone was infected by a partner who had knowingly kept his positive status a secret. It turns out that not only had this happened to our friend, but that this person had done this to several other people around the country and even had a police record of criminal transmission; wherein the disciplinary framework defined the act as "assault with a deadly weapon." It is a bizarre and perverse legalized Aristotelian transformation to have a human body with HIV legally defined as a deadly weapon. As much as a gun has the potential to be a deadly weapon, can we also apply this logic to an infected person? Ultimately, the friend who was infected sent a text to many of his acquaintances denouncing this person and warning other people who may have had sex with him to get tested/beware and is currently pursuing legal action, unintentionally reproducing and buttressing this stigmatization. While knowingly infecting someone is repugnant from the outside, there is still much we don't know about the specifics of this case, including what treatment this man thought he was getting or even if he was adequately informed about his status and his viral load. Texting others, while obviously was nobly intentioned to warn a community and to correct the wrongs done to several individuals, ached of panic and disgust as articulated through concern for public health. I worry that the barbaric machines of the massive prison industrial complex and systemically biased criminal justice system are not capable of

dealing with the politics of disease and desire and only serve to reinforce stigma and prejudice. Furthermore, it forced me to ask myself how and why. How has PrEP changed conversations about status and safe-sex or even elided conversations about sexual health and HIV in the first place? Why is criminalization the only option we are given to rectify this?

I am not anti-PrEP nor am I interested in shaming “Truvada whores,” doing so would be hypocritical. But I am aware of the persistent contradictions and limitations in universal treatment that are taking place. PrEP exists; safe condomless sex is a reality; people are dying from HIV/AIDS-related complications at a much lower rate; but HIV/AIDS is still a health crisis that is not under control, and this battle for treatment and access is definitively racialized, economic, and geographic. We must consider that the conversation about HIV/AIDS is global and spans the gender and racial spectrum, but the conversation about PrEP is still regional and is isolated primarily to the developed West and the Global North. While I acknowledge that a significant effort has been put forth to include women and people of color in the conversation, it must also be acknowledged that the battle for global access is dictated by pharmaceutical companies that monopolize patent laws and control the production and distribution of generics, causing the drug to be prohibitively expensive. I am not saying that pharmaceutical companies and nation-states are in collusion globally over HIV/AIDS preventative medication, but I find it important to remember that many medical and pharmaceutical breakthroughs have historically been paired with a troubling moral and scientific eugenic trajectory that begs us to examine the correlation between populations that are most affected by HIV/AIDS and populations that are the most disenfranchised or subjected to civic violence, be that disciplinary, medical, sexual, or economic. We are at historic level in HIV/AIDS treatment, but we have so much further to go, to reframe our activism and our demands for access to treatment, if we truly aim at eradicating the virus and its stigma.

Because our desire is the backbone of our communities

CM: Back in 2014, I had a conversation with Nathan Lee titled “There is Tremendous Ferocity in Being Gentle” for “Time is Not A Line: Conversations, Essays, and Images About HIV/AIDS Now,” an issue of the *We Who Feel Differently Journal* edited by Ted Kerr. Amongst the topics we discussed was what I then expressed as an *irrational* desire to have condomless sex, a word Nathan challenged as a curious choice. At the time I had just started taking PrEP and my perception of sex was tainted with shame and fear; barebacking seemed to me in many ways like an act of narcissism that denied our community’s history and relationship to AIDS. At some point in the conversation, I asked Nathan: “What if I don’t care to honor the victims of ‘the plague’? What if I choose to ignore the economic politics of the pharmaceutical industry and give myself to individualistic pleasure? What if my notion of care is different? What if, what if, what if?” The PrEP regime has blurred all these questions in my personal and social experience of sex. Yes, I have given myself unapologetically to “individualistic” pleasure, but my notion of care has heightened; I am committed to pushing back against stigma, and I am more aware of the politics of inequality around health care; I feel I am part of a community that is split around access to PrEP, yet I fear no more for my health or the expression of my desire.



@americasnexttobottom, untitled, date unknown. from Instagram

Returning to R's sex party I mentioned above: R. started his party in the midst of the AIDS crisis partly in response to his lover's death due to HIV complications and wanted to start a sex party that was more responsible and safer in light of his experience being a caretaker. In a way, R. literally articulated with his sex party some of Douglas Crimp's most important points around how to live promiscuity and express our community's desire within an epidemic. He has sustained a large orgy for 20+ years in honor of the dead, promoting safe sexual practices while celebrating *debauchery*: because our desire is the backbone of our communities, it is both our greatest asset and our biggest challenge in this patriarchal and homophobic world.

Ours is a post-PrEP relationship, and I have really enjoyed our sexual openness and explorations together. We are both careless and critical, we have built an army of lovers and desire that is intimate and social. I am also happy that we have done all this understanding the history that brought us to this point. It is an interesting time we are living in.

This exchange took place in April 2018.

Carlos Motta's multi-disciplinary art practice documents the social conditions and political struggles of sexual, gender, and ethnic minority communities in order to challenge dominant and normative discourses through visibility and self-representation. As a historian of untold narratives and an archivist of repressed histories, Motta is committed to in-depth research on the struggles of post-colonial subjects and societies. His work manifests in a variety of mediums including video, installation, sculpture, drawing, web-based projects, performance, and symposia.

John Arthur Peetz is an art writer and book editor working in New York City. He has written for *Artforum*, *Art in America*, *PIN-UP*, and *DIS Magazine*. He is currently in the process of writing a book on HIV/AIDS, Activism, and Performance Art in the Global South.

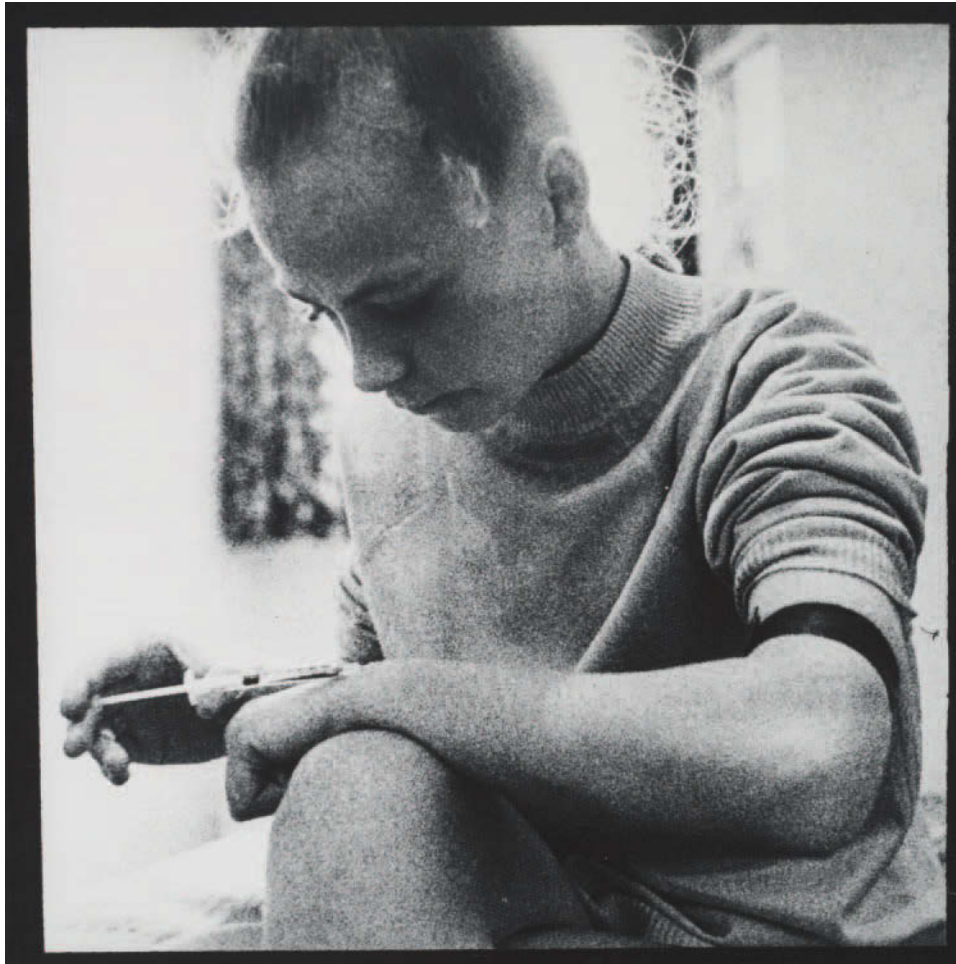
Shooting Up in the Museum: Intravenous Drug Use in Brian Weil's *The AIDS Photographs* Stamatina Gregory

Printed large and tacked directly to the wall is a quiet portrait of a young white woman, her head bent in quiet focus. Shot on 35mm film, the print has been enlarged to produce an exaggerated graininess, obscuring her face and much of the photograph's background, an indistinguishable interior. But details are still discernible: the ribbing on her turtleneck sweater and on her sleeve, pushed up to reveal a tight strap above her elbow, and the ribbon of blood in the chamber of the syringe she holds in her right hand. She readies the push into the top of her wrist, her fingers bent gracefully around the plunger's tip, the receiving hand curled in a fist, at rest atop what might be her own flexed knee. Around her head is a whitish, scribbled cloud: scratched into the negative and burned in the darkroom. What might be a halo is foremost a reminder of a moment made, and not simply captured.

Woman Using a Clean Needle Provided by Liverpool Needle-Exchange Program, Liverpool, England was shot in 1988 by Brian Weil, a New York-based photographer and activist. Weil, who used heroin intravenously near the end of his life, died of an overdose in 1996 at the age of forty-one. At the time, he had publicly ceased to make photographs, and was dedicated full-time to AIDS activism and the establishment of needle-exchanges in New York.¹ Weil's trip to Liverpool eight years earlier was one of a number of research trips to learn from and document local and international responses to the AIDS crisis. With funding from the Academy for Educational Development in Washington, DC: he also traveled to Haiti, documenting the activities of traditional healers in response to HIV/AIDS, and to various ACT UP actions across the US. At that time, he was three years into what would be his most personally meaningful and publicly well-known series, *The AIDS Photographs*: a photographic project which, early in his activism, he never intended to begin.

In 1985, Weil began volunteering with Gay Men's Health Crisis (GMHC), the world's first non-profit community organization dedicated to HIV/AIDS support services and advocacy. In 1985, GMHC employed a range of member-driven tactics and programs. In the organization's language, Weil became a "buddy:" an advocate navigating available social and medical services for hospitalized AIDS patients all but ignored by diffident social workers focused on more morally upright and less terminal clients. His first photograph in the series, *Flavia, age 2* (1985) was made at the request of her mother, a Brazilian graduate student permanently separated from Flavia's father by US immigration laws prohibiting travel to the US by people with AIDS. Weil chronicled her family in and outside of Sloan-Kettering Memorial Hospital, and made portraits of other patients, most of whom had, by then, become friends.

The AIDS Photographs comprised a group of portraits that attempted to create a more comprehensive, systemic picture of the crisis than a litany of images of dying patients. The series includes depictions of the intimate moments of people's lives: the first birthday of Maria's second daughter, and her first swim lesson; ACT UP demonstra-



Brian Weil, *Woman Using a Clean Needle Provided by Liverpool Needle Exchange Program*, Liverpool, England, 1988

tions at City Hall and the National Institutes of Health; portraits of safe-sex instructor and sex-worker advocates in Chicago, Bangkok, and Santo Domingo; traditional healers in Haiti and Zimbabwe; and homosexual “mine marriages” among seasonal miners in South Africa. *The AIDS Photographs*, in both book and exhibition formats, operated through multiple strategies to avoid contributing to the media tropes that British activist and historian Simon Watney called “the spectacle of AIDS” in which affected queer bodies (and, I would add, the bodies of intravenous drug users) are portrayed only *in extremis*: physically deteriorated, near the point of expiration and societal disposal, appropriately corporally humiliated and punished before finally collapsing into a statistic. As Watney notes, “The displacement of epidemiology by a moralized etiology of disease” also ironically likely spread the virus further and faster, distracting attention away from the well-proven means of blocking its transmission.²

Watney wrote primarily about the violence implicit in media images, but two exhibitions focused on photographs of people with AIDS also stood out for their similar tropes of representation in 1988, the year following the publication of his essay. The late, singularly influential art historian Douglas Crimp wrote on the protest by ACT UP of Nicholas Nixon’s *Pictures of People* at the Museum of Modern Art, and on Rosalind Fox Solomon’s exhibition at the Gray Art Gallery, *Portraits in the Time of AIDS*. Both series of portraits emphasized the physical manifestations of illness with little or no

context around their subjects' lives, communities, or desires, much less the structural conditions of transmission and treatment. Nixon, in particular, was unapologetic in his own descriptions of his photographic process, pushing through his subjects' anxieties about participating in a photo shoot with a combination of exasperation and outright disdain, and emphasizing his own tenacity and ruthlessness of artistic vision, stating "I know how cruel I am, and I'm comfortable with it."³



Brian Weil, *Flavia Before Her Death at Two*, Brooklyn, New York, 1985

The task of working against the violence of photography (both real and symbolic), as well as the self-valorizing image of the artist (Weil habitually referred to the group of Magnum photojournalists, which included Nixon, as the “white boys’ parachute club”), seems to have been the guiding ethos of *The AIDS Photographs*. Weil strove to make the viewer aware of the structural interconnectedness of the epidemic on an interpersonal, communitarian, and global scale. His strategies of physically mediating his images—scratching and over-developing his negatives, blowing up his prints to exaggerate the inherent graininess of 35mm film, and manipulating the visibility of his subjects—were intended to help achieve a non-reductive view of its most at-risk subjects, despite the fact that a number of them were photographed weeks, days, or hours from death. Accompanied by lengthy, descriptive titles and texts which oriented viewers to both the immediate and systemic conditions under which the images were produced, the photographs embodied a kind of refusal of the idea that photography alone could impart critical information about the epidemic and its exacerbation by a myriad number of seemingly unrelated factors (homophobia and transphobia, global inequality and economic exploitation, racism, US immigration law, and addiction stigma, among others).

Moral Arcs and “Injection Chic”

A critique of the image of the gay male body, if not widely or fully articulated at the time, surpassed that of the image of the intravenous drug user, which has received little critical attention. However, precedents had already been set for depictions of intravenous drug use, in the museum and in popular culture. Two decades earlier, in the summer of 1991, the film *The Panic in Needle Park* was released, based on a reportage by photojournalist Bill Epperidge and with an adapted screenplay by Joan Didion and John Gregory. Epperidge's two-part *LIFE* magazine article, appearing in 1965, moralistically presented a couple's gradual demise—theft, imprisonment, and a near-fatal overdose—after instantaneous enslavement to their drug addiction, and it followed this bleakness with the hope of redemption for similarly affected American youth through the promise of drug rehabilitation facilities.⁴ In contrast, *Panic* eschewed both this markedly moralistic tone and the promise of salvation and reintegration into respectable society. Instead, what many have characterized as the first mainstream film to present intravenous drug use—using *cinéma vérité* and on-set nurses to consult on the authenticity of scenes depicting injection—it presented its protagonists' “dope-ravaged lives” as an endless slide into depths of deserving depravity and a tragically hip image of corrupted youth.⁵

The image of the junkie that *Panic* presents resonates with the near-simultaneous public exhibition of Larry Clark's *Tulsa* at the San Francisco Art Institute. *Tulsa*, which would be printed shortly after the exhibition as Clark's first photobook, chronicled the lives and deaths of a group of Oklahoma methamphetamine addicts in the 1960s and '70s, a group of which Clark himself was intermittently a part. Over three chapters of images (titled “1963,” “1968,” and “1971”), the photographs create a narrative that begins with two seemingly clean-cut, young white American men, introduces other characters in images illustrating the highs and lows of drug use, and reaches a crescendo of domestic violence, gunshot wounds, the beating of a police informer, and a pregnant woman shooting up, followed by an image of her newborn baby lying dead in a coffin. The series of images ends not with the finality of death, but with a depiction of member of the next generation of *Tulsa*'s drug users (in one image, a young man is slender and shirtless, gracefully bent forward as he searches for a vein). Both Clark's work and Jerry Schatzberg's film presented the culture of using as an opportunity for voyeurism, but also as banal and cyclical—a now-inevitable fixture of human culture wedded to the decline of the American city in the 1970s.

Clark's exhibition in San Francisco (prior to the release of *Tulsa* as a now-iconic photobook) garnered varied responses from critics, their opinions often at odds with one another. One of the first to be published referred to the images as “anguished”: the other, far more distressing to Clark personally, contained the assertion that the subjects looked “no more in the grip of a lethal addiction than so many baseball fans drinking beer.”⁶ Later reviews overwhelmingly positioned the work as harrowing and emotional in its depiction of lives intensively lived in the constant presence of death, and heralded Clark as a successor to Robert Frank and Diane Arbus (who had committed suicide only shortly before *Tulsa*'s book release) in the avant-garde firmament of American photography.

Clark, a participant-observer with close relationships to his subjects, was one of the few photographers Weil openly admired (he was also a fan of Diane Arbus). It should be noted that Weil disdained most of his fellow faculty at the School of Photography at the ICP, deriding even esteemed career photojournalists like Capa as belonging to “the white boy parachute club.” Clark and Weil came to know one another in New York in

the early 1980s, becoming friends and acquiring one another's works. Still, their styles, their methodologies, and their relationship to the practice and the purpose of photography were profoundly different. Unlike Weil's ethereal and quiet portraits of people in the midst of using, Clark's images are a tumult of detail: track marks, black eyes, greasy hair hanging limply over tattoos, bodies writhing on unmade beds. There is ambivalence, but no ambiguity: his subjects are squarely and unapologetically situated in the material conditions of their own lives. And unlike the painstaking statistics and epidemiological details accompanying *The AIDS Photographs*, Clark's ancillary text for *Tulsa is* limited to the briefest of preambles: "i was born in Tulsa Oklahoma in 1943, when i was sixteen i started shooting amphetamine. I shot with my friends everyday for three years and then left town but I've gone back through the years, once the needle goes it in never comes out." In the absence of facts (aside from the stark evidence of violence and death), the viewer is swept along by affect, rendering the narratives of users and their families wide open to personal interpretation—or to collective identification. Critic A.D. Coleman, profoundly affected by *Tulsa* after its first publication, asserted that "in the midst of all this death the characters are in life; and harrowing and painful though Clark's images are, the very involvement they create and the intense emotionality they extract from anyone (and everyone) who encounters them are affirmations of the viewer's own life-urge."⁷ Clark framed his subjects as modern primitives, ruled by pure id, chasing the highs of sex, violence, and drugs until they can no longer outrun their repercussions.⁸ And for all of Weil's admiration of Clark's photographs, representing drug use during a pandemic required a radically different approach.

The AIDS Photographs

Weil considered the *The AIDS Photographs* his most important group of works, having previously gained some art world recognition for his immersive photographic projects on BDSM, homicides in Miami, and New York's Hasidic communities. But the photographs themselves began (or, rather, continued) to be less valuable to him as a product or a practice, than as a useful corollary to his activism. Weil referred to photography as his "excuse": a way to garner funds for travel and research, to grow his activist networks, and to more fully understand the entrenched conditions that activism was facing. Weil also saw photography as an opportunity to circulate more complex images of AIDS to the World Health Organization and other nonprofit bodies, and to facilitate activist and youth education-focused dialogues within arts institutions. Over the course of the project, he ceased his pediatrics work with GMHC, and joined and then left ACT UP (over internal political tension, including the organization's divided positions on harm reduction strategies). Eventually, the majority of his time went into the grassroots efforts to establish and legitimize clean-syringe exchanges in New York. With friends and fellow activists, Weil would distribute more than 4,000 sterile needles and bleach kits in Harlem, the South Bronx, Brooklyn, and the Lower East Side. Purchased in bulk from a diabetic buyers' club, they were encoded (in late-night group painting sessions) with borough-specific stripes of nail polish. With an eye on demonstrating the need for and undeniable results of harm-reduction work, it was a crude means of tracking the distance one used needle could travel within disparate communities of users.

A photograph Weil made in Chicago in 1986, *Men Sharing a Rented Needle at a Shooting Gallery*, provides one image of the conditions of transmission. It shows us an older man seated on the edge of an unmade bed, his forearm being injected by a person to his right, while in apparent conversation with someone outside the photograph's frame. The text preceding the photograph in *The AIDS Photographs* catalog (as well as

in the exhibition's didactics) informs us that one IV drug user in the gallery, a diabetic, receives several clean medical needles a week and rents them out to hundreds of other users: a means of affording his habit. Weil describes watching people sharpen a needle, dulled from extensive use, on the edge of a matchbook; he then notes that while caring for one person with AIDS in a city hospital costs New York City between \$60,000 and \$150,000 over the course of their illness, and that Liverpool's entire needle-exchange program is run on \$75,000 per year.⁹



Brian Weil, *Man Using a Clean Needle Provided by Liverpool Needle Exchange Program*, Liverpool, England, 1988

Women Using a Clean Needle was accompanied by two other Liverpool portraits in the exhibition, all made in the same 1988 visit. The subject of *Man Using a Clean Needle*, performing a version of the deft manual acrobatics that injectable drug users can be adept at, moves his clothing aside to inject himself near his groin: at first glance, he appears to be tenderly cradling something precious in his arms. *Young Sex Workers Injecting Drugs* depicts the same female subject as *Woman Using a Clean Needle*: here, she displays a similar focus while injecting a colleague in the forearm, while another person prepares their own injection in the background.

The placidity of the Liverpool photographs may have represented to Weil and others an image of harm reduction that was nearly utopic in its pragmatism. Exchanges in Liverpool, originally in place to minimize the spread of hepatitis among IV drug users,

grew into a model of harm reduction (the “Merseyside model”) that, after legal struggles, eventually became part of mainstream drug treatment protocols and that attracted activists and policy makers internationally. The city held the first International Harm Reduction Conference in 1990; in the same year, New York City’s sole legalized needle exchange program was shut down by the newly inaugurated Dinkins administration (which publicly opposed the “encouragement” of drug use through the distribution of “paraphernalia”).¹⁰ Weil’s images, through repeated depictions of the moment of injection, whether alone or assisted, also seem to suggest (if not indexically record) a harm-reduction goal that has yet to be achieved in either the US or the UK: the legal availability of safe and controlled injection sites for drug users. This remains a lifesaving goal for harm-reduction organizations, including CitiWide Harm Reduction in the South Bronx, the still-extant needle exchange that Weil founded in 1995. On a tour of the facility by the organization’s director in 2013, I was shown a room that would be dedicated to on-site injection, held ready for the moment that the practice would become a legal part of harm reduction services.¹¹

Inasmuch as the Liverpool photographs represented a legal goal and an activity abhorred by US legislators, they were never the object of outrage on the part of viewers or the gatekeepers of the museum. That ire was reserved for *Safe Sex/Images Created To Eroticize Safe Sex For Educational Purposes* (1987), two photographs shot on the set of a porn film focused on eroticizing condom use between men: an effort to combat the seemingly intractable cultural resistance to the use of condoms in sex work. The images each depicted a pair of men, engaged in erotic posing and masturbation, rendered in Weil’s characteristic grainy, high-contrast style. Before *The AIDS Photographs* opened at the ICP, director Cornell Capa threatened to fire the show’s curator if the *Safe Sex* works were not pulled from the show. Weil reacted by approaching the director himself, threatening massive repercussions by way of activist protest, and daring Capa to “please do it: it will give the show way more attention”). Ultimately, no one was fired, the photos remained uncensored, and neither they nor the injection photographs caused a scandal. However, reviews that mentioned the injection photographs tended to note the ideological conflict between Weil’s activism around needle exchange with the federally sanctioned “Just Say No” approach to education on drug use.¹²

Drugs on View

Since *Tulsa* and *The AIDS Photographs*, a number of photographers have created books and exhibitions about communities of drug users. To uneven degrees, they have absorbed the extensive critiques of documentary and photojournalistic practice put forward by Martha Rosler, Allan Sekula, Susan Sontag, and other artists and theorists in the 1970s and 1980s. Put very generally, those critiques argued that documentary photography needs to adopt more rigorous strategies: that representations of conflict, violence, and inequality must account for systemic and structural forces even (or especially) when the viewers themselves become implicated in that accounting. Eugene Richards’ *Cocaine True, Cocaine Blue* (shown at the ICP in 1994), a series of photographs of three neighborhoods (North Philadelphia, East New York, and the Red Hook projects) marked by drug addiction, was roundly criticized for its lurid depictions (including an image of a woman preparing to exchange oral sex for drugs, a toddler strapped to her back) and insinuation (through its narrow focus) that drug use was solely the province of poor, black, inner-city communities. While the book version included multiple first-person accounts from Richard’s subjects, which made clear the systemic inequality and socioeconomic forces that force them into desperate circumstances, his images portrayed them as indisputably othered. Wild-eyed and ruthless as

they count piles of seized cash and grip syringes between bared teeth, they are served up to middle-class, museum-going audiences as a handy conflation of poverty with depravity; a thrill ride through places best avoided by those ostensibly making good life choices. Richards' project was conceived and produced in the years after mandatory minimum sentencing laws were enacted—legislation that devastated black communities while sparing scores of affluent white users. In his own defense, Richards has pointed out that his project was not “a treatise on all drugs and drug users in America,” and indeed, it was never meant as such. But the politics of drug use and the political instrumentalization of drug users is singularly driven by an image economy in which parts stand in for wholes, and the social crisis engendered by the crack epidemic of the 1980s and early 1990s raised those representational stakes exponentially.



Brian Weil, *Transvestite Safe-Sex Activist*, Santo Domingo, Dominican Republic, 1987

In marked contrast, the 2009 project *Righteous Dopefiend* took those stakes seriously. In their twelve-year anthropological and photographic study of two dozen injectors and crack users in the US, Philippe Bourgois and Jeff Schonberg remind their readers that “letting a picture speak its thousand words can result in a thousand deceptions.”¹³ They insist that their images (which overwhelmingly emphasize their subjects' relationships to family and to social and medical services, rather than moments in the pursuit or use of drugs) are inseparable from their supportive text: an exhaustive analysis of the structural forces that create the conditions for addiction, and produced an intractable shelterless population within one of the world's wealthiest

nations. *Righteous Dopefiend*, which also traveled as a museum exhibition originating at the University of Pennsylvania's Museum of Anthropology and Archaeology, took the position that any serious look at drug use in America had to critically examine the failures not of individuals, but of systems, including structural racism, unchecked capitalism, and aggressive gentrification, as well as an ultimately irrational lack of housing and counseling services (which could be made available to at-risk populations at the fraction of the cost of the American public's preferred expenditure—mass incarceration).

Photography and Complicity

French sociologist Pierre Bourdieu's theory of symbolic violence is useful in thinking about the ways in which inequality and domination are perpetuated and naturalized. Symbolic violence concerns the ways in which hierarchies of power are tacitly maintained by both dominated and dominating groups.¹⁴ Present in legislation and policy, in popular opinion and in cultural norms, symbolic violence upholds and reproduces dominant social systems over time, and works to legitimize actual violence, such as mandatory minimum sentencing and other legal pipelines to mass incarceration. Recent sociological research based on the lived experience of public injecting has shown that the stigma associated with routine public exposure of one's injecting status (as well as other forms of public shaming) contributes to an environment of risk for users, which increases vulnerability to HIV.¹⁵ In laying out the pro-



Brian Weil, *Young Sex Workers Injecting Drugs*, Liverpool, England, 1988

cesses of symbolic violence, Bourdieu uses the term “misrecognition”—a phenomenon that works through culture, anchoring taken-for-granted assumptions about the rituals, actions, and motives of oppressed groups, and legitimizing unequal structures and social inequality.¹⁶ To misrecognize communities in pain—including drug users and people with AIDS—through habitual ways of looking, speaking (or photographing, for that matter)—is to diminish their political representation entirely. It is to, consciously or unconsciously, swap a complex assessment of structural oppression for a moralistic rhetoric of individual responsibility, or an operating logic of dehumanization.

For Weil, like Bourgois and Schonberg, the struggle against this process was waged in part through information—didactic materials that stressed the interconnectedness of the AIDS epidemic with systemic poverty and global systems of oppression. Citing the enormous complexity of studying “a molecule [the virus] within a culture,” the series connected Bangkok shooting galleries to American sex tourists in the Philippines to long-term contracted miners in South Africa to the HIV+ wives of transfused leukemia patients. As Weil told ICP curator Willis (Buzz) Hartshorn in 1991, “To document AIDS is an amazingly presumptuous thing, because the scope of the epidemic is so complex and diverse. [...] When people say that the scope of this project is incredibly broad, I know I’ve just barely scratched the surface. I’ve been confronted with an impossible task. What I have done is try to make little notations on how this disease manifests itself in different cultures.”¹⁷

Weil’s struggle with the impossible was made evident on the photographic surface—a site that was scratched, blown-up, overexposed, or underdeveloped. To stand at a distance is to be compelled to see them up close, to see *more*—and yet, upon examining the images closely, for that desire to be thwarted. The exaggerated grain—conventionally seen as an undesirable mark of amateur and unskilled photography—becomes a shifting, pointillist landscape, in which hard contours of differentiation become impossible to discern, dissolving from one into the next. His portraits were a simultaneous offering and a withdrawal: for viewers, there could be no illusion of knowledge or evidence, no unearned experience, no false recognitions or damaging categorizations. Despite the didactics, the complexity resolves itself as paradox: we can see, read, and learn a great deal in the museum, but there is only so much we can come to understand. Through grains of silver, a child disintegrates, a woman glows from within. We will never know them, but we have our own work to do.

Notes

1 With a group of other ACT UP activists, Weil founded the Bronx/Harlem Needle Exchange, later incorporated as New York Harm Reduction Educators; he later founded the Bronx-based CitiWide Harm Reduction (now BOOM! HEALTH) which still houses a needle exchange bearing his name and image. Roberta Smith, “Brian Weil, 41, Photographer Who Founded Needle Exchange,” *The New York Times*, February 8, 1996.

2 Simon Watney, “The Spectacle of AIDS,” *October*, vol 43, AIDS: Cultural Analysis/Cultural Activism (Winter 1987): 71-86. 80. Watney also wrote the introduction to Weil’s exhibition catalog for *The AIDS Photographs, Every 17 Seconds: A Global Perspective on the AIDS Crisis*. (New York: Aperture, 1992).

3 Douglas Crimp, “Portraits of People with AIDS,” in *Melancholia and Moralism: Essays on AIDS and Queer Politics* (Cambridge: MIT Press, 2002), 58.

4 Bill Eppridge, “John and Karen Two Lives Lost to Heroin,” *LIFE Magazine*, February 26, 1965, 66-92.

- 5** James Bell, "Love and Other Drugs," *Sight and Sound* 21:10 (October 2011): 84.
- 6** Alfred Frankenstein, "'The History of My Life': Romanticism to Reality," *San Francisco Chronicle*, August 17, 1971, 46.
- 7** A. D. Coleman, "Latent Image: The Life-Death Drug Paradox," *Village Voice*, September 16, 1971, 24.
- 8** For more on the comparison of Eptridge and Clark's photo essays, see "The Moral Issue of a Pregnant Woman Shooting Up" *Photo Review* 16:1 (Winter 1993): 2-9. Marshall calls Clark's images "repulsive, voyeuristic facts that has taken us this far in Tulsa as an exact and part symbol of the drug we are craving."
- 9** Artist interview with Willis (Buzz) Hartshorn, 1991.
- 10** Todd Purdham, "Dinkins to End Needle Plan for Drug Users," *The New York Times*, February 14, 1990.
- 11** Yoav Gonen, "De Blasio commits to opening four supervised injection sites," *New York Post*, May 3, 2018.
- 12** "Picturing AIDS: Photos show stories of courage, conflict," *St. Louis Post-Dispatch*, April 19, 1992, 21.
- 13** Philippe Bourgois, Jeffrey Schonberg, Preface to *Righteous Dopefiend* (Berkeley: UC Press, 2009).
- 14** Bourdieu discusses symbolic violence in the context of gender in Pierre Bourdieu and Jean-Claude Passeron, *Reproduction in Education, Society and Culture* (London: Sage Publications, 1977): "The imposition of a cultural arbitrary by an arbitrary power" (p. 19).
- 15** Rhodes, et al., "The Social Structural Production of HIV Risk Among Injecting Drug Users," *Social Science and Medicine* 61(5) (Sept. 2005): 1026-44. Epub 2005 Mar 19.
- 16** Pierre Bourdieu, *Distinction: A Social Critique of the Judgement of Taste* (London: Routledge, 1979, 2013), 388.
- 17** Hartshorn interview.

Stamatina Gregory is a curator and an art historian, whose work focuses primarily on the interrelationship of Photography and politics. She has organized exhibitions for institutions including The Cooper Union, FLAG Art Foundation, the Institute of Contemporary Art, Philadelphia, and the Santa Monica Museum of Art. Gregory was the curator of New York photographer and activist Brian Weil's retrospective at the ICA, Philadelphia, and she was the Deputy Curator of the inaugural pavilion of The Bahamas at the 55th Venice Biennale (2013). She has taught art history, critical theory, and writing at New York University, The New School, the School of Visual Arts, Purchase College, Sotheby's Institute, and the University of Pennsylvania.

Among Four Friends: Conversations Before and in a Hospital Waiting Room

Charan Singh – *Artist Project*

In this immersive story, artist and activist Charan Singh explores the fluid nature of language and identity as mediated through the economy, education, and social locations that are not central to most conversations about HIV/AIDS. We begin in a domestic space where a mother and her son navigate a shared and mostly silent moment in their full house of sleeping family. The son struggles to find an intimate moment before he heads out for the day. The scene then changes, and the young man is in a hospital room, speaking among other HIV-impacted people in the capital city of India: talking about the virus, the response from non-governmental agencies, and the role constructed identity plays in their everyday life. The story comes full circle in the end with the young man returning home, contemplating his day on the bus.

“Among Four Friends” draws up Singh’s experiences as an educator, community member, and artist. He aims to challenge readers to consider notions of the public and private as well as health, and harm reduction strategies as they relate to people who often face discrimination of various kinds. People whose lives have become a permanent feature of epistemological and social studies that then later are reduced to stories of survival. To underline what gets lost, overlooked, and assumed, Singh has included a Glossary of terms at the end of the story, filled with words and ideas that AIDS workers may take for granted.

– Theodore (ted) Kerr

AMONG FOUR FRIENDS Conversations before and in a hospital waiting room

[On a porch]

Her favourite song was interrupted by a news update on the radio: a sign of the turning hour. “Oh, it’s 8 o’clock, *paani chala jayega*. I should fill water in all the buckets before it is too late.” Seven minutes later—she thinks to herself: “Oh ho, I must wake him now.”

“WAKE UP, it’s 9 o’clock, don’t you have to go somewhere?”

You cannot tell by looking at her irritable face that she has just lied about the time; the smirk begins deep within her eyes. There is only one bed in the house, on which his father sleeps until late. The rest of the family member sleeps on the floor. He is in her way to clean the house; put away the bedding, and move on to the rest of the chores. She wants him to get up now. She walks past (over) him to open the window. The sun is strong, already, on a summer’s day.

“Oh god! Is it 9 already?”

He gets up in a frenzy and runs to the porch. It is where everyone in the house takes their bath, brushes their teeth, and where all the other washing and cleaning happens. There is a large barrel with stored water and three buckets, also filled. He sits on the *Patra*, and begins to bath himself. The window is open. His mother can see him through the window. This time, she speaks with her eyes. She points out to him to look at the clock. It is not 9 o’clock as yet.

Perplexity...

And then he tells her, “Oh, you were making an ass out of me?”

He was annoyed that she was watching him. He was almost urging to have a private moment. "I never thought that I would ever get this thing called—privacy, but today I could have done some use of it," he thought to himself, "though, I know, I could not afford privacy, nor would I need it, in any case."

After he left, she wonders why he looked so strangely at her as he bathed. "We always talk to each other in the morning, when others are asleep." It does not matter much to her: she has things to do, thoughts to have, responsibilities to tend to. She will see him later, and that will be nice, like always.

[in a hospital waiting room]

Asif: I can't even begin to tell you how ashamed I am!

Sameer: But why? There is nothing to be ashamed of...

Asif: I knew all about it, but I still got it. It is all my fault.

Reshma: Perhaps! Admittedly, not all of us knew about it, not entirely, not even after all that work.

Udaybir: Sister, I have been coming here for years. It all gets normalised after a while.

Sameer: Don't blame yourself, haven't we all suffered enough, already?

Udaybir: Well, you are straight (almost), and you have a family, it's not bad as it is with us. Coming here has become an inseparable part of my life.

Sameer: Really? Do you think? (pointing towards Asif)

Asif: What he meant is, you can 'pass' safely as straight, whereas ones who 'looks' feminine, like us, face a lot more challenges and violence daily. And trust me, I can relate to it. I used to fear to step out of the house, but then for some of us houses were not the safest place either.

Sameer: Aha! However, I am that 'Giriya' who wasn't even included in those HIV programmes, initially. Moreover, this 'passing' prevented us from accessing 'safe-spaces'—whatever they might be. I feel stuck between marriage and my duty to perform 'masculinity', and to be a man. So 'passing' didn't protect me. So, I still end up here, with you all.

Asif: I know. However, wouldn't you agree that the burden of practicing safe sex was put on our shoulders as if only we control the entire game?

Reshma: Haha. Do you remember that ABC rule?

Asif: Those were bizarre. Abstinence, Be faithful, and use Condom. (they all laughed)

Reshma: Haha. See, I am a Hijra! Neither here nor there. Also, I feel that the 'programme' is not always beneficial. Sometimes what looks like 'help' can paralyse your desire to live, and even to think freely.

Sameer: Why? What's with all that you being divine and with the power to bless and all?

Reshma: Arrey. Those were different times when our *Gurus* were considered to be divine. They had their say and status in the king's court, but these ancient stories, now only good for getting funding, in real-life there is not much currency in them. The truth is that most of us are still not embraced by our families. Everyone looks at us with ridicule or fear—that might curse them. Trust me, when all you want is love, this feeling of rejection is not very pleasant to wake up to, day after day, every day.

Udaybir: This isn't a competition to claim who is more oppressed than other. I am a double-decker, who never gained the trust of any. So, let's fuck this. For better or worse one thing has tied us all, and we are all here. Though, I wish we could have been brought together in some other way.

Asif: You are right. However, my question is, why are we like this? Why do we suffer and for what?

Reshma: Err... We suffer because we are different, and we resist, my dear. Perhaps, if we conformed to their norms, then we might not.

Asif: Who are they? Also, how can they decide for so many of us?

Udaybir: The 'us' always mystifies me, how 'us' is being used, in what context and by whom? Who is included in this 'us' and who is being excluded? It is power as well as oppression. However, it is such a frightening thought. What would we 'be' without the 'us'?

Sameer: Oh drama-queen, please be quiet.

Asif: What, what did you say?

Sameer: See, we don't live in isolation. Here, at this very moment, we have formed our own 'us'. So, we are all part of a more extensive system, which works for whoever is in the majority, even though it is democratic. However, it doesn't work for everyone... sometimes this doesn't even work for those who conform with their 'norms'. Sigh!

Reshma: True. We were all born into it, we are all products of this system which retroactively programs us, and we respond to it inevitably, unconsciously, automatically.

Udaybir: Ahem. Then why do they say democracy is the best possible solution for humanity?

Asif: And silly me, I thought we all are free citizens.

Sameer: We are, but as I always say—freedom is a myth, and so is a democracy.

Udaybir: Haha. Listen to him. You were talking about resisting earlier on. I don't think we resist, consciously, it's quite the opposite. To me, it's an impulsive reaction to this systematic oppression.

Reshma: You are confusing her. Her question is, why do only some of us suffer? One of the answers to that could be patriarchy, the system we have been talking about, that controls the state and societies. It is fundamental to maintaining the hierarchies of all the systems—religious, social, economic—that regulate you and me. So, we are all subjugated by it.

Asif: Yes. But if you remember, as children, we all were forced to believe that there is nothing that matters beyond our family boundaries, that we do not exist outside. That's where this yearning to belong comes from, and we still hope that they accept us, the way we are.

Udaybir: I am not sure why we gave so much leverage to the family and its values... I don't feel the need for my family's approval; they will never give it to me, so why do I even bother? I have other families, I have you all.

Sameer: Yes, and I did all the right things, family, children. Didn't I?

Asif: You did; hence, you are that system, too.

Udaybir: How does it relate to people like us? We are already outside the family structure, so do we even exist?

Reshma: We all exist. We are all flesh and bones. YES, we exist, we are, just not acknowledged by the majority.

Udaybir: You know what, your 'just' is killing me, although it all makes sense.

Asif: But now I am more confused. Patriarchy belongs to men, right? And, we are all men, including you, who was born into a male body. So?

Reshma: Well, now you are talking about gender and its related troubles. However, patriarchy is more complicated, and we all must put up with it. Having said that, be also careful, there are hierarchies within patriarchy based on caste and class, which in other societies could be race and religion.

Sameer: Wait a minute, it would be worth thinking about what this 'we' or 'us' means, which we use so casually?

Udaybir: Oh, dear! You all are sounding like those meetings that we used to attend, years ago, where they gave away so many condoms. However, never translated what was happening in the rest of the world with the disease, so what was the point? How can you all talk like them? How can you all use the same language? A language that isn't us. And yes, I am calling all those people 'them'; they are not one of us. Otherwise, they would be sitting here, right now.

Reshma: That's little harsh to say. Although, I feel your pain.

Asif: Well, it is important that we learn the language of discourse and be aware what's happening in our names. Don't you think?

Udaybir: I know change is natural, but isn't this too much? To me, it's like the victim becoming the perpetrator!

Reshma: Haha nahi re! It's not that bad yet. We are just helping each other to understand things better.

Udaybir: Again, this 'just' is working as salt on my wounds. Maybe, there is no one answer, or am I too cynical about it?

Asif: See, these are the kinds of things that bother me. But, at this moment, my most burning question is, if this is suffering, as they say it is, then why only us? And if this is true, that we are suffering, and it is only 'us' who are suffering, then at this pace, would there be any of 'us' left to suffer in the future?

Sameer: It will get better, trust me.

Asif: How? I am not even talking about the amount of shame we are carrying on our shoulders. I am crumbling beneath it. Sometimes it feels like I will die from the sheer weight of it. And you still believe that things will get better! What do you say to me?

Silence. Although, in these silences, there are voices that started to emerge; voices for dissent, voices for desire.

[On a street heading towards home...]

He is back on the bus home. After a few stops, he found a seat, that was a relief. He takes a deep breath in, one that lasted so long he thought he would be home before he exhaled. A long journey ahead. He was sitting anxiously, mulling over everything he talked about with his friends—systems, the AIDS programme, and its imagined population. His eyebrows were coming together and forming a mountain of worries on his forehead. He couldn't help himself; his fingers were starting to move in the air as if he was telling them to write something. And then, a poem was coming together in his mind –

I was a concept, a description
A number, a table, a graph
but no image

An idea, a noun
an abbreviation
or definition
but not a thing itself
and no image

An apology on a page, on the margin
A footnote, or a quote
An example sometimes
but no image

Real or unreal,
but always elsewhere

Did I even exist?
How can I exist?

After the long bus ride, he arrives at his doorstep, listening to his mother's humming. He can smell the caramelised garlic and onion on the lentil, which brings him a smile.



Charan Singh, *Bench*, 2016. Courtesy of the artist.

GLOSSARY

AIDS

A noun, a name, and a definition that has no real meaning, as far as these high-risk (creatures) communities were concerned. At times, the 'proper' discourse was situated afar, and even the images in most of the early informative brochures were adopted from African countries, which did not have any cultural references to us—the local Indians. Moreover, all in a peculiar, scientific language; and we are dealing with the underclasses here. So how does one make sense of the thing itself? What is AIDS?

Closet

The 'closet' presupposes that you were in fundamental darkness *before*, and that you leave this darkness behind by coming out. The closet also seems to be a repository of shame and a negation of self. And by saying that you are coming out of the closet, it creates an immediate dichotomy between the covert and the overt, sorrow and happiness. Once you are out, you join a transparent world. A world where you then would have a significant role to play. Meanwhile, the closet shapes your mind-set, which needs to be unlearned, undone, in order to maintain the supposed transparency, truthfulness which you may have brought to the world. The danger in speaking in metaphors. How does a culture create its meaning in relation to time and space? Especially when the metaphor is referring to a life, a real life, then there is a lot at stake. No word, no language is ever enough to talk about a life.

HIV

By nature, the HIV virus is not a form-of-life; in fact, it requires an external body, my body to survive, to exist, and to flourish. So how can that be powerful, a virus which does not even have a life of its own? Wait... am I talking about HIV or the agencies who wanted me to learn about HIV? These agencies could not have existed either, without me, without naming me, without calling me the high-risk population. Who needed whom, I wonder?

MSM

According to late 1990s popular mythology—MSM was a homogenous group of men those who spoke vernacular languages as if they were doing something wrong by speaking in their mother-tongue, but did they actually speak? And who was listening to them? Performs receptive role when playing, as if their desires were 'fixed.' And very importantly they were from lower-

socioeconomic-strata, an adjective that doesn't even have a home in my dictionary. This made me think, so much trouble they took to define 'us.' But how can one define a person?

Programme

Programme made in heaven just after the great storm when Noah made his ark. It was to re-invent people, identity, and to create a new form of colonialism. MSM was conceived, a hierarchy of oppression was theorized, and all were grace to MSM, and they also inherit the closet. This resulted in that life embraced as a matter of survival and therefore never lived.

Suffer/ing

They say suffering is good for the soul and for an afterlife. And life seems to be a project whose ultimate goal is to lead a painful life to attain a peaceful death, and it is good for one's character. If death is the only goal of life, then why so much fuss about race, class, privilege, power, refugees, and nationalities? But if the 'life' is what we are meant to live, and not just survive, then the goal should be to live to the fullest. Although, one may ask if people have choices to live or die?

System

Attempt #1

In his speech on Independence Day, Nehru made a promise "to bring freedom and opportunity to the common man," to the citizens of India, those who were starved to dream. Perhaps, this dream is the birth of the system of faux democracy.

System

Attempt #2

System is that pseudo lover who leaves their things everywhere, reluctant to invest in you, and you always feel their presence, but they are never around when you need them. System could also be understood as an ex-lover; the one who can be to blame for all the unfortunate things that happen to you but no one can be held accountable, and you think it costs love and all. But in reality, the system has many lovers, hence, millions of lives are at stake to wash their dirty laundry.



Charan Singh, *Terrace*, 2015. Courtesy of the artist.

Charan Singh is currently a PhD candidate at the Royal College of Art, London. He was an artist resident at the FIAR, New York, July 2017. His most recent published work is *Delhi: Communities of Belonging* with Sunil Gupta, which was shown at CAMH, January 2018, and previously exhibited at sepiaEYE, New York, 2017. He earned a Magnum/

Photo London award in 2016 for his portrait series “Kothis, Hijras, Giryas and Others” that was also shown in “I Am a Camera” at FotoFest Houston, and The Photographer’s Gallery, London in 2015. This series is featured in the Photoworks Annual, UK, 2017.

Fingerprints, Unfinished

A Conversation Between Mavi Veloso and Nicholas D'Avella

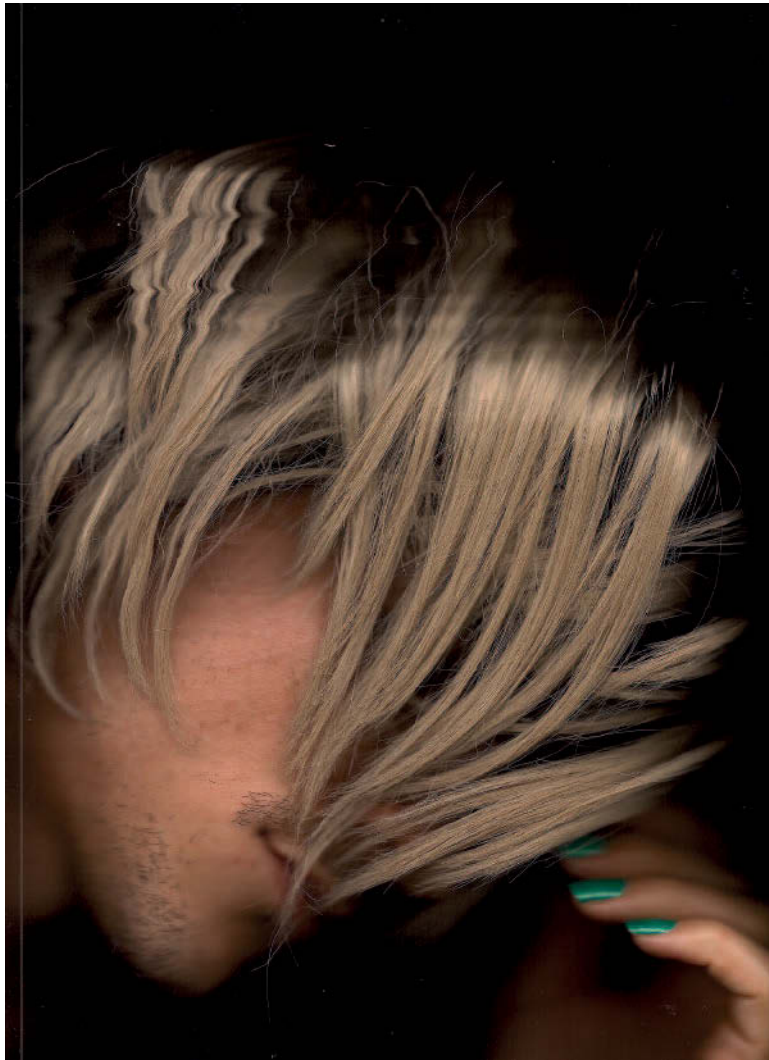
Before I had a chance to speak to artist Mavi Veloso, I had the opportunity to see a series of her images: *Fingerprints_ This Face is my ID Motherfucker* which is hosted under the broader research project *#iwannamakerevolution*. The photos are, on the one hand, a documentation of Veloso's bodily changes as she began hormone therapy. At the same time, the title calls the series into dialogue with state identification techniques, an aspect of trans people's lives that has been a focus of political struggle in light of the dangers and traumas related to an ID that doesn't correspond to one's gender presentation. The images produced by Veloso bear little formal similarity to the photos we know from drivers' licenses and passports. Instead, Veloso's facial scans—her face pressed against the glass, parts of the images blurred—make explicit the distortions she also finds in the purportedly “clear” images offered through state forms of ID. Several images in the series are also accompanied by lines of verse reflecting on ritualistic daily habits including waking up, applying makeup, and preparing food. We reflect together on the ways these small, quotidian, domestic acts can offer sites of refuge, ways of finding peace in a violent world, and then continue to talk about bodies, the state, HIV, migration, and politics.

– Nicholas D'Avella

Mavi Veloso: It's very nice to be interviewed by someone else for a change. Since October, I've been the one doing the interviewing! I have been speaking with other trans people about their voices. I don't know if you are aware, but the voice is one of the important layers of transformation during gender transition. It may happen different for Male to Female transition or Female to Male. In each circumstance and in each body it's different. Estrogen, Progesterone and Testosterone acts in very particular ways depending on the case. The interviews I was doing are for the thesis for Master of Voice at the Sandberg Instituut in Amsterdam. Right now, a lot of the research on hormones and voice is very technical and scientific. I'm interested in looking at it from the lens of performance, the transition process in general and going through the elements of voice therapy. Maybe this approach is more interesting to me because I am a performance artist, dancer, and visual artist.

Nicholas D'Avella: I've seen your series of photographs, *Fingerprints_ This Face is my ID Motherfucker*, and this sounds related to that. Can you tell me a little bit about the series?

MV: When I started making those images, I was not planning that much. I was just letting it happen. I did one, then another, and another. Then I started transitioning, and I thought; “Wow, maybe this can be an interesting way to document a process over time.” I related the process of scanning the face, photographing the face, as similar to fingerprints, which are very strong identification marks that will never change. I was comparing the act of photographing the face with the fingerprint process.



Mavi Veloso, #00 march 13, 2013, 2013. Courtesy of the artist.

ND: Can we talk about that? So, on the one hand, you have the stasis of the fingerprint, which is supposed to be enduring and long lasting, versus the changing of the face, right? So I was thinking about how, with the title, *This Face is my ID Motherfucker*, you are referencing state power through the ID, the ID card, the fingerprint. At the same time, you're also sort of flipping it and making it into something different with the scans. The scan produces an image that's very different from a government ID photo. Here, your process of scanning yourself, to me, seems to link up with struggles trans people have when it comes to the state's supposed role as arbiter of gender. Along with bathrooms, ID cards seem to be this site of determination and struggle.

MV: For me the series is unfinished, an open process. I have not really shown them before. When I think about putting them out into the world, I hope these conversations follow, because yes, I do think about government and the struggle that we have with identification, which I see as a manipulation as much as my photos are. It's a lot of manipulation of the identification idea.

ND: Can you speak about the process a bit?

MV: I try to make a frontal picture and a picture from each side. I always start with a more serious, formal thing, and then I experiment: wearing a lot of makeup, or not so much makeup, seeing what parts of my body I could get in the image and other experiments with distortion of the image during the scan. It is very open and each time I do sessions it is possible to come up with a different ideas.

ND: In some of the writing related to the work, songs or poems, you mention needing to encourage yourself to get up, put on a dress, put on makeup and heels, to let yourself go. I was fascinated by that and about the way you describe your legs and your nerves and your muscles, while also talking about the food that you eat. These things inhabit the lines of poetry, along with mascara, lipstick, makeup, eyelashes, blush “Eyelashes, mascara, chicken and mushrooms, / eyeshadow, blush, rice, some salad and after a tea” you write in one of them. You are keeping us with a sort of quotidian, daily practice. You keep art close to the everyday.

MV: I mean, I am not sure how to talk about this. Maybe, let me say this, in Brussels, leaving my house, dressed as a female, and having a bit of beard, could lead to violence. And it happened. I was attacked several times. It broke something in me. In these moments, I felt the need to sort of document myself, or try to take those confronting



Mavi Veloso, #03 sept 13 2015, 2015. Courtesy of the artist.

experiences to work them. Maybe that is where this impulse to capture not only an image, but details, comes from.

ND: The urgency comes through. There is a sense of the violent and the spectacular, but also the everydayness, the unspectacular.

MV: Yes, a mixture of what you're saying; a daily aspect but also the spectacular. Because I had often experienced a familiarity of living out in the world, having this violent confrontation with then trying to stay home, protecting myself and doing these daily things.

ND: This is interesting because performance is part of our daily life, right? But also, it is part of your specific artistic life. Which is something that is included in the images, a viewer can see a microphone and a pair of heels. Did you understand those to be extensions of your body?

MV: Yeah. At that moment I was considering them also part of an identification process. Again, I bring it back to my situation in Brussels. They were things I was using to process what I was dealing with. The heels were to pick up on the sweetness, the drag, the feminine body that was so provocative to other people. They were extensions of my body, which made me think that they were part of my fingerprints.

ND: And the microphone? Were you performing at the time?

MV: Yeah, I was working, dealing a lot with sound and silence. Then I started manipulating sound from the microphone. Not to sing but to create sound in other ways. Singing is something that came after.

ND: I love this idea of manipulation that you've mentioned a few times around both images and your body. I thought of the way that your scans and especially the way that you press your face up against the glass are part of that practice that makes us conscious of the images' means of production. We know that you are scanning your face. And with this in mind, it is easier for us to realize that the state ID is also part of a process of production, even though that is not made apparent. The state ID is supposed to be just you. But obviously, it isn't, it's the state's depiction of you. I think that is one of the reasons I like what you are doing with the manipulations of the images. They read as manipulated, as if to make us conscious of the way that you are a practitioner of your own image. It's almost like you're marking our access to reality. You're making us know that we're getting an image.

MV: Mmmm, maybe.

ND: Do you think of your work as political? I think the answer is "yes," but can you say more about that?

MV: Yes. Well, it's a very delicate thing. For a long, long time, I refused to think that my work would be political because I didn't have a political engagement in the streets and in social projects. I didn't think of my work as political in that narrow or traditional sense, but eventually I came to understand that being political is not necessarily just that. There are many ways it could look.

ND: I was thinking about politics in relationship to HIV in this sense, too, and thought we could talk about this in relation to your work. It seems to me that a lot of our understandings of HIV and politics, even in the art world, are very grounded in language and formal politics: street protests, signs, and political movements that are very language-based, rooted in statements, manifestos and speeches. But for me, I am often more interested in how HIV can and should be explored as political in the more expanded sense that you speak of. I see this reflected in your work in the ways it brings us into that intimate, quotidian space.

MV: I started getting more interested in performance, discussing the body and questioning the body when I discovered I was HIV [positive]. I was dealing with a very micro-level politics. On one hand I wanted to hide, even from myself, what I had. I would only accept to confront the fact when I would go to doctors to get medication. That was my terrible day. There was this relationship with hiding it, but at the same time I was also talking about it, even if in a manipulated way, in the performance practices I started doing. It was blood, skin, organs, sex, and the touch of the other. Somehow the politics of this thing was always present there. I later started to see that the politics are inside the small acts that you do, that some politics are in the plaza but others are in this other part here [in herself]. We have to occupy different parts of our state.



Mavi Veloso, #12 oct 1 2016, 2016. Courtesy of the artist.



Mavi Veloso, #13 jan 20 2017, 2017. Courtesy of the artist.

ND: I was thinking of your work as part of what it might look like to expand our understanding of what it means to engage with HIV politically but also in this sense of the everyday that we were speaking of in relation to your work. There's an Instagram account, @takemymeds, by Carlos Morenx, who takes a picture of himself taking his medication every day. I love it. It feels very resonant with the things that you say about bringing art close to everyday experience. Here he is, doing this very everyday thing, this almost intimate thing, but that brings this whole corporation and whole medical corporate structure into his mouth every day. So, what does it mean to think about that as a sort of political act, a meditation on what it means to hold close this medical regime in your mouth every day, then also project that and produce an image of that?

MV: Yes, like *Fingerprints*, it's about a body in transformation, the documentation of a process. Living with HIV is dealing with so many things: people, intimacy, and stigma. So, it is so strange when it comes together in a random encounter. I am thinking specifically of this time I met a guy, he was in my house, he was sucking me very hard and his teeth did a scratch on my skin, on my penis. After I said, "Hey, watch your teeth." He said he was sorry, and then later I got this text, "Do you have any diseases? Because I have a girl." I said to myself, I don't have to tell him anything, but I said something to him, in my own way.

ND: Yes, exactly. These moments in which the everyday and HIV come together, and you have to figure out how to interact with both the mundane and exceptional.

I was thinking about this feature of your work, too, in relation to my own ceramics practice. I have begun to experiment with identifying myself, at least in part, as an artist. I make pottery, pots and things. I created a page at the Visual AIDS Artist Registry, and as part of the process you upload images of your work and title them. I never had names. When I had to title them, I started thinking about how to make legible what I see as the politics of my work related to HIV in the way we've been talking about. I started thinking about the very everyday worlds of care that are produced by my work: "This is the plate on which I make food, and I give the food to my friends." "This is a pot that this plant lives in, and the plant makes me feel good." And to valorize that and say, "That's something!" It's part of how I survive. I started giving them these titles that were very much about these caregiving relationships, "This is the bottle that David told me he wanted that I wouldn't give him." Or, "This is the plate that I sold to Sam, and then he made me dinner on it at this party and I met this boy there." These kinds of things to sort of expand out a little bit the circle of relationships that surround and penetrate the object. So, thinking about your work, what we are doing maybe is thinking about the politics of HIV beyond the realm of big P politics. Does that make sense?

MV: It's very interesting. The pot and the plate. Because they are... I don't know if it happened to you, but it happened to me when I discovered I was HIV positive. The first thing that comes to your mind is this idea of a tragedy and that you can no longer touch. The touch changes; touching other people has changed for me.

ND: Yeah, or touching cum even.

MV: Oh my god! When I found out I was positive, I was super afraid of these things. When I tell people I have intimate relationships with about it, there's this recoil from touch, then you have to explain, you have to educate. Those are politics, too.

ND: And it's exhausting to do that work, again and again! Which is why I like my plant. I don't have to explain HIV to it, which is a relief.

MV: Yes. And this is where I can return to your question, maybe. I think I became more engaged when I realized that we have to occupy different parts of our state, or our culture. Nowadays, I am a transgender person in an academy. When I arrived here, I didn't see other trans people around. Now I see more of us, and I started to see that politics can be inside the small acts that we do, like showing up.

But also being here, I see that different places have different ways of doing and seeing politics. In Brazil, the situation there, the fights, and the blood in the eyes, is much stronger than here in a way. In Europe, it seems like people are much more silent. The way of doing and activating the politics here seems to be about being inside boxes. When I go back to Brazil, my sisters are singing and shouting, saying many things in songs and aloud, exploding. It's a very engaged and very activist way of being together. I try to do it too in my songs; I talk about personal experiences, about what people are ignoring. It is in the drama that I see resolution, maybe? We have to make noise, otherwise nobody talks.

In talking about it, I realize when I started accepting things, like my gender transformations, my HIV, and the fact that my work does have a politics, it was then I think I became more of an activist.

ND: Well, maybe related to that, do you think of yourself as a Latin Americanista?

MV: Latin Americanista? I think of myself as a Latin American girl.

ND: But is it something you carry with you? I was thinking a lot about you as a Brazilian artist who circulates internationally. I was thinking about both how powerful that is, but also how much of Brazil, of course, may not circulate with you, right?

MV: I think it has many different layers. Because, for example, when I first left Brazil to come to Europe, the first question was around how my work would transform because of the contextual changes. And it was a good question, because it happened immediately. So, yeah, I am a Latina, I am a Brazilian, not only Latina, but all the mixtures that you always hear about in my country. I started feeling lost while being here in Europe. For others, I am clearly a non-European. It's in my hair, my skin, it's in *my face, motherfucker*. Whenever I enter a place, people look at me and say, where are you from? So, now I have started asking myself, how will the context here affect my performance research?

While I was in Brazil, my body work, my performance work was very much related to all the crazy, fast relations that we have, the way we are speaking, dressing, looking at each other, addressing each other on the bus, and on the street. It is something I think about now because it is completely different here in Brussels from where I used to live and in Amsterdam where I'm currently living. For me, it is overwhelming.

ND: I think it's really important for North American and European audiences to recognize that translations are always incomplete. There are aspects of yourself that don't shine as easily in Europe as they shine in Brazil.

MV: Actually, nowadays it's a very crazy thing. Because I'm living out of my country for already more than three years, when I go back there it's not the same. I don't manifest myself the same way as I would if I was living there. It's a very crazy thing. It's hard feeling as a body not belonging to one place, or another.

ND: I have lived that life as well. I think about it a lot through the lens of circulation. I saw on your blog, a comic book illustrator who was trans who worked in Brazil and whose work maybe doesn't get recognized as art in the way that some of yours might. I was thinking about all the everyday people around us and the people I know in Latin America who don't get treated as part of the art world but who are, I think, producing art all the time but maybe in a more limited sphere. As you are in Europe, do you think about cultural producers in Brazil—HIV positive or trans or nothing or something else—who you could never imagine gaining circulation outside of Brazil? Or, whose work isn't recognized as art by an international community?

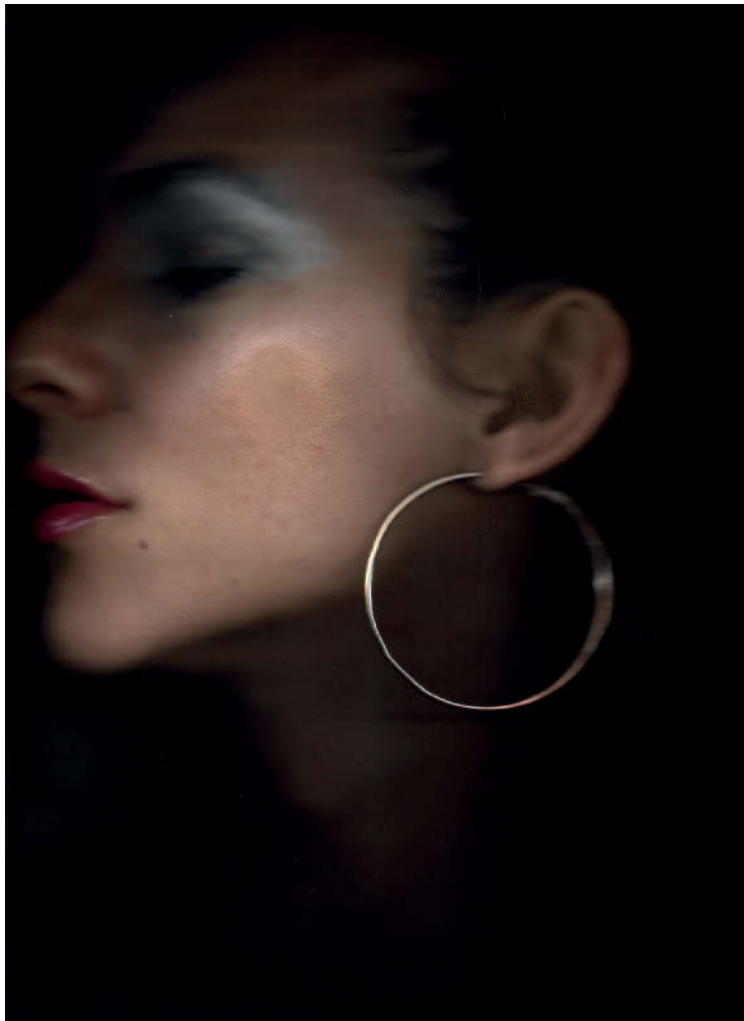
MV: There are several artists in Brazil that are references for me. I think the cartoonist is Laerte Coutinho. Yeah, that's a person that has a remarkable presence in Brazil. Back in the past as a man, she was a very important part in newspapers. Now, she is transitioning around her 60s. Yeah, I like to point to Laerte with the whole long story

that she had as a cartoonist at the newspapers. Now, as a trans woman, she's bringing a lot of visibility and helping create a community to gain voice for trans people.

There is also José Leonilson, visual artist who lived with HIV in the '80-'90s. Actually, he died in '93 of AIDS. I think that I took a lot from him in my drawings, something in the lines and style... I got really influenced by him. In visual art circles, he's a very, very strong name, very intimate work.

I would also like to highlight what these girls are doing in Brazil. Transgender girls that are making music. They are bringing very popular media things, which unfortunately the visual arts, the performance arts, the dance universes, they stay in the dance universe, in the visual arts universe. Fortunately or unfortunately, the music scene, when it reaches a high level of visibility, more people listen to it. These girls they are taking the power to talk about...to bring our existence and living aspects in their lyrics and in their songs. Linn da Quebrada or Linker, As Bahias e Cozinha Mineira...

ND: I will tell you about one of mine. My friend Marlene Wayar is a travesti woman, I don't think her work would be in a museum but she's an important political and cultural figure. She did this interview with the newspaper that I really loved, in which



Mavi Veloso, #16 april 1, 2017, 2017. Courtesy of the artist.

she took her wig and she offers it to the world. In the picture, she's bald holding out her wig and she says, "Te regalo mi peluca," I give you my wig. The idea is that everyone in the world could put on her wig and start to become uncomfortable in their bodies. I was just thinking about her and I don't think she would go in a museum ever, but she's very important to me for thinking about these questions. Her politics is very obviously performative.

MV: Yeah, this action you just described for me was the most amazing thing. That's the best performance ever.

ND: To just think about that, right? This seems to me very much what your work is about—that we're surrounded every day by quotidian, everyday politics, action, and performance that inspire us and that help us keep these issues present for us in a very special way, not reduced to either the things that we think of as big-P political or necessarily as big-A art. Thanks Mavi.

MV: Thank you, Nicholas.

Nicholas D'Avella is an anthropologist, writer, and potter living in Brooklyn, NY. He is interested in the relationship between bodies, technology, politics, and exchange, paying particular attention to how these themes emerge in Latin America. He is the author of *Concrete Dreams: Value, Practice, and Built Environments in Post-Crisis Buenos Aires* (Duke, 2019), and his work has been published in several journals and edited volumes. Currently a visiting scholar at the Hemispheric Institute of Performance and Politics at New York University, he is also a participant in the collective *What Would an HIV Doula Do?*

Mavi Veloso is a Brazilian performer based in Amsterdam who works trans-disciplinarily, integrating visual art, dance, theater, and music. Her work explores performativity, the relationship between performer and audience, trans feminism, and decolonization. As a transgender migrant from South America to Europe, Mavi seeks to embody and appropriate the transformation process, psychological, social, and physical, conflicts and cultural adaptation procedures, as well as fashion, queer, trans, and drag queen elements to question gender technologies, notions of identity, sexuality, placement and displacement. She is currently developing the project #iwannamakerevolution and has presented her work in venues and festivals including the Van Abbemuseum in Eindhoven, Kampnagel in Hamburg, Kunstenfestivaldesarts in Brussels, Les Urbaines in Lausanne, and the 31st Biennial of São Paulo.

Collecting

Abiding Relations Through Recovery, Restoration and Curation

A Conversation Between Jean Carlomusto, Alexandra Juhasz, and Hugh Ryan

EVERYDAY Curatorial Statement

"AIDS is an everyday experience. By this, we mean it is both common and ongoing; quotidian and unending. Yet its history—like all history—is being written in Boldfaced Names and Significant Dates, especially those from the near past. Like the moon that eclipses the sun because it is closer to our frame of reference, the enormity of that moment of the AIDS crisis threatens to blind us to both the sprawling present and the unknowable future. Moreover, the significance of this artist or that day is always less than the significance of the cumulative reality of life in the time of AIDS.

In *EVERYDAY*, we bring together work that engages with the "now" of AIDS, both historically and currently. Some of the work uses the materials of AIDS, from pills to pamphlets, while other pieces chronicle daily responses, from protest to prayer. Much of the work speaks in the vernacular of its own moment, whether that be wheatpaste, VHS, or an app. Some of it is made by professional artists whose gift is to speak of and to the world around them, while other pieces were made by intuitive creators who were driven to respond to the crisis as one mode of survival—the same spirit that drove us to make this exhibition. Someday we will have a cure, and the infrastructure and political will to get it to everyone who needs it.

But until then, AIDS is *EVERYDAY*."

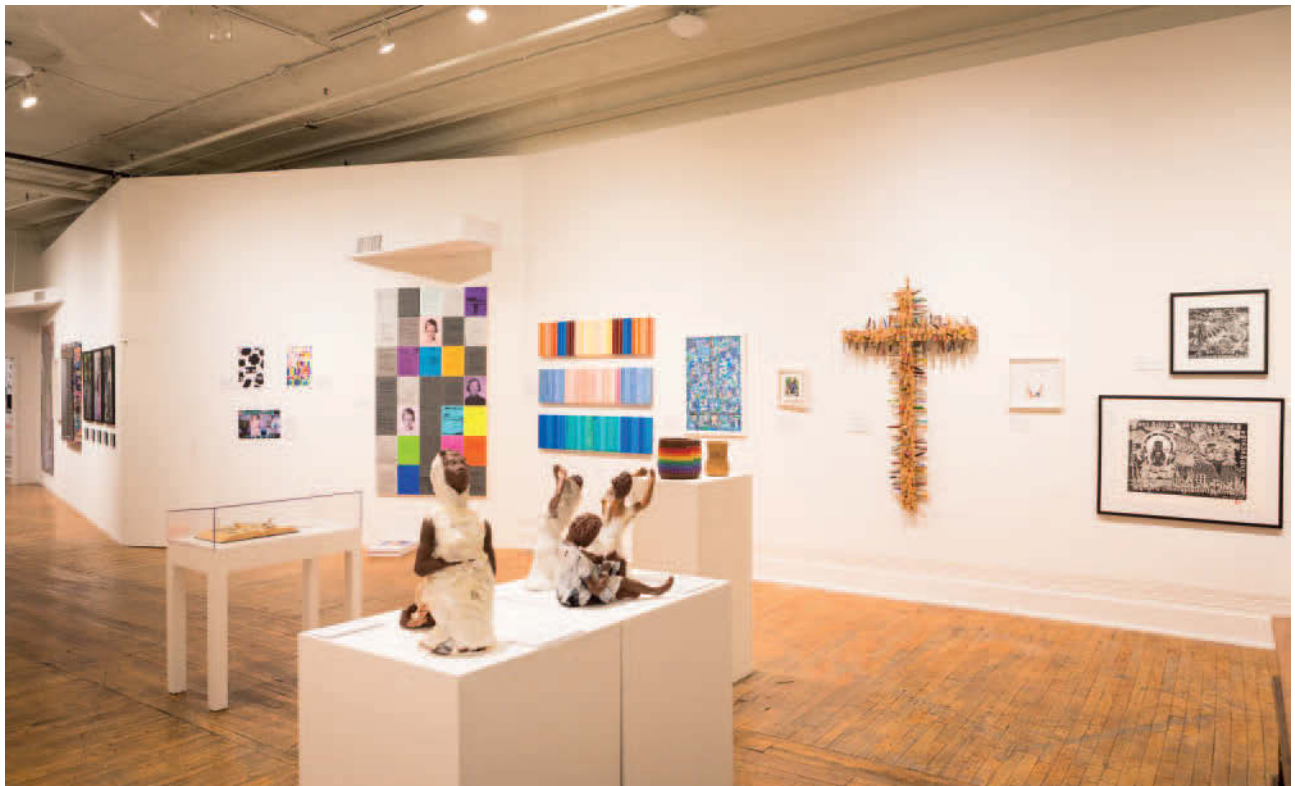
Hugh Ryan: My background in curation comes mostly from my experience with The Pop-Up Museum of Queer History, an organization I founded in 2011 as a response to the censorship of the *Hide/Seek* exhibit at The Smithsonian. While I was incensed that they would remove David Wojnarowicz's film *A Fire In My Belly*, I also felt that it was somewhat ridiculous to protest the removal of a single piece of queer art from a museum in DC, when on a daily basis there was no museum in New York I could visit to see queer art (at least, not if I wanted it to be recognized as coming from a queer perspective). The Pop-Up Museum was my response: a community-based, collaborative intervention that created locally sourced art exhibitions based in queer history all around the country. I came to see curation as a deeply collaborative project.

So, when Visual AIDS first reached out to me in the Fall of 2015 about co-curating a show for Fall 2016, I knew three things right away. First, that I wanted to work with someone older than I was who had direct experience of the first wave of the crisis. Second, because the show was going to be up at the same time as *Art AIDS America (AAA)*—which argued, in part, that the importance of AIDS in American history could be inferred through the way it changed modern art—I wanted to locate the importance of AIDS in American history in another way: through the way it compelled people from all walks of life to make art in response, whether or not they were trained or publicly recognized as artists. And finally, because I knew (from discussions with curator Jonathan Katz that) *AAA* would not be including video art, I wanted to work with someone who was familiar with filmic responses to the crisis.

Earlier that year, Jean Carlomusto and I had both been at a conference about queer history at Syracuse University, and I'd had the chance to see her incredible interactive video installation to AIDS activists, *Offerings*. I'd also recently re-read sections of Alexandra Juhász's book about video responses to the crisis, *AIDS TV* (1995). Both seemed like exactly the sort of people I wanted to work with on this project; it wasn't until the three of us sat down together for the first time that I discovered they had worked together in GMHC's video department in the mid-1980s. Together, we decided to focus our exhibition on the idea of the "everyday": the daily acts of survival, resistance, caring, art-making, fighting, forgetting, hoping, despairing, and simply *being* that make up life in the time of AIDS.

Jean Carlomusto: Now that I think of it, the conference at Syracuse where I met Hugh was specifically on Queer Archives. I was moved by the community-based and collaborative nature of his Pop-Up Museum. It was an intervention akin to what Douglas Crimp termed "cultural activism" back in the 1980s to describe both the ever-present video cameras at demonstrations and the sophisticated use of graphic design by AIDS activists. By nature, these interventions were community-based and collaborative.

I came to curation by collaborating on a large body of AIDS-related works dating back to 1986, when I started the Audio/Visual Unit at GMHC. The mission of trying to get a message out in a deeply repressive and fear-laden environment, with very few resources, required a strong collaborative effort. In making the *Living With AIDS* cable show and projects such as the *Safer Sex Shorts*, Gregg Bordowitz and I collaborated with many artists to try and set forth nuanced messages. Often times, episodes of LWA were comprised of curated works from other videomakers, such as Stuart Marshall,



Kaz Senju, Installation View of *Everyday*, 2016. Courtesy of the artist and Visual AIDS.

Isaac Julien, and John Greyson. In 1987, with the start of ACT UP, there was a creative explosion of AIDS activist art and video. I collaborated with numerous other activist documentarians through the affinity group DIVA TV (Damned Interfering Video Activists) and the Testing the Limits Collective. The sheer volume of original material and source tapes over the years has necessitated my keeping an archive. Those of us who try to keep a personal archive have to find the most stable form of archival acquisition which often necessitates massive digitization—an effort that is not always easy. As an artist, the idea of spending my days digitizing and cataloguing source tapes is burdensome. I prefer to do my archival grazing and digitization in the service of current projects and concerns. My two recent projects *Larry Kramer in Love & Anger* (2015) and *Sex in an Epidemic* (2009) draw heavily on my archive as well as those of many other activists and organizations.

Alexandra Juhasz: As Jean describes, our collective curatorial practice for the *EVERYDAY* show was also committed to finding, sharing, and amplifying little-known archives (including those of the Visual AIDS Artists Registry and some amazing media makers) by placing an emphasis on the everyday art practice of regular people, artists all, whose quotidian existence had been transformed by both their art-making and AIDS. Beginning with these as our search criteria, we found and agreed upon an array of art made by an exceedingly diverse set of makers (across time, genre, and training, as well as gender, race, sexuality, and age). Ours was not another presentation of the usual suspects, like those presented in AAA also in 2016. Instead, we hoped to highlight the work of gay white men and the many others who live and make art everyday about AIDS; we hoped to celebrate work made by already heralded art-world participants and that by artists who never worked within or about that world, or would never be understood as in conversation with that one art history, economy, or set of formal traditions.

To do that, we had to become the thing we wanted to create. Curating *EVERYDAY* with Hugh and Jean, and then also compiling and editing *COMPULSIVE PRACTICE*, our video for Day With(out) Art highlighting work by nine artists obsessed with HIV and video, was an everyday sort of collective curatorial practice. For over a year, we met often on Skype, and a few times in person (when I was in NY). We were slowly getting to know each other by building a shared framework for judgment through a sweet, respectful, growing dialogue that put a premium on how art—its making, viewing, and communal consideration—adds richness, purpose, and pride to a daily existence that can otherwise feel confusing, isolating, painful, or meaningless, especially when saturated by HIV. Our professional friendship—across well-focused differences—became ever more deeply rooted as we developed a shared language of values and a mutual sense of how to speak these ideas. Our everyday curatorial practice was built together across many days of talk and hours of shared looking.

As we learned about each other, we also shared past and current knowledge and experience. I have been working on and about AIDS video since 1987, when I met Jean at GMHC as a recent college grad hoping to volunteer. We ended up making *Living with AIDS: Women and AIDS* together for GMHC's weekly cable access show. It was one of the first videotapes about this issue. We covered the organizing, education, and activism around women's health, lesbian empowerment, and feminist analysis that was happening in New York City alongside the birth of ACT UP and other community-based responses to AIDS. Over the decades, I went on to make many more tapes, I wrote my doctoral dissertation and many more essays on this important, small, devoted field in which I was also a member (for instance, my first book, *AIDS TV*, that

Hugh refers to), and I continued to write about and make AIDS activist video, including two very recent books both in contract review, one with Theodore Kerr, *AIDS Crisis Revisitation*, and the other a scholarly anthology co-edited with Jih-Fei Cheng and Nishant Shahani, *AIDS and the Distribution of Crises*. Over these many years, I had found myself in and out of community, in and out of public expression, and in and out of altering AIDS time and place: past, present, public, private.

Thus, our way of being and working together felt rare and valuable; I looked forward to it; it made me feel honored, seen, and respected by people I grew to esteem more and more. How we saw each other—with love, admiration, attention to the others' unique contributions, and joy in our shared convictions—is just what I hope is expressed in our curation, too: abiding relations to art and people who share a purpose. This is itself an example of collective processes for activism and art-making that Jean and I honed during our participation in queer/feminist AIDS activism in the 1980s. Hugh knew or intuited these ways: respectful, honorable, political comradeship that begins with care for others in our community, often attending with compassion and interest to those least seen and heard. This is what we did together while also being what we were looking for in the work we hoped to celebrate and share through our efforts. We first worked to build and then got to bathe in this curative manner of curatorial practice: different from either the more contemporary understanding of curation as “networking,” or as the more dated (but still ongoing!) patriarchal, stuffy, and stiff work of curation as an effort towards maintaining hierarchies, cementing status, and manufacturing History.

JC: In writing about our collaborative process, I am most drawn to stories of recovery and restoration—curated works that had to be found, salvaged and cared for. In fact, we practiced an aspect of curation that harkens back to its archaic meaning: to heal or cure. As someone who maintains an historic archive, I am keenly aware of the work of the caretaker-curator. Thus, for me the *pièce de résistance* of the *EVERYDAY* exhibition and the *COMPULSIVE PRACTICE* video was the often unspoken efforts of friends, lovers, researchers, and AIDS/queer archivists who had salvaged and preserved the works of deceased artists which we went on to curate into our show. For example, we saw Gin Louie's elegant book sculptures in the Artists Registry at Visual AIDS and wanted to include them. Through the Artists Registry, we were able to track down a sculpture owned by Gin's friend, Eve Sinaiko, who had kept it safely boxed on her closet shelf for years. Eve welcomed the opportunity to display Gin's work once again. Similarly, such herculean efforts were on view when it came to including Edward Hochschild's *The Vial Cross*. Hugh had written about Hochschild's large wooden cross—pierced with test tubes containing pills, blood, hair, and little toys—as part of the Leslie-Lohman Museum of Gay and Lesbian Art collection.

The folks at Leslie-Lohman told Hugh they had Hochschild's work “because some time in the early '90s his friends showed up at the gallery and said that Hochschild had died of AIDS and his landlord was throwing his art out on the street.” LGBT archives are filled with works like this salvaged from the curb.

HR: One of the most incredible parts of preparing the show, for me, was getting to work with the conservators at Leslie-Lohman to repair and stabilize *The Vial Cross*. First, we mapped the entire cross so that we knew where every tube was and what each one contained. Then we carefully cleaned each one. For the broken ones, we stoppered the sharp glass edges with rubber. In a way, it felt like recapitulating the

theme of the entire show: the dailiness of cleaning, being used to preserve this incredible work of art, made as a direct response to the crisis.

JC: And let's not forget the work we did on *COMPULSIVE PRACTICE*. In aspiring towards curating a diverse set of voices, one tape in particular came to mind—*HOMOSEXUALITY: ONE CHILD'S POINT OF VIEW* (1993)—a collaborative work that Juanita Mohammed created with her eight-year-old daughter, Jahanara (Jazzy). It's a creative and passionate defense of love in all its forms. Alex and I share a deep admiration for Juanita's work, but Juanita no longer owned any accessible copies of her videos. Alex found an original 3/4-inch copy in her collection, and I undertook the task of digitizing it. Just to get this warped tape to play in an archival deck required hours of painstaking concentration and advanced technical skill. Ultimately, it was gratifying to be able to include clips from this tape and much more of Juanita's work in *COMPULSIVE PRACTICE*—the video we produced to accompany the show, which was screened around the country on World AIDS Day—and to return a digitized file for her to keep.

HR: Over and over again, *EVERYDAY* became an experience of collaboration: between Alex, Jean, and I; between the three of us and Visual AIDS; between myself and the conservators at Leslie-Lohman; between Jean, Alex, and Juanita; we even worked with our artists to create new collaborations between them. Perhaps the moment that best encapsulates *EVERYDAY*, for me, was playing *Dizzyland*, the videogame that Frederick Weston created in collaboration with the indie game collective, BABYCASTLES. In our phone-obsessed culture, videogames are becoming one of the most everyday forms of art and storytelling, and we wanted our exhibition to speak not only to the present and past of AIDS, but also to its digitally mediated future. Weston joked with us that his first art show featured the Polaroids he put up in the coat checkroom at The 10th Floor, the nightclub where he worked when he first moved to New York in the Seventies. In his game for the show, you create a character who navigates social interactions in a barroom setting; depending on the choices you make, you have the option to share or withhold information (including your HIV status) with the computer-generated characters that inhabit *Dizzyland*. Putting Weston's first-person experience of the dawn of the crisis in direct dialogue with the young videogame makers at BABYCASTLES (none of whom had ever known a world without AIDS) produced a beautiful collaboration that continues to exist long after *EVERYDAY* itself is closed—much like the community we sought to foster among our artists and with each other. *Dizzyland* is a physical and digital representation of that finding-of-commonality-across-difference that proved to be the animating spirit of *EVERYDAY*.

AJ: The night of the opening, I remember Fred speaking about his practice with a participating artist, LJ Roberts, and then later with my children, Simone and Gabriel, amazing artists all. The room vibrated with a stimulating if uncommon admixture of pride, humbleness, and shared recognition, and a sense that we mattered, if briefly, to the world and each other just as some parts of the world fell into free fall. And that was one really great thing about the opening, a good many of our featured artists stepped out to the show and were visibly honored to meet each other and also moved by the power of seeing their work on the stately white walls of La Mama La Galleria, a New York gallery. Peggy Frank came from Canada to see her immense cocktail glass banner installed. Joyce McDonald travelled from uptown in an Uber and delighted in seeing her many sculptures grouped on a table after spending so much time in boxes under her bed. Randy Freedom Clay took the bus from DC to join us. That night, we delighted in seeing our featured artists meet and learn from each other.

JC: It's important to remember that *EVERYDAY* opened in December 2016. Donald Trump had just been elected President. Everyone was a bit stunned. In many ways, it was a perfect time for a show that navigates the terrain between deeply personal expression and socio-political commentary, even if we felt unprepared to confront this reality.

AJ: Yes, in fact, we made a pretty huge curatorial change right before the show opened because of this unexpected shift in lived reality. We had already decided to include fierce pussy's devastating "to do list" (1994). But given Trump's recent election, and the ominous, unrelenting sense of paralysis, confusion, dread, sadness, and disorientation that accompanied it, we also wanted to demonstrate how earlier AIDS art could provide templates for everyday action today. Last minute we decided to hang a usable, store-bought, to-do list next to fierce pussy's earlier piece, hoping to suggest that there were things we could all do everyday today: personal, political, artistic, contemplative, up to you. On the day before we opened, while Jean and Hugh helped to hang the show, I raced to a nearby Staples and bought 5-10 to-do list pads. Our curatorial choice to emphasize engagement, action, and contemplation for participating members of our community was another facet of our shared project.

We added this Addendum to our curatorial statement on November 15, 2016: "The everyday of AIDS changed on November 8, 2016. We invite you to engage with the powerful work displayed in an *EVERYDAY* conceived during the presidential election of 2016. We ask you to leave with a TO DO list in hand of what you will do, everyday, given its results."

Our communal-community focused curatorial practice was never merely a matter of feelings, ideology, or even care. Our specific, unusual, shared compass opened up sight-lines that would otherwise not be available, creating unexpected and critically important reverberations of theme, style, and form as well as community and daily action. For instance, in *COMPULSIVE PRACTICE*, the use of humor by Carol Leigh, Ray Navarro, and Mark King stood in stark comparison to the powerful pull of pathos in the YouTube vlogs of Justin B. Terry-Smith and the VHS videos of Juanita Mohammed, or that of anger espoused so freely by James Wentzy. The hunger for voice was the same whether those caught on tape were religious black women with HIV in the South for the Southern AIDS Living Quilt or stars from the NYC ball scene, also people with HIV, documented and archived on YouTube by Luna Luis Ortiz.

These similarities across so many more obvious differences (race, gender, technology, time period) were striking to us, allowing us to understand that different curatorial commitments lead to new knowings of both HIV/AIDS and each other.

JC: I remember feeling anxious and slightly nauseous traveling to the storage unit containing my video archive with Alex, Hugh, and Kyle Croft, to shoot the opening and wraparound segments for *COMPULSIVE PRACTICE*. Lately, it's become increasingly daunting for me to go through the accumulation of videotapes, packed in white boxes, with my scrawled notes on the side. I used to know what was in every box. Over the years, tapes have gotten added or filed in another box. Or, maybe I'm forgetting, and it's starting to become somewhat chaotic in there. In retrospect, I'm not surprised that, in a totally unscripted moment of desperation documented in *COMPULSIVE PRACTICE*, I discovered I had lost the key for my unit, and a porter had to be called to saw the lock off. As we waited for the porter to arrive, Kyle ran the camera as Hugh, Alex, and I had a chance to talk about how we came to cultural practice around HIV/AIDS. I found this shared moment of reflection very fortifying; in a subtle shift of mission, we weren't

just unpacking my archive, we were creating a space where we could explore an archive that, in this instance, happened to be mine. I felt the restorative endeavor of our collaborative team.

I consider the work of curation to be an act of supreme collaboration, not just among the curatorial unit but within various groups who have kept the works safe and accessible. It is so rewarding to know friends, families, compassionate strangers, and art institutions alike whose own painstaking work makes it possible to curate the work of artists featured in *EVERYDAY* and *COMPULSIVE PRACTICE*.

AJ: The three New York City public screenings that Visual AIDS helped us to organize for *COMPULSIVE PRACTICE* manifested beautifully, in their people and places, our commitments to collaboration within communities. Held at the Brooklyn Museum, the Studio Museum in Harlem, and the New Museum, each one of our living compulsive video artists came to one or more screenings and spoke together after the screening in delightfully idiosyncratic groupings that were equal parts riveting, emotional, bonding, and inspirational. And, as is true of Visual AIDS yearly Day With(out) Art programming each year, our tape also showed all over the world, in any number of diverse settings and communities where daily life and compulsion have their own histories, purposes, and habitual practices.

HR: We also felt it was important, not just to be present at the screenings of *COMPULSIVE PRACTICE*, but to be visible in the gallery space, and accessible to visitors to *EVERYDAY*. Too often, the people who put together exhibitions—the gatekeepers, who in a very real sense decide who is welcome—are invisible; the curators make the decisions before the show ever opens, and the community never has a chance to discuss those decisions with them. Unlike movies, where we all know the names of the directors and can speculate about what it means when so-and-so is tapped to helm this-or-that project, curators are often completely unknown. We wanted to be accountable, and to be accountable, you must first be visible.

COMPULSIVE PRACTICE Statement

For the 2016 Day With(out) Art, Visual AIDS presents *COMPULSIVE PRACTICE*, a video compilation of compulsive, daily, and habitual practices by nine artists and activists who live with their cameras as one way to manage, reflect upon, and change how they are deeply affected by HIV/AIDS. This hour-long video program will be distributed internationally to museums, art institutions, schools and AIDS organizations.

From video diaries to civil disobedience, holiday specials and backstage antics, Betamax to YouTube, *COMPULSIVE PRACTICE* displays a diversity of artistic approaches, experiences, and expectations. The compulsive video practices of these artists serve many purposes—outlet, lament, documentation, communication, empowerment, healing—and have many tones—obsessive, driven, poetic, neurotic, celebratory. *COMPULSIVE PRACTICE* demonstrates the place of technology, self-expression, critique, and community in the many decades and the many experiences of artists and activists living with HIV/AIDS. *COMPULSIVE PRACTICE* highlights subjects ranging from historic actions against government neglect to contemporary issues such as Pre-Exposure Prophylaxis (PrEP) and living with an undetectable viral load. Altogether, the program charts over three decades of AIDS-related video production in the face of the ongoing crisis.

Jean Carlomusto is a filmmaker, activist, and interactive media artist whose work explores the complex nature of unique individuals and marginalized populations. Her films are often unorthodox investigations of LGBT history and HIV/AIDS. Her work has been exhibited internationally in festivals, museums, and on television. She produced and directed HBO's Emmy-nominated documentary, *LARRY KRAMER IN LOVE & ANGER*, which was featured at the Sundance Film Festival.

Dr. Alexandra Juhasz is Chair of the Film Department, Brooklyn College, CUNY. She is a core faculty member in the Interactive Technology and Pedagogy Certificate Program at the CUNY Graduate Center, where she also teaches in the MALS program. Dr. Juhasz writes on feminist, fake, and AIDS documentary. Her current work is on online feminist pedagogy, YouTube, and other more radical uses of digital media and their archives. Her work as media artist, curator, and writer engages with linked social justice commitments, including AIDS, black queer and lesbian media, feminist and queer/trans film, and activist archives and collectives.

Hugh Ryan is a writer, curator, and speaker in New York City. His work is about queer politics, culture, and history. His book, *WHEN BROOKLYN WAS QUEER*, from St. Martin's Press was released in March 2019. He was the founder of Pop Up Museum of Queer History and was the 2015- 2016 Martin Duberman Fellowship at the New York Public Library.

Status = Undetectable: Curating for the Present and Future of AIDS

Marika Cifor

Introduction

“We’ve reached a crossroads in HIV treatment. HIV positive and HIV negative are no longer the only possibilities when discussing serostatus. The word undetectable has emerged in this conversation.”¹ These words begin the Undetectable Flash Collective’s 2014 intervention on undetectability. Undetectability names the status of a person living with HIV who through medical treatment is able to lower the load of the HIV virus in their body to levels that are insignificant statistically. As the Collective proclaims, undetectability is more than a simple description of successful HIV treatment. It names an identity that troubles the established binary of HIV-positivity or negativity. Undetectability is a significant focal point in HIV/AIDS discourses, producing and reproducing concerns about visibility, measurement, temporality, presence and absence, contagion, and bodies and embodiment.² Undetectability surfaces meaningful concerns for curators of contemporary AIDS exhibitions. This article uses “undetectability” as the point of departure to consider the extent to which medicine and public health, humanistic, and artistic and activist engagements with HIV/AIDS affect the question of historicizing and memorializing an ongoing epidemic through curatorial work with and inspired by AIDS archives. I argue that curating with and about AIDS’ archival past requires a critical engagement with AIDS’ present. The lens of undetectability offers curators a crucial means to engage with urgent contemporary concerns of representation and temporality in ever-more-common shows focusing on the presentation of 1980s and 1990s AIDS activism and cultural production.

In 1987, Douglas Crimp wrote, “AIDS does not exist separately from the practices that conceptualize it, represent it, and respond to it. We know AIDS only in and through those practices.”³ Undetectability is now such a practice. For those with access to medical intervention who are able to attain and then to maintain undetectability, the virus’ representation is transformed. Already invisible to the naked eye, the virus is made doubly so in its failure to register in conventional testing. Moreover, it is rendered non-contagious. HIV-positive persons with an undetectable status may be subsequently reframed as “respectable” and “responsible,” while their bodies hold the promise of halting the virus. As Jan Huebenthal writes, undetectability “connotes privilege and fitness for citizenship.”⁴ With undetectability, HIV is conceptualized in scientific, medical, and cultural discourses as less infectious and catastrophic than it once was. However, HIV stigma and discrimination continue to pervade when HIV is bothered to be represented at all in a U.S. context. It is important to note that race, gender, sexuality, and socio-economic disparities curtail access to undetectability.

AIDS, as Susan Sontag noted,⁵ has always been a temporal condition. The virus moves and circulates with a particular rhythm. It takes for many a full decade from infection to first development of symptoms.⁶ Undetectability also names a temporal relation. It marks the advent of the “manageable chronicity of AIDS.”⁷ Undetectable is the current pinnacle of the biomedical intervention. Before the development of an effective

antiretroviral drug cocktail in 1995, a long and relatively healthy life was a near impossibility for those living with HIV and AIDS. As Marita Sturken articulates, the AIDS epidemic from its first medical recognition in 1981 through the early 1990s had a particular temporal meaning. Time was accelerated and the far-reaching devastation called for an “immediate, in the moment, on the street” response.⁸ Biomedical developments have brought a measured sense of security and safety, shifting the temporality of HIV/AIDS again. Undetectability shapes current practices, policies, and the politics of with HIV as well as engagements with the AIDS’ past. It therefore holds direct implications for the ongoing epidemic’s future. Undetectability powerfully disrupts linear notions of temporal progression from past through present into future.

From the 1980s onward, activists and archivists have created, collected, preserved, and made accessible HIV/AIDS knowledge. Archival materials created during the 1980s and 1990s in the U.S. are increasingly being employed by curators within a range of exhibition contexts to develop shows about AIDS and its cultural production. Such shows featuring the archive prominently often focus exclusively on the past of AIDS. That framing threatens to dangerously historicize the epidemic. This article analyzes the New York Public Library’s exhibition and programming for *Why We Fight: Remembering AIDS Activism*, a major exhibition of archival materials documenting 1980s and 1990s AIDS activism. It is through the commissioning of new work inspired by and utilizing these records, the intervention of the Undetectable Collective, that the show



This page and next: Undetectable Collective, *What is Undetectable?*, 2014, Image of lenticular print © Undetectable Collective.

reached successfully into pressing present concerns of the AIDS epidemic. I begin by framing undetectability as biomedical and cultural status. Next, I turn attention the Undetectable Collective's work. Finally, I conclude with a discussion of how the logic of undetectability can inform curatorial engagements of archives with implicated communities as well as the cultural memory of the AIDS epidemic, and hence the very meaning of the epidemic itself.

Undetectable as a Biomedical and Cultural Status

In 1985, the first test kit to screen for antibodies to HIV was developed and approved for use by the Food and Drug Administration.⁹ This test emerged one year after HIV was officially identified as the etiologic agent of AIDS, and five years after the first mention of cases attributed to the virus.¹⁰ The test played a key role inaugurating the fraught categories of "HIV positive" and "HIV negative," a profound binary across the realms of science, medicine, sexuality, politics, and culture.¹¹ A decade later, in 1996, the biotechnical development of highly active antiretroviral therapy offered for the first time an effective treatment for HIV/AIDS.¹² Eventually, those treatments would enable the suppression of the virus to undetectable levels.

In 2008, the first major study by Members of a Swiss Federal Commission for HIV/AIDS found that persons living with HIV on ARV treatments could not transmit the virus through sexual contact if they had viral loads that had reached and stabilized at

WE'RE AT A CROSSROADS IN HIV TREATMENT. HIV POSITIVE & HIV NEGATIVE ARE NO LONGER THE ONLY POSSIBILITIES WHEN DISCUSSING SEROSTATUS. THE WORD UNDETECTABLE HAS EMERGED IN THIS CONVERSATION. UNDETECTABLE ORIGINATED AS A MEDICAL TERM FOR AN "ACCEPTABLY" LOW PRESENCE OF HIV IN THE BLOODSTREAM DEPENDENT ON STRICT COMPLIANCE WITH "SUCCESSFUL" ANTIRETROVIRAL TREATMENTS. MAINTAINING UNDETECTABLE VIRAL LEVELS SIGNIFICANTLY REDUCES HIV TRANSMISSION, BUT IT IS NOT A CURE FOR AIDS & DOES NOT REMOVE STIGMA. NOT EVERYONE HAS ACCESS TO INFORMATION OR TREATMENTS, SO THE EMPHASIS ON ACHIEVING UNDETECTABILITY REINFORCES RACIAL & SOCIOECONOMIC DIVIDES. BECAUSE THERE IS MORE MONEY IN LIFELONG TREATMENT, PROFIT-DRIVEN DRUG COMPANIES HAVE NO FINANCIAL INCENTIVE TO FIND A CURE. UNDETECTABILITY SAVES LIVES. BUT WHOSE LIVES? & WHO PROFITS? WHERE'S THE CURE?

undetectable levels for a period of six months.¹³ Numerous studies confirmed these findings; however, it was not until 2017 that the Centers for Disease Control and Prevention came out in support of the same conclusion.¹⁴ Over the course of the last decade, health-governing bodies and scientific communities have been cautiously supportive of undetectability's potential. Patient advocacy organizations have emphasized undetectability's promise for enhancing the "quality of life" and social integration of people living with HIV/AIDS.¹⁵ It is their, as yet unrealized, hope that undetectability will fundamentally change antiquated understandings of HIV as dangerous and deadly, thus ending persistent fear, discrimination, and stigmatization.

The "treatment as prevention" model that dominates current public health approaches to HIV/AIDS both promotes the desirability of undetectability and works to materially enable it. This model is central to various strategies to end the epidemic by health-governing institutions including governments, non-governmental organizations, advocates, major donors, and the pharmaceutical industry. Treatment as prevention relies, first, on dramatically increasing the percentage of persons living with HIV/AIDS who are tested and are therefore aware of their serostatus. Second, it focuses on increasing the number of those persons who are on ARVs and under medical supervision and continued surveillance. In public health and medical definitions, "the end of AIDS" has come to mean the significant decrease in rates of HIV transmission, rather than a cure for those already living with the virus.

As curator and academic Nathan Lee writes of HIV, "Drugs have curtailed its lethality but not its ubiquity, and the long-term effects of combination therapies, which continue to evolve, are an open question. We know that AIDS is not what it was, but we're not at all sure what it has become."¹⁶ While most literature on undetectability emerges from medicine and public health, the cultural and political implications of undetectability have begun to garner some scholarly attention. Much of this work charts the meanings of undetectability for queer lives, activism, and politics.¹⁷ For example, Kane Race examines how the treatment and monitoring of HIV has impacted conceptions of gay men's bodies, selves, and sexual identities.¹⁸ More recently, Jan Huebenthal describes how undetectability discourses shape homonormative LGBT identity politics.¹⁹ Drawing together queer studies, public health and art, Katrin Köppert and Todd Sekuler examine an exhibition of HIV/AIDS posters to address the extent to which undetectability affects the memorializing of an ongoing disease.²⁰

Curatorial work has been an important space for creating and engaging with cultural and political meanings of undetectability. From the earliest availability of treatment protocols, artists have represented medications and their roles in the complexities of living with HIV.²¹ In 2012, Lee with assistant curator Rachel Cook curated an exhibition titled *Undetectable* for Visual AIDS, a community-based arts organization committed to using visual art to fight AIDS. The show ran that May and June at La MaMa La Galleria in New York City. Through the exhibition of artworks and its catalog,²² the curators and participating artists tackled the complex realities of undetectability. In his opening essay, Lee describes undetectability as "signifying a presence that is absent, predicated on suppression and surveillance, the undetectable occupies an indeterminate space and produces new modes of connectivity, at once increasing the capacity of a body and subjecting it to a relentless regime of control."²³ His words highlight bodily autonomy and the political economy concerns. In the piece used to promote the show, a 2012 proposal rendering for *Nested Voids: The Conspiracy*, artist Bradley Pitts combines scientific and architectural approaches. Pitts depicts a brightly illuminated vitrine in an expansively gray room. Behind the vitrine stands an anonymized translucent human

figure. The vitrine itself is the center point. Its caption notes that it contains the artist's "email correspondence and photos" which document "the clandestine installation of an imperceptible artwork with in 'Voids', a retrospective of empty exhibitions." The artist creates and exhibits his own archive of the undetectable. In his essay, Andy Campbell muses on undetectability as an identity, "How to best convey the feelings of confidence, defeat, survivorship, guilt, power, love, boredom, dailyness, relief, haunting, imbrication, and trauma that no doubt such person's experience?"²⁴ Both Campbell's essay and the exhibition itself are premised on "the specificity of 'undetectable' as an embodied identity that warrants consideration as a part of, and apart from, seronegative and seropositive statuses."²⁵ Campbell reports that the artworks featured in the exhibition are often appropriately "oblique" in their "reference to such a status, which may, in fact, describe the particular geometry of being undetectable."²⁶

"The Collective is Indeed a Flash"

The Undetectable Collective's art intervention contended explicitly with the biomedical, cultural, and political implications of undetectability. The Collective was formed through a collaboration between the New York Public Library (NYPL) and activist, agit prop creator and writer Avram Finkelstein. It was supported by the Library as an epilogue to their exhibition and programming series, *Why We Fight*. The Collective's work was directly inspired by and in conversation with the exhibition, and their work was exhibited and disseminated in public library and museum spaces. Their work complicating an exhibition makes important interventions around the representation and temporality of AIDS activism of the past in the present and with a critical eye for the future. The lens of undetectability employed exposes urgent concerns for curators in conceptualizing, representing, and responding to the contemporary AIDS epidemic.

Why We Fight showcased posters, pamphlets, artifacts, and video footage documenting AIDS activism during the 1980s and early 1990s. Most of these materials were drawn from the NYPL's collections of organizations and individuals pivotal in their responses to the early AIDS epidemic. *Why We Fight* ran from October 2013 to April 2014 in the Sue and Edgar Wachenheim III Gallery in the Library's Stephen A. Schwartzman Building in Midtown Manhattan, a small, but prime location. Jason Baumann, Coordinator of Humanities and LGBT Collections, and Laura Karas, the archivist who had done much of the archival processing of these collections, co-curated the show. It was Baumann who took the lead on curatorial strategy. Rejecting a linear chronological arrangement, he describes the exhibition narrative as resembling a "constellation."²⁷ The vitrines were organized topically around subjects including: "Changing Perceptions of People Living with HIV," "Safer Sex and Needle Exchanges," "Public Mourning," "Healthcare Activism," and "HIV Today." The show was accompanied by a large public programming series for teens and adults in locations across the City. Together, the exhibition and programming were intended to inform and to inspire visitors, both those who had participated in AIDS activism and a general public new to the subject.

Most of the exhibition's wall texts written by Baumann focused primarily, as did the material on display, on the 1980s and 1990s. The notable temporal exception was the exhibition's final wall text, "HIV Today." This text begins "The AIDS epidemic is far from over." It then offered readers a set of current statistics about the epidemic in the U.S. and globally. This text concludes by referencing UNAIDS focus on prevention and treatment, including plans to attain universal treatment access by 2015. In its focus on contemporary realities and responses to the ongoing epidemic, the text makes reference to undetectability and to the "treatment as prevention" model implicitly. It is for the frame of "remembering," included in the exhibition's title, and for its temporal

focus on showcasing archival materials and artworks from the 1980s and early 1990s that the show faced criticism from some in AIDS activist communities. The perceived historicization of AIDS activism is what ACT UP/NY responded to in their die-in action within and outside of the exhibition on its opening night. Art critic and curator Emily Colucci, wrote in her review, "I felt that I was watching a long-ago historical event, rather than a demonstration about a crisis that continues to rage on."²⁸ Colucci called into question why the coverage of AIDS activism in the show ended as the successful cocktail became available in 1996. In our interview Baumann acknowledged the validity of such criticism. However, he frames the temporal limitations of the exhibition as reflective of the very limits of the archives at his disposal. The show "didn't tell the story of the activism that's happening today," he said, because "I don't have that archive...what's happening today, that's not history yet."²⁹

Finkelstein shared, "We are being told people don't care about AIDS, but I disagree after a decade of speaking around the world and having people ask the same question: What can we do now?"³⁰ He notes, "I have come to realize that the answer to the question of how to re-engage a public with the issues surrounding HIV/AIDS in the present doesn't lie in looking at the canon of cultural production from those early days [...] It's in looking through these works, to the resistance strategies that brought them into being in the first place. That's how we might imagine alternative models for the activation of our social spaces."³¹

Finkelstein is a founding member of the Silence=Death and Gran Fury collectives. In his own practice and in his mentorship of younger generations of activist artists, he continues to utilize visual tools to enact social change. Baumann invited Finkelstein to write a series of blog posts to accompany *Why We Fight*. Finkelstein readily signed on, but he offered up his own counter-proposal to organize what he terms a "flash collective." Flash collectives, an idea created by Finkelstein based on his years of collective work, are collective interventions aimed at activating social spaces. Each collective brings together collaborators for a brief duration to create political messages that employ "skills drawn on in collective decision-making with a surgical and fast-paced format intended to cut directly to the point of the work, content."³² The inclusion of a flash collective within the exhibition programming offers important evidence of a curatorial strategy that emphasized bringing archival materials documenting AIDS activism historically into conversation with the present realities of the crisis. The Collective's work also uncovers the contemporary utility of activating earlier activists' graphics and strategies. By turning to a pressing contemporary issue, undetectability, the Collective also showcased an ongoing need for AIDS cultural activism now. The NYPL provided financial backing, and Finkelstein and Visual AIDS provided curatorial assistance for the Collective. Together they issued a call for participation. Finkelstein's work with the Collective animated the archive in many ways, not least of which by establishing himself as a resource, a mentor, and a source of information for other activists and artists. As Finkelstein has put it, "the pedagogy" of the flash collective requires "having interdisciplinary participants in order to have diversity in skills and perspectives."³³ Collective members included: Avram Finkelstein, Alex Fialho, Alina Oswald, Brendan Mahoney, Conrad Ventur, Filip Condeescu, Gerald Mocarisky, hucklefaery, Jano Cortijo, Jorge Sanchez, Kenneth Pietrobono, Lanai Daniels, Mark Blane, Nick Kleist, Pablo Herrera, and Spear Minteh. The members of the Collective are artists, writers, activists, curators, journalists, policy wonks, and Radical Faeries.

Finkelstein and the Library stipulated only two guidelines for the project: first, that it had to address HIV/AIDS, and second, that it had to be engaged with contemporary

issues. At their first meeting, Finkelstein called upon members to critically consider how art could be an effective space for social intervention.³⁴ As Kleist described their work, “The collective is indeed a flash, it is a sudden rush of energy that occurs when all points touch.”³⁵ The difficulty of doing collective work is part of the aim of flash collectives. It is by doing work together, through the sharing of skills and ideas in the same manner that multiple generations of AIDS activists have, that participants gain “the tools and the experience of what it is like to be in a community, however curated it might be, however momentary.”³⁶ The Collective’s work took place over an approximately two-month period.

Together, members began the process of developing their project by working on a series of mapping exercises in order to uncover what HIV/AIDS is and what it does today. The major themes they identified in this early work included: the emergent and ongoing status of HIV/AIDS crisis; the impacts of pharmaceutical development, intervention, and access; the pervasive fear, stigma, and discrimination associated with HIV/AIDS; the complexity of HIV disclosure interpersonally; the racialized, classed, and gendered space of HIV criminalization; and the significance of serodivides within impacted communities.³⁷ It was here that the term, undetectable, emerged as their focal point. Choosing undetectability meant that the Collective had to contend with its definitions, implications, access, and meanings from diverse socio-political perspectives.

In their second meeting, the Collective turned their attention to producing their own intervention. They had to come to a consensus as to how to visually communicate the complex, interconnected concerns that fall under the vast rubric of undetectability. They also had to consider how to engage a diverse and far-reaching public. As a strategy, the group created a Tumblr to work through ideas.³⁸ It includes a series of animated GIFs that illuminate their process. A post by artist and Collective member hucklefaery includes a number of GIFs they created at this stage when directed to make something that would “inspire each other.”³⁹ One GIF begins with a black screen in which an emptied plus sign bounces around. Turning white, the letters “HIV” appear above the plus sign. The words are quickly placed behind a series of bars. Additional text appears, reading “HIV + is not a crime, undetectable, learn the facts on the fear.” Along with the graphic, hucklefaery posted that they intended this work to create needed dialogue within the group around the multifaceted implications of HIV criminalization. Contesting the dominant dialogue on criminalization that focuses exclusively on actual or possible HIV transmission, they ask “how might ‘criminal’ issues be impacted by “Undetectable” individuals [based on emerging data]; and how might HIV Stigma be deepened by these same shifts in thinking?” These early GIFs showcase the range of conversation within the group and the struggle they went through to concisely and powerfully develop a political message about undetectability.

The Collective’s primary intervention consisted of four posters in lightboxes, and 2,500 outreach postcards were circulated and disseminated to the public at four library branches across New York City. In these library spaces, thousands of people move through every month who are likely not there for the art and who are not necessarily thinking about HIV/AIDS. The displays and postcards include the Collective’s statement, “What is Undetectable?” It reads in dark gray capital letters:

We’re at a crossroads in HIV treatment. HIV positive & HIV negative are no longer the only possibilities when discussing serostatus. The word undetectable has emerged in this conversation. Undetectable originated as a medical term for an “acceptably” low presence of HIV in the bloodstream dependent on strict

compliance with “successful” antiretroviral treatments. Maintaining undetectable viral levels significantly reduces HIV transmission, but it is not a cure for AIDS & does not remove stigma. Not everyone has access to information or treatments, so the emphasis on achieving undetectability reinforces racial & socioeconomic divides. Because there is more money in lifelong treatment, profit-driven drug companies have no financial incentive to find a cure. Undetectability saves lives. But whose lives? & Who profits? Where's the cure?⁴⁰

Here, the group's early conversations and creative work around medicine, transmission, economics, and gendered, classed, and racialized experiences of undetectability were activated. The 36-by-36-inch lenticular posters in each of the four lightboxes featured the text over a familiar choice of a blood-red background, provocatively deploying the color associated with AIDS. Lenticular printing on the posters and cards allowed for the print to flash “undetectable” in a plus sign in shades of gray over its surface. As a “visualization of the medical term,” the sign reflected that HIV status itself is in flux through its very appearance and disappearance.⁴¹ None of the selected libraries have formal galleries; the lightboxes and cards were conceptualized as installations that interacted within the central space of that library. The lightboxes in Washington Heights and the Bronx were in Spanish; those on Staten Island and the Village were in English. The outreach cards distributed and dispersed into the hands of patrons at all sites were in printed in English, Spanish, Chinese, and Russian, the primary languages of NYPL users.

Visual AIDS was so taken with the Collective's work that they decided to use it as a basis for a 2015 public program at the New Museum's IdeasCity Festival. The festival that year was themed “The Invisible City.”⁴² Together, Finkelstein and Collective member and Visual AIDS Programs Director Fialho developed the concept of using balloons, on which the Collective's question, “What is Undetectable?,” was printed on one side. At the event, members along with Visual AIDS staff and volunteers posed this question to people passing. Over 300 people responded. Responses from the general public on HIV ranged from, “Can undetectable folks transmit HIV?” to “Personal goals.” They also provided a range of definitions that were not necessarily HIV/AIDS-related. For example, “I saw five flying saucers when I was 6,” and “Inner feelings (and) suppressed emotions.” Visual AIDS and Collective members then had one-on-one conversations about undetectability and the current epidemic. As Fialho described, they were able here to employ their dialogic process with the public, making the Collective's work “even more outward facing.”⁴³

Curating Undetectability

Undetectability has fundamentally changed the contemporary landscape and meaning of HIV/AIDS. The Undetectable Collective demonstrates undetectability's utility as a model for emphasizing the contemporary when curating work grounded in 1980s and 1990s AIDS archives. There is great potential in commissioning new creative and activist works in the context of such archivally focused exhibitions. Undetectability as a curatorial strategy can shift archives, museums, galleries, and online curatorial spaces in the direction of intervening in the present epidemic and towards more ethically and productively serving HIV/AIDS communities.

The work of archives is to document, arrange, preserve, and make accessible the past in contextualized ways. The lens of undetectability allows for curators working with AIDS archival records to animate the power of non-linear temporalities. Undetectability draws vital attention to the continued potential and ongoing presence of the past in the present. Drawing critically on that archival past shapes our ability to

better live in the present and imagine a different and more just future for all impacted by the AIDS crisis. A crucial part of the archives' efforts is community and solidarity-building that reaches across the bounds of space and time. Curatorial work, done by archivists or in collaboration with outside curators and arts organizations, is increasingly becoming understood as an instrumental component of archival work. It is by curating with an eye to the present that AIDS archives can work to ensure that the past is deployed to serve its constituencies and to aid them in constructing livable and vibrant futures. New work such as that of the Undetectable Collective can call for the powerful creative use of the archival collections of AIDS' past in service of addressing HIV/AIDS' present issues and future realities. The Collective's adaptation of image-driven strategies at the intersection of art and activism employed so effectively in the 1980s and 1990s to meet the needs of contemporary social, cultural, and political struggles for justice offers a prime example of the far-reaching implications of curating with AIDS archives now.

With improved, if far from perfect, treatments, the embodied visibility of AIDS has decreased even while infection rates in many communities have not. We are now working in a time characterized by the undetectability of HIV not only in individual bodies, but also in a culture where HIV is often undetectable. HIV is a crisis of visual representation. The frequent invisibility of HIV/AIDS has contributed to the perception of it as a silent killer, unseen but present in the bodies of dangerous others circulating in our midst. The Collective's work at the intersection of art and activism in urban public space renders HIV/AIDS substantively visible again in New York City, moving towards greater attention to contemporary HIV concerns in American society. These actions serve as a reminder of the urgent, continued political necessity for AIDS activism now. Curators hold the power to use their practices to open multiple potentialities for a different AIDS present and future.

Notes

- 1 "What is Undetectable?," Undetectable Collective (2014), <https://whatisundetectable.tumblr.com/>.
- 2 Nathan Lee, "With the Aim of Making it Snap," In *Undetectable*, eds. Nathan Lee and Rachel Cook (New York: Visual AIDS, 2012), 9-12.
- 3 Douglas Crimp, "AIDS Cultural Analysis, Cultural Activism." *October* 43 (1987): 3-16, 3.
- 4 Jan Huebenthal, "Un/Detectability in Times of 'Equality': HIV, Queer Health, and Homonormativity," *European Journal of American Studies* 11, no. 3 (2017): 1-22, 2.
- 5 Susan Sontag, *AIDS and Its Metaphors* (New York: Farrar, Straus and Giroux, 1989).
- 6 Nathan Lee, "Becoming-Undetectable," *e-flux* 44 (2013), <http://www.e-flux.com/journal/44/60170/becoming-undetectable/>.
- 7 Huebenthal, "Un/Detectability in Times of 'Equality,'" 2.
- 8 Marita Sturken, "AIDS Activist Legacies and the Gran Fury of the Past/Present," *emisférica* 9, nos. 1-2 (2012), <http://hemisphericinstitute.org/hemi/en/e-misferica-91/sturken>.
- 9 "HIV/AIDS Historical Time Line 1981-1990," United States Food and Drug Administration, August 8, 2014, <http://www.fda.gov/ForPatients/Illness/HIVAIDS/History/ucm151074.htm>.
- 10 Ibid.
- 11 Lee, "With the Aim of Making it Snap."
- 12 Liz Hunt, "'Cocktail' Opens New Chapter on AIDS," *The Independent*, July 12, 1996, <http://www.independent.co.uk/news/cocktail-opens-new-chapter-on-aids-1328432.html>.
- 13 Pietro Vernazza, Bernard Hirschel, Enos Bernasconi, and Markus Flepp, "HIV-posi-

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19 Huebenthal, "Un/Detectability in Times of 'Equality.'"

20 Köppert and Sekuler, "Sick Memory: On the Un-detectable in Archiving AIDS."

21 Eli Manning, "HAART in Art: Temporal Reflections on Artistic Representations of HIV Medications," *Visual AIDS Web Gallery* (September 2014), <https://www.visualaids.org/gallery/detail/743>.

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26 Ibid.

27 Jason Baumann, interview with Marika Cifor, New York City, August 25, 2016.

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29 Baumann, interview with Marika Cifor.

30 Avram Finkelstein, interview with Marika Cifor, Brooklyn, May 19, 2016.

31 Alex Fialho, "The collective is indeed a flash: it is a sudden rush of energy that occurs when all points touch," *Visual AIDS Blog* (May 29, 2015), <https://www.visualaids.org/blog/detail/the-collective-is-indeed-a-flash-it-is-a-sudden-rush-of-energy-that-occurs>.

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35 Fialho, "The collective is indeed a flash: it is a sudden rush of energy that occurs when all points touch."

36 Finkelstein, interview with Marika Cifor.

37 Buhl, "Undetectable, Not Invisible."

38 The strategy of working through a shared Tumblr was something that previous Flash Collectives led by Finkelstein had done, including the inaugural Flash Collective in Montreal.

39 Undetectable Collective. "What is Undetectable?"

40 Ibid.

41 Alex Fialho, interview with Marika Cifor, New York City, May 25, 2016.

42 Visual AIDS, "What is Undetectable?," *Poz Magazine*, June 23, 2015, <https://www.poz.com/blog/ideas-city-festival>.

43 Fialho, interview with Marika Cifor.

Dr. Marika Cifor is Assistant Professor in the Information School at the University of Washington. She is a feminist scholar working at the intersections of archival studies and digital studies. Her current book project, *Viral Cultures: Activist Archives at the End of AIDS* (University of Minnesota Press, under contract), examines the critical potential of the emotions and memories that are recorded and produced by archives documenting HIV/AIDS activism during the 1980s and 1990s. This project also investigates the activation of these records on contemporary digital platforms by artists, archivists, and activists. She holds a PhD in Information Studies from UCLA and an MA in History and MS in Library and Information Science from Simmons College.

Acknowledgements

The author would like to thank all who have contributed to this research including my participants and dissertation committee. She would like to acknowledge in particular Jason Baumann, Alex Fialho, and Avram Finkelstein, participants whose words are included here. Her gratitude is also extended to the audience and fellow panelists for feedback on an earlier version of this paper presented in a session on AIDS activism at a 2017 American Studies Association conference. The Social Science Research Council and UCLA Graduate Division were instrumental in funding this research.

Fieldnotes from the Afterlife: Lyle Ashton Harris' Living Archive

Lyndon K. Gill

– Review

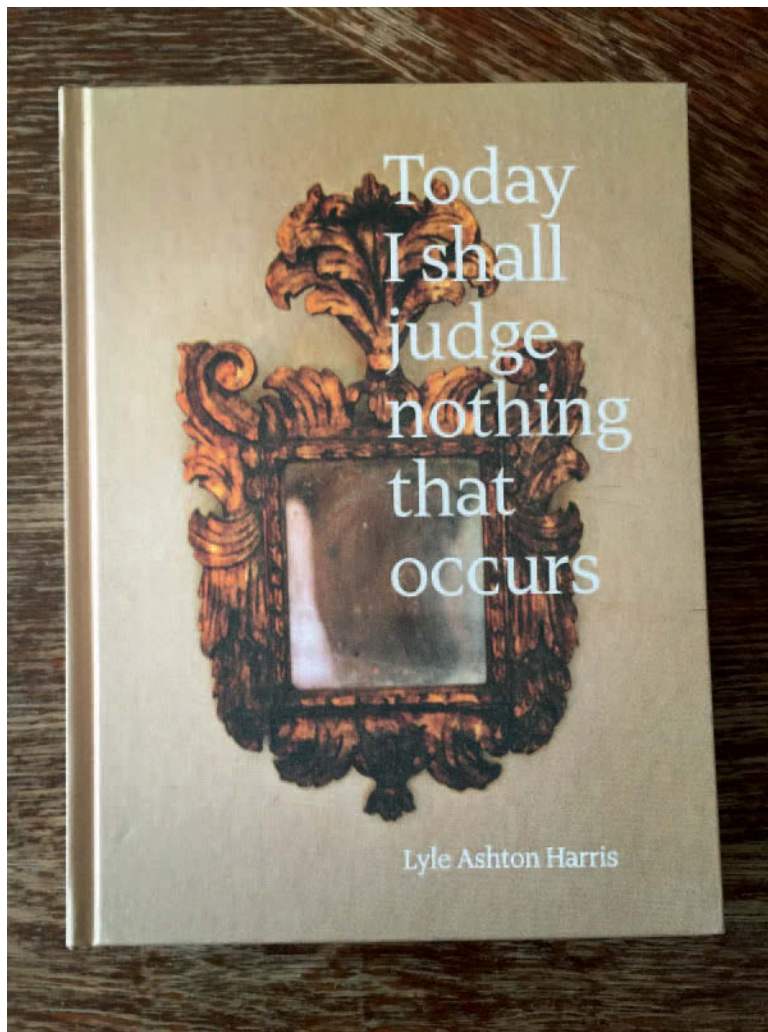
For the living, there is no constituency as formative as the dead.

– Dagmawi Woubshet¹

Relinquishing judgment is a subtle invitation to cede control. Anxious discernment gives way— in a moment that lasts perhaps as long as a prayer— to a steadying recognition of the boundaries of ego, the outer limits of our capacity to know. This meditation on human inadequacy in the face of divine systems of knowing— across a wide range of religious traditions— is at its most revelatory before an altar. So, I begin my sit with Lyle Ashton Harris' *Today I Shall Judge Nothing That Occurs: Selections From the Ektachrome Archive* at one of the many Polaroid photographs of personal altars he creates over time.² The 1997 image “Altar, Koreatown (Journal #1)” is at the center of a blank lined journal page opposite a mantric seven-word seven-line poem in red ink (“Today/I/Shall/Judge/nothing/that/occurs”) that, though untitled, lends itself to the title of this compendium of photographs.³ At once an archive of traces left at the tail end of the twentieth century and a divination table set with thirteen years of images (from 1988 to 2001), this queer collection of time's remains is in many respects also a testament to the complicated artistry that is black gay resilience while living with HIV— as do a disproportionate number of black gay men in the United States.⁴ As a black gay (sometimes “queer,” when I am at my rebellious best) poz discipline of artists like Harris, this altar-conscious testimony is a vital reminder to embrace the imperfections of truly *living* with HIV.⁵

Lyle's altar is a blur of what may be three lit seven-day candles (white, red, blue), a potted aloe plant, a Toucan carved from wood, the fibrous face of a mature coconut, a fleshy black-skinned figurine dressed all in white, a fallen web of beaded adornments, and a photograph— largely lost beyond the polaroid's frame— curling slightly in upon itself on the wall. But these could just as easily not be. The altar preserves its secrets (in shadow and out of focus) so expertly that maybe the few objects I can just barely decipher intend to tell me a story to which the many other talismans refuse to lend themselves. Perhaps they have stories for you alone— ghost stories that summon Albert Sidney Johnson, Jr. (a photographer who was also Lyle's grandfather) and a generation of black gay men snatched by AIDS-related illness before anyone could catch their breath long enough to mourn them properly.⁶

Standing at an altar at a cultural crossroads in the center of one of the circum-Pacific's most cosmopolitan cities— the “K” in K-Town becomes a visual metaphor for this crossroads if we look closely— the seven-line mantra promises that judgment shall have no place in the sacred order of *this* day. This untitled poem cum title also provides instructions for how to approach the untidy oeuvre of a black queer poz phenom eager to be in so many places at once: New York (the Bronx, Fort Greene, SoHo, the Catskills), San Francisco, Los Angeles, Washington, D.C., upper Baja (Mexico), Martha's Vineyard, San Diego, Valencia, Vancouver, Venice, San Juan (Puerto Rico), Santa



I Shall Judge Nothing That Occurs (cover), 2019.

Barbara, Vatican City, Berlin, London, Oakland, Berkeley, St. Kitts, and Nevis. The itinerant artist finds home in the photograph, an orienting technology that he holds precisely at soul center like a compass in the 1997 polaroid portrait “Lyle (Journal #1).”⁷ What if Lyle has always lived at the crossroads— master trickster that he is— and these captured flashes offer us evidence exactly three decades hence?⁸

If the artist uses his medium as common ground between Spirit and flesh, then it serves as a kind of altar to the (after)lives just beyond the camera’s frame.⁹ But objects have afterlives, too— even objects beyond recognition— living beyond their intentions in one moment toward an array of possibilities in the next. Centering a selection from the artist’s over one-hundred kept journals— repositories of his photograph-laden fieldnotes on a life still being lived— turns the camera on this raw material.¹⁰ These mundane to-do lists, affective impasses, snippets from newspapers or softcore rags, lists of longings, found and cherished images, impromptu poems, preliminary poses, and candid test shots would make the more public work possible, coherent, and unrelenting. Journals #1, 6, 8, 19, 75, 76, 78 and 81— with entries from 1997 to 2000— resist straightforward temporal logics in favor of circuitous queer anti-chronologies. These notebooks capture the field of experiences that make the photographs beyond the journals more deeply legible at the same time that they document frontiers of influence and connection just beyond the sightlines of Lyle’s formal work.

These field journals and the Ektachrome archive they at once inform and inhabit are in conversation— by virtue of medium— with a vast archive of photographs and travel writing that the National Geographic Society first began publishing in 1888, exactly one century before Lyle's earliest images in this catalogue. This once academic journal turned popular travel magazine— at the intersection of fine art photography, world cultures, and the natural sciences— had for decades owed the distinctive look of its images to Kodak's Ektachrome brand of film, preferred for color photos that required swift shutter speeds. The film's less technically intricate processing made it a favorite among professional and amateur photographers until Kodak began discontinuing it in late 2009, only to completely phase it out by late 2013. To the deaths of so many of Lyle's subjects in his Ektachrome archive— at once haunted by and attempting to exorcise the spectacle of "otherness" in *National Geographic* with his own queer mundanity— one could have added the final death of the film medium. But death is never a finality.

Kodak's decision to reissue its Ektachrome line— rumoured to begin sometime in 2018— provides an apt allegory for spiritual continuity despite seeming rupture; in essence, death as a moment of transition and not as an end in and of itself. This afterlife for the dead requires a different relationship to what literary theorist Dagmawi Woubshet calls "the calendar of loss," in his book of the same name about mourning in the early era of AIDS— roughly the same decades Lyle's catalogue inventories.¹¹ Woubshet captures the moment in which AIDS forces a temporal reorientation to loss for early AIDS activists— many of whom were themselves poz in a time when HIV/AIDS was a death sentence— who became intimate with the realization that each tragic death they tallied (of lovers, family, and friends) foreshadowed their own.¹² But death is never a finality. The persistence of spirit beyond flesh is an invitation to cede control, to relinquish judgement because we cannot know the hereafter or the promise of reissue it may hold. In offering us his altar and a simple prayer, Lyle Ashton Harris' *Today I Shall Judge Nothing That Occurs: Selections from the Ektachrome Archive* at once reassures and warns us that even death cannot keep us apart.

Today I Shall Judge Nothing That Occurs: Selections from the Ektachrome Archive.
New York: Aperture Foundation, 2017. U.S. \$60, hardcover. 295 pages.

Notes

1 Dagmawi Woubshet, *The Calendar of Loss: Race, Sexuality, and Mourning in the Early Era of AIDS* (Baltimore: Johns Hopkins University Press, 2015), ix.

2 Lyle Ashton Harris, in *Today I Shall Judge Nothing That Occurs*, ed. Lesley A. Martin (New York: Aperture, 2017), 280.

3 *Ibid.*, 46-47.

4 Linda Villarosa, "America's Hidden H.I.V. Epidemic," *The New York Times Magazine*, June 6, 2017, accessed Oct. 7, 2018, <https://www.nytimes.com/2017/06/06/magazine/americas-hidden-hiv-epidemic.html>; "Estimated HIV Incidence and Prevalence in the United States, 2010–2015: HIV Surveillance Supplemental Report," Centers for Disease Control and Prevention (CDC), Vol. 23, No. 1 (March 2018), accessed Oct. 7, 2018, <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-23-1.pdf>; "HIV Surveillance Report," Centers for Disease Control and Prevention (CDC), Vol. 28 (November 2016), accessed Oct. 7, 2018,

<https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2016-vol-28.pdf>.

5 Black gay openly HIV+ artist rebels like Harris and the masterful dancer and choreographer Bill T. Jones continue in an enduring spirit lineage that includes the formidable poet and essayist Essex Hemphill, the tour de force poet, playwright, essayist, and performance artist Assotto Saint, and the daring filmmaker and cultural critic Marlon Riggs (to name only a few). This black gay poz artistic avant-garde has literally and figuratively provided both the road map for my own continued survival and the template for my community-building as co-founder/facilitator of The Woodard Circle, a social support group began in 2016 for black poz men in Austin, Texas, named in honor of black gay poz scholar and artist Vincent Woodard (1971-2008). And in a modest homage to these artists, I feature them prominently in one of my newest, most beloved and deeply challenging courses: "HIV/AIDS, Activism & the Healing Arts in the African Diaspora."

6 Malik Gaines, "A Letter," in *Today I Shall Judge Nothing That Occurs*, 59; Ulrich Baer, "The Sovereign Contingency of Love," in *Today I Shall Judge Nothing That Occurs*, 261.

7 Harris, 48.

8 Vince Aletti, "When the Mood Takes Him," in *Today I Shall Judge Nothing That Occurs*, 52.

9 Roxana Marcoci, "Queer Affect: Lyle Ashton Harris's Ektachrome Archive," in *Today I Shall Judge Nothing That Occurs*, 156.

10 Lucy Gallun, "Heal Me/Use Me: Lyle Ashton Harris's Journal, 1997," in *Today I Shall Judge Nothing That Occurs*, 94.

11 Woubshet, *The Calendar of Loss*.

12 *Ibid.*, 11.

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Public Ruptures, Public Readerships: AIDS in Writing

Heather Holmes

I.

Across the Delaware River from where I live is the city of Camden, New Jersey, where in 1989 an inmate in Camden County Jail named Gregory Dean Smith was charged with biting a police officer's hand after struggling during an X-ray procedure at a nearby hospital. After the alleged biting, Smith, a black HIV-positive man, was then sentenced to the maximum twenty-five years in prison for aggravated assault and attempted murder.¹ In the carceral logic of the prosecutors, Smith had weaponized his own HIV-positive bodily fluid against state agents. Smith died in 2003 in Trenton, New Jersey; he was forty years old.

In an essay in the 2014 collection *Queer Necropolitics*, Che Gossett invokes the spirit of Gregory Smith and the members of ACT UP Philadelphia who have worked to make visible Smith's struggle, as well as ongoing HIV criminalization in its many forms, including but not limited to deplorable conditions in US prisons.² In Gossett's essay, they mention Smith's determination to be heard and understood through written language while incarcerated. As an inmate, Gossett writes, Smith "regularly contributed to the *Critical Path* newsletter and advocated for AIDS education and treatment inside [...], organized People Living with HIV/AIDS (PWAs), published a newsletter about prison and HIV/AIDS issues and also started writing a memoir." Smith saw publication both as a generative outlet while incarcerated as well as a form through which to underscore prison as an HIV/AIDS issue, and in this he was not alone. For more than three decades, publication as form has been used to disseminate radical material related to the ongoing epidemic and also as a strategy of liberation and resistance by those living with HIV/AIDS.

Smith was one of many in the 1990s, both within and outside of prison, using physical publication as a means to attenuate the isolation of illness. Publications like *Diseased Pariah News* (DPN) and *Infected Faggot Perspectives* (IFP), both published continuously throughout the 1990s, mobilized a kind of dark humor to cut through both the seriousness and the stigma of living with HIV.³ In DPN's first issue, the editor's note, written by Tom Shearer, reads, "So what we're hoping to do here is bring some much-needed levity to the experience of HIV infection."⁴ In that issue, articles like "I Fisted Jesse Helms" ran right next to "AIDS Testing Problems in Federal Prisons." Many of the articles published in IFP addressed the reader directly with the words *girl* or *girlfriend*: they reached out casually, conversationally, and intimately through language.

The *Critical Path* newsletter to which Gregory Smith contributed has since shifted to become the informational Greater Philadelphia AIDS Resource Guide, published yearly by Philadelphia FIGHT. It did not share DPN's and IFP's emphasis on humor and irreverence, but similarly addressed several needs, publication being a quick, highly distributable, and inexpensive means of conveyance: correspondence, resource-sharing, and education, all while promoting a sense of togetherness, whether "actual" or "imagined." We know that for people living in prison, letters, newsletters, and other forms of correspondence provide a way for inmates to communicate within the prison

and beyond.⁵ Through his contributions to *Critical Path*, as well as the newsletter he regularly distributed, Smith was able to correspond with fellow inmates and with his peers on the outside in ways not otherwise possible.⁶ And, since publication at its best is a dialogue, Smith also could have encountered himself in the pages of a zine or pamphlet sent to him by a friend. He would have seen his name there—*FREE GREGORY SMITH*—on the signs of ACT UP Philadelphia protesters speaking out publicly against the injustice of his incarceration.

In my previous job at the Institute of Contemporary Art in Philadelphia, Pennsylvania, a little over five miles east of the Camden County Jail, I was given the opportunity and budget to organize ICA's programming for the 2017 iteration of Day With(out) Art. Initiated by Visual AIDS in 1989 as an intervention into art spaces—a call for “mourning and action in response to the AIDS crisis”—Day With(out) Art is recognized annually on December 1 as a prompt for institutions and individuals to take action in various ways. Over the years at ICA, this has taken the form of panel discussions, a ribbon bee, digital projects, and screenings, to name a few. I decided to respond with a publication.

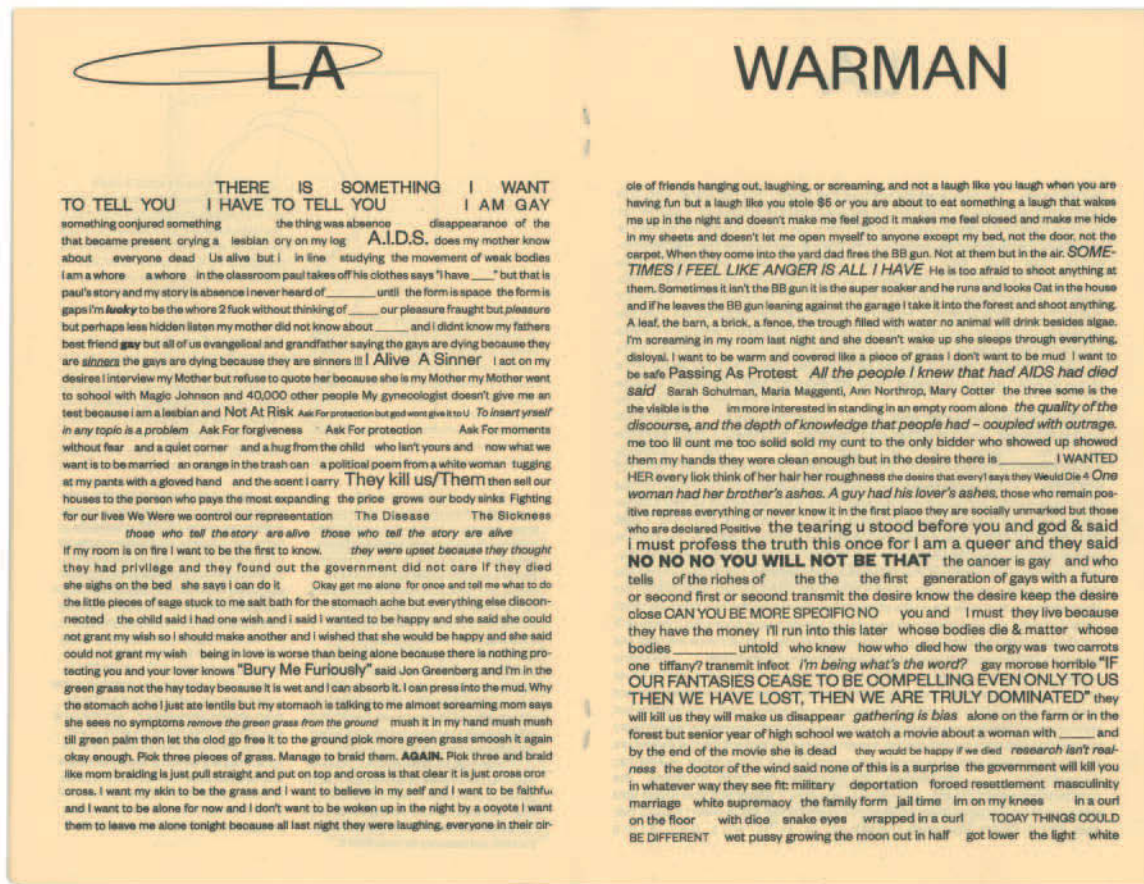


the moon will sink into the street (Philadelphia: Institute of Contemporary Art at the University of Pennsylvania, 2017).

the moon will sink into the street, the resulting object, is an eighteen-page, Risograph-printed, saddle-stitched zine that, when wedged between two books on a shelf, nearly disappears. Its thingness was important to me; though it clearly says *FREE* on the cover, I also wanted it to feel free, like something unprecious enough to put literally in

your back pocket. It was distributed across Philadelphia's LGBT organizations, HIV clinics, student unions, academic buildings, coffee shops, and community centers, in piles as large as each organization would allow. At ICA, I often felt the desire to liberate its exhibition catalogues—some of which sat in storage for years and will for more to come—and set them loose in public where they might be used and loved as intended instead of laying in wait for a potential buyer. In order to actualize some part of this fantasy, *the moon will sink into the street* needed to be light and small enough to traverse the city quickly. I'm excited by the possibilities the proliferation of a free publication creates; it means a passerby can take one, or take a whole handful, or can just have a ready surface on which to write down a phone number or a note for later.

I have come across *the moon will sink into the street* four times since its distribution: once at a bar, once at a library, once at a cafe, and once in the waiting room of the Mazzoni Center, a rapid testing clinic in Philadelphia's Gayborhood. I still find it startling and beautiful to encounter this material in public space: the phrases *white supremacy* or *wet pussy* or *gathering is bias* in a poem by LA Warman; stark and gorgeous portraits drawn by Gustavo Ojeda, the subject of contributor Gabriel Ojeda-Sague's essay. Waiting for my name to be called in the Mazzoni lobby, I glanced over to their table of free materials and saw it there amidst a shuffle of stickers, condoms, flyers, and pamphlets.⁷ I'd gone to the clinic in the midst of the project, the editing of which had made it impossible to ignore how long it had been since I'd gotten an HIV test. There are ways in which, in the act of publication, we become our own publics.



LA Warman, untitled contribution excerpt in *the moon will sink into the street* (Philadelphia: Institute of Contemporary Art at the University of Pennsylvania, 2017): 9–10.

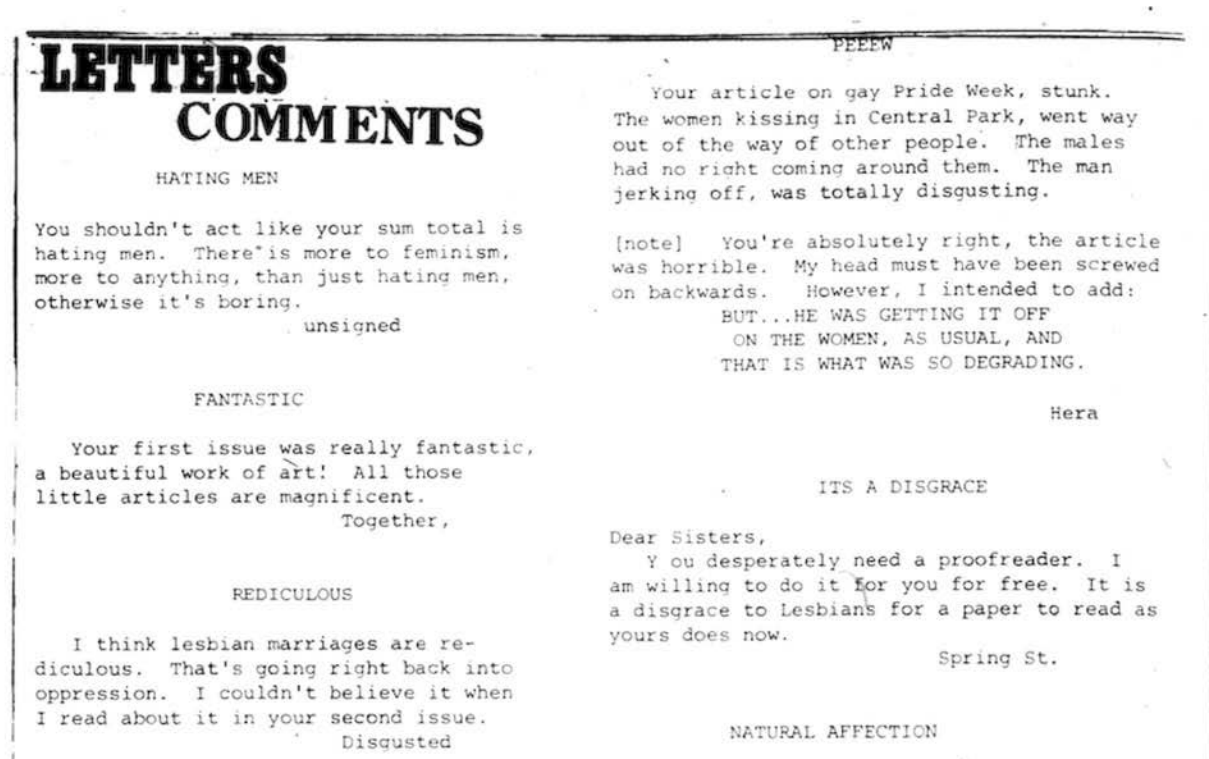
II.

I am not a curator—or, perhaps I should say, the word *curator* has never appeared in my title. It's possible my own dis/identification with the term matters less than I think. Hanna Kuusela defines *literary curators* as “actors who mainly mediate, distribute, (re) present, publish, or exhibit in new contexts texts that have been produced by people other than themselves and who thereby create literary phenomena in the public.”⁸ This figure, Kuusela continues, differs fundamentally from other established characters in the literary field (agents, editors, publishers) in that her individual artistic identity holds such visibility and prominence that it has the potential to substitute or usurp that of the author(s) she “curates.”

Kuusela understands this emerging cultural figure as part of a mappable trajectory “of promotional culture and attention economy,” among other things, but this assessment leaves me wondering how we might imagine differently those curators working to make visible the ongoingness of AIDS and its activists. Can we consider wide-reaching distribution methods for free publications within the context of “promotional culture” and the inescapable metrics of contemporary life (likes, shares, “reach”) but as also as a tactical response—something like a generative mimicry—to the virality of AIDS? Kuusela notes the emergence of curatorial prominence as emblematic of misplaced priorities: essentially a conflict of interest between where our undivided collective focus “should” be (on the author or artist) and where it ends up being partially or completely diverted (the curator). But given the rich histories of how textual exchange has shaped community within the AIDS crisis, as well as the twinned criminalization of and need for visibility for people living with HIV, I think there is room to push back against Kuusela's assessments. Whom does it benefit when curators of AIDS-related material invisibilize their own political investments in the name of avoiding self-promotion? What opportunities for dialogue are relinquished in that concealment?

A research assignment in 2016 had me cranking through lesbian archival microfiche to mark the ways in which queer women were addressing themselves and one another in the 1950s, '60s, and '70s. The newsletters I dug through were marked by raucous debate. Every publication featured a Letters to the Editor page, and the submissions were by and large either heaped-on praise or borderline vitriolic. “I think lesbian marriages are ridiculous [sic]. That's going right back into oppression,” writes one reader (signed “Disgusted”) of the journal *Echo of Sappho* in 1972. “I couldn't believe it when I read about it in your second issue.” Queerness, requiring frequent negotiations and renegotiations, can splinter in the face of a publication that attempts to articulate the political imaginary of an entire group. When it attempts to articulate the group itself. What conspired, in many of these newsletters, was the formation of a Letters *from* the Editor page, comprised entirely of retorts to the letters received.

What now can be narrativized as history was actually, upon closer inspection, many dispersed individuals having these difficult and deeply personal conversations through the form of the newsletter. For all the relief and togetherness offered by publications like *Diseased Pariah News* and *Infected Faggot Perspectives*, those, too, were sites of similar debates and fissures over tone, content, and impact. DPN addressed its readers intimately, featured its editors' voices and faces prominently, and invited its publics into the fold of what was happening behind the scenes. The first five pages of the third issue were devoted to an account of the death of Tom Shearer, the publication's editor. Shearer's collaborator and co-founder Beowulf Thorne takes over from there, writing, “Until I can find a qualified person who wants to *do* DPN, as opposed to doing things *for* DPN, I'll be winging it alone [...] Let me know how I'm doing.”⁹ The zine then



"Letters and Comments" in *Echo of Sappho* (New York), Vol. 1, No. 3, 1972.

proceeds as usual. The tense debates sparked by DPN's editorial mission are, I think, not separate from that impulse to share personal trauma with unknown readers, but part and parcel of the intimacies that publication as form can create.

The formal qualities of publication, and its possibilities in terms of distribution, make me feel hopeful about the present and future of better making space for that dialogue around HIV/AIDS to take place within institutions. Screen technologies have played a crucial role across the globe in combating and mitigating this epidemic, but in Philadelphia, for example—where, as of 2013, over a quarter of low-income households lack access to the Internet—we need to reimagine the ever-onward technological thrust of museums when thinking through questions of access.¹⁰ (This goes as well for institutions that charge admission, that do not meet ADA requirements, or whose buildings are not easily reached by public transportation or are situated squarely within centers of wealth and whiteness.) How can work be accessed apart from your gallery walls? How do you host a conversation? What is the role of museums, especially if they receive public donations or tax dollars, in distributing quality-of-life and life-saving information?

The model of "public publication" in fact works against the grain of the literary curator model Hanna Kuusela proposes—a figure who perhaps thrives in more rarefied institutional niches but becomes wonderfully flattened in public space. In this long tradition, they are simply an editor: someone to whom you may write if they do something terribly wrong or terribly right; someone with whom you may have a dialogue. In this way, I'm hopeful that the distribution of a new publication in Philadelphia, a city that is home to almost no physical arts periodicals, registered as a social gesture, bringing individuals together in conversation in ways that might not have occurred otherwise.¹¹

At the same time, I'm attracted to the way in which a publication about HIV/AIDS does not gloss over the fundamental isolation both of reading and embodiment. One is never generally as alone as when one reads. It's rare to encounter forms of community-building that acknowledge and celebrate this aloneness right alongside a hopeful togetherness. In reading as well as being read, aloneness can mean individuation rather than, necessarily, isolation or loneliness. Institutions and curators have much to learn from people like Gregory Dean Smith, who understood the fundamental importance of making contact, and the significance of publication as a platform for developing human connection and sharing information to better the lives of others. Publication manages to hold these messy and necessary dynamics of being in the world with one another simultaneously—collaboration and conflict, alliance and disagreement—and present them as an ongoing invitation for readers to join.

Notes

1 Joseph F. Sullivan, "Inmate with H.I.V. Who Bit Guard Loses Appeal." *New York Times*, February 18, 1993, <http://www.nytimes.com/1993/02/18/nyregion/inmate-with-hiv-who-bit-guard-loses-appeal.html>.

2 Che Gossett, "We will not rest in peace: AIDS activism, black radicalism, queer and/or trans resistance" in *Queer Necropolitics*, eds. Jin Haritaworn, Adi Kunstman, and Silvia Posocco (New York: Routledge, 2014), 31–50.

3 Daniel Brouwer uses these two publications as case studies in his 2006 essay that explores the modes through which social structures and counterpublics are created through them. See Daniel C. Brouwer, "Counterpublicity and Corporeality in HIV/AIDS Zines" in *Critical Studies in Media Communication* Vol. 22, Issue 5 (2005).

4 Tom Shearer, "Welcome to Our Brave New World!" in *Diseased Pariah News* 1 (1990): 2.

5 Physical mail remains, in many prisons, the slowest but most cost-effective means of communication, both for prisoners as well as their families and friends. In *Carceral Capitalism*, Jackie Wang notes the "extremely high usage fees" of email and so-called digital visitation systems like HomeWAV, which in some cases are also "accompanied by the phasing out of in-person no-contact visits." See Jackie Wang, *Carceral Capitalism* (Cambridge, MA: MIT Press, 2018), 36.

6 Smith's mailing address at South Woods State Prison is still listed on the ACT UP New York website on a page devoted to his case, alongside instructions to contact him directly: "You can also contact Greg: activists on the outside have worked beside Greg through many crises, including getting medication lines for prisoners moved indoors, fighting mandatory health care co-payments, and fighting Greg's termination from kitchen service jobs because of his HIV status." See <http://www.actupny.org/reports/gregsmith.html>.

7 Mazzoni made national headlines in 2017 when, following the resignation of the Center's medical director after allegations of sexual misconduct and medical negligence surfaced against him, more than sixty full-time Center staffers walked out in protest of the organization's CEO. In solidarity and protest, former Center staffer Abdul-Aliy Muhammad publicly refused their HAART medication until the CEO, Nurit Shein, stepped down. "I...concluded that this is a useful form of resistance," said Muhammad in a 2017 interview. "Mazzoni is acting like a corporation and therefore deliverables, funders, and legacy are placed as valuable, while made-vulnerable staff and patients deal with sexual assault, cycles of poverty, and increased surveillance because of poz, trans*, and disabled identities." See Ernest Owens, "Meet the Activist Who Protested Mazzoni With an HIV Meds Strike," *Philadelphia Magazine*, April 4, 2017, <https://www.phillymag.com/g-philly/2017/04/24/abdul-aliy-muhammad-meds-strike-mazzoni/>.

8 Hanna Kuusela, “Publisher, Promoter, and Genius: The Rise of Curatorial Ethos in Contemporary Literature” in *Publishing as Artistic Practice*, ed. Annette Gilbert (Berlin: Sternberg Press, 2016), 118–133.

9 Beowulf Thorne, “Cranky Words: Darn! One of Our Editors is Dead!” in *Diseased Pariah News* 3 (1991): 3.

10 “Ten Facts About Internet Access in Philadelphia,” The Pew Charitable Trusts, November 12, 2013, <http://www.pewtrusts.org/en/research-and-analysis/reports/2013/11/12/ten-facts-about-internet-access-in-philadelphia>.

11 *POZ* Magazine, to name one national publication, has been publishing continuously since 1994—including everything from arts reviews and features to resource guides and quizzes. Visual AIDS has mobilized this publication-as-conversation model effectively and beautifully through their DUETS series (2014–present), which “pairs artists, activists, writers, and thinkers in dialogue about their creative practices and current social issues around HIV/AIDS.” See <https://www.poz.com/> and <https://www.visualaids.org/projects/detail/duets>.

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Precarious Structures: HIV, Museums, and History

Catalina Imizcoz

The recent exhibition, *Imágenes Seropositivas. Prácticas artísticas en torno al HIV durante los años 90* (Seropositive Images: Artistic Practices Related to HIV During the 1990s) was a small show with a big title. It took place in La Ene, a museum occupying a sixty-square-meter, two-room flat in the downtown area of Buenos Aires, Argentina. Although open during the months of November and December 2017, it was by appointment only—usually one of the museum directors, or maybe one of the exhibited artists, would be available to unlock the door and attend to the space upon request. Curated by PhD candidate¹ Francisco Lemús, *Imágenes Seropositivas* was a unique hybrid of historical survey and DIY exhibition.

The first room displayed two artworks: a series of five photographs and a video piece. Both authored by photographer Alejandro Kuropatwa, the latter was done in collaboration with the eclectic artist Liliana Maresca. During the early 1980s, Maresca produced sculptures and portraits in collaboration with another photographer, Marcos López, which bear a deep sense of awareness of her body as a tool of defiance but also as a place of memory—as both an intimate and public repository of experiences and histories. It was later in the decade, in 1987, that Maresca was diagnosed with HIV—the series of photographs displayed as one entered the space of the exhibition were taken in 1994. Maresca greeted the exhibition visitor half-naked, captured in a storyboard sequence that constructs a passionate dance piece, a ceremonial performance with which she appears to be shaking off HIV's effects on her body.



Alejandro Kuropatwa, *Liliana Maresca*, 1994, photography. Courtesy of La Ene.

In the video, it is Kuropatwa himself who is being portrayed. The footage shows him playing the host—smartly dressed and lively—as he shares the evening with the guests to his exhibition on the walls of his room at the Hotel Meurice in Paris in 1992. First diagnosed with HIV in 1984 and having struggled with the disease since, Kuropatwa planned this exhibition as his last one. Deciding to see himself off in style, he booked a suite at the luxurious hotel, mounted a one-man-show on its walls, and then invited friends, colleagues, collectors, and dealers to enjoy this evening of *vernissage* and farewells. The documentary film is titled *El País de K* (K's Country), and it registers the event from the hanging of photographs across the room to the end of the party, when Kuropatwa is getting ready to die and lies in bed to say his last words in front of his guests. (He passed away more than a decade later, in 2003.)

Bright and yet somber, joyful but laden, these pieces conveyed a powerful “vitality”—the term is the one used by the curator to map connections between the two artworks in the room and across the exhibition at large. Lemús insists on the works' energy because they both stress how resourceful these artists became when faced with accepting HIV's worst consequences. Maresca's dance and Kuropatwa's video address what the artists believe to be an inevitable end with a kind of obstinacy—one rooted in fantasies, and above all, in the immortality of stylishness, almost as if it had the power to defeat death. And yet this fervent rush of energy was immediately brought to a halt as the visitor moved forward, through a short corridor, towards the second and last room in the exhibition. Nine posters were aligned on one of the corridor's walls, arranged in chronological order. These are not artworks, but publicity that the NGO Fundación Huésped and the governmental department in charge of official advertising campaigns issued during the decade.² The effect was simple and assertive: the tone that runs through these posters is far from Maresca's and Kuropatwa's vital language. Instead, they communicate down-to-earth—bordering on aggressive—warning messages. They portray a very different reaction to the unknown reality of the virus, compared to the vital impulse that overpowers the artists and artworks in the first room. Risk, fear, and aversion to that which is not controllable underpin the posters. In Argentina, the first cases of HIV were reported in 1982, but it wasn't until the 1990s that it spread dramatically. The somewhat joyous mood of the first room appears to belong to a time before its time: Kuropatwa's and Maresca's work exist in a solitude where HIV/AIDS can be addressed intimately, facing the unknown with hope and a shy desperation. When the official campaigns begin later in the decade, this hopefulness seems disconnected, and is crushed as a result of the unreality it instills.

Probably the most recognizable artwork in the exhibition was *Cóctel* (Cocktail, 1999): a different series of photographs by Kuropatwa that flirt with portraying HIV's compound medication frivolously, using pop, advertisement-like imagery to set the mood. The ad aesthetics are attractive—steering clear of the intimidating tone of the aforementioned governmental campaigns. Ken Barbie doctors toy with pills and remedies, raising the medication in what could be interpreted as a “Eureka” gesture; while in other photos, it is Barbie who poses seductively with an HIV vaccine or has homosexual intercourse inside a lavish circle of tablets. Famous not only for being one of the first local artworks to address HIV/AIDS openly, in its complex treatment of the disease's drugs as desirable goods, Kuropatwa successfully depicts the neoliberal conditions pulling the strings behind the epidemic crisis. The four photographs chosen for display in *Imágenes Seropositivas* had never before been shown—they are part of a larger series, and its most iconic images belong to private and public collections. Even if the whole series is irreverent in its tone, the photos chosen for this exhibition are probably cruder than other better known works.³ In the space, they were joined by a



View of the corridor displaying graphic advertisement posters. Courtesy of La Ene.

Xerox copy of a text published by the artist as a paid-for announcement in the local newspaper in 1997—“La gente con sida debería tener la misma oportunidad que yo” (People With AIDS Should Have the Same Opportunities As Me). Kuropatwa’s candid plea for a broader access to medication is honest, inspiring, and deeply moving. For those who were denied this cocktail (Indinavir+3tc+D4T), the HIV/AIDS positive diagnosis meant trying out endless combinations of tablets only to get by day to day, but without any guarantee of being able to live with the virus—in Kuropatwa’s own words: “I wasn’t speaking anymore, I didn’t know what drug to take and I was actually having over 60 pills a day... I was afraid of dying.” The artwork and the piece of documentation shown side by side gave insight into the artist’s dual approach to the subject—in one case, ironic, in the other, frank—and to the multiple ways in which his obsession with the medication that kept him alive impacted his practice.

On the facing wall, a framed T-shirt with the words “Yo tengo Sida” (I have AIDS) and a table displaying related objects, provided entry points to a 1993–94 artwork—whose author was a fictional advertising agency called “Fabulosos Nobodies” (Fabulous Nobodies), integrated by artists Roberto Jacoby and Kiwi Sainz. Again complemented with a piece of text that the viewers could grab and take with them, these objects documented the public campaign that the agency launched in the midst of the AIDS crisis in Buenos Aires. The T-shirt’s colors and typography present a friendly declaration, introducing the component of solidarity into the discussion on the epidemic. The performance or public campaign was the mere act of wearing the t-shirt, breaching the taboo that dominated in society at large when it came to admitting that one had the virus. The accompanying material, posters, leaflets, and other graphic pamphlets also bear messages that extend bridges across different sectors of the population—notably, one that states that discrimination is based on the generalized belief that AIDS equals the other. The performance piece looks to discuss the underlying issues that HIV/AIDS victims face: its capacity to divide society and enhance elitism.

The artworks of the second room shared the space with a selection of videos from official TV footage and other kinds of broadcast media on the subject of HIV/AIDS.



Fabulosos Nobodies, *I have AIDS*, 1993–94, performance documentation. Courtesy of La Ene.

One such clipping is from a hugely popular lunchtime show, where a celebrity TV presenter, Mirtha Legrand, hosts selected guests at her table and discusses a variety of topics. On this occasion, it is the use of condoms, with AIDS activist Alex Freyre demonstrating how one should be applied for protection using a banana. Hilarious—especially since, most probably, the exhibition-goer did not expect to encounter any such material—it is also revealing to watch that most of the other guests at the table listen attentively and are finding the demonstration informative and useful, despite their abashed discomfort and pretended disinterest. This material completes a narrative of dual approaches that was present throughout *Imágenes Seropositivas*. Multidisciplinary and multipurpose, the exhibition disclosed the diverse and layered expressions through which HIV was discussed in Argentinean culture during the 1990s. In its engagement with artistic output as well as graphic and television advertisements, it managed to present the tensions that this subject provoked at the time, bringing the official discourse into a dialogue with the artistic one. Displaying these elements together, the curatorial proposition was to encourage an understanding of the practices as social documents of resistance. While the official strategy communicated fear and insisted on the application of protection measures over anything else, the art would encourage a familiarity with the virus. A case in point is the text that sits next to the performance material—“Proyecto fallido para un folleto sobre Sida” (A Failed Project for an Aids Brochure) by Roberto Jacoby, published in November 1993—in comparison with the first of the posters, from 1992. Both materials address the use of condoms as an important prevention measure. Jacoby tries to reach out to his readers by putting together a list of the most common excuses to avoid using condoms—from “it destroys my erection” to “she doesn’t trust me, she asks me to wear a condom”—while the billboard instead uses a threat: an image of five condoms arranged to form an Olympic Games logo bears the end-line “Be very careful with the other games.” During the 1990s, the artistic community of Buenos Aires saw a growing list of artists—Kuropatwa and Maresca, but also Feliciano Centurión, Omar Schiliro, Santiago García Sáenz, and Sergio Avello, among others—develop their work whilst fighting the virus. However, the material on display in *Imágenes Seropositivas* is partial and does not include a full spectrum of practices. Even if the title suggests a broad

scope—*Artistic Practices Related to HIV During the 1990s*—the exhibition is limited to exploring only a few names. What could seem like a curatorial oversight (or a pretentious title) instead becomes valuable information for understanding the institutional apparatus behind the exhibition.

The acknowledgements paragraph at the end of the curatorial leaflet discloses the precarious structure that is, at the same time, the show's condition of possibility: "The exhibited works and documents belong to the archives of Alejandro Kuropatwa, Roberto Jacoby [...] This project wouldn't have been possible without the help of Liliana Kuropatwa [the photographer's niece], Roberto Jacoby and Kiwi Sainz [...]." It is thanks to the sharing and collaborating of the exhibited artists, friends, and colleagues that the show is assembled. In its precariousness—and consequential partiality—the exhibition stands as a unique institutional enterprise.

It is remarkable that an exhibition that is relevant to local and global art histories would be left in the hands of the voluntary collaboration of individuals. There hasn't been another local exhibition with a similar scope to that of *Imágenes Seropositivas*. The first Latin American retrospective of Canadian collective General Idea toured from Fundación Jumex in Mexico City and reached the Museum of Latin American Art in Buenos Aires (MALBA) in the beginning of last year; it was followed closely by a relevant batch of individual retrospectives—Sergio Avello and Liliana Maresca at Buenos Aires' Modern Art Museum (MAMBA)—that could be cited as precedents or connected shows, however tangential.⁴ Amongst the most prestigious institutions in the city, MALBA and MAMBA are museums that occupy impressive buildings, guard substantial collections, and organize their public programming on a considerable budget—private funds in the case of MALBA, mostly public for MAMBA.

Imágenes Seropositivas, however, took place in a very different institution. The Nuevo Museo Energía de Arte Contemporáneo (New Energy Museum of Contemporary Art, known by the shorter name of La Ene) opened in 2010. It has assembled its collection since—it did not become a museum to protect a given group of historical artworks but, inversely, its contemporary collection is an ongoing effect of its institutional constitution. As such, it amounts to twenty-six pieces in 2018, and its storage space is an external hard-drive. The artworks belong to the collection insofar as the artists have given authorization to set these up and display them. La Ene owns the copyright permission to reproduce them, and therefore stores instructions or files that may be reprinted indefinitely. By creating the works anew each time they are shown, the institution remains perennially site-specific—it can be fully present in its two-room space in Buenos Aires, and anywhere else in the world.

La Ene sets out to question the basis of the museum of the twenty-first century, anchoring its critique in its local institutional history. Buenos Aires' Modern Art Museum was founded and directed by poet and critic Rafael Squirru in 1956 but was a homeless institution until 1960. Squirru famously took over commercial art galleries and urban public areas to host exhibitions and events as part of the museum's incipient program during the 1950s. His "ghost museum," as it was nicknamed at the time, had its inaugural show on board a touring boat—an event that was approached as the topic of one of La Ene's exhibitions. Also part of La Ene's genealogy is André Malraux and his visit to Argentina in 1959—a time when his famous essay "Museum Without Walls" had been published in its two first editions (1947 and 1951). Unquestionably, assembling an institutional collection on a hard-drive is inscribed in a tradition of gestures that have sought to reposition the collection's need for physical-

ity—and they start with Malraux's practical reimagining of the museum. In the 1950s, it was Squirru himself who welcomed Malraux into the country, and the subject of Buenos Aires' Museum of Modern Art came up between them. The story goes that when Malraux inquired about the possibility of visiting the young museum, Squirru's legendary reply was: "Le musée, c'est moi." In 2013, artist Leonel Pinola used a cultural merchandising aesthetic to register this moment in Argentinean art history, one that is at the same time an ideology orchestrated by one person, as well as a landmark for local institutions and their charter. The artwork—a T-shirt—is part of La Ene's collection.

Understanding the institution that hosts *Imágenes Seropositivas* provides further insight into the limitations and incongruences that traverse its curatorial project and display conditions. It is hard to strike a balance between praising La Ene for stepping up to be the contemporary art museum in the city and holding it responsible for doing so. A broader discussion, one that ponders the insufficiencies of other local institutions and how these cascade into La Ene's role, would need to be undertaken in order to analyze this institutional project with weight—and that exceeds the scope of this text.

With all that in mind, this exhibition missed an opportunity to include the larger spectrum of practices its survey-like subtitle appears to promise, and instead limits the display to less than a handful of (famous) names. Exclusion dynamics, that traction to create unrepresentative canons, are not new to the culture of AIDS—nor to Western art history in general. The narrow inclusion perpetuates a writing of history that delivers but a peephole view of HIV/AIDS artistic practices and risks a fetishization of the subject matter—so distant from the virus' reality at the time, and even more so if we consider the people who are still fighting it today. Was the show wide-reaching



Leonel Pinola, *Le musée c'est moi*, 2013, printed t-shirt. Courtesy of La Ene.

and accessible? Was it rooted in a tug of war between institutional apparatuses and an effort to affirm that “the museum is me”? If museums are entitled with a history-writing authority, do they bear a responsibility of opening up this prerogative? What does it mean that someone would have to email someone in order to see the exhibition? How is this an echo of possible stigmatizing practices the artists themselves may have been interested in tackling?

Imágenes Seropositivas can be read as the case of the non-institutional museum presenting a non-survey exhibition in the void of its constituent liberty. The DIY element traversing both the venue and the show gives this exhibition its power. The curatorial proposition could be realized thanks to a fascinating reunion of unconventional structures, and it offered this exhibition during a time that is prone to exploring HIV/AIDS-related art practices. In their atypical nature, the small survey show with the big title and the tiny space that calls itself a museum deliver without proselytizing.

Notes

1 CONICET, Literatura, Lingüística y Semiótica, Buenos Aires.

2 Fundación Huesped is an Argentine organization with regional reach throughout Latin America that has been working since 1989 in the public health field from a human rights perspective focused on HIV/AIDS, STIs, as well as sexual and reproductive health. See <https://www.huesped.org.ar/institucional/english/>.

3 One of the best known (also titled *Cóctel*, 1999) depicts a rose with a pill gently laid on its budded petals, with a dreamy pink background and a soft light setting the mood. The treatment here is more clearly recognised as advertisement, and the image is less bitter.

4 Exhibitionary canons are a relatively new academic undertaking; a disciplinary prop that emerged together with the growing interest in curatorial studies and then developed into one of the backbones of the nascent field of exhibition studies. [see Catalina Imizcoz, ‘Fieldwork: Extending the Study of the Exhibition Across Geographies’, available here]. If one such canon could be sketched of the exhibitions around the subject of HIV/AIDS, in the West, it could start with Group Material’s 1984 exhibition ‘Timeline: A Chronicle of U.S. Intervention in Central and Latin America, AIDS Timeline’ as an important precedent, followed more than thirty years after by ‘Aids in America’ (Bronx Museum and Tacoma Art Museum, 2016)—notably, with its surrounding controversy around the substantial omission of Black artists. The latter was accompanied by a cluster of smaller shows in New York City and the rest of the country that same year, ‘A Deeper Dive’ and ‘Person of Interest’, among others, as well as the Peter Hujar at the Morgan Library and David Wojnarowicz at the Whitney Museum of American Art. In the United Kingdom, a germane allusion to the subject was done in ‘Positive Living: Art and AIDS in South Africa’, which took place at Birkbeck University in the end of 2015. Arguably related is the show on Queer British Art held at Tate Britain in 2017—which opened the space to minorities strongly connected to the HIV/AIDS crisis. Spain has had shows like ‘Perfect Lovers’ in 2014, anticipating much of the curatorial work that happened elsewhere in the following years.

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AIDS Politics of Representation and Narratives: A Current Project at the Museum of European and Mediterranean Civilizations (Mucem) in Marseilles, France

Renaud Chantraine, Florent Molle, and Sandrine Musso

Stuart Hall, in his book on “Cultural Studies Policies,” highlights how AIDS is an extremely important arena for struggle and protest:

In addition to the people we know who are dying, or have died, or will, there are the many people dying who are never spoken of. How could we say that the question of AIDS is not also a question of who gets represented and who does not?¹

The struggle against AIDS has continued to be the scene of crucial issues in relation to representation policies, visibility, and invisibility to which people living with HIV have been assigned, so any museum writing project regarding HIV is faced with these challenges. In the French context, these are shaped by a unique political history with regard to the notion of citizenship. The French “republican model” refers to two significant features with regard to its relationship to the question of alterity, which is particularly mobilized in the question of sick bodies, but which concerns, beyond all references to “communities”: on the one hand, a conception of relations between state and citizens involving the reference to abstract individuals without distinction of gender, origin, and religion and, on the other hand, moral commitment to universal values. Beyond the deconstruction of the “national myth”² to which this model lends itself, the questions raised by the struggle against the epidemic have themselves been put to the test in this regard. They concern state intervention in the spheres of intimacy, sexuality, and practices defined as deviant. They also imply recognition of the diversity of these practices and the link to the collective experiences and social worlds in which they unfold. Thus, the prevention of HIV and the social history of the related struggle have continued to raise the question of who was or was not represented and framed in the health devices. For the people affected, the struggle against AIDS may have been the scene of a reclamation for a public voice. This demand required some of them to speak, either on their own initiative or on behalf of the groups and communities from which they come.

The purpose of this article is to report on a unique experience of bringing the topic of AIDS into a museum in France, and to describe and document the distinctive questions and practices of the museum that “exhibiting AIDS” implies. We will first present the context of the emergence of the AIDS issue in a society museum and then in the creation of a heritage fund. We will consider what stages in the history of the museum and the epidemic can be distinguished. Then we will discuss how, within a scientific committee and then in a broader community committee, we have planned to

discuss the issues related to the local memory of AIDS, taking into account its global dimension, as well as the challenges involved with the museum setting.

A Project Over 25 Years

Nearly 25 years ago, as new forms of expression of memory emerged in the face of the mass death caused by the spread of the virus, transforming AIDS into a “political epidemic,”³ the National Museum of Popular Arts and Traditions (MnATP) initiated a reflection on the role it had in welcoming, supporting and analyzing these events.

Since then, the different lives of the Mucem,⁴ which are part of the more general metamorphosis of European society museums,⁵ have accompanied and marked the development of this museum collection dedicated to the history and memories of the struggle against AIDS. The social history of the epidemic, from initial silence to the hypothesis of an end to transmission,⁶ and the evolution of the role played by some patient associations in the management of their health,⁷ also structure the representations and uses of this recent past.

The Metamorphosis of a Society Museum

The MnATP was created in 1937 in the reforming spirit of the socialist leaders of the Third Republic and in accordance with the aspirations of its director, Georges Henri Rivière, who wanted to set up a museum dedicated to documenting the transformations of rural French society. The museum first found its place at the *Palais de Chaillot* before moving to its Bois de Boulogne premises in 1972, where it was designed both as a “synthesis museum” of popular cultures and a “laboratory museum,” as it was associated in 1965 with the *Centre d’Ethnologie Française* (CEF), a laboratory specializing in humanities and social sciences. In terms of museum presentation, this dual identity is illustrated by the creation in 1972 of a study gallery dedicated to researchers and a cultural gallery intended for a wider public in 1975.

In keeping with the evolution of research in the social sciences and under the guidance of Georges Henri Rivière’s successor, the sociologist Jean Cuisenier, the museum’s orientations began to open up, in the mid-1970s, to social rather than technical issues: religion, kinship, identity, and urban life supplanted the old research themes. This development of research towards the study of social facts more difficult to depict in a museum was carried out at the expense of exhibition galleries. The decline in the number of visitors and the persistent gap between research and museum led to a necessary “reinvention” of the institution.⁸ Thus, the decision was taken to move the museum to Marseille under a different name and according to a new scientific orientation based on a chronological, geographical, thematic, and disciplinary enlargement. The Museum of Civilizations of Europe and the Mediterranean (Mucem) opened its doors in 2013.

Giving A Voice to Those Who Don't Have One

In this institutional context, in the midst of the reorganization of the 1990s, a group of anthropologists (Françoise Loux, Stéphane Abriol, and Christophe Broqua) from the CEF took an interest in the new rituals linked to the AIDS epidemic. With a view toward organizing an event at the museum on December 1, 1994, they decided to contact the main French associations involved in the fight against AIDS.

The association of the *Patchwork des Noms*, a French version of the *Names Project* founded in San Francisco in 1985, was the first to answer them. The original intention of the researchers was to exhibit the quilts in the museum hall, as they were seen as a

central testimony to the fight against the epidemic. This first proposal was rejected on the grounds that the deployment had to take place as part of a ritual.⁹ The association then invited the museum to take charge of this ritual, which the researchers accepted, judging that the association's proposal corresponded to the role of a society museum, namely "to encourage the passage from collective mourning within a group of people concerned [...] to the taking charge of this mourning and memory by the entire social community, represented by the museum."¹⁰

After this deployment, meetings and debates were organized each year around December 1, mainly focused on issues of mourning, rituals, and memory related to the epidemic. Researchers, caregivers, museum staff, community volunteers, and people living with HIV were also invited to these meetings. They inaugurated the beginning of a collaboration and a relationship of trust between the museum and a heterogeneous group of actors involved in the fight against AIDS. "We put [...] the reflection and action of associations on a different level, but equal to ours. In biomedical research [...] patients have struggled to have a voice, particularly in the development of therapeutic trials. Also in the social sciences, the legitimate desire of some people concerned is also to be seen not only as objects for research but also as 'partners.'"¹¹

With these meetings, a special body of knowledge developed at the crossroads of the academic and associative worlds. Michel Colardelle, then director of the MnATP, supported this project in order to continue Georges Henri Rivière's adage, "to give a voice to those who don't have one" and to make it possible to confront points of view in order to provoke a heuristic contradiction.

The End of a First Phase of Silence?

It is symptomatic to note that the emergence of this public debate in a national museum came at a time when the development of AIDS associations was booming. After a first silent phase of stigmatization of the social groups most affected by the disease, that is to say gay men and intravenous drug users, followed by denial of the selective spread of the epidemic,¹² the second half of the 1980s saw an increase in the number of associations in France. A process of institutionalization was taking place with the emergence of a field in the fight against AIDS and the transformation of a "minority" cause into a cause of general interest. However, it would seem that the associations, involved in the actions of struggle on the ground, were not necessarily sensitive to the stakes of preserving and organizing the traces of their struggles and memories.

At the same time, the questioning at work at MnATP in the 1990s came after a silent period concerning the consideration of the social history of AIDS in the French patrimonial domain. With the arrival of treatment, the representation of AIDS as a plague changed; organizations were confronted with the problem of universal access in the Global South and patients who had problems with precarity. A questionnaire sent by MnATP researchers to 257 museums in 2000 revealed the absence of this heritage in French institutions.

Seven questions were asked:

1. What is your position today on the "museum setting" of the contemporary?
2. Does your museum present themes related to the contemporary?
If so, what are they? And how are the selection criteria established?
3. Are you leading a reflection on how to introduce AIDS into the museum?
If yes, could you clarify? If not, what is your position on the issue?

4. Have you included AIDS-related works or objects in your collections? If yes, can you specify which ones and explain how the decision was made?
5. If you have not included AIDS-related artwork or objects in your collection, do you plan to do so in the future? If yes, in what form?
6. Have you organized an exhibition on the theme of AIDS, or have you mentioned this theme among others? (illness, epidemic, sexuality, etc.)?
7. Have you participated in any way, this year or another, in AIDS-related events (December 1, Sidaction, etc.), or have you organized outside exhibitions, symposia, or debates on this theme in your premises? Could you specify?

For the majority of the museums questioned, which affirmed that they were in favor of or engaged in a reflection on the patrimonialization of the contemporary, the issue of the epidemic was only very rarely included. The reasons given were multiple: the specific theme of their institution did not lend itself to this, but above all, the lack of someone in the museum staff, having conducted a scientific reflection on the problem of its integration into public collections. In any case, there had never been a systematic collection, and there were few examples of museums that had exhibited or possessed objects related to AIDS.

However, we can mention the Musée de l'Assistance-Publique Hôpitaux de Paris, which had included objects made by HIV-positive patients in its collections, the Saint-Quentin-en-Yvelines ecomuseum, which kept condoms and prevention posters, and the Musée de la Publicité, which was interested in the graphic design of these posters. We should also mention that some museums and cultural spaces participated in AIDS-related events, such as December 1.¹³

The Creation of a Heritage Collection

Faced with the magnitude of the pandemic and the social mobilizations that were organized to respond to it, but strengthened by the observation of the absence of memorial care—institutional and associative—of the social history of this disease, the museum decided to support the project, elaborated by Françoise Loux and Stéphane Abriol, to collect testimonies and archives. A survey acquisition campaign¹⁴ on the history and memories of AIDS in France, Europe, and the Mediterranean began in 2002 at MnATP-Mucem and would last four years.

The first year of this campaign focused on the French context, but the following ones have gradually widened the spectrum to more than 35 countries from Northern Europe to Turkey and the Maghreb. In total, approximately 12,000 artifacts have been collected (posters, leaflets, documentation, films, prevention materials, objects of events, etc.).

The work stopped in 2006, in the context of the move of the MnATP's collections from Paris to the Mucem in Marseille.

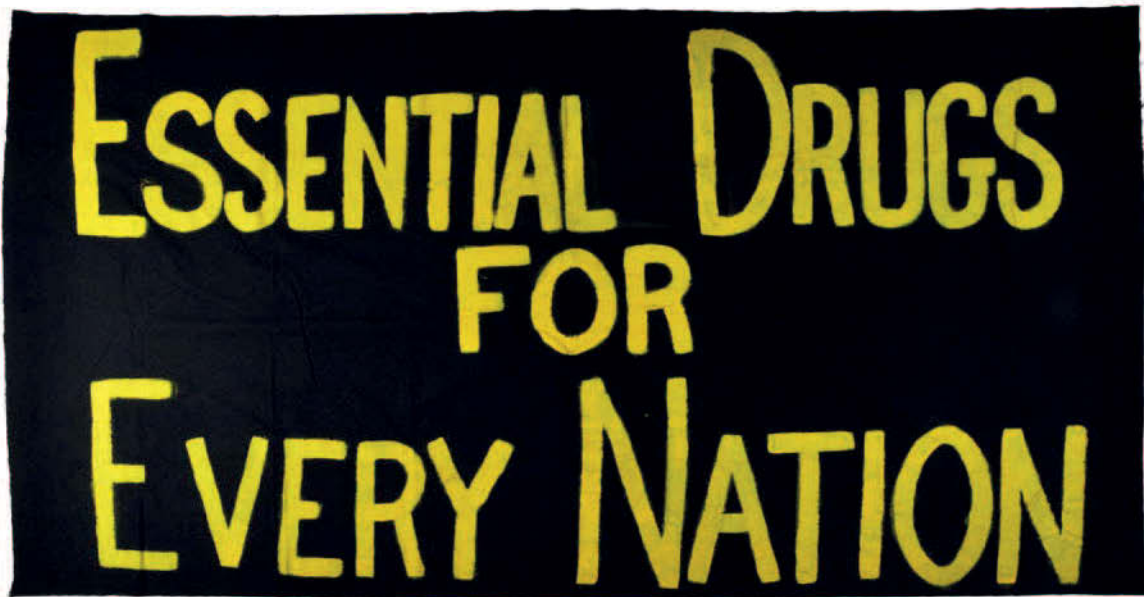
According to Stéphane Abriol: "The museum's approach to this collection has always been to work together with individuals and AIDS associations. [...] At each meeting or contact with an association, we asked them to tell us: among the objects they gave us, which ones made more sense to them and why? [...] By offering a space for discussion and reflection to the people concerned and by collecting a fragile and yet so necessary memory of the fight against the epidemic, the museum placed itself at the service of society and asked questions about the legitimacy of a museum's role as an actor in the fight against AIDS and in what ways."¹⁶



Two examples of objects collected by the Mucem.

Above, ACT UP-Paris, Poster "Sida. Politique sécuritaire, catastrophe sanitaire" (AIDS. Security policy, health catastrophe), 2002, gift from the CRIPS¹⁵ Île-de-France. Courtesy of Mucem (Inv: 2003.99.13).

Next Page: Multiple AIDS associations: Banner "Essential Drugs for every nation," deployed in July 1999 at the International AIDS Conference in Durban, South Africa. Courtesy of Mucem (Inv : 2004.211.33).



“Witness Objects”: But of What?

This “comprehensive approach” has allowed for the creation of a new but inevitably partial fund. Beyond the definition of “object witness,”¹⁷ which is selected by the ethnographer and is supposed to represent a lifestyle, culture, or social phenomenon, the objects of the HIV/AIDS collection rather reflect another approach, in which heritage relevance is no longer solely designated by an expert but also in part by, or at least with, the social actor.

In addition, the chronological portion of the survey falls within the period that Theodore Kerr describes as a “second silence”: “A period where the epidemic went from explicit due to the hard work of activists and people living with HIV to make it visible, to implicit: from public to private. [...] as beginning in 1996 with the release of life prolonging medication, and ending in 2008 with the start of the Revisitation and the release of the Swiss Statement.”¹⁸ The objects thus collected, although contextualized by the testimonies that accompany them, do not reflect the major changes and transformations of the epidemic that occurred before and after the collection period. They do not make it possible to embrace the full complexity of the interlinking of local and global, subjective and collective scales linked to this epidemic.

Following the collection, a phase of inventorying, marking, and documenting the collections marked the beginning of a second silence, this time one related to heritage, which accompanied the moving of the collections and the difficult breaking of the link with the donators and actors of the struggle against AIDS who participated in the project.

The Opening of the Mucem: New Proposals for Donations

Within a few months of opening, the new Mucem was approached by two donors. The first was a press photographer of American origin who lives and works in Paris. Tom Craig began his militant career in New York with the Gay Activist Alliance, then ACT UP-New York in 1988. In the early 1990s, he moved to France and from 1994 onwards followed ACT UP-Paris in all its events, debates, actions, and conferences. He also photographed all the Gay Prides and December 1 events since his arrival, as well as the



ACT UP-Paris, *Poster "Retour au silence" (Back to Silence)*, December 1, 1998, gift from Christophe Broqua. Courtesy of Mucem (Inv: 2004.212.11).

actions of other Parisian AIDS associations, such as AIDES, Sidaction, and the Sisters of Perpetual Indulgence.

For the photographer, these images were “testimonies,” “historical pieces.” He deplored the fact that the struggle against AIDS and for the defense of LGBT+ rights remains so little known to the general public, even though it has been part of French social history for the last thirty years. He feared that his archives would disappear after him and wanted them to enter the museum’s collections so that they could be protected, communicated, and disseminated to as many people as possible.

For Mucem, the Tom Craig Collection has the advantage of documenting the social contexts of the outbreak of this epidemic and the reactions of civil society and associations to the disease. Acquiring these photographs has allowed the museum to both considerably diversify the sources of the association’s knowledge and to acquire witnesses (photographs) of the contextual use of objects otherwise kept in the collections.

The second donation is a set of objects directly related to the ACT UP-Paris association. Following the contact with Tom Craig in 2013, Yves Grenu, then head of the archives and documentation group at ACT UP-Paris, asked to meet with the Mucem curator in charge of the AIDS collection. At the time, the situation of the association was dire. It was experiencing great financial difficulties as a result of the gradual decline in public subsidies and donations, as well as the drop in the number of activists. This led it to leave the historic areas occupied since 1989 as a matter of urgency. What was to be done with the memory of the association and all the objects and archives gathered in these premises?

The archivist's solution was to transfer the entirety of the materials held at that time to the association's premises. In the absence of an LGBT+ Archives center in Paris, to which he would have preferred to give the entirety of the collection, he contacted the National Archives, which agreed to collect the documents, but not the objects. The latter—office objects representing the daily life of the association and more spectacular objects for targeted and demonstrative actions (shows, zap, die-in)—would finally join the Mucem collections in 2016. This set of 266 objects was being studied for presentation to the acquisition commission at the end of 2018.

The Development of a Valorization Project

Since the end of the 2000s, an "AIDS Crisis Revisitation"¹⁹ has been perceptible in the space of artistic, cultural, and scientific production. In the USA in particular, numerous exhibitions have been established,²⁰ and in Europe, research projects are being organized to look back on the history and memory of the epidemic at local, national (in the United Kingdom, Sweden, Ireland, Switzerland or Spain), or supranational (like Europatch²¹) levels.

In France, this need to "bear witness to the present of the past that does not pass,"²² was expressed in cinematic production in particular, with the success of the film *120 Battements par minute* in 2017, which won the Queer Palm at the 2017 Cannes Film Festival. In the area of heritage, there has also been a movement toward institutionalizing the associative memory, notably with the transfer of the archives of AIDES and ACT UP-Paris to the national archives or donations proposed to Mucem dating back to 2013.

However, the pursuit of the process of heritage preservation that began in 1994 raises questions about the museum's role and the decisions to be taken in a project to enhance this history. Should the museum be a mere "conservatory"? In what ways should we approach this story, with whom, and in what directions?

Faced with these initial questions, a scientific council was set up in 2015 to identify gaps in the collections, to continue the collection work, and, more generally, to reflect on the future of the "AIDS survey-collection" in a future exhibition. Two mechanisms have been set up: a community committee and a series of study days.

The Creation of a "Community Committee"

Clearly, designing a valorization project on a theme such as the fight against AIDS required mobilizing the "people concerned" and the actors in the fight in the broadest possible way. One of the singularities of the history of the epidemic, or even what some have called the "subculture of AIDS,"²³ is the reformulation of the power relations between doctors and "patients." The "people living with AIDS," to use the words of the 1983 Denver Principles, have emphasized the notion of non-specialist expertise. But how can this be done, given that this logic of co-construction is far from really being at the heart of the way French national museums work?

In response, a call for participation was drafted and widely disseminated in the local networks of the scientific committee members. The form of the "address" was conceived in such a way as to highlight the questions raised by the museum narrative and the necessary co-construction of this narrative, in accordance with the social history of the fight against AIDS. Activists, associations, caregivers, researchers, and people outside the association, particularly in cultural or media circles, will receive the invitation and constitute a plural assembly of people affected by the epidemic in their entities,

their professional trajectories, and/or their commitments. The group, formed as of May 2017, is open and currently brings together around forty people, who have committed themselves to following and nurturing the project development process by attending and contributing regularly to the various meetings (meetings, study days, etc.).

The community committee is thus associated with the exhibition's scientific committee in order to define ways of enhancing the value of the existing collection, in particular a collection of duplicate²⁴ objects that are not subject to the constraints of the heritage code. Members of this committee can also contribute their testimonials to improve or complete the knowledge of existing collections or identify heritage elements in other private or associative collections. Another role of the community committee is to define, together with the scientific committee, axes for a future exhibition. Finally, the scientific committee proposes to offer training to the members of the community committee (archiving, conducting interviews) to promote the organization of heritage linked to the epidemic. Finally, the community committee offers a way for the museum to re-create links with the people concerned and to rethink the sharing of authority over museum collections.

A Series of Study Days

Following the valorization project, a series of study days were organized to shed light on various aspects of the memory, museum, and exhibition of the fight against the HIV/AIDS epidemic. It is both a theoretical foundation and a repertoire of practices, which are also intended to bring together the views and knowledge of different actors, whether they are French or foreign museum professionals (curators), academics from different disciplines (anthropology, sociology, history, art history, epidemiology, public health), or a diversity of actors coming from the social and associative fields, the



Workshop around “collection bis” during a study day. Courtesy of Sasha Ertel.



Sample of objects from the "collection bis." Courtesy of Sasha Ertel.

hospital sector, the public health sector, or the private sector. It is also a question of establishing common benchmarks within the community committee on how these issues have been dealt with in other contexts, under different skies, and by other institutions and professions.

Two main themes will structure our exchanges during upcoming meetings: narratives and scales of taking the epidemic into account.

Scales of the Epidemic

Indeed, while the collection was carried out first on a national territory, then on a Euro-Mediterranean level, it is extremely complex to come up with a whole set of scales that communicate and sometimes contradict each other at the global level. How to report on the history of the post-colonial circulation of the virus between the two shores of the Mediterranean? How can we account for this in the continent that remains most affected today, the African continent, when recent work on the origin of AIDS²⁵ shows how much the scenario of its genesis is partly linked to colonial history? How can we think of and explain what the epidemic was at the local level in Marseille and the surrounding region, a site where the epidemiology and social history of the virus, as well as its political treatment, take on singularities with regard to a Parisian history of AIDS, and how can we talk about AIDS in France without mentioning the overseas territories in which prevalence is totally different? How can we talk about ACT UP-Paris without talking about ACT UP-New York?

While the first pandemic referred to the globalization of misery, AIDS has not affected all regions of the world in the same way. According to societal flaws,²⁶ the selective spread of the virus among and within societies cannot be reduced to the distinction between "AIDS in the North" and "AIDS in the South" mentioned after the advent of

treatment in 1996. On the one hand, this is because the social history of the epidemic has shown how massively the “south of the north” could be affected by marked inequalities of prevalence in the countries of the north, according to social and racial conditions. For example, the disproportionate rates of HIV infection in overseas territories are a cardinal element, even if only in terms of the number of cases and deaths, to understand the French history of HIV, revealing unequal and unevenly accessible treatment here and elsewhere.

What Kind of Storytelling?

Isn't the fight against AIDS a unique arena of encounters, convergences, and confrontations between different perspectives on the virus and ways of fighting it: stories from researchers, caregivers, public health officials, decision makers, activists, and people living with HIV? What are the differences and invariants between these stories? How can they be used in the context of an exhibition?

In addition, what are the questions that the actors of this story can testify to when there is no “trace” left? The fragility of associative memories, the fragile tools that some of these actors had at their disposal to “make themselves heard,” or even the assignment to silence, partly consented to because of the impossibility of claiming a stigma: all this counts in defections or speaking out about the virus.²⁷

The issue of narratives intersects with that of scales: the discovery of the virus and research into how it is detected, treated, prevented, and managed has affected many disciplines, from virology to immunology, from public health to clinical research. A variety of professional worlds, caregivers, and associations have been involved in the history of AIDS: from infectious disease services to places where people who use drugs are accommodated, from “sexuality education” practices to those of public communication about the disease, including hospital hygiene practices and legal issues raised by the status given to the disease (penalization of transmission and funeral care, for example).

Conclusion

In short, the complexity of the questions raised justifies that the mechanism designed to try to shed light on them is inspired by some of the lessons of this epidemic: to consider AIDS as a social and cultural object and not only as a medical object, to take note of the plurality of social worlds involved in its struggle or modified by it, to consider the forms of visibility and invisibility that have traversed its history, to involve affected people in the reflection on the stakes of its “exhibition.”

In the opening sequence of the “end of AIDS” story, the challenge is also that a project of this type is not only a passage from memory to history, but can also take into account the contemporary and current stakes of the epidemic: the place of the sick, inequalities and discrimination, views on minorities, pharmaceuticalization, selective spread of the virus, and forgetfulness are all far from being questions belonging to the past.

Notes

1 Stuart Hall, “Cultural Studies and its Theoretical Legacies,” originally published in *Cultural Studies*, Lawrence Grossberg, Cary Nelson, Paula Treichler, eds. (New York and London: Routledge, 1992) 277-294.

2 Suzanne Citron, *Le Mythe national, L'Histoire de France revisitée* (Ivry-sur-Seine: Éditions de l'Atelier / Éditions ouvrières, 2008).

- 3** Patrice Pinell, Christophe Broqua, Pierre-Olivier de Busscher; Marie Jauffret-Roustide, and Claude Thiaudière, *Une épidémie politique : la lutte contre le sida en France (1981-1996)* (Paris: PUF, coll. "Science, histoire et société," 2002).
- 4** Martine Segalen, *Vie d'un musée. 1937-2005* (Paris: Stock, 2005).
- 5** Denis Chevallier, *Métamorphoses des musées de société* (Paris, La Documentation française, 2013).
- 6** François Berdugo, Gabriel Girard, *La fin du sida est-elle possible* (Paris, Textuels, 2017).
- 7** Christophe Broqua, *Agir pour ne pas mourir ! Act up, les homosexuels et le sida* (Paris: Presses de Sciences Po, 2006).
- 8** Michel Colardelle, *Réinventer un musée - Le Musée des Civilisations de l'Europe et de la Méditerranée à Marseille* (Paris: RMN, 2002).
- 9** In anthropology, not all definitions of the term "ritual" are homogeneous. The debates held on this occasion were also aimed theorizing this issue: "Are these really rituals or something else? What is the real novelty? Can there be profane rituals?" (Christophe Broqua, Françoise Loux, Patrick Prado, eds., "Sida : deuil, mémoire, nouveaux rituels," *Ethnologie française* 28 (1998)) These are all questions that these days were designed to answer.
- 10** Stéphane Abriol and Françoise Loux, "La place du sida dans un musée de société," *Musées et collections publiques de France*, special issue "Histoire douloureuse" 237 (2002/3).
- 11** Broqua, Loux, Prado, "Sida : deuil, mémoire, nouveaux rituels."
- 12** Broqua, *Agir pour ne pas mourir ! Act up, les homosexuels et le sida.*
- 13** Renaud Chantraine, *La patrimonialisation des traces des minorités sexuelles : étude de cas* (Master's thesis, Ecole du Louvre, 2014), 87-88.
- 14** The survey-acquisition campaign is a research device used at MnATP-Mucem with the aim of collecting documentary data to build tangible and intangible heritage collections. Through an ethnographic survey, the objective is to document a social fact, collect material manifestations of it, and qualitative interviews conducted to gather the views of the actors of this phenomenon. The ambition is to observe and report on a universe of meaning, symbolically and materially mobilized by the actors of a social fact. This method is essential to account for social realities and not to construct a decontextualized discourse.
- 15** Centre Régional d'Information et de Prévention du Sida, Regional AIDS Information and Prevention Centre.
- 16** Paper presented at the Mucem study day, "Preserving and Exhibiting Epidemics and the Fight against AIDS," October 27, 2017, Mucem.
- 17** Fabrice Grognet, "Objets de musée, n'avez-vous donc qu'une vie ?," *Gradhiva* 2 (2005).
- 18** Theodore (Ted) Kerr, "AIDS 1969: HIV, History, and Race," *Drain Magazine* 13:2 (2016).
- 19** Theodore (Ted) Kerr, "The AIDS Crisis Revisitation," Lambda Literary, accessed February 13, 2018, <https://www.lambdaliterary.org/features/oped/01/04/the-aids-crisis-revisitation/>.
- 20** Elisabeth Lebocivi, *Ce que le sida m'a fait : Art et activisme à la fin du XXème siècle* (Paris, JRP Ringier, 2017).
- 21** More information: <https://www.euroethno.hu-berlin.de/de/forschung/projekte/europach>
- 22** Elisabeth Lebocivi, *Ce que le sida m'a fait : Art et activisme à la fin du XXème siècle* (Paris, JRP Ringier, 2017).
- 23** Alice Desclaux, "Stigmatisation, discrimination : que peut-on attendre d'une approche culturelle ?," UNESCO, ed., *VIH/sida : stigmatisation, discrimination : une approche anthropologique* (Paris: UNESCO, 2003).
- 24** The Mucem "AIDS collection" has a very interesting feature: at the time of the survey, double copies (even triples and more) were sometimes given by associations to

anthropologists. Once the objects had entered the museum, it was decided not to include them in the inventory of heritage so as not to subject them to the constraints of heritage laws. Once registered in the inventory, a transfer of ownership takes place between private property (the donor's property) and public property (the state property), and the museum object becomes inalienable and non-transferable. Its loan must be subject to agreement by the museum that keeps it, and the structures related to applying for a loan must ensure stable conditions of humidity and temperature. Therefore, an association that has been given an object and wishes to be able to use it again would not be able to do so if it cannot fulfill these conditions. These duplicates, which the collectors call the "collection bis," escape this logic, since it has a status of study material, which allows for a variety of use and much greater flexibility. Also, the aim is to be able to lend it quite freely to associations or individuals who wish to use it, for example, for pedagogical or memorial purposes.

25 Guillaume Lachenal, "La quête des origines du Sida," *La Vie des idées*, 17 octobre 2014.

26 Paul Farmer, *AIDS and Accusation: Haiti and the Geography of Blame* (Berkeley: University of California Press, 1992).

27 A.O. Hirschman, *Face au déclin des entreprises et des institutions* (Paris, Éditions Ouvrières, 1972).

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Florent Molle is a heritage curator, part of the scientific direction of the Mucem, and head of the sport and health department, following academic training in health anthropology and professional training at the Institut National du Patrimoine. His curatorial work focuses on popular cultures and the relationships that the museum can develop with communities. He curated an exhibition about football in 2017 and was the editor of the catalogue. He is coordinating the exhibition project about AIDS as a member of the scientific committee.

AIDS and the Medical Museum Gaze: Collecting and Exhibiting Science and Society

Manon S. Parry

Many involved in the response to the emerging AIDS epidemic in the US were aware that they were participating in a major historical event, and activists, community organizers, caregivers, and health professionals kept records and objects documenting their activities. Relatively early on, historians, archivists, and museum curators recognized the importance of collecting this material, organizing major conferences in 1988, 1989, and 1993 to discuss strategies for preserving this “history in the making.”¹ As a result, there is a wealth of historical items housed in archive and museum collections. In the words of Judy Chelnick, a curator in the Division of Medicine and Science at the Smithsonian’s National Museum of American History, HIV and AIDS presented “a unique opportunity [...] to document an epidemic from its beginnings.”²

As curators have drawn on these collections for exhibitions, however, it has become increasingly apparent that they are dominated by a fairly narrow range of objects, namely public health campaign materials, HIV testing kits and drug samples; posters, badges, and pamphlets produced by activist groups; and props from protests, such as signs and costumes. I thus argue here that we have underestimated the challenges of collecting the material culture of HIV and AIDS, and as a consequence, museums are ill-equipped to exhibit a broad narrative of the pandemic in the past and to address its continuing impact.³



Action on AIDS gallery, *Against the Odds; Making a Difference in Global Health*,
Exhibition at the National Library of Medicine, 2008-2010. Courtesy of the National Library of Medicine

In this essay, I consider the dynamics that have shaped the characteristics of HIV and AIDS collections and the exhibitions that draw on them. I address aspects of curating that occur behind the scenes, in the identification and accession of objects for museum collections, as well as the public side of exhibitions, and I explore the connections between the two. I focus specifically on museums of science and medicine, which are worth considering as a specific venue for several reasons. Due to the complex “epidemic of signification” that they constitute, HIV and AIDS underscore the limitations of traditional approaches to collecting and interpreting medical heritage.⁴ The pandemic cannot be understood as a solely biological, social, or cultural phenomenon. Instead, intertwining discourses influence how it is conceptualized, studied, and treated in medicine and policy, as well as how it is remembered and represented in culture. All of this, in turn, shapes experience. Clearly medical museums, just like other types of heritage institutions, do not have the collecting mandate, nor the space or the resources, to accession a wide enough range of objects to reflect this. In fact, traditional definitions of what counts as medical heritage has further narrowed their scope. Objects may be rejected if they are not considered sufficiently scientific, and medical museums have rarely collected materials that relate to patient perspectives.

Medical heritage is also vulnerable to destruction, due to the undervaluation of its significance in medical settings, where resources are focused on contemporary health issues rather than the preservation of the recent past. In crisis situations, where there are medical emergencies and a high death toll, collecting objects for museums is not a priority. In the aftermath, approaching groups still grieving is a difficult task, as curators collecting material related to Ebola outbreaks and the Pulse nightclub shooting have reported.⁵ Furthermore, there are specific challenges to acquiring and exhibiting some kinds of material within medical research or education facilities, especially those representing, or funded by, health agencies or pharmaceutical companies.

Despite these complexities, curation at museums of science and medicine has received far less analysis than exhibitions of artworks and activist ephemera. As Katrin Köppert and Todd Sekuler have argued, installations of public health materials have “rarely been attributed to theories about the performative practices of memorializing and archiving” by scholars.⁶ This is particularly problematic given that these histories are just as mediated as any other. They may, however, be less likely to be understood in this way, due to the broad tendency to view scientific thinking as outside of social influence, and to value scientific knowledge more highly than other ways of knowing.⁷

In the analysis that follows, I consider continuities and shifts in the presentation of the history of HIV and AIDS in museums of science and medicine in the US, beginning with one of the earliest exhibitions from 1993. I compare this phase with activities surrounding the thirtieth anniversary of the emergence of the first cases identified as HIV, in 2011, drawing on my own work as a curator at the National Library of Medicine. I conclude with a discussion of current trends, including a new crop of projects launched to coincide with the 2018 centenary of the influenza pandemic.

Science versus Stigma in the 1990s

The first exhibitions about AIDS in American museums of science or medicine opened in the early 1990s, more than a decade after the initial cases of the new disease had been identified there. These projects reflect the climate of fear and controversy at the time, an atmosphere that served as an impetus for curators to campaign for a more “scientific” approach to the topic. In 1991, staff from eight American science museums formed the National AIDS Exhibit Consortium to discuss the need for an exhibition. Barry Aprison, of the Chicago Museum of Science and Industry, set out their rationale in the journal *Curator* in 1993, arguing that exhibitions “can enlighten visitors about

the biology of a dangerous virus.” Science museums, he continued, “are seen as impartial sources of reliable information,” making complex information comprehensible to a broad audience in a “nonthreatening setting.” As a result, they “may enable museum visitors to adopt behaviors that reduce the risks of transmission of HIV and may foster compassionate, humane attitudes towards persons affected by the disease.”⁸ Although no one institution was sure how to frame such an exhibition, their mission was thus defined as public health education, and destigmatization of people with AIDS. The consortium was awarded \$2 million by the Centers for Disease Control and Prevention, reflecting and reinforcing this idea of the usefulness of museums for public health.⁹

Aprison was careful to frame the supposed impartiality of science museums as a public perception rather than reality, but his suggestion that AIDS could be made more manageable, and less frightening, if set aside from its social and cultural baggage, expanded as the consortium developed their work. Their first exhibition cost \$500,000, including funding from the British pharmaceutical company, SmithKline Beecham. *What About AIDS?* launched at the Franklin Institute Science Museum in Philadelphia in 1993, before traveling around the country.¹⁰ *The New York Times* reported that while other museums and galleries had held exhibitions “intended to raise public awareness of AIDS and related issues, none had ever presented the subject through the lens of science.” The Franklin Institute’s senior exhibition director, Roberta G. Cooks, also emphasized the value of their scientific perspective, and claimed that the science museum was “a neutral place to talk about the issue.”¹¹

Despite such assertions, development of the exhibition was highly politicized and contentious. The first hurdle came from within the museum itself, among staff who were “terrified” of having the project in-house. As Cooks later recalled,

Some were worried that people living with HIV would come into the museum bathrooms and infect other people. Others were worried about how visitors and potential funders would react. How would the public view our museum for creating an exhibit about a virus that is passed on by dirty needles and sex?¹²

Far from providing a zone of neutrality and objectivity then, the museum was staffed by people with the same anxieties and prejudices as in wider society. To address this, the organizers arranged training by members of the American Red Cross for everyone from exhibit developers to security guards, on scientific knowledge and misperceptions, public health policies, and ways to discuss these topics with visitors.

The exhibition team also encountered difficulties with the predominantly Catholic education committee of the museum’s board of trustees, who focused primarily on the need to emphasize sexual abstinence in the exhibition. Cooks stated that the curators “certainly felt that abstinence was the best choice for teenagers, but we also knew that many teens are sexually active and need accurate information on how to protect themselves.” They aimed to find an approach, as they stated, that “we felt we could live with and explain to our administration and board of trustees,” and did so by claiming that the exhibition avoided telling people how they should behave.¹³ As public health information inherently involves “telling people how to behave,” however, this strategy sits uneasily alongside the goals of the project and of the National AIDS Exhibit Consortium more broadly.

The 3,000-square-foot exhibition was divided into sections addressing scientific knowledge about AIDS, how HIV is transmitted and ways to prevent it, and the response from a range of people, including partners and community organizers as well as scientists. The middle section on transmission, titled “Protect Yourself” was set apart, with banners proclaiming this a “PG 10” zone, because the education committee

was “uncomfortable” about the large proportion of museum visitors aged six and seven accessing sexual content.¹⁴

This zone included a video discussion between teenagers and the actor Edward James Olmos, available in English or Spanish, on safe sex and condom use, and abstinence. An exhibition panel titled “101 Ways To Make Love Without Doing It” described situations such as watching the moon or eating ice cream together as ways to be intimate with a partner without having sex. There was also a separate section for younger children that focused on issues such as AIDS stigma and the risks of picking up used needles found on the street.

The museum's public relations staff asked that the exhibition open for a trial period of three months, with an opportunity to make changes before the official launch. They invited religious groups, educators, press, and AIDS activists to preview the project. *The New York Times* reported that sections on “an animated illustration of how to put on a condom, and a recommendation by Mr. Olmos that spermicide improves the chances of birth control,” were “remarkably graphic.”¹⁵ Father John Dennis, coordinator for the Philadelphia Archdiocese's AIDS programs, praised the exhibition overall, but wished “the discussion of condom use could have been ‘a little less blatant’ [...] and said he thought it ‘encouraged, rather than discouraged’ teenagers from engaging in sexual activities.”¹⁶

In contrast, another reviewer concluded that the exhibition promoted abstinence, complaining that, “The specter of death is being harnessed to promote a traditionalist moral agenda—at the expense of healthy, positive attitudes toward sexuality.”¹⁷ Although the curators claimed to avoid “telling people how to behave” then, visitors interpreted the exhibition as doing exactly that, even as they disagreed over which behaviors were encouraged. Clearly, they did not assume that a science museum would have a neutral stance and looked critically at the messages embedded in the narrative. In fact, as a project on a public health issue at a science venue, it is likely that visitors would be especially likely to interpret the exhibition as promoting particular behaviors to prevent the spread of HIV.

Although the exhibition was not altered in response to the criticisms of condom use, it was adapted to identify more people as gay. At first, the only living gay man pictured was shown alone, while there were four heterosexual couples featured.¹⁸ Homosexuality was mentioned only once in the exhibition text. Although curators said they had not deliberately minimized the topic, AIDS activists argued that by attempting to show that everyone was at risk, the first version “glossed over” the specific risks for gay men.¹⁹ This push for inclusion was not common to all groups affected by HIV. Around the same time, staff at Brooklyn Historical Society creating another exhibition on HIV and AIDS struggled to recruit drug users and members of minority groups to the project. Parents of children with AIDS were similarly reticent, all “[i]n contrast to white gay males, who often volunteered.”²⁰ This imbalance reflects the uneven gains of AIDS activism, which continue to play out today. The process is self-perpetuating, with the most stigmatized groups unlikely to volunteer to be featured in public exhibitions, and their underrepresentation contributing to their continued stigmatization. Similarly, these groups are underrepresented in museum collections and as museum visitors, with each side of this dynamic reinforcing the other.

The strategy of holding previews and responding to some of the criticisms of *What About AIDS?* helped ensure its success. To prepare staff at other venues to host the exhibition, the Franklin Institute held annual workshops to provide training and to share their own experiences of visitor reactions. In the subsequent tour, few objections were raised.²¹ Where problems did arise, they were overcome. Schools local to the Cranbrook Institute of Science in Bloomfield Hills, Michigan, for example, declared that each school principal would need to approve the exhibition for their students, and

that parents would be required to sign permission slips. Nonetheless, students at many schools were allowed to attend. The public health value of the project was endorsed by Blue Cross, who paid admission fees for their members to visit. In Charlotte, North Carolina, a local school board official up for reelection announced that students should be barred, so the Museum of Life and Science, Discovery Place contacted the local newspaper. Community protests in response to front-page coverage of the announcement led to the requirement that every middle and high school class attend the exhibition as well as a course about the immune system.²²

The Franklin Institute project paved the way for more activities. A year after its launch, the Chicago Museum of Science and Industry announced their plans for the country's first permanent exhibition on HIV and AIDS. However, the notion of science museums as the ideal venue for such a project was still disputed. The *Chicago Tribune* asserted that Chicagoans associated the museum with exhibitions about "agriculture, coal mines and submarines [...] [n]ot sex, condoms and death."²³ In fact, the exhibition represented a transition into more controversial areas, according to Barry Aprison, the museum's senior scientist and project director for their AIDS exhibition. He told the press that the exhibition was part of a move to address more "cutting-edge" topics, such as genetics and biotechnology.²⁴

AIDS: The War Within was initially planned as a project of 2,500 square feet with a budget of \$1 million financed by a grant from Abbott Laboratories.²⁵ By the time the exhibition opened in March 1994, it had expanded to 4,000 square feet and a cost of \$1.3 million. The installation included floor-to-ceiling graphics in the style of comic book illustrations, and a computer-animated voyage through the immune system. Five hundred circles representing HIV particles were spread throughout the walls, floor, and ceiling.²⁶ Multimedia screens played video "messages" from people with AIDS, apparently including some who had died before the exhibition opened.²⁷

Several advisors to the project were critical of the dramatic style of the presentation. The title reflects the tone, conveying a sense of invasion and internal battle, using the military metaphor of war common to scientific narratives of the "fight" against disease. After reviewing the exhibition script, Dale Rhodes, director of the state of Illinois' AIDS Hotline, expressed concern that "some of the comic book illustrations would instill fear." In response, the designers revised the graphics to be "more sensitive to people with HIV."²⁸ Even so, newspaper descriptions of the finished version emphasize the spectacle it conveyed, with the museum "depicted as being under attack from the HIV virus, represented by large blue spheres that adhere to and seep into the gallery's walls."²⁹

The *Chicago Tribune* also noted that a section of the exhibition on "detection" of HIV was "largely given over to a display of the widely-used HIV test marketed by Abbott Laboratories of North Chicago," who had funded \$1 million of the \$1.3 million cost of the project.³⁰ Museum president David R. Mosena asserted that the exhibition was "not designed to sell a product, it's designed to educate," and that rather than "blatant commercialization [...] [i]t's understated and enlightened," confirming nevertheless that commercialism had made some way in.³¹ In keeping with the tone of the rest of the exhibition, the language of "detection" asserted the dramatic notion of a hidden threat that needed to be revealed. As is common in science museum narratives, science was cast in the heroic role, here by identifying the invading agent, HIV.

Aprison compared *AIDS: The War Within* to an existing exhibition on heart disease, saying that in keeping with the educational mission of the museum, the exhibition provided "the latest in scientific knowledge." He argued that in both, "The museum refrains from condoning or condemning any lifestyle or activity, just showing factors that contribute to a disease and efforts to detect, treat and prevent it."³² Yet, the exhibition text delivered an explicit public health message, recommending "abstinence,

exclusive long-term relationships and condom use” to prevent the spread of HIV. Although some anti-abortion groups had threatened to disrupt the exhibition due to the inclusion of condoms, only one protestor attended the launch.³³ In contrast to the Franklin Institute project then, the messaging was more self-consciously directive, and less controversial.

It is likely the general image of science museums as having an educational mandate, and the growing consensus of the value of public health messaging to address the epidemic, helped mute criticism of both of these projects. In subsequent years, the role of science museums in tackling health topics was further supported. The Consortium was renamed the National Health Science Consortium, and later took on an exhibition project on women's health, before lobbying Congress for the provision of ongoing resources for such exhibitions. When these efforts successfully resulted in the establishment of funding through the National Institutes of Health, the Consortium dissolved.³⁴

Exhibiting Thirty Years of AIDS

Museums preparing to mark the thirtieth anniversary since the country's first cases of HIV in 2011 faced considerably better circumstances than during that first wave of projects. In the intervening twenty years, the development of effective treatments for AIDS, and the slowed spread of HIV, had transformed the US epidemic into a less urgent threat, and the climate of fear and stigma had dissipated substantially. Historical accounts of the early years commonly cited government inaction as a leading factor in both the scale of the crisis and the accompanying panic and discrimination. However, the legacy of the terrorist attacks of September 11, 2001 and the subsequent war in Iraq, created new challenges for curating this history. Curators faced the difficult task of accounting for the anger and activism of the past at a time when critique of the government was labeled unpatriotic.³⁵ Furthermore, celebrating the progress made while calling attention to ongoing challenges risked drawing implicit associations between the values of the governing Republican party and their predecessors in the Reagan era, especially with regard to (homo)sexuality, sex education, and sexual health services.

In this context, I curated an exhibition at the National Library of Medicine (NLM), on the campus of the National Institutes of Health, to mark the fiftieth anniversary of the World Health Organization. The project, *Against the Odds: Making a Difference in Global Health*, was displayed at the NLM from 2008-2010, accompanied by an exhibition website, and a traveling version.³⁶ The total cost for these components was \$800,000, funded from the Exhibition Program budget of the NLM.

Preliminary research for the project revealed that Americans tended to view “global health” as something that was relevant only for other people, in poorer countries; that infectious diseases are the biggest threat; that the problems are so big that governments, not individuals must take the lead; and that the main reason the US should be involved is because problems “over there” are likely to become problems “over here” in our globalized world. Target audiences also tended to prioritize high technology solutions, to overestimate the amount of aid spent by the US on health issues in other countries, and to consider these issues insurmountable given this supposed investment and the continuing need for aid.³⁷

A key goal of the exhibition was to challenge these misconceptions, and so case studies were selected to address, for example, health inequalities that could be solved by community-led programs, health risks caused by poor nutrition and lack of access to healthcare, and the role of weapons and warfare in destroying health care systems and disabling and killing civilians. Health as a human right was the central concept. “Action on AIDS” was divided into three sections. “A New Disease” focused on the scientific research since the first cases were identified, and “Fighting Discrimination”



Multimedia installation in the gallery, showing homophobic quotes from politicians and public figures alongside the rising death toll caused by AIDS. Courtesy of the National Library of Medicine.

on stigma and activism in America. A multimedia presentation on three video screens was displayed between these two, juxtaposing homophobic and stigmatizing statements by politicians and religious leaders with the rising death toll.³⁸ “The Global Response” highlighted the role of the World Health Organization and strategies of AIDS education in Thailand.³⁹ Nearby, panels from the AIDS Memorial Quilt were displayed along with an interactive digital touchscreen table, where visitors could scroll through digitized sections of the quilt to look more closely at a wider range of panels.

Overall, in comparison to the Chicago Museum of Science and Industry exhibition, the style was considerably less dramatic, with an emphasis on collaborative and ongoing efforts to address health challenges rather than urgent crises and medical solutions. The multimedia presentation in the AIDS gallery was intentionally more theatrical, using slow fades between black-and-white images, punctuated by stark quotes and the rising death toll as the early years advanced, with red visual accents and a somber soundscape.⁴⁰ This was intended to contextualize the anger of activists and the intensity of the protests in the urgency of the time that they erupted for visitors who were too young to remember, and to provide a quiet moment for reflection on the lives lost. The team rejected the designers’ first proposal for an all-black room, however, and chose instead a revised design featuring colorful large-scale murals across the surrounding walls, to emphasize action rather than death.

As a project situated on the campus of the National Institutes of Health (NIH), stakeholders there expected the exhibition to include the work of their own scientists, and indeed the AIDS gallery was one of several points in the exhibition to do so. “A New Disease” described the identification of the HIV virus first by the Pasteur Institute in France, and then by NIH scientist Robert Gallo, and their later agreement to share the credit for the discovery, in text panels on the wall with photographs of some of the scientists involved. A vitrine included the microscope of Anthony Fauci, the NIH scientist appointed in 1984 to lead AIDS research there as director of the National Institute of Allergy and Infectious Diseases, and text panels reported on his efforts to develop an effective vaccine.⁴¹



Women's activism on display in the exhibition, including the efforts of the ACT UP Women's Committee to expand the definition of AIDS in 1990-1991. Courtesy of the National Library of Medicine.

The narrative then shifted to the work of other NIH scientists, and the protests by ACT UP on the NIH campus against the slow pace of drug development. The “Fighting Discrimination” section also included a profile of Ryan White, a 13-year-old boy with hemophilia and HIV, who was barred from school and harassed and became a national advocate for people with AIDS. White was chosen to represent hemophiliacs and also as a figure likely to have special resonance for school-age children, who were the main audience for the exhibition. I also focused on the work of the Women’s Committee within ACT UP to challenge limited notions of the risks of heterosexual sex and the AIDS symptoms common to women.

As Alexandra Juhasz notes in her essay, “Forgetting ACT UP,” their “confrontational” activism is only one dimension of a much broader range of activities undertaken by a more diverse group of people, but the former is more “photographed or even photographable.”⁴² This kind of action is also more collectible, as evidenced by the preponderance of ACT UP ephemera in museum collections. To broaden the representation of AIDS-related activism, video clips and focused on other figures including Dr. Victoria Cargill, Director of Minority Research of the NIH Office of AIDS Research in Bethesda, discussing her work in a community clinic, and medical students involved in AIDS activism.

The exhibition did draw on some well-known ACT UP materials, although their display at the venue where they had been used in protest rendered these objects newly resonant for visitors from across the NIH campus. At the time, many of the staff scientists had been shocked to become the targets of such anger, having seen themselves as allies working to stop the spread of the disease and to help those already infected with HIV. While I was leading curator’s tours of the exhibition for NIH staff, I was told repeatedly by people who had been involved in AIDS research that the exhibition helped them to reconcile their view of their role with the perspectives of the activists.

In fact, the exhibition highlighted the transformative impact of activism on policies for testing drugs, sharing research results, and collaborating with patients and their advocates. This view was publicly expressed by Anthony Fauci, and his emphasis on ACT UP’s role in changing practices at the NIH helped to legitimize this curatorial stance.⁴³ The exhibition also benefitted from the willingness of AIDS activists to contribute and be represented in the exhibition. Sarah Schulman, for example, agreed to be interviewed for a guest column on the exhibition website, and objects and images were loaned by the Lesbian Herstory Archives in New York and the GLBT Historical Society in San Francisco.⁴⁴ Others were more hesitant about whether a government venue could be trusted with this history. One group was reluctant to donate materials that included documentation of activism, as they were concerned it could later be used to prosecute the participants. A photographer also withheld the rights to use their photographs as their personal protest against the Iraq war. A major community organization was reluctant to collaborate, having previously been deceived by a media company who had requested video material from their archives and then used it to portray gay men negatively. During a conversation lasting several hours, my contact there cried repeatedly while explaining the grief and distrust that still remained. I left the meeting with a better understanding of the ongoing emotional toll of the early years of AIDS in America for members of this organization, but without any objects or images to represent their experiences in the exhibition.

Against the Odds: Making a Difference in Global Health was successful according to the measures of the Exhibition Program. Attendance levels were consistent with previous projects, educational resources were well utilized by school groups, and the project won several awards and generated positive feedback. A traveling version had toured to sixty sites across the US by the end of 2018. Since then, the NLM has developed a second traveling exhibition focusing specifically on AIDS and curated by Jennifer Brier, indicating recognition there of the ongoing relevance of historical projects on the

topic—as well as wider support and enthusiasm among collaborating institutions to host the exhibition and undertake associated public activities to engage their audiences on the themes.⁴⁵ Anecdotally, other museum professionals told me that they were pleasantly surprised that the exhibition theme of health as a human right, and the constellation of case studies including AIDS, landmines, and community-based health-care had survived the processes of negotiation and review that accompany exhibition projects, particularly given the status of the NLM as a government institution.

The process was undoubtedly helped by tackling the topic of AIDS as one element inside a larger project. The timing and location were also important factors, with the exhibition opening three years before the anniversary of the first cases of HIV, displayed from 2008-2010, and held at a venue just outside Washington, DC rather than in a more high-profile location such as one of the Smithsonian institutions. The atmosphere had become considerably less favorable by 2010, when the National Portrait Gallery's exhibition *Hide/Seek: Difference and Desire in America Portraiture* attracted controversy and censorship.⁴⁶ This fueled anxieties about “controversial” museum projects among politicians, funders, and museum practitioners, and as a result, a small exhibition planned for 2011, *HIV and AIDS Thirty Years Ago* at the Smithsonian's National Museum of American History, was closely scrutinized by the director of the museum and senior Smithsonian staff. Curator Katherine Ott recalls that this reflected concerns about the reaction of Congress to the representation of government inaction in the Reagan years, and perceptions of a “gay agenda” driving the focus on this topic. As in the first exhibition at the Franklin Museum in the 1990s, museum staff also raised concerns about the suitability of the topic for children, leading to the location of the exhibition within a science exhibition out of the main traffic of the larger exhibitions.⁴⁷

At the NLM, the project also had the advantage of shared support for the curatorial approach from both the head of the Exhibition Program, Patricia Tuohy, and the chief of the History of Medicine Division, Elizabeth Fee, with the latter also an important scholar of the history of HIV and AIDS. Their commitment to the themes and their confidence in navigating the institutional hurdles was especially impressive given that across the federal museum sector, curators commonly assume that some of these topics are off-limits or that particular objects as un-exhibitable due to the political climate, collecting instead for a time in the future when it might be less controversial to display them.

Conclusion

As this special issue goes to press, we are in the midst of a new wave of AIDS exhibitions in museums of science and medicine, inspired by the centenary of the 1918 global influenza pandemic occurring in 2018. *Countdown to Zero: Defeating Disease*, developed by the American Museum of Natural History in New York, in collaboration with the global health non-governmental organization the Carter Center, includes HIV in a section on infectious diseases that cannot be “defeated,” alongside influenza and Ebola virus disease.⁴⁸ The Smithsonian also included AIDS in *Outbreak: Epidemics in a Connected World*, which opened at the National Museum of Natural History in May 2018.⁴⁹

Situating HIV and AIDS in these narratives of ongoing threats and emerging infectious diseases appears like a step backwards, using drama and risk in a manner that may fuel fear, while privileging scientific solutions without contextualizing the problems of poverty and lack of health care infrastructure that undermine efforts to contain the spread of infectious diseases and mitigate their impact on the health of individuals. Part of the problem stems from the mission of medical museums and their past emphasis on scientific discoveries and those who made them.⁵⁰

Moreover, as Katherine Ott notes, today's audiences, "especially younger visitors [...] have no sense of the urgency, stigma, controversies, and what people were facing [...]. How do you convey dramatic historical events without re-stigmatizing or victimizing or sensationalizing when contemporary audiences respond with aversion or shock?"⁵¹ In my view, the challenge for medical museums is to take a broader view than the narrowly defined "scientific" perspective that has been their default, and to collaborate with other institutions to borrow objects that can contribute to this wider perspective. Even so, the current state of collections relating to the history of HIV and AIDS in all kinds of museums needs to be assessed and reconsidered, and a new agenda for collecting should be defined. As a step towards such efforts, I am involved in projects to film interviews with people from groups underrepresented in museum exhibitions and to gather ideas for objects that could be accessioned, building on the occasion of the International AIDS Society conference of 17,000 delegates in Amsterdam in July 2018 as a platform for gathering input.⁵²

Notes

1 Virginia Berridge, Review of Victoria A. Harden, *AIDS at 30: A History, Social History of Medicine* 27:3 (2014): 620-621; Victoria A. Harden, *AIDS at 30: A History* (Washington DC: Potomac Books, 2012), Ch. 6, "Communicating AIDS."

2 Judy Chelnick, "Collecting an Epidemic: A Curator on Preserving the AIDS Quilt," *The Atlantic*, February 1, 2012, accessed February 13, 2018, <https://www.theatlantic.com/health/archive/2012/02/collecting-an-epidemic-a-curator-on-preserving-the-aids-quilt/252190/>. She notes that a small group met at the annual meeting of the American Association for the History of Medicine in New Orleans in 1988 to discuss collecting priorities.

3 For further discussion of this issue in a different context, see Manon S. Parry and Hugo Schalkwijk, "Lost Objects and Missing Histories: HIV and AIDS in the Netherlands," in Joshua G. Adair and Amy K. Levin (eds.), *Activism, Unruliness, and Alterity: Gender, Sexuality and Museums*, Volume 2 (Oxford, UK: Routledge, forthcoming 2019).

4 Paula Treichler, "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification," *October* 43 (Winter, 1987): 31-70.

5 Email communication from Katherine Ott, curator in the Division of Medicine and Science of the National Museum of American History, a Smithsonian institution, March 27, 2018.

6 "Sick Memory: On the Un-detectable in Archiving Aids," in "AIDS and Memory," *drain*, 13:2 (2016), accessed March 15, 2018, <http://drainmag.com/sick-memory-on-the-un-detectable-in-archiving-aids/>. The exhibition they discuss, *AIDS. Based on a True Story*, was exhibited at the German Museum of Hygiene in Dresden from September 5, 2015 to February 21, 2016, with some elements later shown in an exhibition at the International Museum of the Red Cross, Geneva, titled *The Fight Against AIDS in Images*, from April 4, 2017 to January 7, 2018.

7 John V. Pickstone, *Ways of Knowing: A New History of Science, Technology and Medicine* (Chicago, IL: University of Chicago Press, 2001).

8 Barry Aprison, "The National AIDS Exhibit Consortium," *Curator: The Museum Journal*, 36:2 (1993), 88-93, 88.

9 Roberta Cooks, "Is There a Way to Make Controversial Exhibits That Work?," *The Journal of Museum Education*, 23:3 (1998): 18-20, 18.

10 The forty venues nationwide included institutional members of the Association of Science-Technology Centers (ASTC). *Ibid.*, 18.

11 Michael Janofsky, "Exhibit Views AIDS Frankly For the Young," *The New York Times*, August 8, 1993.

- 12** Cooks, "Is There a Way to Make Controversial Exhibits That Work?" 18.
- 13** Ibid.
- 14** Ibid.
- 15** Janofsky, "Exhibit Views AIDS Frankly For the Young."
- 16** Ibid.
- 17** Julia M. Klein, "Exhibit AIDS a Fortright Show at the Franklin Institute on the Science of AIDS Offers Some Prescription for Behavioral Change. Its Goal is Saving Lives," *The Philadelphia Inquirer*, November 1, 1993.
- 18** Mubarak S. Dahir, "The invisible (gay) man. (National AIDS Exhibit, Philadelphia, PA; New York, NY; Richmond, VA)," *The Progressive*, 57:11(1993): 15(1).
- 19** Eline Wilner, spokesperson for the Franklin Institute, paraphrased in Charles Storch, "Exhibit To Touch Aids Issue With Kid Gloves," *Chicago Tribune*, May 8, 1994.
- 20** Victoria A. Harden, "AIDS/Brooklyn; AIDS' Human Faces," *Journal of American History*, 82:1(1995): 164-168, 164.
- 21** Cooks, "Is There a Way to Make Controversial Exhibits That Work?" 19-20.
- 22** Ibid., 20.
- 23** Storch, "Exhibit To Touch Aids Issue With Kid Gloves."
- 24** Ibid.
- 25** Charles Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy," *Chicago Tribune*, March 14, 1995.
- 26** Karen Young Kreeger, "Science Museums Attracting Customers And Controversy," *The Scientist* 9:13 (1995): 1.
- 27** Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy."
- 28** Kreeger, "Science Museums Attracting Customers And Controversy."
- 29** Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy."
- 30** Ibid.
- 31** David W. Dunlap, "Chicago Museum of Science Sometimes Strays," *The New York Times*, May 24, 1999.
- 32** Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy."
- 33** Ibid.
- 34** David Chittenden, Graham Farmelo, and Bruce V. Lewenstein (eds.), *Creating Connections: Museums and the Public Understanding of Current Research* (Lanham, MD: AltaMira Press, 2004), 175-176.
- 35** In 1992, President George H. W. Bush labeled ACT UP a "terrorist organization," and this view took on further significance under his son's presidency. See Belinda Robnett, Carol L. Glasser, and Rebecca Trammell, "Waves of Contention: Relations among Radical, Moderate, and Conservative Movement Organizations," in Patrick G. Coy (ed.), *Research in Social Movements, Conflicts and Change* 38 (2015): 69-101, 92.
- 36** The exhibition was on display from April 17, 2008 to December 17, 2010. An online version of the exhibition is available at <https://apps.nlm.nih.gov/againsttheodds/index.cfm>, accessed March 15, 2018. For the traveling exhibition schedule, see "Book Now/Tour Itinerary" at <https://www.nlm.nih.gov/hmd/about/exhibition/againsttheodds-bookinfo.html#>, accessed March 15, 2018.
- 37** For a fuller discussion of the research on these views and how they informed the curatorial framework for the exhibition, see Manon Parry, "Exhibiting Human Rights: New Narratives of Global Health," in *Inspiring Action: Museums and Social Change* (Edinburgh: Museums etc., 2009 and revised 2016): 148-167.
- 38** This element is not included into the exhibition website as it could not be rendered online.
- 39** On the exhibition website, a multimedia presentation of the AIDS Memorial Quilt shown in the gallery is replaced by a fourth section on the origins of the quilt and its

public display on the National Mall. See https://apps.nlm.nih.gov/againsttheodds/exhibit/action_on_aids/action_on_aids.cfm. Accessed March 15, 2018.

40 You can view a shortened, silent version of the film in the exhibition installation online, although it does not convey the full gallery experience. <https://vimeo.com/album/1764665>

41 See Fauci quoted in, for example, Dennis Hevesi, "Martin Delaney, 63, AIDS Activist, Dies," *The New York Times*, January 26, 2009, accessed March 15, 2018, <http://www.nytimes.com/2009/01/27/us/27delaney.html>. He spoke frequently on this topic after the exhibition opened, and during media coverage of the thirtieth anniversary of the emergence of AIDS in 2011.

42 Alexandra Juhasz, "Forgetting ACT UP," *Quarterly Journal of Speech* 98:1(2012): 69-74, 72.

43 See note 41.

44 "Guest Column: HIV and AIDS. Meet Our Featured Guest Columnist: Sarah Schulman," accessed March 15, 2018, https://apps.nlm.nih.gov/againsttheodds/guest_column/hivaids/index.html.

45 "Surviving and Thriving: AIDS, Politics, and Culture," accessed September 27, 2018, <https://www.nlm.nih.gov/exhibition/survivingandthriving/>.

46 For a full discussion of these events, see Richard Sandell, *Museums, Moralities and Human Rights* (Oxon: Routledge 2017), Ch. 1, "Progress and Protest."

47 Email communication from Katherine Ott, March 27, 2018. For an announcement about the exhibition, see NMAH, "30 years of HIV and AIDS in America," accessed March 15, 2018, <http://americanhistory.si.edu/blog/2011/05/30-years-of-hiv-and-aids-in-america.html>.

48 "HIV and influenza because their viruses mutate too quickly and Ebola virus disease because it survives in non-human hosts." Jamie Green, "Countdown to zero: defeating disease," *The Lancet Infectious Diseases*, 15:5 (2005): 518.

49 Daniel Lucey, Sabrina Sholts, K. Blond, Robert Costello, S. Murray, "Exploring Epidemics: A Smithsonian Museum Endeavor for the Public," *International Journal of Infectious Diseases*, 53, (2016): 82; Also, *Spit Spreads Death: The Influenza Pandemic of 1918-1919 in Philadelphia*, opening at the Mütter Museum in 2019, accessed March 15, 2018, <http://muttermuseum.org/exhibitions/going-viral-behind-the-scenes-at-a-medical-museum/>.

50 Manon S. Parry, "abNormal," *Bodies in Medicine and Culture*, in Shelley Ruth Butler and Erica Lehrer (eds.), *Curatorial Dreams: Critics Imagine Exhibitions* (Montreal, Canada: McGill-Queens University Press, 2012): 246-264.

51 Email communication from Katherine Ott, March 27, 2018.

52 *Voices of the Epidemic*, a film of interviews in Dutch with English subtitles, can be viewed online at <http://www.manonparry.com/films/voices-of-the-epidemic-2018/>.

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Viral Memories: The Making of Institutional History and Community Memory in the HIV/AIDS Crisis

Ricky Price

How do dominant ideas about HIV/AIDS get established, maintained, and proliferated? If we are in a moment of AIDS-Crisis Revisitation, as Theodore Kerr argues,¹ where the dominant narratives about HIV/AIDS are rearticulated and challenged in new ways, then this paper asks how did these narratives get produced in the first place? As a political scientist, I'm interested in the ways in which U.S. public health institutions have helped forge these dominant narratives about the crisis. While media scholars, critics, and creators have shown the way in which popular media produces a false narrative about AIDS—where helpless minorities stricken with a new disease were saved by a benevolent apolitical public health system—this paper looks at the ways in which institutions, like the National Institutes for Health (NIH) and the Centers for Disease Control (CDC), have curated their histories amidst this crisis to help produce this dominant narrative.

Within the NIH and CDC's earliest efforts at self-historicization is the evidence of omission—a consistent and repeated effort to tell a story about AIDS that excludes the people most affected. I begin by bringing some of the latest scientific research on memory into conversation with insights on collective memory and identity. This opens into a discussion between the relationship between memory, identity, and history through an analysis of the NIH's "In Their Own Words" online history project and the CDC's David J Spencer Museum. This is not an attempt to find the best version of this history, but to try to evaluate the context within which these projects came into being. In doing so, we can better understand how dominant narratives were influenced by the CDC and NIH telling their institutional histories.

Viruses, Memories, and History

In a January 16, 2018 press release titled, "Memory gene goes viral," the NIH announced that research they funded at two separate universities demonstrated a novel way in which genetic material is transferred between neurons (nerve cells). The research suggests that a gene that "play[s] a vital role in the brain's ability to store new information," and employs a "virus-like strategy" to transmit information between cells.² I'm less interested in the specifics of the biology of memory, and more interested in the way in which thinking virally, going viral, and virology have come to influence the way we think and talk about the history of how our bodies and societies work. Biologists talk about cells in terms of behaviors, structures, and information—in terms that often sound like social practices rather than biological interactions. In the cellular world of memory then, it wouldn't be too far a stretch to understand the difference between short- and long-term memory to be one of different practices between neurons. Where short-term memory is established through one type of interaction between cells, and long-term memory is established through a different set of interactions involving repetition (knowing how to get home by driving the same route every day), context (life-changing events), and neuroplasticity (the ability for these neural connections to change over time).³

At the risk of generalizing and oversimplifying the distance between our brain cells and our social worlds, some of these aspects of cellular memory are useful in thinking about individual and collective memory more broadly. Centrally, the roles of repetition, context, and change seem to be at work both in our brain's ability to create long-term memories and communities' ability to create collective memories over generations. The connection between the individual and the collective or the short-term and the long-term has to do, in part, with 1) repetition, 2) context, and 3) surviving change.

Repetition, in terms of collective memory, happens at individual and institutional levels. Memory scholars William Hirst and Gerald Echterhoff argue that collective memory should be studied from an "epidemiological perspective," where "collective memories are widely shared individual memories, not just socially maintained public symbols."⁴ The sharing of the interpretation of symbols, events, and experiences between people and communities over time lays the path for recognizable collective memories. Days of remembrance, saying the names of those who have passed, and annual Pride celebrations are all examples of practices of memory that use repetition to transfer memory. This works on the institutional level as well: the repetition of statistics, talking points, the churning of political bureaucracy, national holidays, annual budgets, etc. These everyday practices created the context within which dominant and counter narratives are created about the crisis.

To understand the second notion outlined above, context, within memory and historical practices, it is crucial to understand the relationship between the speaker, the audience, and the institutions that produce these memory and history projects. Why were these projects produced at the time they were? To what ends, towards what goals, and for which audiences? For Hirst and Echterhoff, central to understanding context is the role of reception. Whose stories are transmitted and to which audiences is a crucial aspect of the transmission of shared memories. They note that, "What a speaker says will influence what a listener remembers." The creation of collective memories requires a shared sense of reality to be received.⁵ The corollary of which might maintain that what a speaker omits also influences what a listener remembers. These institutional projects often seem at cross-purposes with activists and community projects, not because one side is telling an accurate story and the other is telling a false story, but rather, because these stories are being told by people situated at different levels of power. These discrepancies in reception help explain why mainstream cultural representations of HIV/AIDS rely on institutional sources over community sources. Institutional stories about HIV/AIDS are "official" and are taken up, repeated, and reprinted by the media and serve as the main source of HIV/AIDS education in the public sphere. This version of HIV/AIDS history is buttressed by reception of these stories as "official" and works to create a collective memory of HIV/AIDS in this image, one rooted in perspectives from officials managing the disease, rather than people living with the virus.

Communities most devastated by HIV share a different perspective on this history, which is not documented within these government institutions but rather through stories, community histories, and rituals focused on remembering the crisis. The communities who confront the virus are heterogeneous, and so HIV/AIDS community histories are nested in longer struggles against poverty, racism, sexism, and homo- and trans-phobias. The community within which a person develops the virus; the place in which a person encounters the virus; and the time in which a person seroconverts create different constellations of collective memories reinforcing different shared realities with the same virus. The picture from an institutional perspective is unified by

comparison, so much so that we speak of institutions having voices, when we are really talking about people in positions of power making choices. The idea of reception helps to explain why institutional memories are understood as histories and community histories are considered memories.

The third aspect I isolated above was the notion of neuroplasticity, which has become a buzzword, but I'm fundamentally interested in the idea behind the buzzword—the ability to negotiate change and remember over time. For philosopher Ross Poole, temporality is central to the ideas of memory and identity. He notes the way in which memory is central to accountability: “We could not have a practice of holding *other* people accountable for what they did in the past unless we also had a practice of holding *ourselves* accountable.”⁶ Memory, then, is crucial in aspects of justice but complicated by what Poole calls “temporal complexity,” where the offending event or action takes place in the past, “but the ‘I’ who performed the action is *not* located in the past: it is the very same ‘I’ that exists now—and for that matter, will exist in the future...memory involves the sense of a *continuant* self, a subject of experience that not only exists *in* time, but also exists *through* time.”⁷ This notion of “temporal complexity” is exemplified in the multiple histories of HIV/AIDS produced at institutional and community levels. The idea of a “continuant self” is not only a matter of individuals, but also of institutions. The CDC and NIH use their memory projects to help explain and historicize the choices and decisions made by individuals vested with institutional powers. HIV/AIDS has changed the course of individual lives and the large-scale priorities of public health institutions. Understanding the temporal complexity that surrounds the historicization of the virus is crucial to any push towards a more just public health system. Is the CDC of 1982 the same CDC of 2018? How has the identity of this institution changed over the course of the last few generations? How might it change in the future?

On the community level, Poole's notion of “temporal complexity” is evident as new generations encounter the virus in different contexts than in previous decades. Media scholar, producer, and ACT-UP member Alexandra Juhasz in collaboration with Theodore Kerr, a writer and organizer, analyzed cultural representations in their 2014 piece *Home Video Returns: Media Ecologies of the Past of HIV/AIDS*, Juhasz highlights how mainstream popular culture presents the epidemic as a distant threat to most Americans, and emphasizes the difficulties people “inside” the epidemic have in creating a full and accurate depiction of their experiences:

Those of us inside [the epidemic] [...] have never been a homogenous group. When there were more of us making media, we used to reach out separately to women, or blacks, or urban women of color as discrete communities within the HIV/AIDS community. Now, add to that, mediamakers must factor in *time* as a key differential, not just “identity.” That is to say, audience members who are long-with-AIDS, those who are newer to it, and those who are long-with-AIDS-activism-and-culture and those who are newer to it, or even those being invited to join for the first time.⁸

Juhasz and Kerr point to the ways in which cultural production around AIDS often fails to grasp the lived realities of the people who endured the early years of the response and fails to account for its persistence. Many of the productions essentially present AIDS as something from the past and not of the present. For Juhasz, people who are “long-with-AIDS,” and “long-with-AIDS-activism-and-culture” must operate as figures in the past and the present: “We were in the past, and we are of the past, and

we want to remember and learn from the past but we are also of the present,”⁹ which echoes Poole’s notion of temporally complexity. Juhasz’s re-visitation of the past is not about memorializing, she does not “want to reign in history, like it’s over and it’s mine; I want to know it better inside myself and my community so as to share it, learn from it, and use it as a catapult from which to continue to inspire, feel, and converse.”¹⁰ As Juhasz contends, *time*, when one encounters the virus, is a crucial intersectional dimension that historians of the virus, in any capacity, must deal with.

I began this section by talking about the molecular structure of neurons to think about the way that we talk about memory at individual and collective levels. Structure matters in terms of how information is transmitted to new cells and new generations of people. That collective memories are particular, that they define the borders of communities, and that they denote a shared sense of reality make the sites where they are produced crucial to understanding power relations in the ongoing HIV/AIDS crisis. The central and most obvious difference between the institutional organizational structures of ACT UP and the NIH and CDC is that the bureaucracies were hierarchical and outwardly mono-vocal while the activist group was poly-vocal and decentralized.

The CDC and NIH both fall under the jurisdiction of the Department of Health and Human Services (HHS), which is led by a cabinet level officer appointed by the President and confirmed by Congress.¹¹ This person is responsible for creating the research and budget priorities that dictate these giant bureaucracies’ agendas, coordinating with Congress on legislation, and working with the executive branch. The other primary component to HHS is the Operating Divisions, which include the CDC and NIH, and nine other “independent” agencies that fall under the directive of HHS, such as the Food and Drug Administration and the Administration for Children and Families. These agencies are supposed to be “non-political” in the sense that their directors, researchers, and bureaucrats often serve during multiple administrations.

These agencies have each played crucial roles in the governmental management of the crisis, and they each have recognized the historical significance of HIV within their own self-historicization. In telling their story of HIV history, they are telling a larger story about the importance of the particular institution, and these histories are made to be proof of their utility.

ACT UP Oral History Project

In 2001, activists and artists Sarah Schulman and Jim Hubbard sowed the seeds of what would become a fifteen-year oral history project interviewing nearly 200 former members of ACT UP NY. The project formed after Schulman heard National Public Radio cover the twentieth anniversary of the AIDS crisis:

I had long been disheartened by the false AIDS stories told in the few mainstream representations of the crisis. [...] But now that lie was being extended beyond the arts to actual history. We were being told AIDS activism never existed. Instead, the dominant culture simply “came around.”¹²

The project conducts long-form interviews with surviving ACT UP NY members, recording and transcribing the interviews, posting them online, and touring with the material across the globe. Schulman also notes that the project set out to provide data for researchers so that, “The social universe that ACT UP engaged would be cumulatively accessible to inspire and inform the future.”¹³ The project looks backward and forward, and centrally at what drove people to take action, risk their bodies, careers,

and lives in sharp contrast with institutional histories that forefront new discoveries and medical breakthroughs.

In providing the opportunity for people to tell their stories and actively working to disseminate those stories, the project offers an important corrective to institutional histories. It demonstrates the everyday, persistent labor necessary for marginalized populations to be heard. The interviews themselves document an array of different actors who made up the social movement, supplanting myths that ACT UP was only made up of white gay men. It investigates their biographies, their beliefs, and their infighting—and seeks to proliferate some of the stories left out of the institutional histories.

In what follows, I explore in-depth the institutional memory projects of the NIH and CDC, institutions that were the direct objects of many of ACT UP direct actions. Although social movement actors helped force these institutions to change, these actors were essentially absent from these institutions' early self-historicization projects. What is significant for this essay is that the ACT UP Oral History archive was borne out of correcting a dominant narrative, not that it is the correct narrative.¹⁴ That the motivation for the project was an intervention against a repeating story about governmental success in the AIDS epidemic at the twentieth anniversary of the first cases of AIDS is an important moment in the historicization of the epidemic. Understanding how the institutional side of this story was initially presented before this intervention provides insights in this history, but also on the everyday practices by people embedded in these institutions that affect our everyday lives.

In Their Own Voices

In June of 2001, the director of the Office of NIH History, Victoria Harden, PhD, created an online repository for oral histories of twenty-eight of the most prominent NIH and CDC researchers, doctors, nurses and administrators who directed the course of the institutional response to HIV/AIDS, entitled "In Their Own Voices: NIH Researchers Recall the Early Days of AIDS." Harden was the originator of the Office of NIH history in 1986, developing the office in conjunction with the NIH's celebration of its 100th anniversary and the twentieth anniversary of the discovery of AIDS. In addition, Harden is responsible for the creation of the Stetten Museum at the NIH, which is devoted to the tools and instruments developed and used by NIH researchers.¹⁵

The architecture of the NIH "In Their Own Words" project is as revealing as much of the oral history interviews. The project posts full transcripts as organizes them into five periodizations. In addition to the transcripts, the site hosts a number of published and previously unpublished reports, meetings, and talks. Finally, the online project has a small photo archive and a timeline of the CDC and NIH's actions from 1981-1988, the period the oral history project covers.

The five periods are divided into the following categories: 1) First encounters: in this section researchers recall their first interactions with patients with the virus or reports of the first cases; 2) Tip of the Iceberg: this section explores how scientists came to realize the scope and gravity of the case; 3) Mobilizing: this section covers the ways in which the scientific community and public health apparatus mobilized to fight the virus; 4) Discovery of HIV: this section covers the development and implementation of the first blood tests for HIV in 1984-85; 5) Search for Treatments: this section details the early research for antiretroviral therapies.

The timeline presented is based on source material from doctors, scientists, and researchers who worked for these institutions. If we encounter only this version of events, we are blind to the robust social and political forces that were also at work in 1981-88, which framed these scientific discoveries and breakthroughs. The project's scope ends in 1988, a year after the creation of ACT UP. The project also makes no mention of activist groups and organizations that existed during this period like the Gay Men's Health Crisis (GMHC) and the People with AIDS Coalition. The only outright reference to activism is in the photo archive section under a page titled: "AIDS Activism." Here there are four pictures with short descriptions: a picture of the AIDS Quilt, a picture of activist Larry Kramer, a picture of protesters standing behind a line of police with no date simply stating, "AIDS activists organized to promote AIDS research and to make experimental treatments more widely available," and finally a picture of the Red Ribbon, with no mention of the Visual AIDS Artists' Caucus, the group of people who came together under the auspices of Visual AIDS, who designed and first promoted the ribbon.¹⁶

It isn't simply that activists are absent from this exhibit, but more that they are not understood within this context. For example, in James Curran's interview, then-director of the CDC, he recounts his interaction with activists. He notes that he received nearly 20,000 postcards with a target around his face:

I had an award from the Atlanta Business and Professional Guild, which was a euphemism for the Atlanta gay business community. They gave me that award in 1982, and then my staff, when I moved from one job to another, gave me a blowup of this target with my picture on it. I put that underneath that award in my office. I did that to show the award and the target postcard came from essentially the same community, and I was the same person.¹⁷

His assertion, made in 1998, that these two groups—the protesters and the business association—are “essentially the same community” belies the fact that he did not understand the various communities that made up the membership of ACT UP in 1990, in addition to the fact that there are multiple different communities of LGBTQ people. Put simply, there is no singular gay community, and ACT UP was made up of much more than gay men.

For Curran, the protests that centered upon the role the CDC had in defining the disease, researching and testing new therapies, and producing accessible and affordable solutions to manage the epidemic were not only misguided but misdirected. He sees no common cause, no opportunity to ally with the activists against public health funding cuts. In the interview he accords no contribution from activist mobilizations to his medical research and breakthroughs; highly trained experts, not ordinary people fighting for their lives, produce breakthroughs and advances from this vantage point. While the NIH's oral history project may not present a fulfilling explanation for the history of the virus, it does provide essential insights into how the individuals nested within these powerful institutions made decisions and understood—or misunderstood—the people that they were tasked with serving.

What the oral history project does do well is to situate the history of the vast operation of the NIH within a larger system of governmental decision-making and authority. While the NIH and CDC hold tremendous influence, they are not all-powerful institutions; they are constrained by budget choices and research priorities influenced by which party is in power in the White House and in Congress. In this way, the oral

history project helps to illuminate the complex layers of the bureaucratic state, and the ways in which these institutions were facing their own political constraints while dealing with an enduring biological threat.

The NIH's oral history paints the picture of an institution at the behest of conflicting political demands unable to address the exponential problems created in the wake of the virus. This oral history supports Jennifer Brier's analysis in her 2009 book, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis*, which makes two central claims: first she demonstrates the ways in which the crisis splintered the burgeoning conservative movement in the early 1980s; secondly, she argues that a movement that started in response to government inaction "became an alternative vision of what progressive politics should and could start to look like at the turn of the twenty-first century."¹⁸ Taken together, Brier's work and the NIH's oral history project present a layered set of politics at work between U.S. public health institutions, political administration, and Congress all creating the field upon which the politics of the virus play out.

"In Their Own Words" was created in 2001 and acts as a sort of virtual time capsule, presenting a picture of how the history of the virus was understood by the NIH at one moment in time. The NIH has supplemented this project in recent years through collaborations with the National Library of Medicine in traveling educational exhibitions such as 2008's *Against All Odds: Making A Difference in Global Health*, which featured exhibits on HIV/AIDS research, science, and global activism, and 2013's *Surviving and Thriving: AIDS Politics and Culture*,¹⁹ which was guest curated by Jennifer Brier and includes the voices and work of activists as an important addition to the "In Their Own Words Project." These institutional revisitations have been influenced, in no small part, by the development of activists' archives and stories, such as the ACT UP Oral History Project and documentaries like 2012's *United In Anger: A History of ACT UP*. The scope of the crisis is much larger than any one exhibition can hold, but a better understanding of this complex and layered history is possible when these stories, archives, memory projects, and histories cross-pollinate. Without the interlocution of outside experts like Jennifer Brier, and the persistence of activists like Schulman, these self-historicization projects lack a reflective quality that helps position these stories within a larger context.



AIDS Epidemic Exhibit, David J. Spencer Museum, 2014. Photo by author.

The David J. Spencer Museum, Atlanta, GA

The David J. Spencer Museum on the campus of the CDC was established in 1996 to commemorate the fiftieth anniversary of the CDC and the opening of the Olympic Games in Atlanta. Coincidentally, the museum was created the same year that antiretroviral therapy was administered as the main biomedical strategy to stem the spread of the virus. The museum recounts the history of the CDC and its work on diseases from smallpox to Legionnaires' disease, to its anti-smoking campaign. The brochure for the museum asks if visitors have ever "wondered how CDC scientists merge old-fashioned detective work with high tech science to crack the cases of mysterious diseases?"

Unlike the NIH's easily accessible history project, the David J. Spencer museum is only accessible after passing through security and metal detectors. From here, you are led down a spiral walkway that begins the permanent exhibit, *The Story of the CDC*. Beginning in 1946, the exhibit walks you through the history of the agency, beginning with fights against malaria and typhus, charting the expansion of the agency's mandate towards broader public health issues. The final and largest section of this exhibit is dedicated to the CDC's work in the AIDS crisis, called *The AIDS Epidemic in the United States: 1981 to the Early 1990s*.

The AIDS Epidemic in America mirrors the periodization of the NIH "In Their Own Words" project, moving visitors across five black and red circles that detail the discovery of the disease, the naming of the virus, early prevention strategies, the development of HIV testing, and antiretroviral drugs. At each point, the CDC is seen as leading the way; the exhibit "chronicles CDC's historic role in investigating the first cases of AIDS."²⁰ Like the NIH oral history project, the exhibit excludes the role outside actors had in the advances of the CDC. Activists are only mentioned twice in the entire exhibit. In one case, a framed HIV awareness poster is displayed from the Atlanta-based group. The second case is in a section detailing the CDC's 1987 national awareness campaign, *America Responds to AIDS*, the campaign:

America Responds to AIDS, clearly had results: by 1991 more Americans were informed about HIV infection and AIDS. On the other hand, the campaign was criticized by AIDS activists for not including more direct messages to people most at-risk. Throughout the campaign, the issue of HIV infection and AIDS continued to be sensitive and controversial.²¹

This wall text is demonstrative of the how the CDC understands its relationship to the activists and to its own past. The CDC cites the success of their media campaign but misunderstands and mischaracterizes the scope of AIDS activism during that time span. Since this exhibit has been set since 1996, it lacks the addition of new generational narratives from the CDC itself as well as communities most affected by the virus and new scholarship on HIV/AIDS history.

The exhibit also misrepresents the CDC's role in communicating the effect the epidemic was having on communities of color. In a piece called *Addressing Disparities*, the CDC claims:

Early in the epidemic, CDC scientists recognized that a disproportionate number of AIDS cases were among African Americans and Hispanics, a trend that continues. In 1988 CDC launched a program that supported HIV prevention efforts by national racial and ethnic minority organizations.²²

The wall text itself raises an immediate question: if these disparities were found so early, why did it take six years to coordinate with these organizations? The CDC's own surveillance reports—presented weekly in the Morbidity and Mortality Weekly Report, and blown up and put on display in this exhibit—did not offer a comprehensive report breaking out AIDS cases by race until 1988.²³ Again and again, the credulity of the institutional story is difficult to maintain when compared to their own archival documents and coupled with community history projects. This should not be understood as the CDC simply getting the history wrong, but as an important way of understanding how dominant narratives of the virus proliferated in the 1990s. The exhibit seems outdated, namely because it stops at the development of antiretrovirals in the mid-nineties even as the science and politics of the virus continued into new debates and controversies. Unlike the NIH project, which offers internal documents and long-form interviews, this exhibit was created in part as a celebration of the CDC itself, for its fiftieth anniversary and the Olympics. The exhibit then should be understood less in terms of what it says about HIV/AIDS than in terms of how the CDC perceives and presents its vitality and importance as a public institution through HIV/AIDS.

In Adam Geary's 2014 book, *Antiblack Racism and the AIDS Epidemic*, he argues that poverty, from the vantage point of institutional actors, seems unmovable. That poverty is described as “a relatively static and suffusing environment or condition rather than the resultant of structured relations of domination and violence that have themselves organized bodily vulnerability and incidents of exposure to HIV.”²⁴ Geary highlights the ways poverty and racism, which can be understood as systemic and *changeable* issues, are the central drivers for the disproportionality of infection rates. Similarly, these institutional memory projects reflect the limits of institutional thinking alone, as this project lacks any cross-pollination with other voices, and therefore appears stale and outdated. In doing so, the permanent exhibit reads HIV as another foe defeated by U.S. public health institutions, along with polio, malaria, and smallpox.

The David J. Spencer Museum's reach goes far beyond this singular exhibit. Each summer, young aspiring epidemiologists take courses at the museum underlining the fact that the primary purpose of the museum is to educate the public about the history of the CDC. Field trips, courses, teaching aids, etc., all disseminate from the museum and help to construct the dominant narrative around HIV/AIDS. The repetition of these stories about HIV/AIDS gets taken up not only in the ways in which these institutions educate the public, but they become a primary source for media narratives about the epidemic. The CDC's statistics alone are a central technology in describing the scope of the epidemic to the majority of people unaffected by the crisis. The question isn't how to make this exhibition perfect, but how to approach a version of institutional history that is self-reflective rather than self-aggrandizing.

Cross-Pollination

I began this essay by analogizing cellular memory with community memory. I argued that repetition, context, and the ability to withstand change were central to both processes. I have attempted to show how different community-based and government institutions have gone about historicizing the HIV/AIDS crisis, not to discover the final truth, or to paint one side as righteous and the other as malevolent, but rather to think about the numerous forces and the multiplicity of sides that make up this shared reality. Each of these projects came about in response to some combination of anniversaries, the fiftieth and 100th for the CDC and the NIH respectively, and in response to the media narratives presented at the twentieth anniversary of the discovery of AIDS for the ACT UP Oral History Project.

The rise in community and activist-based memory projects over the past twenty years demonstrates the ways in which this institutional story *alone* is cracking over time. Its explanatory value lacks utility in explaining the complicated multi-generational history of HIV. By breaking the repetition of a singular mono-vocal story, these alternative histories offer a powerful corrective to the institutional narrative, but they also offer much more insight into how to continue to live with the virus, and how to prepare for future environmental and political threats. The ACT UP Oral History Archive, along with the numerous contemporary projects aimed at chronicling this history offer a blueprint for political action and self-historicization—one that should be buttressed by cross-pollination with institutional projects like the ones I've outlined in this essay.

While there may be many similarities between cellular memory and collective memory, there is at least one important distinction I want to close on. Though we may be able to shepherd our individual memories, by cramming for an exam, or through mnemonic devices or performance-enhancing drugs, at some point all of our bodies break down. Our inability to remember is often one of the first signs of our bodies and brains slipping from our control. This is one of the central reasons why institutions matter. Institutions may be made up of individuals, but they are set up to last longer than any singular person. The stories they tell matter. Whereas we can only control our individual memories so far, we have the ability to collectively decide and curate what merits remembrance, what should be repeated, and how best to convey the context of why all this remembering matters.

Notes

- 1** See for example: Theodore Kerr, "A History of Erasing Black Artists and Bodies from the AIDS Conversation," *Hyperallergic*, December 31, 2015, <http://hyperallergic.com/264934/a-history-of-erasing-black-artists-and-bodies-from-the-aids-conversation/>.
- 2** "Memory Gene Goes Viral," National Institutes of Health, January 16, 2018, <https://www.nih.gov/news-events/news-releases/memory-gene-goes-viral>.
- 3** Mauro Costa-Mattioli and Nahum Sonenberg, "Chapter 5 Translational Control of Gene Expression: A Molecular Switch for Memory Storage," *Progress in Brain Research Essence of Memory* 169 (2008): 81-95.
- 4** William Hirst and Gerald Echterhoff, "Creating Shared Memories in Conversation: Toward a Psychology of Collective Memory," *Social Research* 75, no. 1 (Spring 2008): 186.
- 5** *Ibid.*, 201.
- 6** Ross Poole, "Memory, Responsibility, and Identity," *Social Research* 75, no. 1 (Spring 2008): 267.
- 7** *Ibid.*
- 8** Alexandra Juhasz and Theodore Kerr, "Home Video Returns: Media Ecologies of the Past of HIV/AIDS," *Cineaste Magazine* (Spring 2014), <http://www.cineaste.com/spring2014/home-video-returns-media-ecologies-of-the-past-of-hiv-aids/>.
- 9** *Ibid.*
- 10** *Ibid.*
- 11** "HHS Organizational Chart," U.S. Department of Health & Human Services, accessed May 28, 2019, <https://www.hhs.gov/about/agencies/orgchart/index.html>.
- 12** Sarah Schulman and Jim Hubbard, "ACT UP Oral History Project," May 12, 2003, <http://www.actuporalhistory.org/about/statements.html>.
- 13** *Ibid.*
- 14** Just as the institutional histories are contested within this crisis, so are community histories. For more context within activist and community history-making, see: Jih-Fei Cheng, "How to Survive: AIDS and Its Afterlives in Popular Media," *WSQ: Women's*

Studies Quarterly 44, no. 1-2 (2016): 73-92.; Alexandra Juhasz, "Forgetting ACT UP," *Quarterly Journal of Speech* 98, no. 1 (2012): 69-74; Marita Sturken. *Tangled Memories: The Vietnam War, the AIDS Epidemic, and the Politics of Remembering* (Berkeley: Univ. of California Press, 2009); *United in Anger: A History of ACT UP*, directed by Jim Hubbard, produced by Sarah Schulman and Jim Hubbard (2012), film.

15 "Victoria A. Harden, Ph.D. Bio," National Institutes of Health, Office of History and Stetten Museum, June 15, 2016, <https://history.nih.gov/about/harden.html>.

16 "In Their Own Words: NIH Researchers Recall the Early Days of AIDS," Office of NIH History, 2001, <https://history.nih.gov/NIHInOwnWords/index.html>.

17 "Oral History Interview with Dr. James W. Curran," Interview by Victoria Harden, May 19, 1998, "In Their Own Words: NIH Researchers Recall the Early Days of AIDS." https://history.nih.gov/NIHInOwnWords/docs/page_06.html.

18 Jennifer Brier, *Infectious Ideas US Political Responses to the AIDS Crisis* (Chapel Hill (N.C.): University of North Carolina Press, 2009).

19 See: "Against The Odds: Making a Difference in Global Health," U.S. National Library of Medicine, April 17, 2008, <https://apps.nlm.nih.gov/againsttheodds/index.cfm>; and "Exhibition - Surviving and Thriving - NLM Exhibition Program," U.S. National Library of Medicine, September 2013, <https://www.nlm.nih.gov/exhibition/survivingandthriving/index.html>.

20 "David J. Sencer CDC Museum," Centers for Disease Control, Accessed August 1, 2016, <https://www.cdc.gov/museum/pdf/ghomuseumbrochure.pdf>.

21 "The AIDS Epidemic in the United States," Centers for Disease Control, accessed July 24, 2014, David J. Sencer CDC Museum, Atlanta, GA.

22 Ibid.

23 Richard M. Seik, M.D., Kenneth G. Castro, M.D., and Marguerite Pappaioanou, D.V.M., Ph.D., *Distribution of AIDS Cases by Racial/Ethnic Group and Exposure Category*, CDC Publication, SS-3 ed., Vol. 37 (1988).

24 Adam M. Geary, *Antiblack Racism and the AIDS Epidemic: State Intimacies* (New York: Palgrave Macmillan, 2014), 122.

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Love Happened Here

Nelson Santos

– Artist Project

“What examples of your curating have fed you the most?” is the question artist Nayland Blake posed to Nelson Santos for this issue of *On Curating*. To answer the question, Santos, an artist, curator, current Interim Director of Curatorial Programs at Leslie-Lohman Museum, and former Executive Director of Visual AIDS, created a series of digital collages, bringing together decades of AIDS cultural production including his influences, some of his own visuals, and work he has commissioned over the years.

Through these collages, Santos puts into conversation the familiar, overlooked, new, and unknown to tease out themes that while dominant within the ongoing response, are nevertheless, often left under-discussed. Politics, cross-generational activism, the ongoing-ness of crisis, anti-black racism, gender and sexuality, and identity writ large are issues, ideas, and frameworks that emerge amid the assembled memes, posters, photographs, artist projects, and text.

Santos originally worked with Nayland Blake in 2007, when he asked Blake to visually respond to the question “Where did the love go?” for a series of artist-designed AIDS awareness projects. As Santos tells it, “The question was triggered by what seemed to be an abundance of silence and apathy around HIV/AIDS at that time. After decades of loud and passionate activism, AIDS was no longer front-page news, bowls of condoms were no longer sitting on every bar, and red ribbons were only for logos not lapels, meanwhile HIV infection rates continued to rise.”

Blake’s response was the creation of a vinyl sticker that read LOVE HAPPENED HERE at the top, with a space for a viewer to write in a date, followed by a text that read: IT CAN HAPPEN AGAIN / BRING LOVE BACK / KEEP YOUR LOVERS SAFE. Blake intended these 4”x6” stickers to be placed in public

spaces. As he stated at the time of the project, “When I move down the streets I’m always aware of the fact that every inch of this city has at one point or another been the witness to births, breakups, protests and first loves. I think about the ways that particular spots are no longer ‘the corner store’ but now ‘where Phil and I had that fight and we were both crying on the street.’ The sticker is a way for people to commemorate their love as well as a reminder to not give up, to keep making love visible and public.”

Blake’s sticker, being seemingly simple, made up of text and design, can also be considered an assemblage of sorts, bringing together Blake’s commitments as a lover, artist, curator, friend, and educator who has lived through many periods of the crisis and bore witness to the foundational praxis around the role that care and love play in the face of neglect, apathy, stigma, suffering, and death. The notion of “keep your lovers safe” may seem like a standard “safer sex” message ubiquitous within AIDS cultural production; at the same time, it can also be read as a call back to the very creation of safer sex itself. “How to Have Sex in an Epidemic: One Approach,” a 1982 pamphlet written by Richard Berkowitz and Michael Callen with assistance from Dr. Joseph Sonnabend, was among the early calls for gay men to use condoms, and suggested that while much was left to learn about the epidemic, it was possible that “mutual affection” was the community’s “best protection” against premature death and suffering.

Blake’s bringing together of history, design and heart to an art object is alive and well within Santos’ collages, and like the very question Blake posed—What examples of your curating have fed you the most?—are generous in their visual and affective offerings.

– Theodore (ted) Kerr



untitled panel (Nayland Blake #LoveHappenedHere 2007/2014 x Tom of Finland #TomsRockwell 1968 x #Wanna Riot 2019), digital collage, 2019



untitled panel (Silencio=Muerte 1987 x Let's Talk About This 2013 x Noah Lyon #SafeSexRules 2008 x Michael Mitchell #RubbersAreFun! 2008 x Chris Johanson #SafeIsSexy 2005), digital collage, 2019



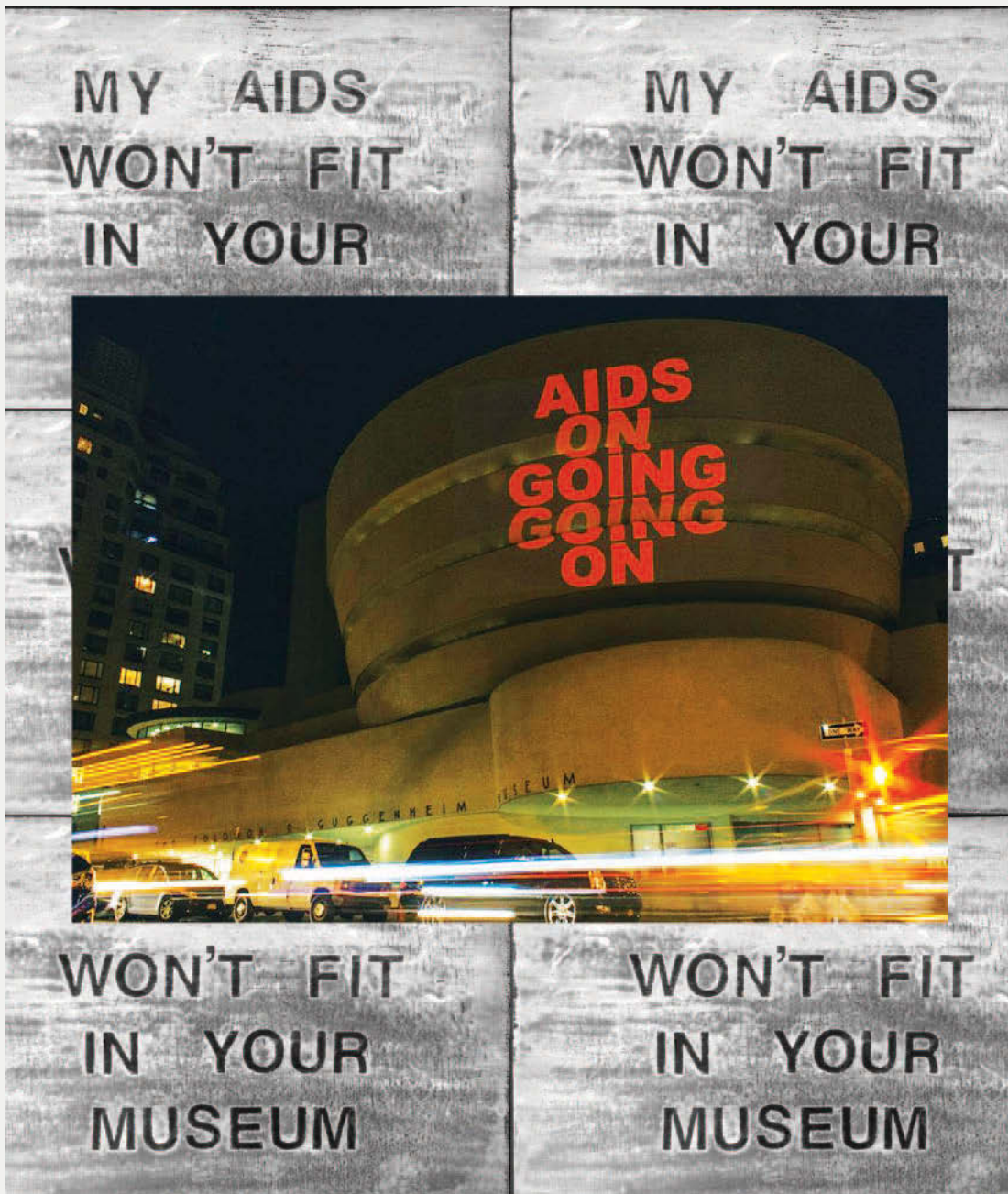
untitled panel (Joe Brainard #Pansies 1967 x Fire Island #SunscreenTestBoulevard 2015 x Ben Cuevas #ifellforyoubellhookslinandsinker 2016 x Jayson Keeling #PlaySmart 2013), digital collage, 2018

I want a dyke for president. I want a pe
 with aids for president and I want a fa
 vice president and I want someone with r
 health insurance and I want someone who
 up in a place where the earth is so satu
 with toxic waste that they didn't have a



made mistakes and learned from them. I w
 Black woman for president. I want someon
 bad teeth ~~and an attitude~~, someone who h
 eaten ~~that nasty~~ hospital food, someone
 crossdresses and has done drugs and, been
 therapy. I want someone who has committe
 civil disobedience. And I want to know w

untitled panel (Zoe Leonard #iwantapresident 1992/2016 x ACT UP #SurrenderDonald 1989 x Here We Go Again #AfterGranFury 2017), digital collage, 2018



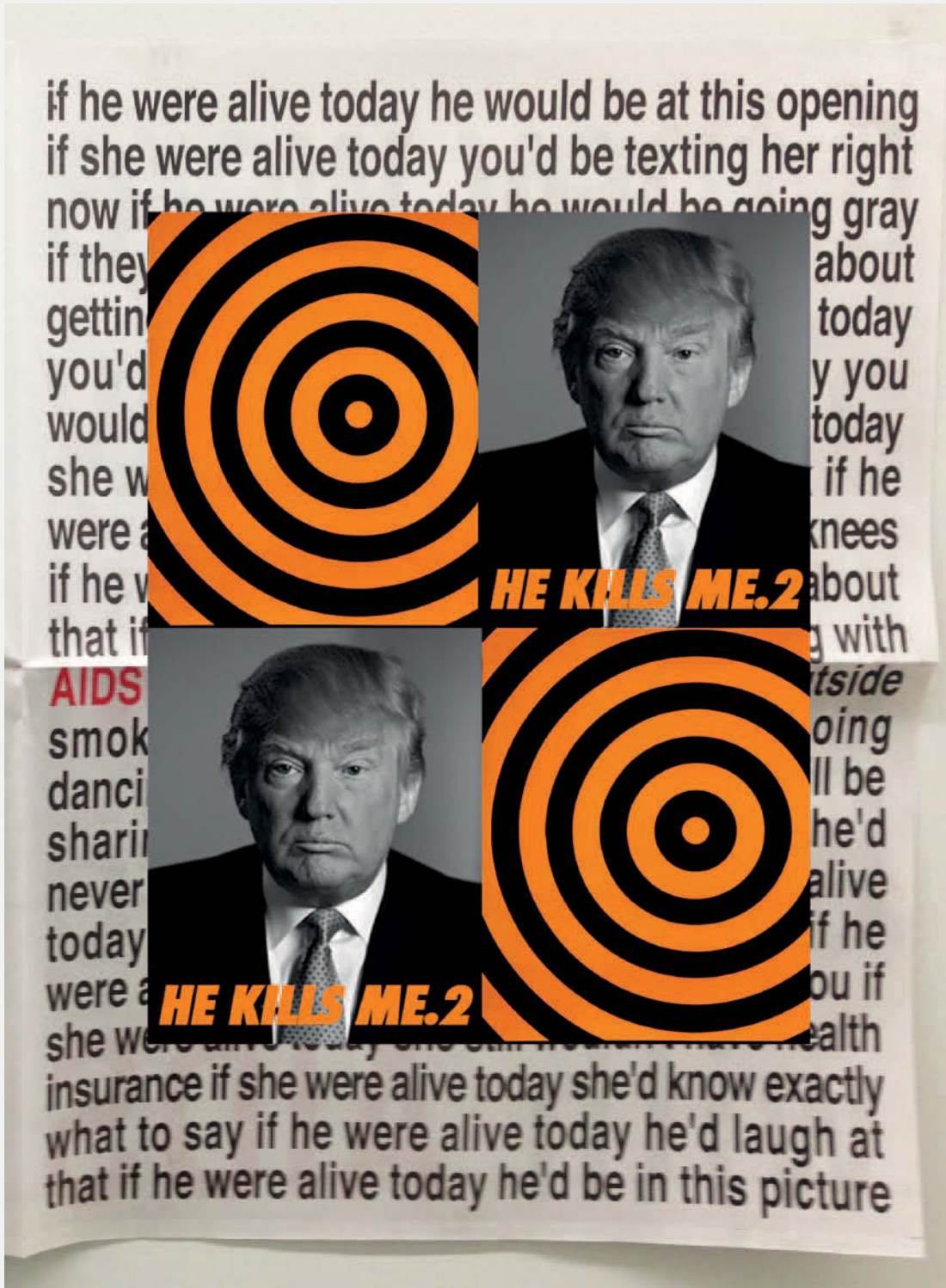
untitled panel (Shan Kelley #myAIDS wont fit in your museum 2015 x Kay Rosen #AID-SONGOINGGOINGON 2013 x Day With(out) Art: Radiant Presence #Guggenheim 2015), digital collage, 2018



untitled panel (Nancer LeMoins #WillArtSaveMyLife 1996 x Carmine Santaniello #PlaySmart 2013 x #ACTUP 2017), digital collage, 2018



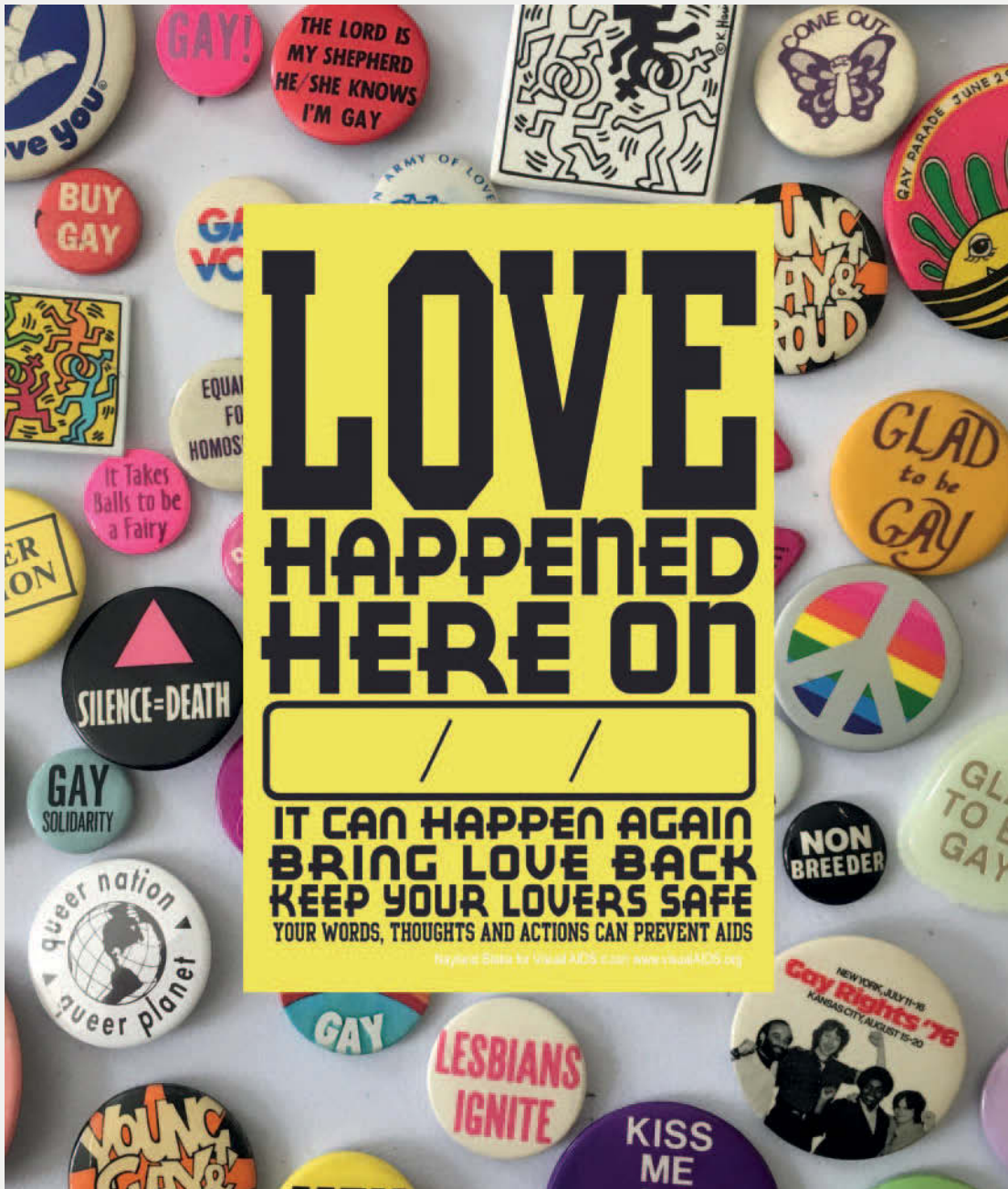
untitled panel (Profits: #HIV x #Prison x #AIDS x #Pharma 2013/2018), digital collage, 2018



untitled panel (fierce pussy #forthecord 2013 x He Kills Me.2 #AfterDonaldMoffett 2017), digital collage, 2019



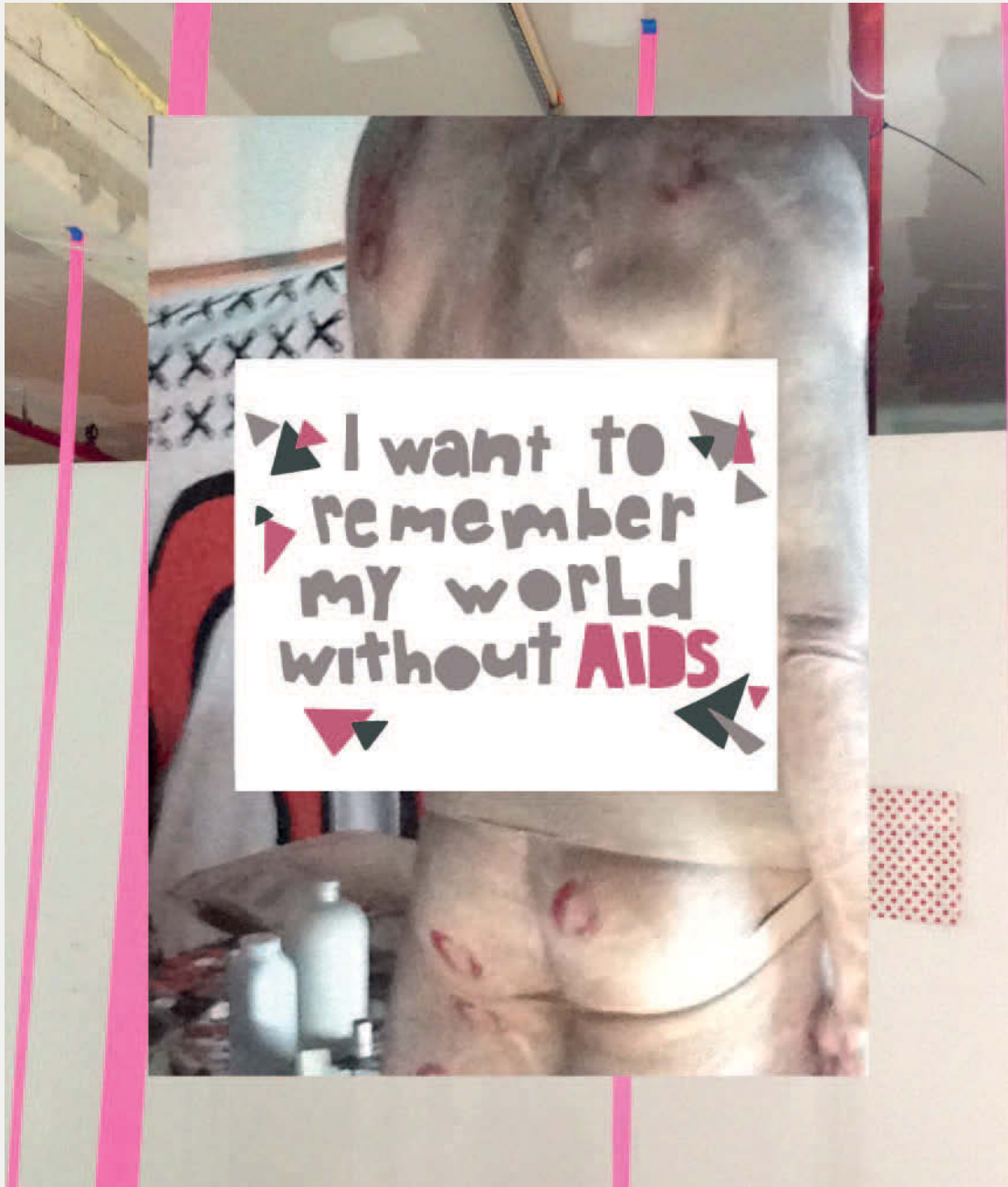
untitled panel (Chloe Dzubilo x #PowerToThePeople 2019 #AfterMarshaPJohnson 1970 x Kia Labeija #MyBodyIsNotABiologicalWeapon #PlaySmart 2016), digital collage, 2019



untitled panel (Nayland Blake #LoveHappenedHere 2007 x The LGBT Community Cen-ter National History Archive #lgbtqbuttons #YallBetterQuietDown 1970-2019), digital collage, 2019



untitled panel (1989 x ACT UP x Taylor Swift), digital collage, 2018



untitled panel (Jessica Whitbread #iwanttoremember x Tony Feher x Peter Cramer & Jack Waters #ephemeraasevidence), digital collage, 2019

Artist Statement

When asked by Nayland Blake, “What examples of your curating have fed you the most?” I turned to the Latin root of curate, *cura*, which means “care,” and I reflected on how caring/curating issues around HIV/AIDS has fed my life and my work. I think about the shared stories of love, community, desire, passion, activism, strength, and survival alongside issues of stigma, race, phobia, silence, injustice, and lost histories—but most of all I think about caring for each other.

For this issue of *On Curating*, I created a graphic patchwork of visual stories, stitched together like a quilt. They include images from artist projects I worked on at Visual AIDS by Nayland Blake, fierce pussy, Jayson Keeling, Shan Kelley, Michael Mitchell,

Chris Johanson, Carmine Santaniello, Kay Rosen, Kia Labeija, and Jessica Whitbread. In these panels are also political and graphic works of other artists I am inspired by—Nancer LeMoins, Joe Brainard, Zoe Leonard, Donald Moffett, Touko Laaksonen, Ben Cuevas, Chloe Dzubilo, Gran Fury, Tony Feher, and Peter Cramer & Jack Waters—woven together with text and images, both borrowed and personal.

Together I hope this mash up of art, culture, recollections and activism reflects some of our stories and the love that happened—and happens—here.

I dedicate this project to Douglas Crimp (1944-2019) and Barbara Hunt McLanahan (1964-2019).

Nelson Santos (he/him) is an artist, curator, and Interim Director of Curatorial Programs at the Leslie-Lohman Museum, responsible for the museum's LGBTQ-focused exhibitions and collections. He is also Director Emeritus of Visual AIDS, a non-profit arts organization that utilizes art to fight AIDS and supports artists living with HIV/AIDS. Over the years, he has worked with hundreds of artists, curators, and historians to produce and present public programs, exhibitions, visual art projects, and publications. He has edited multiple artists' publications including the DUETS series, which pairs artists, activists, and writers in dialogues about their creative practices, alongside HIV/AIDS

and social justice issues. Santos has curated exhibitions and screenings at the Leslie-Lohman Museum, NY; the Bureau of General Services Queer Division, NY; The Bronx Museum, NY; The Center, NY; Schroeder Romero / Winkleman Gallery, NY; Miami Dade Art Gallery, FL; and Spin Gallery, Toronto. He received his MFA from the School of the Art Institute of Chicago, and his artwork has been exhibited in New York, Chicago, San Francisco, Los Angeles, Miami, Spain, and Japan. Santos is a 2018-2019 QAM Mentor in Curatorial Practice and sits on the boards of the Fire Island Artist Residency (FIAR) and Queer|Art.

#StopErasingBlackPeople

Tacoma Action Collective

– Reprint

Tacoma Action Collective began as a structure within which activists who were committed to black joy, love, and success could organize, perform direct action, and support others doing related work. When members of TAC viewed the national traveling exhibition, *Art AIDS America*, at the Tacoma Art Museum, curated by Jonathan David Katz and Rock Hushka, they were dismayed at the lack of black representation in terms of the art and artists involved. This only further echoed the diversity issue TAC members had already seen on view at the museum. To address the exhibition, and the larger structural issue, TAC organized an action. On an open museum night before the exhibition's closing, TAC occupied *Art AIDS America* with signs that read #StopErasingBlackPeople, and they staged a die-in. In the press release below, TAC outlines their demands and justifications for the action.

TAC's demands were met by the museum, and in every subsequent iteration of *Art AIDS America*, black

artists and other local artists were better included in the exhibition. The culmination of the exhibition's evolution was the final stop of the national tour in 2017 at Alphawood in Chicago. Many new artists had been added, a new catalog was produced, and an additional related standalone exhibition was commissioned at nearby DePaul Art Museum. That show, entitled *One Day This Kid Will Get Larger*, curated by Danny Orendorff, was on view during the Alphawood run of *Art AIDS America*.

TAC and the curators of *Art AIDS America* raised the bar on AIDS culture representation, setting a new standard in which the meaningful inclusions of black artists living with and impacted by HIV was the new minimum. TAC produced a short film about the *Art AIDS America* action for Visual AIDS' 2018 Day With(out) Art series, entitled *Alternate Endings, Activist Rising*, which can be viewed at vimeo.com/300077176.

– Theodore (ted) Kerr



Tacoma Action Collective, Screenshot from #StopErasingBlackPeople, 2018. Courtesy of the artists and Visual AIDS

Press Release**Tacoma Action Collective****Die In Protest 12/17 at Tacoma Art Museum demanding:**

- more Black staff at all levels of leadership within Tacoma Art Museum.
- staff/board retraining in Undoing Institutional Racism (UIR) at all levels of leadership among Art Museum personnel.
- that the artist Roster for Art AIDS America be changed to include greater representation of Black Artists before the show tours nationally in 2016

Art AIDS America, which purports to “explore the whole spectrum of artistic responses to AIDS” almost entirely excludes Black artists. Black Americans represent over 40% of the death toll¹ (nearly 270,000 AIDS related deaths since the 80's) but only 4 out of 107 contributors to the exhibition are Black. When confronted about the lack of Black artists in an interview, TAM curator Rock Hushka explained “You have to wait for the next one.”

This gross negligence is unacceptable. The die-in will mourn and honor the over nearly 700,000 Black Americans² past and present who have directly suffered in this epidemic and for whose lives Tacoma Art Museum, Bronx Museum Jonathan Katz, and Rock Hushka have shown no concern. This is critical because arts movements have been the center of raising public visibility throughout the history of the HIV AIDS epidemic, and while HIV prevalence decreases in nearly every US demographic, it continues to increase among Black Americans due to lack of access to medical care.

For Black Americans the crisis is not over. 1/3 Black trans women are diagnosed with HIV³ and 57% of all HIV diagnoses under age 24 are of Black youth⁴. Black Americans also die more frequently and sooner from AIDS related complications than any other group in the US based on lack of access to medical care and identification of the virus in late stages of development. In an era when Black bodies are targeted from seemingly every direction, the fundamental lack of empathy or regard by TAM and Bronx Museum is disturbing. The exhibit which largely displays HIV as a white crisis from the 80's. these two institutions are willfully continuing to erase the reality of black suffering in the HIV AIDS crisis, by showing and almost exclusively white gay perspective.

This show is the natural result however of a predominantly white organization with zero Black full time staff in its entire history (besides grounds/security services) developing a project addressing HIV (and partnering with no Black organizations or curators in that development). Sadly this approach is consistent with TAM's leadership and engagement model for the past 3 decades. Other than a quilt show 4 years ago the last project at TAM that Rock Hushka remembers emphasizing Black contributions was in 1993. This is typical of a museum that targets “whole families” at the center of it's marketing strategy.

Still there is no excuse. Beyond the fact that Hushka admits to not being familiar with the racial demographics of those impacted by HIV, the museum is actually failing all Tacoma residents by propagating a deeply distorted and false history of our society.

This action is necessary to make a bold statement to art museums and historical institutions across the country that we are not waiting until “the next one”. We refuse to be relegated the second class slot relegated by TAM. We have engaged in dialog. We have asked for changes to the show. We been given no choice but to take direct action.

Our efforts are not to discount works included in the project. Many artists contributed strikingly relevant to Art AIDS America about resilience and loss. We deeply respect the work that has been contributed, especially the 4 Black artists included. Nonetheless, to create a project about HIV in the US and discount the nearly 270,000 Black lives lost in this epidemic (1) is not only grossly negligent from a historical standpoint, but contributes to the lack of visibility and lack of public concern that keeps the epidemic at large.

This show paints HIV as an issue faced predominantly by white gay men, when in fact the most at risk group are currently black trans women. After resistance by groups such as ACT up in the 90s successfully pressured the government and medical industries to support the fight against HIV/AIDS, the benefits of those movements were enjoyed primarily by white gay men and others with the privilege of medical access. HIV affects black communities disproportionately, and white gay America has been content to look at HIV AIDS as a non issue because they are no longer affected. New developments like Truvada have been heralded as the end times HIV, but the access to the tools of HIV

prevention/treatment for Black americans and Black Trans Women remains largely ignored.

“To say that the reason black people account for only 12% of the U.S. population yet nearly half of all newly infected HIV cases each year, is because of something black people are doing—is anti-black. However, this isn't the first time “black behavior” is blamed for black suffering. If only he wasn't wearing a hoodie. If only she listened and didn't keep running her mouth. If only he didn't take his hands out his pocket so fast. If only he didn't shoot himself—while handcuffed in the back of a police car. It is also important to note that this sort of rationale isn't only particular to “them” but we, black people, also tend to cite such anti-black logic ourselves. When we say statements such as, “HIV/AIDS is God's reckoning for the deviance of the gay community,” we actively participate in a white supremacist agenda, that in turn kills us and resurrects a bolder, whiter, more resilient Jesus.

Epidemic is defined as “a widespread occurrence of an infectious disease in a community at a particular time.” The word I wish for us to pay most attention to in this definition is “community.” The greatest advances in population health, especially in the twentieth century, were predicated on raising the general health of populations through social investments in drinking water, nutrition, safe housing, sanitation, and environmental safety, among other social investments. With this in mind, we can not properly have a conversation about HIV within the black community without also having a conversation about gentrification, or minimum wage, or food justice, or gender justice, or climate change, or poverty, or most importantly prison. “Timothy DuWhite - Hunted by the State: HIV, Black Folk & How Advocacy Fails Us

Black people worldwide should not be dying from a disease we have the resources to treat and prevent. White supremacy, gender justice, economic inequality and access to medical care are not sideline issues in the topic of HIV but central and entrenched within the subject of race. Until we face the ongoing epidemic in front of our eyes the whitewashed narrative of the HIV AIDS crisis will continue to astound middle-class “whole families” nationwide while Black Americans who can't afford museum memberships continue to die in mass.

For inquiries please contact:
tacomaactioncollective@gmail.com

#DieInAtTAM will take place tonight (7pm)
at Tacoma Art Museum.

Please read the full interview with curator Hushka at:
<http://postdefiance.com/exclusion-of-black-artists-from-art-aids-america/>

To access this action through social media please refer to the following hashtags as well as our twitter account @tacoma_action

#DieInAtTAM #StopErasingBlackPeople
#BlackPOZlivesmatter #BlackTRANSlivesmatter
#allBlacklivesmatter

Sources

1 “HIV Among African Americans”

<http://www.cdc.gov/hiv/group/raciaethnic/african-americans/>

2 700,000 Black people Affected was determined by combining the number of Black people killed by aids and those currently living with HIV. “Mortality Slide Series” http://www.cdc.gov/hiv/pdf/statistics_surveillance_hiv_mortality.pdf

3 1/3rd of all transwomen being hit positive is based on self reporting studies, other studies suggest black transwomen may have infection rates closer to 56%.

“HIV Among Transgender People” <http://www.cdc.gov/hiv/group/gender/transgender/>

4 “HIV Among Youth” <http://www.cdc.gov/hiv/group/age/youth/>

Tacoma Action Collective (Tacoma, WA) is a partnership of black community organizers working in grassroots action and education in Washington State. TAC works to eliminate systemic oppression and structural violence while empowering people to build autonomous communities rooted in equity and justice. In 2015, the collective staged a die-in at the Tacoma Art Museum in response to the white-washing of the exhibition *Art, AIDS, America*.

Making

How to Have A Lecture Series In An Epidemic

Jordan Arseneault

There is one book about AIDS that every graduate student I know who works on this topic owns: Paula Treichler's *How to Have a Theory in an Epidemic* (1999, Duke U P). Almost twenty years after its publication, Treichler's thesis that – beyond its very real and felt biopolitical impacts – AIDS was an “epidemic of... signification” borne from violently dualistic language, is unflinchingly useful. Gay/straight, North/South, sex-worker/boring-people, drug-user/morally-upright-citizen, and, *mutatis mutandis*, all the way to the PrEPedemic dyad of good-poz-people/bad-poz people and the Truvada whores who love them.

The antinomies of AIDS are manifold, and Treichler's tome is still a go-to for understanding AIDS and its semaphores. The title of the book itself was a nod to the Richard Berkowitz/ Michael Callen tract, *How to Have Sex in an Epidemic: One Approach* (1982) (which was also remixed in a very useful zine about navigating HIV disclosure law in Canada, *How to Have Sex in a Police State*, by two semi-anonymous Toronto anarchists).¹ Treichler is just one of nearly 100 scholars, artists, activists, and artist-activist-scholars who have presented at the Concordia University Community Lecture Series on HIV/AIDS. The Lecture Series would have celebrated its 25th anniversary in 2018-2019, making it the most significant and longest-running event series of its kind in Canada. Under the aegis of Montreal's Concordia University, the Series is the very public face of an interdisciplinary undergraduate course of the same name that is taught for credit in Humanities and Fine Arts at this most socially conscious of Anglophone Canadian universities, located in a city that is as well-known for its linguistic and racial divides as it is for its sexy *Beautiful Losers*.

The Series has hosted everyone from scholars like Treichler to cultural icons like Ron Athey (*Pleading in the Blood*, 1999) and Diamanda Galás (*Updating the Plague and the Mass: Prayers for the Infidel*, 2009), scientists, social historians, front-line workers, dancers, writers, and even some HIV positive people. Even as a poz person myself who believes in the principles of the greater involvement of people living with HIV (aka GIPA), I am always surprised that most of my favorite lectures from seventeen years of attending the Series have not been by out HIV+ people, but the Series has made deliberate efforts to include us nonetheless. For twenty-five years, the Concordia Community Lecture Series on HIV/AIDS has deftly juggled issues of stature, disciplinary, and perceived popularity in its choice of speakers following its ambitious mission to “challenge the academy to confront the societal crisis engendered by HIV/AIDS and nurture the next generation of researchers, activists, and teachers.” I have had the privilege to moderate a few Q&As after these lectures, and sometimes been immoderate after them. But the Lecture Series has impressed me and saved itself from elimination² over successive administrations, austerity, and the vicissitudes of how AIDS has been studied and fought and lived. Even though the staying power of the “sage on the stage” style of event was thought to be waning, the nature of the Series as a site of monologue—and feisty Q&As—may keep it around until the “End of AIDS,” whenever that's supposed to be!

The Waugh Factor

"When we started the series in 1993, it was still three years before effective treatments began emerging, and we were still watching many of our students, teachers, colleagues and friends dying from AIDS," founder Thomas Waugh tells us.³ "It was in this atmosphere of crisis that Concordia felt a need to respond by sharing information with the community and engaging the public in meaningful discussions."

A film scholar and renowned Sexuality Studies provocateur, Waugh was the director of the Series and its champion for over twenty years. He was instrumental in asserting the need for the academy to respond to the crisis in the myriad ways that people were living, dying, researching, and creating in it.

"The 25 years were full of surprises for me, mostly about how quietly lucid and brilliant people who have looked death in the eye can be," Waugh recalls. "One or two we almost didn't go with because he or she seemed to be a system sellout or whatever was magically transformed to astute radical visionary in front of a mic."

The issue of "selling out" did raise its ugly head in the Lecture Series planning, however, as he and organizers made the choice to accept funding from once-reviled pharmaceutical giant Burroughs Wellcome in order to expand and improve their programming. The series continues to accept funding from "Big Pharma," but in the age of pre-exposure prophylaxis wonder-drugs, rad kids and salty activists alike seem less bothered by giving visibility to these corporations. Concordia's underfunding of the Series, a bureaucratic choice stemming from rules allowing many initiatives access to only "matching funds," is also to blame. In the annual scramble to pay for the speaker fees, travel, accommodation, and student labor, the Series has to fundraise as much as it receives from the school, in many cases.

The interdisciplinarity of the Series has always been part of what made it so hard to fund, and so rich for its audience; but for Waugh, the spectatorial pleasure the lectures deliver always outweighed the stress of countless grant application deadlines. "The annual artist was always very special to me," Waugh reminisces, "from Athey to Galas to [John] Dugdale... they all knocked my socks off without exception."

The personal has always been present and political in the Series, but especially during the crisis. "When a speaker would pass away a year or more after they had presented, like [video artist] Esther Valiquette or Winstone Zulu or Eric Rofes, my heart would always be torn out," he adds. On a lighter note, he also recalls when students and hangers-on would unabashedly vie for certain speakers' attentions, and watching in bemusement at the flirtations was a happy pastime for the founder.

Thanks largely to Waugh's advocacy inside and outside the institution, the Series stood the test of time, from the nadir of the crisis, to the advent of HAART, to the so-called "Second Silence,"⁴ into the complex current era of AIDS historicization. The era of thinking about AIDS *as history* has included high-profile guests like Sarah Schulman and Jim Hubbard ("United in Anger" in 2009 and *United in Anger* in 2012), AA Bronson (who gave a moving lecture about grieving his General Idea collaborators in 2002), and New York downtown walking archive, Sur Rodney (Sur). Originally from Montreal, Sur gave a prescient talk, "I Am not Alone in this Way: Queer and Black in Contemporary Art" at the Montreal Museum of Fine Arts in 2015, just as the ire of AIDS activists was gathering around the much-maligned *ART AIDS AMERICA* exhibition at the Tacoma Art Museum.⁵ The list goes on, and there are currently over ten years of video and

audio recordings of the Lectures available for free online, if you would like to get an idea of the breadth of this Series.⁶

Gender, Race, and Classrooms

“They’re difficult lectures to give. You want someone to understand that it’s not just ‘You’re famous, come and do your shtick,’” says Concordia Research Chair on HIV/AIDS, Viviane Namaste. “One of the best was Elizabeth Pisani [*The Wisdom of Whores*, 2008, Lecture: 2009],” she recalls. “She did an excellent job speaking to the way in which knowledge gets organized, and how not all students are aware of those,” Namaste told me over tea. Holding an umbrella over the organization since 2017, Dr. Namaste oversees a committee of teachers, graduate students, community stalwarts, and actual HIV+ people who help decide, year after year, how the lecture series can adequately reflect HIV/AIDS discourse across disciplines, ever aware of the high stakes of representation and inclusion that have been core concerns since the project’s inception. Namaste’s influence over her sixteen-plus years of collaborating on the Lecture Series curation can be felt in her focus on several of the epidemic’s less famous aspects, from highlighting Haitian experience, to recruiting experts on poz grieving, and the multi-year *On Life and Living*, a documentary theatre project about the history of local AIDS service organization, AIDS Community Care Montréal.

History and Geography: New York VS Everywhere Else

One trend curators anywhere are susceptible to, and Lectures Series organizers were no exception, is the tendency to skew “New York” when discussing AIDS activism or art, and by the 2010s, the backlash had begun. “One of the recurring themes at the decision table was limiting the influence of New York activists,” says Columbia University PhD candidate Ian Bradley-Perrin, who had the Sisyphean task of speaker outreach and fundraising for the Series in his role as coordinator from 2013 to 2015. “At the time I struggled to truly understand this, given the success and vibrancy of NY AIDS activism; but I came to understand that it is used as a stand-in or a metonymic device for all AIDS activism to the detriment of people’s historical imaginations.” That said, Bradley-Perrin was instrumental in bringing activist artist Avram Finkelstein to present in the Series in 2015. The “Silence = Death” co-founder’s lecture at the Canadian Centre for Architecture that winter is consistently recalled by almost everyone I interviewed for this article as one of the most memorable in recent years. I would have to agree, and not just from personal interest.

“I loved everything about Avram Finkelstein’s visit, for so many reasons,” says Karen Herland, who holds the reins in the classroom and is part of the curation in all its myriad detail. “Avram was thoughtful and engaging and the workshop the next day was wonderful—a skillshare, productive working group... formed, flashed and faded in a day. [It was] such a great model for creation,” Herland told me via email. Herself a storied activist who organized around the 1989 Montreal International AIDS Conference, Herland is one of a handful of people who seem to embody the soul of the Lecture Series course and overall project: an activist, a historian, and a lover of culture and the affect of sharing knowledge on this topic.⁷

“Special and Right”

When I asked the 2015-2017 coordinator of the Series, Kaitlyn Zozula, to tell me which lecture was the most memorable for her, I was brought back to a tense evening last winter that, I'll have to agree, exemplified the brilliance and the battle that is the Lecture Series: performance artist, interdisciplinary historian, and Arizona State professor, Marlon Bailey's 2017 “Right Time, Right Place: Black Queer Sex, Love, and Life in the Age of AIDS,” which he had to deliver while a student choir at McGill was stubbornly rehearsing in an adjacent space, almost drowning him out at times.

“I remember feeling like that event encapsulated the kind of overlap and integration of the community/academic spheres that I think is so integral to and important about the lecture series as a project. Just something about having that many people (I think around 240 in total!) in a kind of makeshift auditorium listening to Marlon share his work that is so fundamentally built on reimagining and repurposing academic disciplines or research methodologies to meet the needs and document the realities of specific communities, and then all of us sharing a big meal afterwards, felt very special and right to me,” Zozula wrote me. In Marlon's lecture, a chorus of voices from outside overshadowed the lived experience being shared from within, but my memory of the event is all more visceral for it.

The HIV Positive is Political

I had my first real adult public cry about AIDS in 2001, listening to dancer laureate Margie Gillis lecture in which she spoke about her brother, dancer/choreographer Christopher Gillis, whom she lost to the disease in 1993. I did not attend at all for the two years after I received my diagnosis, in 2006. I had my *second* Lecture Series Q&A fight with a student who asked the legendary South Carolina hairdresser-turned-prevention-activist DiAna DiAna (subject of Ellen Spiro's 1991 *DiAna's Hair Ego*) why she hadn't done more to influence national American policy on AIDS. Hopefully the white male student in question will have a chance to see *DiAna's Hair Ego REMIX*, commissioned for the VisualAIDS 2017 “Day Without Art” omnibus, to get a better sense of how clueless his question was. “The potential is great to shine a light on subjects still unrecognized,” Prof. Namaste helped me conclude.

After Bailey's lecture, perhaps prodded by its logistical and sonic zaniness, I had a bit of a breakdown about the Lecture Series that ultimately helped me understand that the Series is important to me, to my community, and to how I have come to think about HIV.

But that night, I wasn't so clear-minded. In the nearby William Shatner Ballroom, after Marlon spoke, what I remember most was the food, a buffet from Montréal's most beloved Lebanese lunch counter, and around it, the sight and site of community: a black gay academic/artist/historian wowing us all; a classroom of undergrads actually eager to learn; a gaggle of teachers, journalists, former activists, and activists-to-be. And there it is: the Lecture Series is food: a nourishing reminder that academia feeds on stories of lives lived, on questions and solutions born from a Derridean *différend*.

How, then, are we to have a lecture series in, beside, and against an epidemic? Eat all the food. Cater it for those who are hungry; let the Q&As always leave room for a gluttony of pain, and argument; raise up the silenced, mouths full; share the wealth (bring reusable containers to take home the goods). Listen. Listen. And share.

CONCORDIA UNIVERSITY
COMMUNITY LECTURE SERIES
ON HIV/AIDS 2016-2017
PRESENTS:

MARLON M. BAILEY
PHD
ASSOC. PROF., SCHOOL OF SOCIAL
TRANSFORMATION, ARIZONA STATE
UNIVERSITY

**RIGHT TIME,
RIGHT PLACE.**

**BLACK QUEER SEX,
LOVE, AND LIFE
IN THE AGE OF
AIDS**

9 FEB 2017
7PM
LOCATION TBA

LECTURE IN ENGLISH

(1) James Concerra, photographed for
THINGS, a 1995's queer night, JAMA from Chicago

Drawn from his ethnographic study
of black gay sex and subjectivity,
Marlon Bailey will deliver a lecture-
performance that explores what it
means for black queer men to experience
sex, pleasure, and love in the age
of AIDS. Through a combination of
enactment and analysis, Bailey will
share narratives from his research
and explore the complexities of
this community's relationship to
the pandemic.

(2)

(3) Film Still, *Brothers United* (1991) by
Marlon Bailey

(4)

Marlon Bailey is an Associate Professor
in the School of Social Transformation
at Arizona State University. His
performance ethnography on ballroom
culture, *Butch Queens Up in Pumps:
Gender, Performance*, was published
by the University of Michigan Press
in 2013. *Butch Queens Up in Pumps*
won the Alan Bray Memorial Book Prize
from the GLQ Caucus at the Modern
Language Association (MLA) and was
a finalist for the Lambda Literary
Book Award in LGBT studies. Bailey
has published essays in *Feminist
Studies*, *Souls: The Journal of Gay
and Lesbian Social Services*, *AIDS
Patient Care & STDS*, *LGBT Health*,
and in several book collections.
He is also an accomplished actor,
director, and performance artist,
performing at professional theatres
in San Francisco, Washington DC,
Louisville, Minneapolis, and Detroit.
Bailey holds a PhD in African American
Studies with a designated emphasis
in Gender, Women, and Sexuality
from the University of California-
Berkeley. He also sits on the Board
of Directors of *Brothers United*, a
Black gay HIV/AIDS prevention agency
in Indianapolis.

Butch Queens
Up in Pumps
Gender,
Performance
and
Ballroom Culture
in Detroit

Marlon M. Bailey & Butch Queens Up in
Pumps

ViiV
CATIE
ACCM
COG-SIDA
PACT

Lucas Larochelle for the Concordia Community HIV/AIDS Lecture Series (2016-2018), *Right Time, Right Place*, 2017. Digital Poster. Courtesy of the Concordia Community HIV/AIDS Lecture Series.

Notes

- 1 Anonymous, "How To Have Sex In A Police State: One Approach /// Comment Baiser Sans Se Faire Baiser Par Les Flics," 2015. <http://howtohavesexinapolicestate.tumblr.com/>
 - 2 "Chi Chi DeVayne vs. Thorgy Thor, RuPaul's Drag Race Season 8," <https://youtu.be/0EWW03g1xYA>.
 - 3 Julie Gedeon, "Daring HIV/AIDS lecture series turns 20," in *The Concordian*, January 15, 2013, <http://www.concordia.ca/cunews/main/stories/2013/01/15/daring-hivaids-lecture-series-turns-20.html>.
 - 4 Theodore Kerr, "AIDS 1969: HIV, History, and Race," in *Drainmag* 13:2 (2016), <http://drainmag.com/aids-1969-hiv-history-and-race/>.
 - 5 Andrew Rose, "Compartmentalized Compassion: a 30-year Survey of AIDS-related Art in the US," in *Hyperallergic*, December 1, 2015, <https://hyperallergic.com/257877/compartmentalized-compassion-a-30-year-survey-of-aids-related-art-in-the-us/>.
 - 6 Concordia University HIV/AIDS Project Archives: <https://www.concordia.ca/events/projects/hiv-aids/archives.html>.
 - 7 See Alexis Shotwell and Gary Kinsman's interview with Karen Herland on the game-changing Carleton University website AIDS Activist History Project: <https://aidsactivisthistory.ca/interviews/montreal-interviews/#Herland>.
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Jordan Arseneault (b. 1980) is a performer, translator, and cultural researcher living in Montréal. He employs song, cello, drag, and mixed original/found text in his staged work, which he has developed in parallel with two social practice workshops, *Fear Drag* (2010-present), and *Disclosure Cookbook* (with artist Mikiki). His collaborative performances, *SEROGENE* (with Matthew-Robin Nye, *MIX NYC*, 2014) and *Propositions for the AIDS Museum* (projets_hybris, 2014-2017), and participative works address issues of criminalization, stigma, HIV/AIDS, addiction, queerness, and community. His agitprop poster/virus "SILENCE=SEX" (for Toronto's AIDS ACTION NOW!, 2012) decries HIV criminalization through graphic détournement. Also known as Peaches LePoz, his drag persona regularly makes appearances throughout Montréal and sometimes on the road. His contribution to the La Mama Galleria/VisualAIDS exhibition *Cell Count* in June 2018, accompanied by Mikiki, presented a scene from (*MORE*) *Propositions for the AIDS Museum...* (2017), that has become a work in progress ("The Two Steves' Lament"). By day, he translates from French to English, and coordinates the Queer Media Database Canada-Québec, based out of Concordia's Faculty of Fine Arts.

Thoughts on How to Include Spirituality in Exhibitions about HIV and AIDS

Rev. Michael J. Crumpler

I believe that all people experience spirituality. It informs us of our “why.” Why am I feeling this way? Why am I reacting this way? Why is this the thing that I want at this moment in time and in this particular way? As a person living with HIV, despite my good health and social acceptability, what hurts most are the spiritual complications of my disease. These are my questions: Why am I feeling ashamed of my HIV status? Why am I validated by undetectable lab results? Do I need to have safe and respectable sex in order to not feel ashamed? Similarly, people living without HIV/AIDS may ask similar questions of their positive counterparts. Why are you feeling that way? Why are you acting that way? Why is that the sex you are having? These are all spiritual questions, simply posed but not easily answered. I would argue these spiritual obstacles are the very reason HIV and AIDS exist today.

The same spiritual crisis that resulted in the slaughter of 50 million indigenous bodies and the indentured servitude of 12 million black bodies, led the Reagan administration, with their hatred of poor people and drug users, and their homophobia, to let a virus turn into an epidemic killing of 35 million worldwide. Many Reaganites argued the plague was God's punishment for the sin of homosexuality and drug addiction; that the “abominable sin” of gay sex was reason enough for the government to do nothing. In so doing, they opted for the spiritual cure of a radical conservative faith to lead their actions. When seen this way, it is easy to understand how HIV is as much of a spiritual problem as it is a public health crisis.

When I contracted HIV, I was in my second year of seminary and in my sixth year of marriage to a heterosexual cis-female. I was in the process of becoming a commissioned as a protestant Air Force chaplain and training for my fifth marathon in as many years. I was 32 and a self-proclaimed ex-gay, which I had only disclosed to a handful of friends. A black cis-man from southeastern North Carolina, no one in my Southern black family knew about my sexuality and to tell them seemed like suicide, or at least spiritual suicide.

While many gays, and in my experience, many white gays, turn away from God, I could not. Even when faced with my HIV diagnosis. I had spent my life thinking that the answer to all my whys was God. As my Southern roots taught me, I was well trained to “hold to his hand, God's unchanging hand” to understand my American black experience. And learning I was HIV positive was no different. In fact, because I was gay and black and scared, I turned to God. I needed God's hand to shield me from the doom of my gayness, my blackness, and my sickness in a society that does not value any of the three. I feared being that cautionary tale whispered about by many, counted among the number of shameful black deaths of men who caught AIDS after having sex with white men. But after years of fearing God and family, my greatest fear had finally come to fruition: I was positive. But nevertheless, there I was, a married Christian minister, gay, HIV positive, and struggling to hold God's unchanging hand.



Joyce McDonald, *Mothers Prayers*, 1999. Courtesy of the artist and VisualAIDS.

Twelve years later, divorced, out, and healthy, my powerful story is not unique. Whenever and wherever HIV-positive friends are gathered, I hear my story as if I were baptized into a sacred community of survivors. Nearly every poz person has God or not-God in their story. There's this feeling of being abandoned by God or by a family member who claimed to love God. God has either given them purpose and power to overcome the stigma, or they've had to let go of God to overcome the stigma. In most cases, we've had to create our own God, a God of our understanding intimately acquainted with our chronic illness and our resilient survival.

As such, it is impossible to depict our HIV and AIDS experiences without also depicting our spiritual experiences of coping with HIV and AIDS. Epidemic exhibitions are good at capturing the suffering, the pharmaceutical angle, the dying lover, the sexuality, the activism, and the anger. While these are all spiritual experiences for sure, they do not represent the totality of what it is to live with HIV for me and the many friends I have who are also living with the virus.

When you don't include spirituality, you miss a chance to capture the everydayness of church incarnate in our spiritual communities of survival and resilience. Our faith-based tactics for living and thriving and our sacred rituals that inform our life choices become invisible, particularly among black and brown folk. Perhaps this is due to the passive atheism that seems pervasive in queer white HIV and AIDS communities and the art world. As a black Christian, I have learned to censor my spirituality in mainstream HIV and AIDS forums, so as to not offend or seem unintelligent. I imagine spiritually inclined curators, artists, and others in the art world might do the same. I have friends who say it is easier to come out as gay than it is to come out as Christian. In the rare occasion I see HIV represented in exhibitions, I wonder if the curators have considered the spiritual implications of the virus? I wonder what their connection to spirit or the virus might be. I don't understand, how can we talk about HIV without talking about God? To help me understand this question, below are some thoughts on how to include spirituality in exhibitions about HIV and AIDS.

Feature artists who have positive religious experiences living with HIV and AIDS.

We've all seen *Angels in America* where the Midwestern mom is mystified by the urban gay son living in close proximity to the AIDS pandemic. Or when HIV becomes the symbol of black disappointment in *Tyler Perry's Temptation* as an estranged lover seeks to rescue his distressed damsel from the violent arms of an HIV-positive love interest. What we rarely hear about is the one whose faith added meaning and fulfillment to their HIV and AIDS diagnosis, or dare we say vice versa. What about the prodigal survivor whose father welcomes him home with open arms as depicted in the Gospel of Luke. Yes, these are rare, but also true and more common than we may think. Curators can include healthier narratives alongside tragic ones.

Towards Spiritual Liberation in HIV and AIDS Exhibitions

Just beneath the civil rights movement of the 1960s was a theology revival that gave spiritual expression in both North and South America. James Cone's black liberation theology in the north alongside Gustavo Gutierrez's Latin American liberation theology in the South provided great hope for those living on the underside of imperialism and white supremacy. Their gospel was God's solidarity with the Latin poor and oppressed black masses. While angering Catholic nobility and frustrating mainline protestant elitism, these polarizing theologies liberated those in need of God the most. A parallel spiritual truth is available to the downtrodden living with HIV and

AIDS. Far from a death sentence, the liberation gospel subverts the experience of shame, sorrow, and stigma into an experience of justice, joy, and triumph. Such spirituality is manifest in the work of painter, sculptor, songwriter, and poet Joyce McDonald,¹ who serves her church's AIDS ministry and leads the youth choir. She reveals the existence and resilience of non-white, non-gay, non-male bodies, yet beautifully bearing the yoke of HIV and AIDS.

Capture the experience of black women and children

For the better part of thirty years of HIV and AIDS in America, the experiences of white gay men have been at the center, as the rest of us strive to attain their asymptomatic undetectable standard of perfection. Art exhibitions would be well served by moving beyond such narrow depictions of communities impacted by HIV, starting with meaningful and rigorous explorations of spiritual practices of women and children living with HIV and AIDS. Depicting the spiritual experiences of all women, especially women of color, would provide a fuller perspective as to how the disease impacts single mothers, multiple births, parenting, poverty, and extended family support. Katherine Cheairs' film *Ending Silence, Stigma and Shame: HIV in African American Families*, follows the impact of HIV through the lens of black women living in Atlanta. For a historic and ongoing view of HIV within the lived context of black women and children, Lenn Keller² is too often overlooked. While not everyone in Keller's photos is living with HIV, the ubiquity and interconnection of HIV in their lives is palpable.

Depictions that capture full/whole lives, rather than a crisis in time.

My final thought on how to include spirituality in exhibitions about HIV and AIDS is to feature biopic depictions that extend beyond diagnosis and treatment and capture the whole person. Since the dawning of the age of AIDS and HIV, the lives of the sexually liberated have revolved around our diagnosis. Thus, nullifying our liberation. Healthy sex is considered safe sex and spiritual maturity is presumed to be free of risk. People living with HIV and AIDS are often perceived as sympathetic, or just plain pathetic people because all our accomplishments are viewed through the prism of our diagnosis. Art that captures the full stories of people living with HIV and AIDS moves beyond the diagnosis to embrace all the flaws and futures of one's life. The result will be a spirituality that sustains and uplifts throughout a life of trials and tribulations, celebrations and triumphs.

The work of Ronald Lockett exposes the deepest tragedy of AIDS, that we have been robbed of souls who reveal who we are. Gratefully, Lockett left behind works that bear witness to the dexterity of life lived by blacks in the South. His works are as definitive as they are abstract, as he weaves together tin and rust and grate and wood that seem to tell of the travesty of being black and gay in the Southern United States.³ His works attest to a life lived in exile long before and long after AIDS claimed his body.

One last thought—it was said by James Baldwin that he left the pulpit to preach the gospel. And so it is with many a black gay preacher, like myself. Like Baldwin, we all have that *Go Tell It On the Mountain's* “threshing floor” experience that forces us from the faith of our fathers and mothers into a faith that is not old, but not new. It's the faith that liberated our ancestors from that old world of antebellum slavery and liberated us from that old world religion that demonized the gay son alongside white massa. The sons of Baldwin who left home to have our sex and live our lives have found resilience and meaning in the black spiritual tradition that not only liberated us from slavery's chains, but also from the chains of despair that comes with being diagnosed with HIV. We have learned to accept our disease with the same grace with which we had already accepted ourselves.

Notes

1 <https://visualaids.org/artists/joyce-mcdonald>.

2 <http://lennkeller.com/about.html>.

3 <https://www.visualaids.org/artists/detail/ronald-lockett#>.

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Touch Across Time: Familial Loss and its Remains in Art During the Ongoing HIV/AIDS Pandemic

Emily Colucci

"I was an epidemic child, not birthed but raised by AIDS," writes artist Oli Rodriguez in the prologue of the catalogue for *The Papi Project*, his multidisciplinary engagement with the death of his father—and other father figures—due to complications from AIDS.¹ Rodriguez's statement is deceptively simple. By labeling a childhood lived in the wake of the pandemic as being "raised," he places HIV/AIDS firmly within the family unit, as an influential and guiding figure.

While discussing his specific rearing in what he described to me as "a queer nuclear family" in Chicago, Rodriguez speaks to the complex and challenging questions confronted by artists who investigate the intersection of HIV/AIDS and family. What does it mean to be in a family that includes HIV/AIDS? What does that family look like? What is inherited—the virus, its history, its stigma, its countless losses? How can a family member come to rectify personal and familial mourning within the wider context of the ongoing pandemic?

None of these questions come with easy answers. Family, particularly the biological family, can be a fraught topic in the context of HIV/AIDS, largely due to the socially marginalized communities that have historically been and still are at risk. The AIDS pandemic, according to Julianna Pidduck in her essay "Queer Kinship and Ambivalence: Autoethnographies by Jean Carlomusto and Richard Fung," "exacerbated a kinship ontology characterized by exclusion, disappointment and discontinuity."² Conversely, the height of the pandemic also saw the rise of alternative forms of kinship, or, as Kath Weston termed, "families we choose," as friends, lovers, and other community members came together to care for those affected by the disease.³

Unsurprisingly, perhaps, due to the tight-knit arts communities in which they inhabit, artists and exhibitions that aim to address the ongoing AIDS pandemic often primarily represent families of choice. Take, for example, the seminal 1989 exhibition *Witnesses: Against Our Vanishing* held at Artists Space, which brought together artists from curator Nan Goldin's East Village community such as David Wojnarowicz, Mark Morrisroe, Kiki Smith, and Greer Lankton. Further demonstrating the bonds of kinship between the artists on the walls, the show temporarily held the working subtitle *The Family of Nan*.⁴ With this influential precedent, the majority of recent exhibitions about HIV/AIDS still predominantly feature artworks depicting families of choice—even shows that explore private, domestic responses to the pandemic such as 2017's *AIDS At Home: Art and Everyday Activism* at the Museum of the City of New York, which included artists such as Luna Luis Ortiz's tender photographs of the self-fashioned families in New York's ballroom community and archives of communities of care like the GMHC's Buddy Program. This isn't to say there weren't any works that focused on the biological family in the exhibition. In particular, Lori Grinker's multidisciplinary installation *Six Days From Forty* created both a moving portrait of her late brother

Marc, who died from complications from AIDS in 1996, and their relationship in his last days as she acted as his caregiver at home.

Like Grinker's installation, over the years, there have been a growing number of cultural responses to the intersection of HIV/AIDS and family. These range from films such as Cecilia Alarondo's *Memories of a Penitent Heart*, memoirs like Alysia Abbott's *Fairyland: A Memoir of My Father*, personal essays including Mathew Rodriguez's "Do You Know Who My Father Is?" on *TheBody.com* and academic studies such as Jaime Shearn Coan's "I don't know what made this 'private' in the first place.: Neil Greenberg's Not-About-AIDS Dance and The Disco Project" for *Drain*, about performer Neil Greenberg, whose own dance pieces engaged with the death of his brother Jon due to AIDS-related complications and his own HIV-positive status.⁵ Online platforms, such as The AIDS Memorial Instagram account and The Recollectors, a website and community platform for people who have lost parents to HIV/AIDS, have also emerged as significant social forums for people to share stories of lost family members, as well as the experiences of being raised in the pandemic.

Visual artists, too, are currently confronting HIV/AIDS and the family—both the biological family and families of choice. In their late 20s to early 40s, many of these artists were not yet adults during the height of the AIDS pandemic in the 1980s and 1990s, but still experienced—and continue to tangle with—its losses. When viewed together, these artists, including Rodriguez, Kia LaBeija, Pacifico Silano and Caroline Falby, reveal the diversity of familial relations to AIDS. While each of the four artists has lost a family member due to complications with AIDS, their stories and relationship to the crisis vary widely. Allowing for a range of gender, racial, and sexual identities, as well as serostatuses, these artists and their connection with family provide a snapshot of the numerous narratives of the pandemic, disrupting the notion that there is a singular overarching AIDS story.

Despite their differences, what brings these artists together is their continual engagement with loss and its remains as a means of producing an enduring cross-generational dialogue. In the introduction "Mourning Remains" of their edited collection *Loss: The Politics of Mourning*, David L. Eng and David Kazanjian position two questions in relation to mourning: What is lost? And what remains? "That is," they write, "loss is inseparable from what remains, for what is lost is known only by what remains of it, by how these remains are produced, read and sustained."⁶

This, as they observe, "continuing dialogue with loss and its remains" is exemplified by the work of artist and performer Kia LaBeija, in particular her 2014 photographic series *24*.⁷ Titled after her then age and the floor number of the Hell's Kitchen apartment in which she lived with her late mother Kwan Bennett, the series of self-portraits documents LaBeija's sustained connection with her mother, who died from an AIDS-related illness in 2004, as well as explores her own experience living with HIV. In *24*, Kia's enduring kinship with her family becomes symbolically embodied through physical spaces and personal objects.

Take, for example, *Kia and Mommy*, which presents LaBeija, in an elegant red sequined dress, lying on the floor of a bedroom in her childhood apartment with her legs placed on a dresser. In her arms, she cradles a photograph of her mother, hugging the frame as if posing with another figure. *Kia and Mommy*, rather than merely a self-portrait, is, in reality, a dual representation of mother and daughter. When she began to pursue photography, LaBeija recounts to Alex Fialho in *ArtForum*: "I had a moment of wishing

I could take a portrait of my mother and me together. I was angry that I couldn't—but then I realized I still could."⁸ In this way, the image, at once, makes visible her mother's absence and her continued presence through objects and her daughter. *Kia and Mommy* portrays, what Carolyn Dinshaw calls in *Getting Medieval*, "a touch across time."⁹

More subtly, *Kia and Mommy* also engages with families of choice in regards to LaBeija's current role as the mother of the iconic House of LaBeija. In an interview with *BH Is Vogueing*, LaBeija describes the ballroom community as another type of family, explaining that, for a young HIV-positive queer person of color, "it was the first time since my mother's death...that I felt I was not alone."¹⁰ Not only referencing this lineage by taking on the LaBeija name, the artist also uses her physicality and performance in her photographic work to create a connection with this chosen family. According to LaBeija, she "vogues" in her photographs by "using elements of fantasy and glamour that are part of the LaBeija history."¹¹ In *Kia and Mommy*, for instance, the artist, with her perfectly posed legs, dazzling dress, and direct gaze, offers an intergenerational nod to her foremothers in the ballroom family.

Like LaBeija's *24* series, Oli Rodriguez's *The Papi Project* began as a search for a "touch across time" with an ad posted to Craigslist by Rodriguez seeking men who may have had sex with his late father. It read: "I am looking for men who had sex with my dad. He was known as Troy, Peter, Pedro and other aliases in the late 70s/80s/early 90s before his death from complications of AIDS in 93. I'm his son and I want to hook up with you. I'm open to a drink, dinner or other ideas? I am giving, but no reciprocation. Below is his picture. If you had relations with him, please contact me."

Rodriguez explained to me that he didn't expect to receive any responses, seeing the posting as "a call of absence given that the men he [his father] knew and that were fathers to me passed." While he did receive a variety of responses, which have been



Kia LaBeija, *Kia and Mommy*, 2014. Courtesy of the artist. Thanks to Visual AIDS.

exhibited as a part of the project, including those questioning his mental health, he met with one man, which is documented in a two-channel video. In it, Rodriguez acts as a submissive, scrubbing the floor on his hands and knees in one frame, while being slapped by his dad's potential former partner in the other. The man, however, is nearly invisible in this footage—only implied by a disembodied hand smacking the artist's reddened face. Through this editing, Rodriguez highlights the loss of these “papis,” as well as the ephemeral connection between a queer son and his queer dad.

For three years, Rodriguez continued to launch a new phase of *The Papi Project* every year on his father's birthday. This includes a series of desolate landscape photographs of former cruising spots in Chicago, Key West, Los Angeles, and Berlin, recording the loss of sexual community, and a series of archival images belonging to the artist's father. The archival images, which exist both as prints and a slideshow set to disco music (reminiscent of Nan Goldin's *The Ballad of Sexual Dependency*), depict, Rodriguez says, “a triad of queers, kids and cats.” From children's birthday parties to his father's friends and lovers cavorting in domestic settings, these family photographs, as well as *The Papi Project* as a whole, assert the existence of a “multi-ethnic, multi-gendered, multi-generational unit that persists even as its members are whittled away with each passing year,” as Kemi Adeyemi writes in “Landscapes of a Queer Life Lived.”¹² Even under the specter of AIDS, in which “literally 95% of men in the photographs have all passed,” *The Papi Project* contrasts stereotypical imagery of illness and death by showing, as Rodriguez observes, “There is also family—there are bonds and there is laughter.”

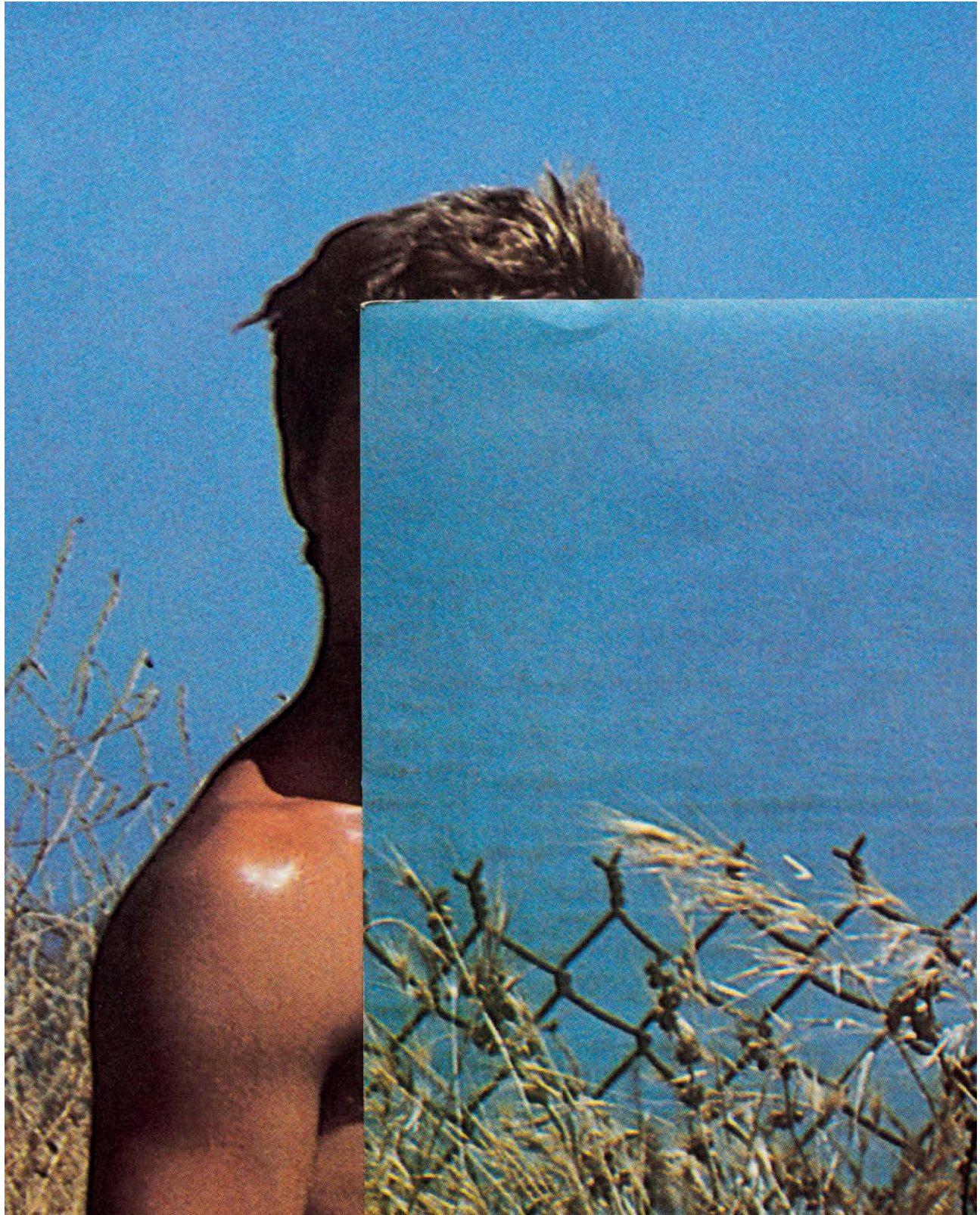
Pacifico Silano also depicts a generation of gay men lost due to the AIDS pandemic in relation to his own familial loss in his photographic series *Tear Sheets* and *Pages from a Blueboy Magazine*. However, unlike both Rodriguez and LaBeija, Silano didn't know his uncle Frank Silano, who was estranged from his traditional Brooklyn Italian family due to his gay identity. “His death was always a history, as if he never existed,” Silano tells me, “I feel that loss. Even though he's no longer here, I feel a strong attachment to him. I feel like we're sisters in arms.” With originally only one Polaroid of his uncle (after making work about this loss, he has since received more photographs from his uncle's friends and former lovers) and limited information from his family, with whom the artist also has a fraught relationship, Silano began to wonder, feeling a link to this absent figure: “Who was this person? What did he do? What was he like? Who were the people he surrounded himself with? Where did he go dancing? What kind of music did he listen to?”

These questions are reflected in Silano's artwork, which features imagery sourced from vintage gay male porn magazines from the 1970s, before the height of the pandemic, to represent a multitude of absences. By appropriating and rephotographing mass-produced images rather than the photograph of his uncle, Silano not only refers to the loss of one individual, but a more universal loss of an entire community of gay men, as well as the sexual freedom of disco-era gay culture. “I'm interested in the emotional and physical voids that we feel from an entire generation being swept away from AIDS,” he explains to me.

While Silano's earlier *Pages from a Blue Boy Magazine* features a grid of the oft-mustachioed faces of porn stars from *Blue Boy Magazine*, leading viewers to question if these men are still alive, his *Tear Sheets* series and more recent work cut and crop parts of bodies, abstracting the figure. Rather than just focusing on the figural, these works also include views of desolate landscapes from the backgrounds of porn shoots and leave copious room for white space between the images in order to signify these voids.



Pacifico Silano, *Pages of a Blueboy Magazine*, 2013.100 8.5x11" Archival Pigment Prints



Pacifico Silano, *Blue Void*, 2019. 50x40" Archival Pigment Print

While understated, Silano's alterations of these magazine pages correspond to José Esteban Muñoz's observation of the ghosts of public sex in *Cruising Utopia: The Then and There of Queer Futurity*. He writes, "To see these ghosts we must certainly read the 'specific dealings, specific rhythms' that bring to life a lost experience that needs to be read in photo images, gaps, auras, residues and negations."¹³

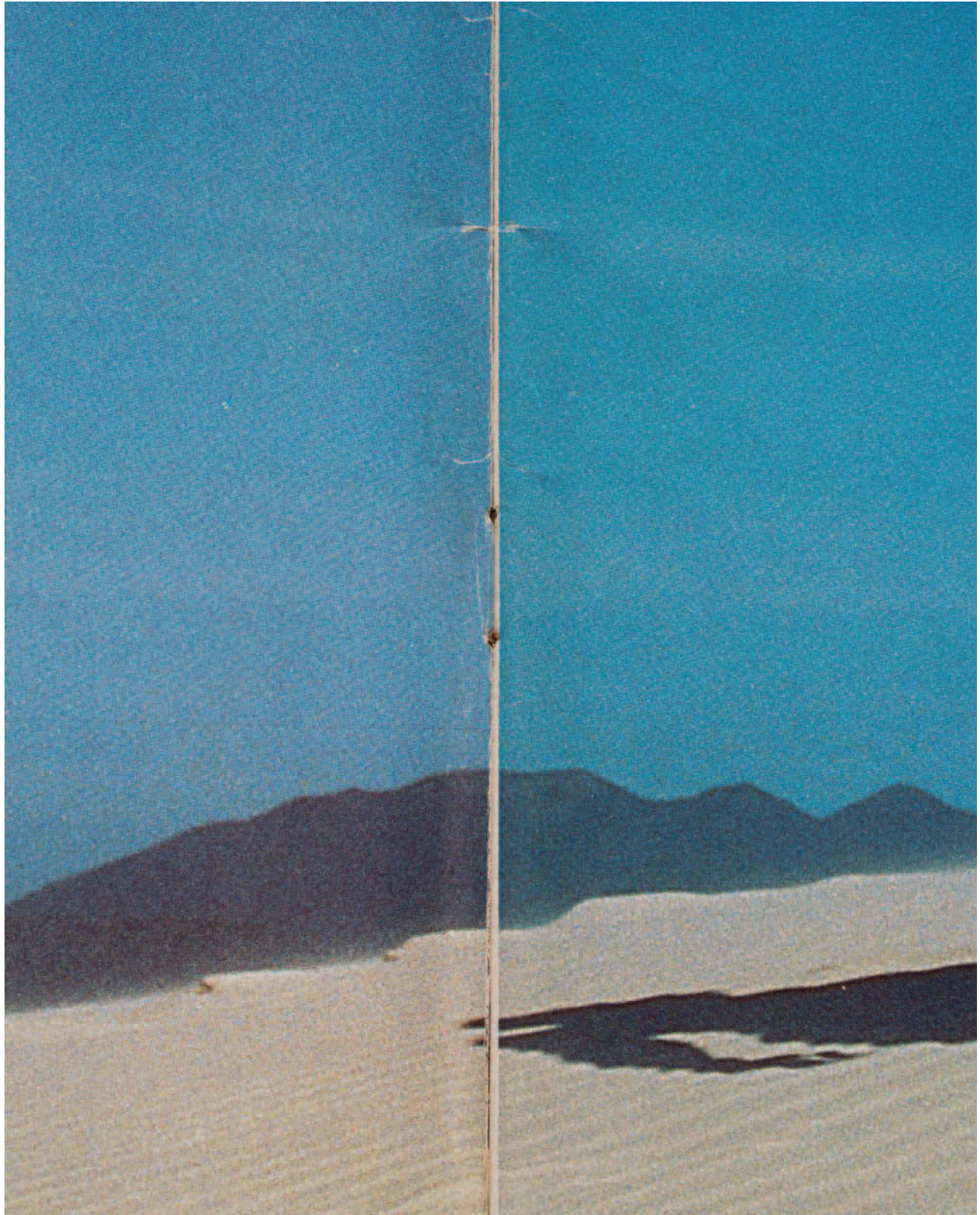
In a similar manner, Silano's photography also captures the haunting of lost family-biological family and experiences of kinship between men through these gaps, auras, and residues. Speaking to the ability of conceptual photography to record this lack, Silano notes, "An image of an obscure hand on a head, juxtaposed against a sky that's vast and empty, can be this poignant metaphor. It can be about the experience of loss that I feel in relationship to my uncle. At the same time, it's this broad stroke where people can enter into and imbue it with their own experience."

Like Silano, Ontario-born, New York-based artist Caroline Falby uses porn and other found images to speak to her relation to HIV/AIDS and family. Falby's work, though, expresses how the continued silence, shame, and stigma around AIDS can also be inherited. Proving that the AIDS crisis is not, in fact, over, Falby's father died from complications from AIDS in 2015 in his 70s. At the time of his diagnosis, he was closeted about his sexuality and even after his passing, only a select few knew of his cause of death. Falby told me that his decline and death was a shock to the family. "My experience was an emotional rollercoaster," she explains, "It was grounded in so many secrets."

Family was previously a rich subject for Falby's artistic practice, as seen in her installation *Mother's Death Tape*, an allegory of an overbearing maternal figure through the imagery of Jonestown. With Kool-Aid cups, collages from vintage women's magazines and signs that say, "Mom says what's the magic word?" Falby not only draws from her relationship with her own mother, but also her life as a mother of twins. She also, ironically, previously exhibited in a show about HIV/AIDS— *Framing AIDS*, curated by Hector Canonge at the Queens Museum in 2009—years before she would know of her father's diagnosis. Being HIV-negative with no immediate familial connection to HIV or AIDS at the time, her inclusion, she divulges, made her feel "like a fraud."

Considering her "practice coming before this was so disclosing and personal," Falby admits that creating work after her father's death and her new connection to the pandemic has been a challenge. Titled *Animations of Mortality*, after a collection of Terry Gilliam's art, Falby's recent digitally printed and collaged works on board contain an amorphous mix of 1950s-style floral wallpaper from the 1980s, barely identifiable pieces of bodies from porn magazines, representations of viruses, and images of walkers and other medical equipment. With copious diaphanous cloud shapes, the works are indicative of the progression of the disease and its opportunistic infections with tumor-like forms, while in their abstraction, they seem to reflect the loss of clarity in the "coded conversations" she would have with her father about his illness and sexuality.

With her vintage sources, such as the prim flowered wallpaper, the works reference earlier more conservative periods, including the 1950s and even the Victorian era, pointing to the stigma of both the closet and an AIDS diagnosis that her dad felt and that she, inadvertently, finds herself taking on. Unsure of disclosing her father's sexuality and cause of death in deference to his wishes, she mirrors that remaining emotional chaos of non-disclosure in her work. She reveals, "The shame narrative is something that's not expressed—the stigma of having a parent or a relative dying and the resentment that comes from someone passing on their shame. It's an inherited shame."



Pacifico Silano, *Boys In The Sand*, 2019. 20" x 16" Archival Pigment Print



Caroline Falby, *The Animation of Mortality: The Renaissance*, 2017. Courtesy of the artist.

In *Loss: The Politics of Mourning*, Eng and Kazanjian state, “To impute loss a creative instead of a negative quality may initially seem counterintuitive.”¹⁴ With the long and expansive legacy of visual art made in the context of the ongoing HIV/AIDS pandemic, finding a creative quality in loss may be less surprising than Eng and Kazanjian theorize. But for artists who explore HIV/AIDS in the family, despite the diversity of their artwork and narratives, there seems to be a central drive to continually and creatively transform loss to maintain “an active and open relationship with history” – both in terms of their family history and the larger ongoing history of HIV/AIDS.¹⁵ By engaging in an intergenerational dialogue with the memories of their biological families and families of choice, the artists, taken together, construct, as José Muñoz articulates in *Cruising Utopia*, “a politics that ‘carries’ our dead with us into battles for the present and future.”¹⁶ As Silano expressed to me: “Some people ask me, ‘Why are you making work about the past? What about now?’ But this is now. This is about now. What is lost and what do we have to carry on?”

By questioning what we have to carry on, these four artists and their multifaceted articulations of the intersection of HIV/AIDS and family raise the notion of inheritance. What is inherited through a family affected by HIV/AIDS or even, a culture that has been transformed by the pandemic? In “I don’t know what made this ‘private’ in the first place: Neil Greenberg’s Not-About-AIDS Dance and ‘The Disco Project’ for *Drain*, Jaime Shearn Coan writes, “My own position, as a familial and cultural inheritor, is one who is haunted.”¹⁷ As someone who has been publishing about HIV/AIDS since 2010, but has been writing about AIDS since my freshman year in college when reading David Wojnarowicz’s *Close To The Knives: A Memoir of Disintegration* put my own familial experiences of loss due to complications with AIDS into a cultural context, I



Caroline Falby, *The Animation of Mortality: Old Ladies*, 2017. Courtesy of the artist.

am a familial and cultural inheritor who is haunted too. This haunting also transferred into my curatorial work. When co-curating *Party Out Of Bounds: Nightlife As Activism Since 1980* for Visual AIDS in 2015, I recall remarking to several colleagues that I felt as if I was dealing with ghosts. Even if many of the included artists were still alive, there was still a sense of responsibility in honoring and producing a curatorial dialogue with those who were not.

The cultural inheritance of AIDS isn't only for people born with HIV, living with the virus, or those, like me, who have experienced a family member dying due to AIDS-related illnesses. When part of a culture that sustained losses due to the pandemic, whether the New York arts or LGBTQ+ community, the absence of those who would potentially have acted as mentors or made up our families of choice is inherited, too, as is their continued presence through their remaining archives and cultural objects. Admittedly, it seems strange to attribute silences and limitations in the mainstream representations of HIV/AIDS, and copious amounts of loss as something that is inherited. However, I understand this familial and cultural inheritance as something ephemeral and not always conscious. It exists as a sustained and potentially haunted drive to revisit, rework, and revise the gaps in this inheritance, trying to find that touch across time even if it's through what remains.

Notes

- 1 Oli Rodriguez, "Prologue," *The Papi Project* (2017), 12.
- 2 Julianna Pidduck, "Queer Kinship and Ambivalence: Autoethnographies by Jean Carlo-musto and Richard Fung," *GLQ: A Journal of Lesbian and Gay Studies* 15, no. 3 (2009): 442.

- 3** See: Kath Weston, *Families We Choose: Lesbians, Gays, Kinship* (New York: Columbia University Press, 1991).
- 4** Sophie Junge, *Art About AIDS: Nan Goldin's Exhibition Witnesses: Against Our Vanishing*, translated by Laura Radosh (Berlin: De Gruyter, 2016), 96.
- 5** See also: Visual AIDS's panel *The Personal And The Political: Losing Parents to AIDS*, with Alysia Abbott, Kia Benbow, Mathew Rodriguez, and Sarah Schulman, hosted by the New York Public Library, which is archived on YouTube (<https://www.youtube.com/watch?v=BnZsMDEZV98>).
- 6** David L. Eng and David Kazanjian, "Mourning Remains," in *Loss: The Politics of Mourning* (Berkeley: University of California Press, 2003), 2.
- 7** *Ibid.*, 1.
- 8** Kia LaBeija, as told to Alex Fialho, *Artforum* (January 2018), accessed online January 12, 2019, <https://www.artforum.com/print/201801/kia-labeija-73184>.
- 9** Carolyn Dinshaw, *Getting Medieval: Sexualities and Communities, Pre- and Postmodern* (Durham: Duke University Press, 1999), 21.
- 10** "Five Questions for Kia LaBeija," *BH Is Voguing* (22 February 2016), accessed online January 12, 2019, <http://www.bhisvoguing.com/kia-labeija-english/>.
- 11** Kia LaBeija, as told to Alex Fialho.
- 12** Kemi Adeyemi, "Landscapes of a Queer Life Lived," *The Papi Project* (2017), 110.
- 13** José Esteban Muñoz, *Cruising Utopia: The Then and There of Queer Futurity* (New York: NYU Press, 2009), 42.
- 14** Eng and Kazanjian, "Mourning Remains," 2.
- 15** *Ibid.*, 1.
- 16** José Esteban Muñoz, *Cruising Utopia: The Then and There of Queer Futurity* (New York: NYU Press, 2009), 46.
- 17** Jaime Shearn Coan, "I don't know what made this 'private' in the first place.: Neil Greenberg's Not-About-AIDS Dance and The Disco Project," *Drain Vol. 13:2* (2016), accessed January 12, 2019, <http://drainmag.com/i-dont-know-what-made-this-private-in-the-first-place-neil-greenbergs-not-about-aids-dance-and-the-disco-project/>.

Emily Colucci is a writer, curator and co-founder of *Filthy Dreams*, a blog analyzing art and culture through a queer lens and a touch of camp. Emily is the recipient of a 2016 Creative Capital|Warhol Foundation Arts Writers Grant for *Filthy Dreams*. Writing for print magazines, online venues, and exhibition catalogues, Emily has contributed to *VICE Magazine*, *POZ Magazine*, *Flaunt Magazine*, *Muse Magazine*, *ArtVoices Magazine*, *Salon*, *LA Review of Books*, *Art Papers Magazine*, *Hi-Fructose Magazine*, *Malibu Magazine*, *Art F City*, *Ms. Magazine*, *Frontrunner Magazine*, *CRUSH Fanzine*, *New York Magazine's Bedford and Bowery*, *WhiteWall Magazine*, among others. In 2017, she curated a group exhibition, *Night Fever at Pittsburgh's Future Tenant*, on disco and its aesthetic legacy. She also co-curated Visual AIDS's annual exhibition *Party Out Of Bounds: Nightlife As Activism Since 1980* at LaMaMa Galleria, as well as its satellite installation *Courtship Disorder* by John Walter in London's White Cubicle Toilet Gallery at the late George & Dragon Pub. *Party Out Of Bounds* was featured in *I-D Magazine*, *OUT Magazine*, *Hyperallergic*, *The Art Newspaper*, *Unicorn Booty*, *New York Magazine's Bedford + Bowery*, *Posture Mag*, *Paper Magazine*, and *Sang Bleu*. Deemed (by herself) the "art critic of trash," told that she writes from a "contrarian personal sensibility" and that she represented "everything stupid about the Internet in 2017 in one tweet," Emily is interested in nightlife, trash, AIDS activism, and queer activism in art. emily-colucci.com

Positive Space: An Exhibition Project on HIV/AIDS in Turkey

Alper Turan

While I was writing this text, I took a break and invited a guy to my house from Hornet (a sex-app widely used by gays and transgenders in Turkey after Grindr got banned by the government). After the preliminary chit-chats, I went downstairs and when I came back, I saw him looking at my computer screen populated by the text you are about to read, and I thought to myself, "Fuck! Now I have to explain HIV to him." But no, on the contrary, he asked: "Are people still getting depressed when they get HIV?"

I did not know what to say, so I turned the question back to him: "What do you think?" I breathed a sigh of relief when he began talking about his ex-ex-ex-boyfriend from Georgia who is a depressed gay guy living with HIV for more than three years now.

After he stopped speaking, it was quiet between us. I was not sure what to say. Finally, I think as much to me as to his ex-ex-ex, or the world, he asked, "HIV, What's the big deal?"

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Exhibition shot *Positive Space* curated by Alper Turan, artists: Ardıl Yalınkılıç, Artık İşler, Can Küçük, Ceren Saner, Furkan Öztekin, Elmgreen&Dragset, Güneş Terkol, İz Öztat, Leyla Gediz, Nihat Karataşlı, Onur Karaoğlu, Özgür Erkök, Operation Room, İstanbul, 2018. Courtesy of Operation Room.

Being inspired by artistic and activist interventions of the 1980s AIDS crisis; seeing curating as collective and affective process of thinking; and as someone dealing with HIV since I was twenty years old, I curated an HIV/AIDS exhibition with the motivation of initiating a contemporary, lively, local discourse on HIV/AIDS in Turkey which has never been studied in art or in the social sciences. The project's foundation laid with the participation of my fellow artists, and then became more broad. I spread the word, asked around, and invited a few Turkish contemporary artists who are HIV+ and HIV- or with undeclared serostatus; self-defined queer, gay, and cis-heterosexual; established or emerging artists to either produce new artworks questioning and exploring the issue, or to show their earlier works which could be interpreted in this context of HIV. The motivation was to render HIV/AIDS discussable through the power and freedom of artistic practice and to create a "positive space" where this often undetectable, hush-hushed issue can be on display in a polyvocal, dialogical, relational, and discursive manner.

The exhibition opened on December 1, 2018 in "Operation Room," a project space of a private and high-class Turkish hospital, the American Hospital (inherited from Red Cross). Curatorially locating HIV in the medical environment raised eyebrows among some friends, but the aim was to wash away the sullen hospital experiences many seropositive and many queer individuals have, with the environment itself. By penetrating the medical gaze with an exhibition, we were also declaring our presence in the public as queers and people living HIV. *Positive Space* strategically legitimized talking about queer sexualities within the frame of HIV/AIDS and used that frame to create "queer corners," a term Dina Georgis uses while giving a definition to her book, *The Better Story*, which is "ultimately a search for the stories of the discarded in history, which is why we need to look in queer corners."¹ Georgis' book offers deep insights on creative and subjective narratives as coping mechanisms with collective historical trauma.

Many local and international NGOs attempt to erase the "gay disease" label from AIDS, to make possible donors and other gatekeepers feel comfortable and to guarantee cooperating opportunities with often conservative governments. This exhibition antithetically gave privilege to queer artists' participation. The idea was not to conceptually marginalize the virus nor to exclude the other vulnerable groups, rather, the inclusion of queer artists was essential with regard to HIV/AIDS's both ongoing tangible impact on the community and its ongoing trauma. To create queer corners was also a necessary attempt to draw from the 1980s, a time in which queer communities in the West united in the struggle against HIV/AIDS and, in this struggle, fought for their sexual freedom and culture and against discrimination and marginalization.

Among the participants of the exhibition, there are artists whose personal experiences, traumas, and transformations with HIV were known by me beforehand. But I didn't want to just include positive artists; inviting only people living with the virus to exhibit is not a good curatorial strategy. In addition to the fact that segregating seropositive artists would be problematic for those who are not open about their status, it is clear that HIV is not a problem only for those who have it, but most of the time, more a haunting concept for those who are attached to their fantasies about it. The exhibition intended to contaminate the metaphorically loaded meanings of HIV following Treichler, who brilliantly exposed the discursive dichotomies inherited by HIV/AIDS such as self/not-self, perpetrator/victim, vice/virtue, love/death, sex/death, science/not-science, knowledge/ignorance, doctor/patient, guest/host, virus/victim,² but also with positive/negative, sterile/abject, vulnerable/protected, risky/safe, monster/victim, stigmatized/stigmatizer, secret/disclosure. The hetero-serostatus setting of the

exhibition's participants facilitated these dichotomies from different perspectives to be discussed and to be put into porous dialogues, and this variety of perspective nurtured the artworks exhibited: some of them tackled the issue as social phenomenon, others offered an intimate confessional experience, others psychoanalytical shatterings. Some artists explored HIV as a seronegative heterosexual; some felt like an advocate for being HIV+, some wanted to say what had not been verbalized, show what had not been visible, embody what was contagious, monstrous, abject in the form of art. What was common among all the participating artists was the desire to take action. Just like what artists both collectively and individually did in the 1980s, by creating another level of aesthetic which makes visible heretofore unintelligible social and political forms, the artists involved in this project created an aesthetic of being-together.³

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The exhibition was divided by a wall into two sections within the gallery space, creating two contrasting areas and a liminal space—the wall itself. Behind the wall, there was an inner black space which stood for an “interior,” inside of the body, deep inside of the issue, but also for invisibility, secretiveness, or secretive intimate sexuality, while the outer white-walled space, under white lights, resembled an “operating room” or a public realm which tackles with HIV by documenting, interrogating and analyzing it. The wall between was full of real and imaginary holes, cracks, and interspaces, and with that nature, it imitated a porous skin. They entered and exited public and private spheres, social and intersubjective bodies.



Exhibition shot *Positive Space*, video documentation: <https://vimeo.com/335860129?fbclid=IwAR0f51w1NNkbjYqmhk2iM2c3hYZC49mJlmDvi20a-gL-0ktqHx2GA6HqpKjI> by Beril Ece Güler. Courtesy of Beril Ece Güler.

Upon entering the space, positioned on the shelf next to the exhibition texts and maps, there was a modest gift—a heap of temporary tattoos. Artist Can Küçük took the biohazard sign, used by some HIV positive people to announce their status by tattooing the symbol on their bodies and turned it into temporary tattoos, inviting everyone who entered this space to ephemerally mark themselves with it. Sociologist Erving Goffman defined stigma as “an attribute that is deeply discrediting within a particular social interaction.”⁴ Tattoos, once used as a mark made on the skin of enslaved and incarcerated people; stigma is a mark placed upon the body “to indicate that the bearer is somehow inferior, polluted or corrupt.” Since an individual living with HIV in the contemporary post-life-saving medicine era does not often have any physical symptoms, the illnesses have become invisible in public; therefore HIV “visibility” depends on “disclosure,” which is giving certain comfort to those who do not want to verbalize their serostatus, but consequently that invisibility and ongoing non-disclosure of HIV mystify the virus, which does not have reliable, tangible public testimony in Turkey.

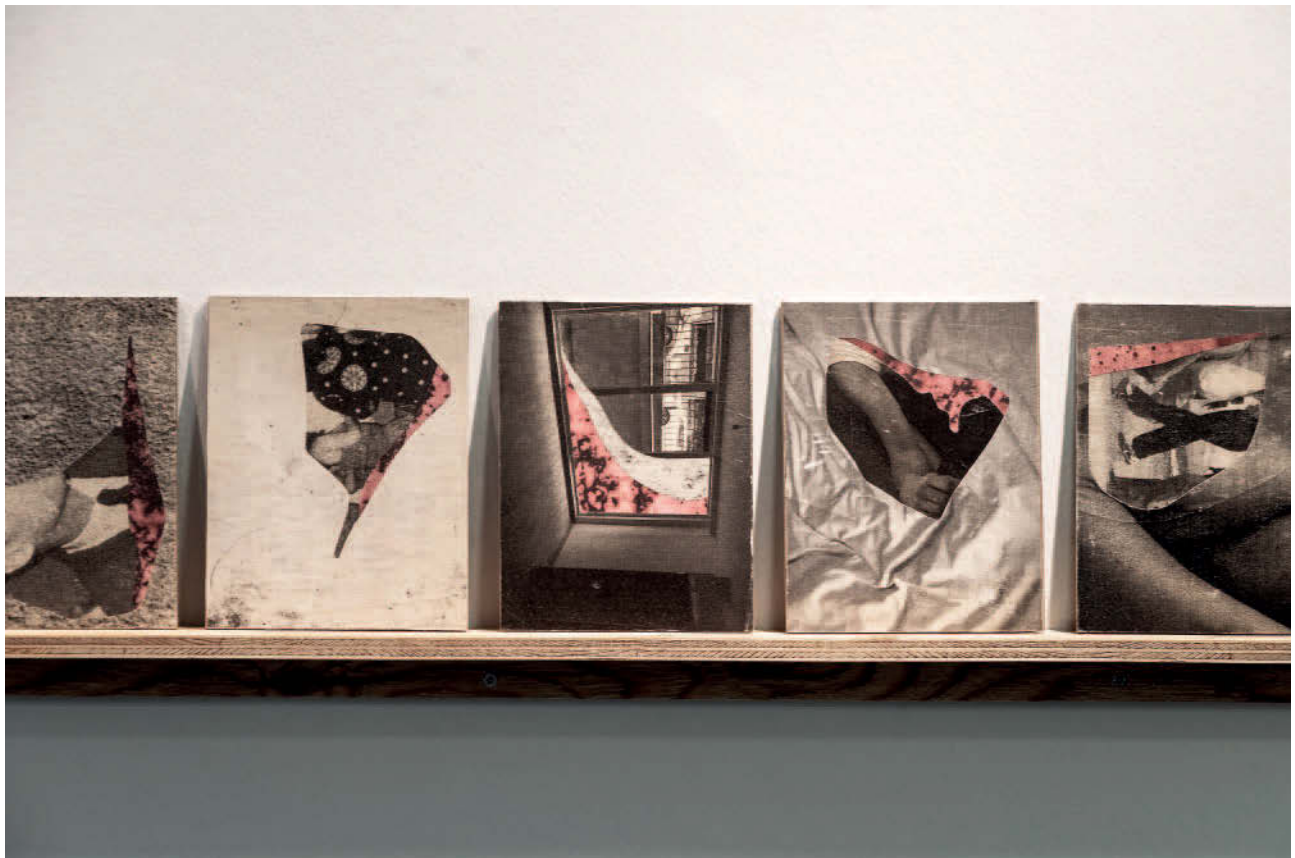
This invisibility is interconnected with the hypervisibility of repressed queer sexualities in Turkey. Turkish authorities issued a ban on events held by LGBT groups ostensibly over concerns for “public security.” With the same pretext, Pride marches, which are different from contemporary Western ones, have been banned for the fifth year in a row now. We have not been allowed to gather legally and publicly, but we do. We still fill the streets by dispersing the march into every possible corner of the city instead of gathering together as a bulk of people; we march knowing every march is a Pride march, we raise flags, dance, and fuck until forcefully dispersed by tear gas and rubber



Can Küçük, *Temporary tattoo*, 2018. (The artist applied his tattoo work on his neck). Courtesy of the artist.

bullets. Turkey has one of the worst records of human rights violations against LGBTI+ people, and the highest transgender murder rate in Europe. Entering the exhibition, two pairs of jeans with two sets of underpants on the floor greet visitors, after the invitation of the temporary tattoo. These anonymous, abandoned Levi's pants and Calvin Klein underwear side by side are the work of Elmgreen & Dragset, the exhibition's unique international participants who were the curator duo of the last Istanbul Biennial. The work, titled *Powerless Structures*, *Figure 19*, is part of the duo's multi-piece series of object transformations and is referring to the absence of the body, the vanished body, the invisible naked body. The homosexual body here is marked by absence, by the eroticism of the absent. The owners of the pants, the two invisible, unclad bodies are either together having fun in the darker space or disappearing into it.

Furkan Öztekin's collage series titled *Tab* practices an online search for AIDS visuals in Turkish. He opens tabs with the sensational images of AIDS cases he found in Turkish media archives, images from the *KAOS GL*⁵ magazine, some drawings, some photographs taken from inside and outside of the hospital where the exhibition also takes place. Copied, recorded, and created images come together and contaminate each other; they become as neutral as a virus, mixing positive and negative spaces of the conventional composition. Öztekin hides the faces and identities, accentuates the invisibility. We can detect the archival images very partially from Öztekin's collages, which appeared in an in-your-face manner on the shelves displaying Serdar Soydan's research material. Soydan pulls from his archive and displays magazines, posters, and books that draw the attention of the Turkish public to AIDS in the 1980s and 1990s, while dictating norms of public health and morals that demonize implicitly queer



Furkan Öztekin, *Tab Series*, (detail), 2018, Courtesy of Ali Betil.

(since discussing queer sexuality in the public realm has never been really possible) but explicitly all sexualities taken outside of the family structure.

Drawing from Soydan's study and performative presentation as a part of *Positive Space's* programming, I want to open up a space to talk about Murteza Elgin who is the first victim/hero of AIDS in Turkey. When the new and fatal infection first emerged and during the epidemics' crisis in the 1980s, AIDS was highly scandalized and mediatized in the public sphere, just like anywhere else. In November 1985, after a year-long transfer and translation of international AIDS news, Turkish media finally found its own local tangible object of display and pity, of judgment and curiosity, of inspection and fear. On November 2, the banner headline of the popular daily newspaper *Hürriyet* was sharp and direct: "Here is the Turk with AIDS." This targeting phrase is reminiscent of a description made by the *New York Post* about the widely believed patient zero of AIDS in America: "The Man Who Gave Us AIDS." The first local example of HIV/AIDS in Turkish media appeared with the help and initiative of a professor of medicine, Hüseyin Sipahioğlu, who later ironically became the chairman of an AIDS association in the Turkish Mediterranean. At the beginning, Elgin's name was hidden by popular media and he was mentioned as "M."; however, because Elgin was a known figure in the mainstream entertainment business of the 1980s and he was a peer of popular sex stars, singers, and actresses, it didn't take long for his face to become associated with the fatal disease. From there, he became a long-lasting target of public interest. After the announcement Sipahioğlu made without any regard for Elgin's privacy, the Turkish Ministry of Health denied the claim, blamed the doctor, and simply said: "There is no recorded case of AIDS in Turkey." Later on, Elgin was put under observation by state officials and was forced to be tested and isolated while he tirelessly made statements to the newspapers that he did not have AIDS. In the show, I included one of the pictures taken when Elgin was set free from the hospital, where he was forcibly kept in segregation under medical observation by the state, as exhibition promotion material. In this photo, showing him exiting the hospital as a hero, his arms are wide open in the air since his release meant for him that he did not have HIV and that his doctor, as well as the state officials, were wrong. We put this photo, found by Soydan in media archives, on the outer windows of the gallery printed in a large format so that Murteza could salute both the exhibition and hospital visitors.

The mainstream newspapers labeled v as a "public-enemy." One of them published a list of people from show business who were still in physical contact with Murteza Elgin. These public faces, as well, became the objects of suspicion since they might have AIDS. While Elgin had been shown as someone to run away from, his fame tripled as a result of being a viral sensation, and a year after his first appearance on the newspaper, he got on the stage at the İzmir International Fair, the oldest trade show and international display-ground in Turkey, which hosts a series of simultaneous festival activities and concerts. Besides being a stage of Turkish secular modernity, this fair was famous for a queer 'display': in 1980 on the same stage, Bülent Ersoy, the hypervisible transgender singer, showed her freshly operated breasts to her curious and enthusiastic audience, and this led her to being banned from stages for a long time. Elgin must have been rightfully inspired by Ersoy, and by taking advantage of being a figure of public interest, made a spectacle of his body with AIDS, and the people came to see him. Elgin was the only visible public figure living with AIDS, though his structured visibility which was the co-production of phobic biomedical and media discourses only contributed to producing more stigma among the general public. When he died of an HIV-related opportunistic infection in 1992, apparently there was no progress. Even after his bare life evaporated, the body suffered. Out of fear



From Serdat Soydan's archive: *Murteza Elgin leaving the hospital where he was segregated.* (image manipulated by Umut Altıntaş), Courtesy of Umut Altıntaş.

of contamination, his body was washed, wrapped in nylon, put into a zinc coffin, and buried in a lime pit. There were three people at his funeral, and no one wanted to carry his casket; it took hours for journalists who were present at the funeral to feel pity and carry his body to a waiting hearse.

Since Elgin, representation of HIV/AIDS in the media has always been related to scandals akin to the ones taking place in States: the isolation of a six-year-old HIV+ student in a public school (with a certain emphasis on the innocent child as future citizen, the future of the nation versus sinful parents); the panic of hospital staff members facing an HIV+ patient; transmission of the virus via the blood taken from Turkish blood-banks; the question of sex workers' status; confinement of a Russian sex-worker in a single cell (highlighted by misogyny and xenophobia). If not a scandal, there has been no information on or no representation of HIV/AIDS, no public figure disclosing or verbalizing her status; even among our immediate queer entourage, it's an "open secret," a handful of people feel comfortable talking about it. Ultimately, no matter how great the medical progress has been in the last two decades, the virus is still being mystified by the general public, which causes internal and/or external stigmatization in Turkey.

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When I was first diagnosed five years ago, I was desperately in need of attributing a “face” to that virus. My question was simple enough: “Who has HIV other than me now?” In my immediate circles, on the other hand, what was known about the virus was just some rumors about some “marginal” homosexual people who have it and who were said to be having unsafe sex regardless of their status, moreover, in order to spread the virus. The faces of these marginal “homosexuals” were blurred with the information coming from third parties. For the twenty-year-old me, it was somehow acceptable not to know much about HIV. Even that itself explains the lack of sufficient discourse on HIV and its transmission. Nevertheless, another persistent factor in the face of HIV was denial. I knew that there was something called AIDS, but I did not know how and when the knowledge had been transmitted to me. I was not willing to know more about it before I tested positive. I could easily comfort myself, saying that there must be no people with AIDS in Turkey since we do not see any of them. The only people who got AIDS were international singers, artists, or philosophers from the past.

Soydan's archive work offers an opportunity to examine how information, trauma, and fantasy were constructed in the recent past. He invites viewers to dig deeper into the causes as to why HIV-positive people had to hide their faces, and how HIV was turned into a shameful crime. This connects us to Leyla Gediz's portrait of a figure who hides his face. In her work titled *Cocoon*, she draws the portrait of a friend who had freshly



Leyla Gediz, *Cocoon*, 2009, Courtesy of Leyla and Arif Suyabatmaz

tested positive in her paintings dating back to 2009 that had never been displayed in Turkey. As the figure on the canvas tries to adapt to this new piece of information, he is introspective, he is about to turn into a cocoon. Like this painting to which the pain of others refers, one of the issues that has to be taken into account today is how the collective trauma and post-memory reveal themselves in the face of AIDS as intergenerational transmission trauma, and what AIDS means for the generation who was born during or after '80s. Why is it still that traumatic to learn that you are HIV positive in the contemporary era in which the destructive effects of HIV can easily be fully controlled thanks to ever-upgrading life-saving medicines?

I was not a witness to the first international AIDS crisis since I was born in 1993, just before the discovery of life-saving medications. Consequently, I was not subjected to the mediatized images of ill and contagious bodies. From my generation onward, the first contact with HIV/AIDS must be different from the first reactions against the epidemic. Nonetheless, seeing the silenced, invisible, and taboo nature of it, fundamental knowledge about HIV/AIDS comes with rumors or unreal assumptions. I remember being told the urban myth about the “contagious” needles left on seats in movie theaters by hateful, perverse, criminal, probably homosexual individuals in order to spread the virus. Even for us, who were born into a world where AIDS did not have to be a fatal disease anymore, the everyday reality is different. Thus, the traumatic resonance, independent of medical progress, remains with the infection.

When I was diagnosed, I was lucky enough to have access to “reliable” sources where I could get information about the virus, but for quite some time, I was sure that this virus would still steal at least ten years of my life. Later on, I met some people who could not get over their suspicion about the transmission of HIV even though they knew a lot about the limits of the virus. I also know someone who locked himself in a room for months after learning his serostatus and did not want to know anything about the virus. And this is one of the participant artists of the exhibition. Ardil Yalınkılıç, as a young generation artist, use this experience in his confessional art piece, and probes his personal history by displaying this correspondence with his mother in 2012 simply by printing out the e-mails. Upon learning his serostatus, at the age of twenty, Yalınkılıç isolated himself for months and he just let himself go into long-lasting depression, believing that there was no treatment for AIDS and that he would die soon. After three months of self-segregation, he found out that he was actually HIV-. It was a “false alarm” but its being false does not make it less alarming since HIV is most commonly traumatic combination of three initials. The letters between Ardil and his mother starts when he finally knew his actual serostatus; this “relief” let him rebuild up a conversation with his mother who was restlessly trying to reach him. Ardil and I were quite skeptical about putting these letters on display, since they might offend some HIV+ individuals with these highly dramatized, politically-incorrect, even HIV-phobic, statements full of disinformation and exaggeration quite obviously uttered in these written dialogues. When the bitter reality epitomized in these conversations was taken into consideration, it was necessary to show these shameful testimonials of two generations' reaction to HIV/AIDS. He offers evidence of what it can mean to have the easily repressible fatal virus, and the role that expression and communication can play within the ongoing crisis.

How come the image or the idea of death is so persistently associated with HIV/AIDS? Is it just because of the lack of knowledge about the virus? Alternatively, is the image of death, consciously or unconsciously, something to be called upon and have a place in the general picture in any case when the question is HIV/AIDS or even any disease?

March 13, 2012 1:54am

Firstly, I want to tell you a story of mine with a positive ending. I was afraid that Ahmet could contract ^{HIV}AIDS and was very worried about it since last year. I had a test done in a private hospital a few months ago. The result was 0.25 positive. Below this value, it is considered negative whereas above it is considered positive. So, you can imagine my mood when I found out I had ^{HIV}AIDS. It was a very difficult and trying time for me. But, a few days ago, I had the test done again in a state hospital and I found out that I was not ^{HIV}AIDS positive. I think that the private hospital wanted to make money by assigning a mean value in order to administer further tests after the Elisa test. That was not all, of course. Although I was glad I didn't have ^{HIV}AIDS, I was in a bad mood because of all the things I had been thinking during that period. I feel I'm getting better with the negative result. The medication started to show its effects. This was one of the reasons for my anxiety disorder.

But in any case, I'm angry with you. Maybe you don't realize that you put the blame of the negative things you go through on me, but that's the reality. ^{This is not true} For example, I'll never forget that you put the blame on me about the breast cancer the last time I came to Ankara. Also, about your anxiety problem, ^{HIV}AIDS was just the thing to feed your fears. So, I couldn't allow it.

I have a confession to make. If you tell this to my father, we'll really have a falling out with you. I will say this because I am aware that secrets in relationships, like homosexuality, cause problems. When I got the false news of positive for ^{HIV}AIDS, I turned my back on people, and even life. I had morbid thoughts on death. I didn't leave my room for a month, and failed all my classes because of absence. But that's OK because life is really worth living. Even when I felt death was very near, something happened and I left my room. They say what doesn't kill you makes you stronger. It's a cliché but it is so true. Actually, I realised many clichés are true. But of course while making you stronger, they also take away things, too.

But like I said, life is good. I'm recovering the sense that I'm protected. I see that I'm loved and can love. I have a feeling that everything will be alright. Knock on wood. I feel good. The past months seem like a bad preparation phase. Kisses.

March 13, 2012 4:32pm

Ardil, if there is a God or a supreme power, may He not make me suffer your loss and give you what's left of my life. How did you carry such a heavy burden, son? I beg you not to hide anything from me. We'll do whatever we can. I cannot get rid of the pain even though the result is good. I experienced it as if it happened. All these things worried me. Please go to a university hospital again, son. Be especially careful about this. Oh, Ardil! I am so sorry for everything you hid from me, for all the risks you've taken, for the possibility that it can happen. Of course I won't tell anyone. School is not important. You can complete your courses later. Don't you tell anyone, either. Everyone will turn away from you. Son, all these will come to pass. Just make sure to survive. Write to me the results so that I can ask other doctors. Son, although I make mistakes, I can do anything for you. Don't you forget that.

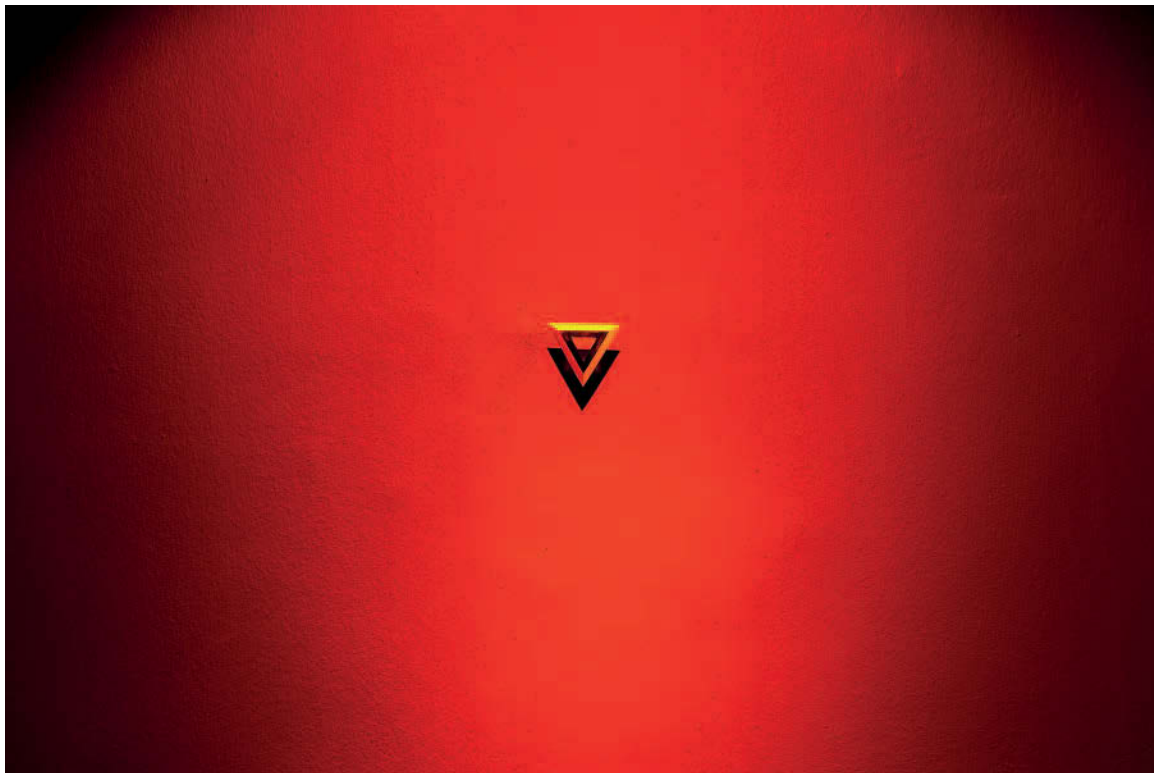
I apologise for the breast issue. We'll talk about the reasons later. Maybe I did it so that you felt more responsible towards me. Of course you're not responsible. Nothing may happen after all. I'll go in for a follow up in June. Even very young people get it. It is very common nowadays. Especially after what you've written, I don't care. Everything will be alright. We just

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Similarly, the image of the sick body with AIDS was so penetrating that after the discovery of the medicine, a healthy body and its image became something to be achieved among homosexual males. Many see the contemporary phenomenon of the super-healthy, hyper-masculine, muscular, over-sexual gay body image as a reaction to the sick and skinny, vanishing "AIDS" body.

Again, I know some seropositive Westerners much older than me who witnessed the first period of the epidemics but who were infected much later, and many of them mentioned how devastated they were mentally for a long while after they first got diagnosed, even though they already knew many PLWHA and they were residing in countries where the public awareness is much higher, and stigmatization is much lower.

Regardless of the changing nature of the HIV since the 1980s, its construction has not been shattered, since the gained progress in medicine and regained quality of life of HIV+ individuals do not attract as much attention as the past. Getting infected by HIV is still universally seen and consequently experienced as a traumatic event that makes one ultimately vulnerable. What is taking a stand against HIV's normalization, I believe, is the lack of testimony from the present, and the ongoing intergenerational and transnational trauma that is transmitted via post-memory in the field of HIV-related and queer cultural production. Marianne Hirsch describes post-memory as "an intersubjective trans-generational space of remembrance, linked specifically to cultural or collective trauma [...] defined through an identification with the victim or witness of trauma."⁶ As to the question of HIV/AIDS in Turkey as a taboo topic, the trauma bringing the ongoing construction around it has been transmitted via its silence, invisibility, and unrepresentability. This is what my exhibition was about, and what much of my work since continues to explore.



Iz Oztat, *Untitled*, 2018, Produced by Brac Knives, Courtesy of the artist.

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Now that I have finished this text, I think back to my Hornet hook-up, and his question: "HIV, what is the big deal?"

And I realize that this is the question I too have been asking.

Notes

1 Dina Georgis, *The Better Story: Queer Affects from the Middle East* (New York: SUNY Press, 2014).

2 Paula A. Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham, NC: Duke University Press, 1999).

3 Jacques Rancière, *The Emancipated Spectator* (London and New York: Verso, 2009).

4 Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York: Simon & Schuster, 1963).

5 The magazine of the oldest LGBT organization based in Ankara, founded in 1994.

6 Marianne Hirsch, "Surviving Images: Holocaust Photographs and the Work of Postmemory." *The Yale Journal of Criticism* 14.1 (2002): 5-37.

Alper Turan (b. 1993, Ankara) lives and works in Istanbul. Turan is freelance curator and co-founder of Das Art Project, a curatorial collective that uses thematically-specific buildings, often with historical significance, to realize ephemeral exhibitions with mostly younger generation artists. Turan, most recently, curated *Positive Space*, an exhibition project on HIV/AIDS in Istanbul. This project also lays the ground of his Cultural Studies master research in which he merges critical reading of art works with (auto)ethnographic accounts. Turan works on curating as ethnography, queer curating and exhibition making strategies.

How to (Dis)quiet a Vampire

Vladimir Čajkovac

Based on research of the international AIDS poster collection of the German Hygiene Museum in Dresden, the essay reflects on the museum exhibitions as a tool / method for disrupting the well-established scenarios and symbols of the AIDS epidemics and an opportunity to introduce Rashomonic destabilization into the official medical and cultural narratives of this phenomenon.

– Vladimir Čajkovac



Vladimir Čajkovac, *basis (AIDS Based on a True Story)*, 2015. Courtesy of Čajkovac.

“Based on a true story,” “Based on true stories,” or “Based on true events” is an idiom borrowed from the film industry. Used very often and abused even more. A mere mention of this phrase is intended to provide credibility to the stories and promise authenticity to the audience. It is a framing method used to reaffirm the recipients with the assurance that it is more than safe to suspend their disbelief and accept the upcoming unfolding of events as a witnessing endeavor.

As museum fellow and curator at the German Hygiene Museum in Dresden from April 2013 to September 2015, I had chance to delve into the presumably largest, continuously growing collection of AIDS-related posters, consisting of more than 10,000 posters from more than 150 countries worldwide. The project “AIDS as a Global Media Event” and resulting exhibition *AIDS - Based on a True Story*¹ (with Kristina Kramer-Tunçludemir)

examined points of transition where the AIDS posters went from being instruments of health education to museum artifacts, highlighting processes of transformation of the epidemic from an illness into a historical narrative. Although the primary intention of the fellowship was to build keywords systematics, which was supposed to bring more order into the collection, very soon it became rather obvious that order and cleaning are the last thing that research on HIV/AIDS narratives should provide. Instead, the research focused on deconstructing one of the overarching keywords used extensively in museological representations of the HIV/AIDS epidemics, particularly in the genre of the HIV/AIDS poster exhibitions: the fight against AIDS.

G rard Genette defined “paratext” as materials supplied to the main text by the authors, editors, printer, and publishers. “More than a boundary or a sealed border, the paratext is, rather, a threshold. It is a zone between text and off-text, a zone not only of transition but also of transaction: a privileged place of pragmatics and a strategy, of an influence on the public.”² A zone of transition and transaction is an uncannily correct description of the processes that were following the unraveling of the medical and societal definitions of AIDS, dissected as the epidemics of significations by American scholar Paula Treichler. Treichler considered “Turner’s postulates” useful in “rewriting the AIDS text”: “(1) disease is a language; (2) the body is a representation; and (3) medicine is a political practice.”³ In the context of the (museum) creation of AIDS-related narratives, we can add: history is a (tagged)⁴ image.

The critique of professor Dr. Claudia Stein poignantly describes shortcomings of using *the fight against AIDS* as the predominant *paratext* of HIV/AIDS narratives in the AIDS poster exhibitions: “By collapsing two decades of national histories into a singular and would-be unified world fight against HIV/AIDS, the history of HIV/AIDS was visually constructed in terms of this new global subjectivity. Not only were particular constructions of the recent past left out—the local struggles around these objects—but also the construction of the present—the global media industry’s selling of itself through the attack on HIV/AIDS as a ‘global problem.’”⁵ AIDS poster exhibitions reduced to the selection of witty or shocking images with no background stories, pushing the narrative of a global unified response against AIDS, ignore past, present and future struggles and inactivities. Rather than the *fight in* images, it would be more appropriate to talk about the *fight for* images—as in fact it always was the case with HIV/AIDS.

“Total media coverage of HIV/AIDS increased during the early 1980’s, peaked in 1987, and declined steadily through 2001. While this decline in coverage seems to mirror a decline in new AIDS cases in the U.S., it began about six years before the decline in cases, and continued even as the cumulative number of AIDS cases in the U.S. rose above 500,000. Minor peaks in coverage after 1987 coincided with major developments in the epidemic, occurring in: 1991 (Magic Johnson’s announcement that he was HIV positive), 1996 (the introduction of highly active antiretroviral therapy), and 2001 (increased attention to the global epidemic).”⁶

– “AIDS at 21” by Brodie et al.

The above research results, as well as similar findings by Everett Rodgers and James Dearing⁷ (to name only a few), show particularly how AIDS images were shaped as a newsworthy commodity, notably through the US media industry. Rock Hudson and Ryan White were selected as newsworthy victims: “The impact of these two news events [White’s and Hudson’s, author’s note] events upon subsequent media coverage of AIDS was enormous.



Vladimir Čajkovac + Theodore (ted) Kerr, *tell me a story (AIDS Based on a True Story)*, 2015 + 2019. Courtesy of Čajkovac + Kerr.

For instance, prior to July 1985, our six media combined carried approximately 14 AIDS news stories per month. After July 1985, the average number of news stories produced by the six media jumped to 143 stories per month, about ten times the previous rate”⁸ Equally, due to mis/interpretations of Randy Shilts’ 1987 book, *And the Band Played On*, Gaëtan Dugas was falsely cast as the villain who brought AIDS to North America.

It may be surprising to learn that the peak of media interest in the epidemics was in the late eighties, in the year 1987. The vast majority of images and the most common global representations and symbols of AIDS are from a few years surrounding and following this period. It seems as if the concentration on a few selected symbols, such as the pink triangle (1987), the red ribbon (1991), the Benetton campaign (1992), and the movie *Philadelphia* (1993) created more of a distraction and illusion of the public interest, while the media coverage was in constant decline. Through the impact of 20th- and 21st-century mass media, the American lifestyle and images from art and popular culture have left their mark on everyday life around the world, and most of these representations of global epidemics are from the USA. Or, to be precise, the metropolitan areas of California and New York—while defining the AIDS imaginary, the vast inland of the USA is more than often as equally omitted and invisible as the rest of the world.

In the article “Just when you thought it was safe to go back in the water...,” American literary scholar Daniel Selden rewrites the narrative of the AIDS epidemics as Steven Spielberg’s ‘70s blockbuster *Jaws*. For Selden, the

concise summary of the Hollywood film is a perfectly suitable scenario for outlining the AIDS epidemic in its essential points: uncontrollable nature, a deadly primal organism, marginalized groups, and a savior embodied in the proverbial heroism combined with traditional values. Selden's poignant analysis details how closely the AIDS-related stories were and are shaped to fit media tropes of heroes and villains.

The new editing possibilities and aesthetics of mass media were equally documenting and co-creating well-established images of the epidemics in the same ways they have been shaping the reality of the romanticized and supposedly authentic everyday history of *small people*. As a result of this, documentary, personal, and/or fictive accounts are somewhat hard to disentangle. As in the poster campaigns, rather than taking them for granted, it is therefore extremely important to approach the heroes and villains of the epidemics as social and media constructs inappropriate for representing the manifold local responses and effects of the epidemics worldwide. Using the structure of the classical heroic drama, starting with the *exposition* and ending with all the conflicts resolved, it seems to me more appropriate to approach HIV/AIDS narratives as a means of manipulative production akin to the non-linear editing of reality shows.

The first ACT UP actions were carefully staged for the best possible television framing, and the red ribbon was the product of a carefully choreographed campaign for journalists, the media, and the camera.

Geoffrey Bowers and Alex Londres succumbed to the disease, but their story was much better known and reenacted by Denzel Washington and Antonio Banderas in the movie *Philadelphia*, with Bruce Springsteen's soundtrack.

Pedro Zamora was in the hospital and died a several hours after the prerecorded final episode of the reality show *The Real World: San Francisco* aired.

Ryan White had a cameo role in his biopic *The Ryan White Story*. He played a random patient meeting Ryan White, played by Lukas Haas—two real and two fake Ryans, depending on the reality in which we are grounded.

Therese Frare's photography of David Kirby on his death bed used in Benetton campaigns was black and white. For the campaign, Benetton appointed Ann Rhoney, a colorist who worked by hand with oil paints to colorize the photo, because they wanted it to be more realistic.

Microscopic representations of the virus are commonly colorized and composed of multiple single images.



Vladimir Čajkovac, *story begins (AIDS Based on a True Story)*, 2015. Courtesy of Čajkovac.

Considering this, my research concentrated primarily on posters that led to confrontation, misunderstandings, and controversies during the processes of image negotiations all over the USA. Who produced the campaign? Who financed the campaign and what was the aim? How did the interests of the financiers of the respective campaign determine the content of the posters? And how much do marketing and product sales effect health campaigns? Who were the people in the photo: AIDS activists or professional models, “real” people, or the personification of social and political constructs and statistical surveys? And how is the virus itself reimagined in science and tradition? How much did we actually know, after everything had seemingly been solved?

These poster images and poster campaigns are the result of a negotiation between various stakeholders and, like Freudian slips, highlight sometimes rather contradictory social, political, and economic interests:

There was a young black man who is afraid that his mother would recognize him in the embrace of another, white man.

- *There were drag queens looking after their community.*
- *There was a young designer who could not stand bad posters.*

- *There were volunteers who operated telephone services from living rooms.*
- *There was a young, black HIV-positive woman raised by alcoholic parents.*
- *There were seemingly "harmless" subjects deemed inappropriate, such as an unmade bed censored in Oregon, a pair of jeans in Arizona, or a female purse in New York.*
- *A problematic "Star-Spangled Banner" and a white gay guy in San Francisco.*
- *A young Native American woman posing with her dog.*
- *A parka store from Anchorage.*
- *Teepees in boarding schools in Kansas.*
- *Chains in North Carolina.*
- *There were celebrities who were terrified and those who raised their voices.*
- *Barefoot supermodels in NYC.*
- *Ghanaian symbols in the Midwest.*
- *Standards for maintaining, collecting, and presenting federal data on race and ethnicity, federal funds and private fundraisers.*
- *Elephants, superheroes, stilettos, and umbrellas.*
- *And the countless designers, photographers, sponsors, activists, and artists whose stories are preserved in the posters.*

I am not providing names here, as I want to avoid carelessly replacing one token representation with another one. The 10,000 posters in the DHMD collection offer 10,000 ways to retell the messy, hopeful, and hopeless, uncomfortable and complex story of the disease and the phenomenon of AIDS according to true events. Each of these posters has a story waiting to be discovered and (re)considered.⁹

Serbian writer Borislav Pekić wrote *How to Quiet a Vampire* in 1977, a disturbing and fascinating study of confrontation and manipulation. Written in the genre of a *sotie*—a satirical play—the metatextual letters of Konrad Rutkowski, a professor of medieval history and former Gestapo officer who is determined to renounce or perhaps (self)justify his incriminating past, are intertwined with historical facts and philosophical references to Western literature and philosophy. Written thirty years after the end of World War II, the novel mercilessly exposed the intellectual mechanisms of the societal processes of denial and whitewashing.

The period of disinterest in the epidemics of HIV/AIDS after 1996 (or rather 1987?) coincides with the rapid development of the Internet and the availability of images and editing possibilities in unprecedented quantities. In the new settings of a multiverse of images, the processes of a re-emerging interest in the epidemics are less interested in making a new edit of the full story but instead rely on regurgitating and adapting/manipulating the batch of established images. Like in the works of Felix Gonzalez-Torres, a more specific reference lies in the parenthesis, be that (para)tag, label, legend, link, or meme. These framing particles change this history with every use until a commonly accepted consensus and a genuine



AIDS Based on A True Story, DHMD, 2015. Photo: David Brandt, Courtesy of DHMD.

disinterest agree to accept one meaning as canonical. It is too early to succumb to and plainly wrong to accept a clean victory in the unified fight against AIDS as the selected narrative to be preserved for the future.

In the end, three agencies rise up to meet the challenge: law and order, biomedical technology, and old-style ingenuity and self-reliance. Together these three forces join to combat with the peril and, after much self-sacrifice and Herculean effort, the deadly organism is isolated, studied, and eventually wiped out. Many are dead, but American society can now return to normal.

– Daniel L. Selden,
“Just When You Thought It Was Safe
to Go Back in the Water...”

“Based on a true story” as a frame used to describe the AIDS narrative therefore has been purposed to highlight mechanisms of storytelling when approaching the AIDS epidemics and make us aware of the manipulative nature of heroic narratives; to prevent closing of the AIDS stories as resolved and successfully finished; to restock the limited image pool selected to represent global epidemics; to destabilize timelines; to provoke doubt, to undermine credibility, and to disquiet the Vampire.

Notes

- 1** The German Hygiene Museum (German: *Deutsches Hygiene-Museum (DHMD)*) is an interdisciplinary museum in Dresden, Germany. It conceives itself today as a “forum for science, culture and society.” You can learn more about the exhibition and collection at: <https://www.dhmd.de/en/collections-research/research/aids-as-a-global-media-event/>.
- 2** G. Genette, “Paratexts : thresholds of interpretation”, Cambridge ; New York, NY, USA : Cambridge University Press, 1997.
- 3** A. Mooney, “Some Body Wants to Be Normal: An Account of an HIV Narrative,” *Medical Humanities* 31, no. 2 (December 1, 2005): 72–80, <https://doi.org/10.1136/jmh.2005.000198>.
- 4** In the digital setting, we could potentially define this paratext as a paratag. In the regime of subjectivity, a paratag would be a tool of shared imaginaries of everyday life. With images freely and uncontrollably distributed and editing systems being an undisputable staple of the communication repertoire, a paratag is a negotiable zone between image and off-image. The images are constantly in the zone of transaction and transition. a paratag is a parenthesis: it doesn't describe the image but fills it with temporary meaning and takes it further.
- 5** Claudia Stein and Roger Cooter, “Visual Objects and Universal Meanings: AIDS Posters and the Politics of Globalisation and History,” *Medical History* 55, no. 1 (January 2011): 85–108.
- 6** Mollyann Brodie, Elizabeth Hamel, Lee Ann Brady, Jennifer Kates, and Drew E. Altman, “AIDS at 21: Media Coverage of the HIV Epidemic 1981–2002,” *Columbia Journalism Review* (March/April 2004, supplement).
- 7** Everett M. Rogers, James W. Dearing, and Soonbum Chang, *AIDS in the 1980s: The Agenda-Setting Process for a Public Issue* (Association for Education in Journalism and Mass Communication, 1991).
- 8** Ibid.
- 9** The exhibition *AIDS - Based on a True Story* was shown at the DHMD in Dresden from September 2015 until February 2016 and later in 2017 at the International Red Cross and Red Crescent Museum in Geneva, where ironically without the author's consent the name was changed to *The Fight Against AIDS in Images*.
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How to Catalogue a Crisis: An Afterword to *Lost and Found: Dance, HIV/AIDS, New York, Then and Now* (2016) Jaime Shearn Coan

One day someone asks¹ you to remember, to return to a time you don't return to often, and to do so in public, in print, uneraseable. It is both an honor and a burden. You send your words to an email address, a name you don't recognize, and then you get an answer back. The name you don't recognize has read your words and treated them with care, sent them back to you caressed and clean. This is a new feeling and unexpected. You start to think of the name you don't recognize as having dimension, having listening ears, and you know nothing about them except the way they handle your words.

You are writing about ghosts to a ghost, and then you are no longer a ghost, or your ghosts are no longer ghosts. They enter into a three-way with you and your ghosts, they know things although they weren't there. They are the bridge that puts you into relationship with the others. You can't know what the others are writing, but you feel the edges around you, you feel them waiting to receive you. How do you know you can trust your own memory, your own way through the words and the years?

You wanted to create a memorial, or you wanted to destroy one. You wanted to speak clearly but softly. You wanted an apology, or to apologize. I was cc'd. The managing editor. I had all these strings hanging from me. I was hungry and exhausted and needy, but quiet about it. You were surprised at how closely I looked, how I took apart the words in my hands and reshaped them before they could harden against themselves.

I. Platform as Curatorial Model and Iteration

Danspace Project's *Platform 2016: Lost and Found* reckoned with the impact of HIV/AIDS on downtown dance in New York. More specifically, it sought to explore how the early years of the epidemic affected multiple generations of dancemakers. It did so by taking a multifaceted approach, including performance reconstructions, newly commissioned dance works, film screenings, readings, conversations, a zine project, a vigil, and a catalogue. The Platform model, an artist-curated "set of exhibitions that unfold over time,"² was developed in 2009-2010 by Judy Hussie-Taylor, Executive Director of Danspace Project.

Lost and Found was co-curated by Ishmael Houston-Jones and Will Rawls, two black queer men of different generations, backgrounds, and aesthetics, both connected to downtown dance and invested in questions of blackness, queerness, and experimental dance. They desired to mitigate the erasure of people of color from historical and contemporary narratives of HIV/AIDS, to emphasize the current demographics of

HIV/AIDS, and to address and honor the work of grieving and caregiving that has so often been performed by women.³ The initial impetus for the Platform was Houston-Jones' rediscovery of a zine he and his friends had made in 1998 on the 10th anniversary of the death of their friend John Bernd. Thus, the Platform was initiated by an archive but also by an absence—what dance works might have been brought into existence? What were the effects of illness, trauma, and death on aesthetics, on relationships, on younger artists deprived of mentors and teachers?

II. What's in a Catalogue?

I was brought on as a Curatorial Fellow to work on the Platform primarily because my doctoral research focused on queer sociality and performance in '80s-'90s New York in the context of the advent of HIV/AIDS. Additionally, I was, and am, a dance writer and active in the community. Long accustomed to working independently, I suddenly found myself part of a curatorial team (a durational performance if there ever was one). We would sit around a table in a windowless conference room on Second Avenue: Will, Judy, Ishmael, Lydia Bell, (Program Director at DSP), myself, sometimes others. The walls were orangey-pink, and we could choose lamplight or overhead fluorescents. We met and we swapped ideas, threw out names of performers, allocated tasks, created timelines. This was a collaboration, nothing belonged to anyone, we had a common goal and we wanted to get there together. It was beautiful, the way our minds worked together: high-speed, short-cutting, adding to, dialogic.

The catalogue was an ambitious project, not only because of the far-reaching and interdisciplinary nature of the Platform, but also because of the weight of representing historical and ongoing HIV/AIDS: it was a too much/not enough problem.⁴ We wanted archival materials, seminal texts, fresh approaches; we wanted poetry, and interviews, and artwork. We wanted a lot of voices, and we wanted them to talk to each other. Will was interested in queer zines as a “locale where fandom, rage and sex can meet feminist, minority and queer politics and history,”⁵ and he helped drive the catalogue in the direction of a zine, with self-contained sections, and strange bedfellows on opposing pages—eventually it even took on the aesthetics of a zine, with the aid of the designer, Judith Walker. Will brought in other anthologies and catalogues for inspiration, including the two-volume anthology *Queer Zines* and the catalogue for *This Will Have Been: Art, Love & Politics in the 1980s*. I brought up the relevance of black gay literary anthologies such as *In the Life*, *Brother to Brother*, *Blackheart*, *Other Countries*, and *The Road Before Us*, also independently published in the '80s and '90s, which provided much-needed space to address the impact of HIV/AIDS as it intersected with racism and homophobia.

While the zine (short for fanzine), is generally associated with DIY punk music/culture,⁶ the anthology as a genre goes back to the early 17th century—and was generally a collection of poems by various authors (its literal translation from the Greek is *flower-gathering*).⁷ The word catalogue derives from 14th-century French and means “list” or “index.”⁷ The zine, the anthology, and the catalogue have different histories, functions, and economies; our catalogue aimed to incorporate elements from all three. Exhibition catalogues involve, at a minimum, the documentation of included works and often provide critical context for an exhibition.⁹ Documenting a Platform made up of live events poses unique challenges, not the least of which is the fact that the catalogue is printed before the events take place. So, while there is a schedule of events to be found at the back of the catalogue, as well as a bio for each artist involved, it is inevitable that the catalogue would be skewed more towards the critical apparatus, and look to documenting and archiving through other means.^{10 11}

Documenting the impact of HIV/AIDS brings with it its own set of challenges and anxieties. Beyond providing evidence: *We were here, this really happened*, etc., we wanted to ensure that we didn't fill our pages with the most visible and oft-cited voices. We wanted to respect the traumatic losses experienced by survivors of the early years of the epidemic while also avoiding the reinforcement of the mistaken notion that AIDS is "over" and no longer a crisis. We sought to do this by creating space for younger voices and perspectives and by putting them in intergenerational conversation. But no matter what, as Will Rawls wrote of the Memory Palace section of the catalogue, "It is an unfinished building"¹²; the catalogue, as evidence, as an object that lasts, reflects a live dialogue among people with the limitations of their own knowledge and experiences, as well as the material constraints of time and budget.

III. Editing and Intimacy

It was agreed early on that I would be the Managing Editor; while the conceptualization of the catalogue was collaborative, I was to manage the workflow. The curators sent out invitations and requests.¹³ The curatorial team created the structure together, and then I began to receive the real effects of the invitations: the texts. I began working one-on-one as an editor. (Full disclosure: for the catalogue, I edited an essay by Theodore Kerr, the editor of this issue of *On Curating*.) It was careful work, requiring timeliness, attentiveness to the texts and to the politics and emotions around them, and really, care. I was conscious that a lot of the contributors were caretakers and survivors, had taken care of others without necessarily assessing the toll that had taken on them.

I received the texts, and they were still partially attached to real people. I had to carefully remove them, and sometimes they were still wet and I had to proceed with caution, with care. It was impossible not to develop intimacy. I became a repository for fears, for doubts, for anger, for I don't know what else. How did I proceed? Intuitively. The words, my love for them, what moved between us, they made us unstrange to each other, as we both strove to make them stronger. Track changes, phone calls—it wasn't just the process of writing, it was the occasion (the harrowing, revelation, doomsday) that we were marking.

Editing is largely an invisible labor. It's collaborative, and it requires compromise. It was agreed upon that I could be promoted to co-editor because of my role in suggesting contributors and materials, the fact that I edited each piece (not always exclusively), and that I worked closely with the designer. I considered, and consider, myself extremely lucky to have been able to enter into such direct relationships with so many people that I admired. I knew that I could edit, due to my background as a writer, reader, and over a decade of teaching writing, but it wasn't until this project that I learned I was a skillful editor, and had that labor valued. The intimate nature of the editing process meant that the import of my work often did not travel outwards, was not necessarily legible. There was also my status as a curatorial fellow—my involvement in the Platform was significant but not really explicit. When the catalogue release party was planned to take place at the New Museum, aside from being asked if I had suggestions for who should read, I was not invited to take part in the event. Honestly, that did not feel great.

IV. Letters and Limitations

How does editing relate to curation? How does editing relate to HIV/AIDS? Some intersections include caretaking, patience, the conditions of/around the writing, grief, and trauma. Past exclusions. Relational fissures. There is also the specificity of the medium of written language and the unease around writing that many people experience. HIV/AIDS was the connection between us. By nature, the role of the editor is to focus on the writer. As for myself, I was somewhat anonymous, a supportive and skillful procurer, not clear about my own stakes, and yet my stakes and my experience very much shaped the feedback process. Participating in the process of extending catalogue invites, I saw that a mere invitation could not possibly make up for decades of exclusion and under-citation, for resentments and splits within the dance community, often along the fault lines of race and gender.

This awareness crystallized in the context of my communication with the artist Julie Tolentino, who has helped me to see how the Memory Palace invitation, and its prescribed length, was not quite as neutral as we imagined it to be. While we had specified one hundred words max in the call, informally we decided to just work with what we got—sometimes the contributions were so long that we took them out of the Memory Palace section. However, I imagine that not everyone felt equally entitled to push beyond the space they were allotted, did not view the parameters as negotiable, according to their own histories of marginalization. Therefore, we were complicit in reinforcing already existing access and privilege patterns. The word limit was an effort to equally distribute page space—in retrospect though, that's not really how equity works, is it? I'm grateful to Julie for taking the time to illustrate with grace the emotional weight that accompanied her inclusion in the catalogue. Here's an email she sent during the editing process, used with her permission:¹⁴

Subject: Re: Lost and Found: Memory Palace
Date: July 10, 2016 at 11:29:59 PM EDT

Dear Jaime:

Appreciate others who can be so concise to meet the parameters for submission.

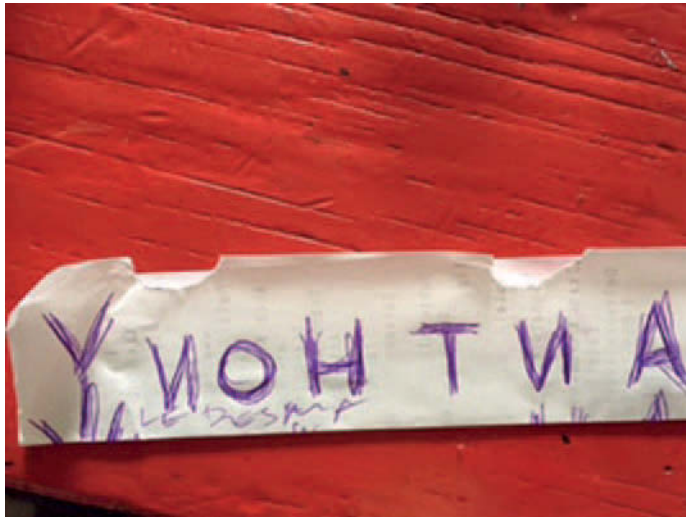
I write about, with, and for a fellow brown queer dear friend who had limited time here - and in (the) dance (world.)

I offer too much: A self with another and its imprecise, rambling, righteous disassembly/composition of words, secrets, realness, reading, & resistance.

*A "photo or 100 words" could never get us there.
(This border-crossing into 445+ words is a meager offering.)*

Appreciate sharing with you.

Means the world.



Julie Tolentino, *Anthony Ledesma (rear view)*, 2016. Pen on paper. Courtesy of the artist.

That last phrase of Julie's: "Means the world," conjures not just a gesture of gratitude, but also, the tender and difficult ways of knowing, of being, that make our worlds. The people we are in relationship with and those whose legacies we bear have shaped the way our worlds mean. As cultural producers and curators who care about HIV/AIDS, how do we ensure that all these worlds keep meaning? How do we care for the survivors, the living-linked-to-the-dead, the currently impacted, ourselves, as we attempt to expand and reconstitute histories of HIV/AIDS?

V. On Canon(s)

I believe that the strength of the catalogue lies in its multiple modalities—its non-linear and non-chronological approach, enabled by the content and design, to some of the intersections of HIV/AIDS and performance. It wasn't until we were a couple drafts in, working with the designer, that someone, I think Judy, noticed a huge proofreading error. The word "forward" rather than "foreword" was featured in blocky bolded letters at the start of the essay with which she opened the catalogue. We all laughed (with relief) at the discovery. The foreword is preparatory, meant to ready the reader for what is to come, and forward is future-looking. But with a little digging, I found that the two words are not as distinct as they appear to be. The word "foreword" didn't come into use until the mid 19th century and seems to be an adaptation from German.¹⁵ It is differentiated from a preface by usually being written by an outside commentator rather than the author, and being signed. "Forward" proved a little more complicated: Forward (adj): Old *English* (16th century) *forewearde* "toward the front, in front; toward the future; at the beginning."¹⁶

It is everywhere at once. It is pointing in multiple directions. In Derrida's 1995 text, *Archive Fever* (written before the arrival of protease inhibitors in 1996, so that I can't help but read into it the specificity of HIV/AIDS), he refutes the assignment of archives to the past. Rather, what archives bring into being is:

[T]he question of the future itself, the question of a response, of a promise and of a responsibility for tomorrow. The archive: if we want to know what that will have meant, we will only know in times to come. Perhaps. Not tomorrow, but in times to come, later on or perhaps never.¹⁷

If we consider the catalogue as an archive (imperfect as it is), each time it is engaged with, passed on, thumbed through, it tangles out into more possibility. “The archivist produces more archive, and that is why the archive is never closed, it opens out of the future.”¹⁸ An epilogue promises to provide closure, to tie up any remaining loose knots, but to do that here would be to do violence, much as the call for “the end of AIDS” raises the question of where that places those who are currently seropositive. I hope this essay can operate as an Afterword, providing more but not all of the context for the production of the catalogue, which will continue to circulate, growing more historical by the minute. At the same time, I wish for the catalogue a continual expansion—through shadow texts, addendums, appendixes, hyperlinks, marginalia—a multi-directional forward movement.

Some of you may be familiar with the term from dance composition, “canon,” where a unison movement phrase is begun/ends at different points in time (variations in facing, pacing, etc. are also possible) by a group of dancers. Many more of you are likely familiar with the term as one that denotes a literary or artistic list of great works; a term associated with legacies of power, patriarchy, colonialism, etc.^{19 20} I first made the connection between these two canons while watching *Stage-Gun-Dance* (1988) by Neil Greenberg (a choreographer also involved in the Platform)²¹ on video about a year ago, as part of my research into his long-standing, often playful but not apolitical, interrogation of the ways in which meaning-making occurs in dance. In this dance, Greenberg projects a slide that reads, “A canon.” as the dancers are seen dancing, indeed, in canon. A few minutes later, using the same formatting, he projects a drawing of a cannon, which garners a few laughs.

While a phrase danced in canon has no inherent subversive value, it does provide a visceral experience of taking in more than one approach at once. This choreographic strategy has been adapted from musical composition, where it is described as the “strictest form of contrapuntal imitation.”²² Counterpoint, in turn, is defined as:

The ability, unique to music [sic], to say two or more things at once comprehensibly. The term derives from the expression *punctus contra punctum*, i.e. “point against point” or “note against note.” In common usage the word refers to the combination of simultaneous parts, each of significance in itself and the whole resulting in a coherent texture, and is, in this sense, synonymous with polyphony.²³

There is something generative I think, in applying this choreographic tool to the work of curation related to HIV/AIDS. Rather than fixing and reinforcing canons in performance and the arts more broadly, rather than looking only at individual works and individual artists, we can look at alliances and disconnections, overlaps and cross-overs, work that was created at the same time but facing different directions. “[F]or music to be truly contrapuntal there must always be a balance between independence and interdependence.”²⁴ Inclusion *and* interrelation. Counterpoint is a useful heuristic to take up in relations to counternarratives. Rather than thinking of counternarratives as opposed to or against a mainstream or authorized narrative, we can think of them as simultaneous, polyphonic. This also guards against the essentializing and simplifying that can occur when one counternarrative is offered to the exclusion of many others.

Dancing in canon is about relationship across difference. Although performing in canon can imply a hierarchical structure (there is some “original, true phrase” and its reconfigurations), the pleasure and excitement that comes with witnessing this movement lies in the feeling of familiarity and estrangement: Have I seen this before?

On another body, in a different spatial arrangement? It's often impossible to pinpoint an origin, an originary appearance. It's all variation. When did it begin? When did it end? Who is leading? And then suddenly everyone falls into unison for a moment and you are pleased and relieved—you hadn't imagined it after all, it was there the whole time.

Notes

1 Echo of *One Day Pina Asked*, a documentary film by Chantal Ackerman that follows the work of the choreographer Pina Bausch (1983).

2 "Programs," Danspace Project website, <http://www.danspaceproject.org/programs/>.

3 Ishmael Houston-Jones, "Lost and Found: Scenes from a Life" in *Lost and Found: Dance, HIV/AIDS, New York, Then and Now*, Jaime Shearn Coan, Ishmael Houston-Jones, and Will Rawls, eds. (New York: Danspace Project, 2016), p. 10.

4 The inclusion of a catalogue has been a component of Judy Hussie-Taylor's Platform model since the beginning, and she and her editors have undoubtedly also grappled with a lot of these questions.

5 Will Rawls, "Letters and Numbers" in *Lost and Found: Dance, HIV/AIDS, New York, Then and Now*, p. 19.

6 "Zine," *Wikipedia*, <https://en.wikipedia.org/wiki/Zine>.

7 "Anthology (n)," *Online Etymology Dictionary*, <https://www.etymonline.com/word/anthology>.

8 "Catalogue (n)," *Online Etymology Dictionary*, <https://www.etymonline.com/word/catalogue>.

9 The history and generic specificity of exhibition catalogues is a vastly underwritten topic. Frits Seers, former Curator of the Stedelijk Museum Amsterdam, outlines some early history and editorial approaches in "Preliminaries for a Bibliography of Museum Collection Catalogues: Some Historical Observations on a Hitherto Neglected Aspect of Museum History," *Art Libraries Journal* 22:2 (1997): 26-34.

10 In addition to the catalogue, I edited an issue of the online Danspace Project Journal, in consultation with Judy Hussie-Taylor and Lydia Bell, and with the assistance of Lily Cohen and Michael DiPietro, which served as an extension of the Platform (and catalogue), as it provided documentation via video clips (edited by Alexis Moh), and responses to the programming by writer-in-residence Alex Fiahlo, as well more supplementary materials, including oral history interviews by Svetlana Kitto, music playlists, recommended reading lists, excerpt of Storycorps, and excerpts from the catalogue and other relevant, recent publications. The content of the journal accumulated over the course of several weeks, providing an experience in line with the temporal unfolding of the Platform.

11 One other text-based project was produced within the span of the Platform. Will Rawls coordinated zine residencies with two collectives: AUNTS and Le Petit Versailles/Allied Productions, Inc., each of which cultivated a temporary social gathering space for performance and zine construction. Zines were consequently handed out at Platform events.

12 Rawls, "Letters and Numbers," 29.

13 In the aftermath of the Platform, I noticed that artists often mentioned who had personally invited them to participate, either Will or Ishmael, often noting the significance of the generation each is associated with. This demonstrates how the collective curatorial work was not visible and also how deeply personal and emotional these asks were—embedded in historical relationships both social and professional.

14 Tolentino included this image in her correspondence in order to contextualize her Memory Palace contribution, which addressed and invoked her friend, the artist Anthony Ledesma.

15 “Foreword (n.),” *Online Etymology Dictionary*, <https://www.etymonline.com/word/foreword>.

16 “Forward (adj.),” *Online Etymology Dictionary*, <https://www.etymonline.com/word/forward>.

17 Jacques Derrida, *Archive Fever: A Freudian Impression*, trans. Eric Prenowitz (Chicago: University of Chicago Press, [1995] 1996), p. 36.

18 Ibid. p. 68.

19 “Canon (n.),” *Online Etymology Dictionary*, <https://www.etymonline.com/word/anthology>.

20 For more on canons and curation, see Issue 11 of *Manifesta Journal*: “The Canon of Curating” (2010-2011).

21 My writing on Greenberg can be found here: <http://drainmag.com/i-dont-know-what-made-this-private-in-the-first-place-neil-greenbergs-not-about-aids-dance-and-the-disco-project/>

22 “Canon,” *The Oxford Dictionary of Music* (6 ed.), Tim Rutherford-Johnson, Michael Kennedy, and Joyce Bourne Kennedy, eds. (New York: Oxford University Press, 2012). Current online version: 2013.

23 “Counterpoint,” *The Oxford Dictionary of Music* (6 ed.).

24 “Counterpoint,” *The Oxford Companion to Music*, Alison Latham, ed. (New York: Oxford University Press, 2011). Current online version: 2011.

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[INSTRUCTIONS FROM CHLOE], A Curatorial Statement

I.n. Hafezi
– *Reprint*

Ephemera As Evidence was an 2014 exhibition curated by Joshua Lubin-Levy and Ricardo Montez for Visual AIDS in which the curators also worked with Montez' students from The New School to engage in related research projects. Theorist and performer I.n. Hafezi was one of Montez' students who—with fellow student and writer Nayeli Portillo—researched the work and impact of artist Chloe Dzubilo, whose work was included in the exhibition. Hafezi was taken by Dzubilo's work, and as part of the exhibition their own writing was blended with writing from Dzubilo to create a new text was then turned into a Visual AIDS online exhibition entitled *[INSTRUCTIONS FROM CHLOE]*, which appears below. The two never had a chance to meet. Dzubilo died in 2011, and Hafezi died in 2017. Their work lives on. To view the images Hafezi curated from Dzubilo's career to include with the text, visit: visualaids.org/gallery/detail/-instructions-from-chloe-

– Theodore (ted) Kerr

BE A SMART PLAYER WORK IN SYSTEMS WHEN
ABLE PLUS DON'T FORGET GENDER NON-
CONFORMING OR INTERSEX PEOPLE, HIPPIES
HIPPIES TRANS HIPPIE 'THE DSM 4' IN 20 YRS
THIS WILL ALL BE COMMONPLACE WATCH
TAKE NOTES POLITICAL CORRECTNESS CAN
KILL, BRUISE, GASH, HURT TO THE BONE, SUCH
A GAME THAT'S PLAYED. THE PERFORMANCE OF
THE POLITICALLY CORRECT. THE ATROCITIES
OF THE OPPRESSION OF THE GENDERQUEER.
TIRED. OMISSION. POLITE LIES. THE WAY TO DO
BIZ. JUST THE WAY IT IS. WILL THE CHRISTIANS
BURY ME (WOMAN) AS A MAN + WOMAN? OR
THE TRANSPERSON? I HAD TO STOP MY LIFE TO
EDUCATE THEM. NO PROGRESS. ACCESS TO
PRIVILEGE. ACCESS TO THE STREET. ACCESS
TO CULTURE. ACCESS HOLLYWOOD. IN TWENTY
YEARS. NO PROGRESS. ...may your heart stay warm in
winter/may your soul flow up from the ground in
spring... INSPIRE CHANGE EVEN IF YOU THINK
YOU MAY NOT PULL THRU THE LATEST HEALTH
CARE SURPRISES/HELL. NADA IN VAIN. WORK IT
TO SURVIVE KEEP JOURNALS. ONE MAY NOT SEE
ALL THE SUBTLE BULLSHIT UNTIL MANY YEARS
PASSED. PRIVATE ROOM. HOPE.

((All words verbatim from about a dozen art works from Dzubilo's archive. Phrases have not been altered, but were pasted together//alongside each other, scrambling syntax and imag(in)ing several tones/textures/sentiments that I found reaching across and through Dzubilo's work.))

Upon my first visit to the archival materials of Chloe Dzubilo at the Visual AIDS office—where they were stored temporarily enroute to the Fales Library and Special Collections at New York University— I was surprised by the texture/s of my own affective response/s to holding Chloe's work and seeing it up close. I had spent some time pulling my face closer to my computer screen, attempting to read every word of a given art work through this website's online archive. Too, as is

common place when trying to track down a queer/ed or trans/political artist and her work, I had a lot of difficulty finding even traces of Chloe in the ether of the internet, even with the resources of a well-connected university whose population is largely made up of art and design students (a university that also happens to be Dzubilo's alma mater).

And so, upon interacting with her work, I was struck by how clearly I could hear Chloe. Her work's commentary on the systems that constitute our surround and fuck with our abilities to access the things that we need (while simultaneously condoning the socio-political actors who seek to annihilate us on the daily) struck so many nerves in my young, broke, trans/queer, not-quite-white but not-quite-brown-either, Brooklyn-Based bodymind. (Too, the work is just punk as fuck.)

Newly able to see/read/decipher the text/s that work dialogically (that is, the words are working largely to be communicative, and to be read and understood, rather than observed in some other way) in much of Dzubilo's recent work, the framework "Instructions from Chloe" manifest almost immediately (following my quiet awe at the sheer volume and proximity of her work in front of me).

Dzubilo's work gestures toward, moves through, and bumps up against José Esteban Muñoz's work on "the live" and the "burden of liveness" (in *Disidentification: Queer of Color and the Performance of Politics*). The formal aspects of the works curated into this gallery—largely renderings in ink on notebook paper—indicate and activate the temporal landscape of the minoritarian subject who must leave behind notes, because she will be targeted for annihilation whether she leaves traces of herself and her surroundings or not.

She makes these notes quickly—they're scrawled in cursive and crammed into boxes and thought bubbles. The writing often goes awry. We have to tilt the page or crane our necks to read these field-note-like asides.

The cursive is rapid. It moves. There is no time for a more careful hand. This shit is urgent. And we need it.

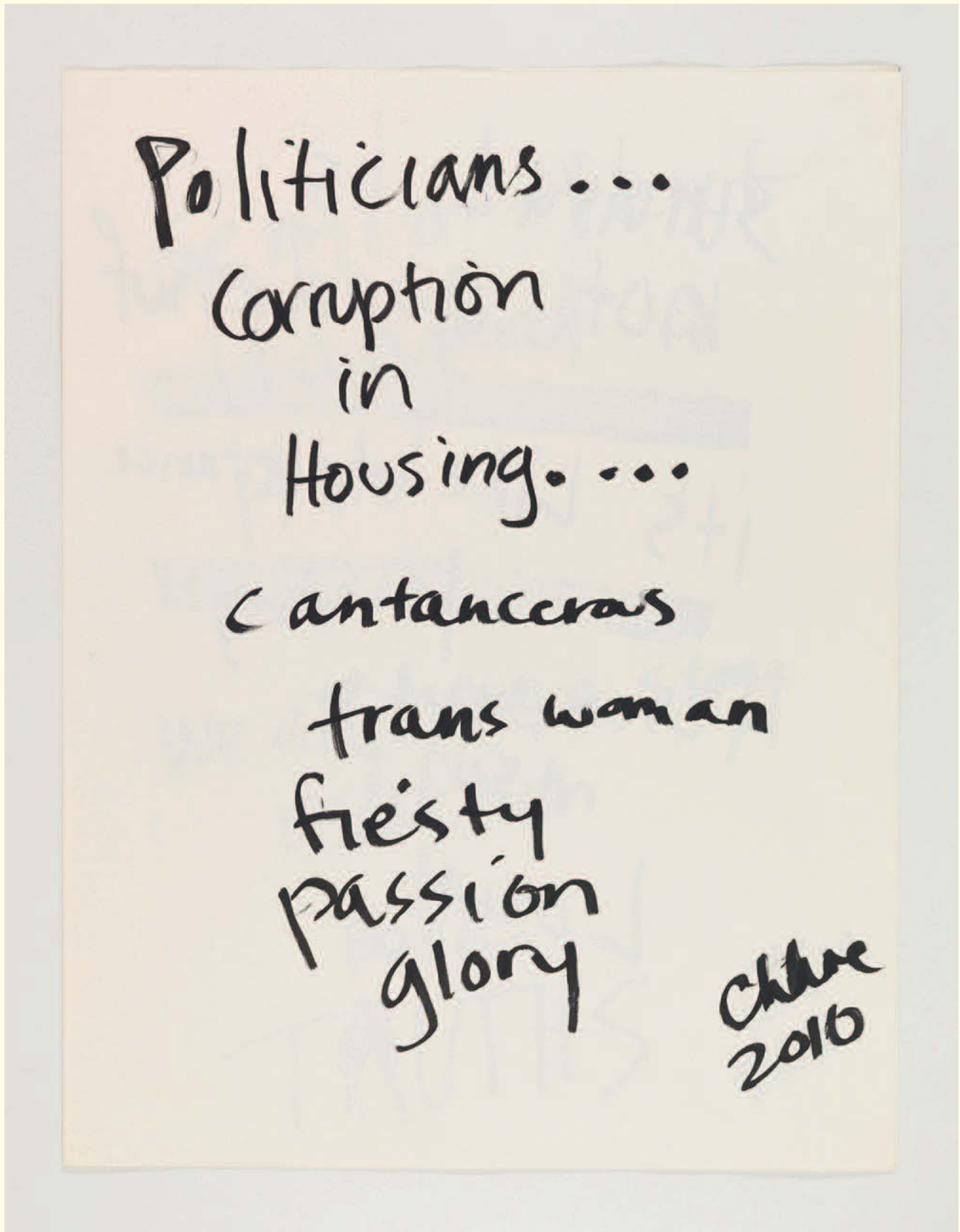
With a polyvalent praxis and multiple practices, Dzubilo instigates new conversations --as she pokes holes at the fuckery of the current discourses-- regarding advocacy by and for trans people and positive people (especially trans women and positive women), femmes, gender non-conforming people, sex workers, people of color,

sexual assault survivors, and others who face unwanted, heightened contact with and intervention into their lives by the police state. She tackles the medico/psychological/prison industrial complex and all of its satellite appendages.

The women in her work, depicted most often in ink on notebook paper (and frequently autobiographically inclined), watch, they take notes, they advocate for themselves, and they (radically) demand the same forcibly compelled disclosure and transparency of the systems of the gatekeepers. The politics of disclosure and being forcibly interpellated through violent(/ly reductive) readings are familiar territories for the abject bodies who are never given the opportunity to choose disclosure and transparency over withholding and refusal.

AIN'T NOTHING LIKE KNOWIN' WHAT IT FEELS LIKE... WHEN YOU SLIP THRU THE CRACKS OF SOCIETY, POLITICAL NICETIES, POLITICAL CORRECTNESS, HEALTH CARE, CORRUPT DRs. HOUSING, EMPLOYMENT, WEALTH, SHOE STORES, SUBWAYS, FAMILY OUTINGS, HOLIDAYS, SYSTEMS, SYSTEMS SYSTEMS AIN'T NOTHING LIKE KNOWING THESE FACTS DEEP IN ONES BONES. WHEN YOUR A TRANSEXUAL. AIN'T NOTHING LIKE KNOWING TRIUMPH OVER ALL OF THESE ADVERSITIES. (Chloe 2008)

Chloe Dzubilo was an artist and AIDS and transgender activist. Chloe studied art at the Parsons School of Design and received an associate degree in Gender Studies from the City University of New York City College 1999. A native of Connecticut, Chloe moved to New York in 1982 where she briefly worked at Studio 54. She soon became the ad director at the downtown art magazine the *East Village Eye* just when the neighborhood's art scene began to explode. In the '90s, she was an icon of downtown nightlife. She wrote plays for and performed with the Blacklips Performance Cult at the Pyramid club and edited the group's zine, *Leif Sux*. She was the lead singer and songwriter for the punk-rock band the Transisters, who played at CBGB, Squeeze Box at Don Hill's, and other trendsetting hubs of downtown culture. She was diagnosed with HIV in 1987 when her partner of nine years, Pyramid Club founder Bobby Bradley,



Chloe Dzubilo, *Politicians*, 2010. Courtesy of Visual AIDS.

died of AIDS. Following her diagnosis, Chloe advocated for civil rights, adequate health care and dignity for people living with HIV/AIDS, transgendered people and drug users. A longtime volunteer for the LGBT Community Center's groundbreaking Gender Identity Project, she served on its transgender HIV prevention team conducting prevention outreach in bars, night-clubs, and on strolls. She spoke at national and international conferences, in public service announcements and training workshops for health care and mental health providers. Chloe was involved with the political action group the Transsexual Menace and went on to direct one of the first federally funded HIV prevention programs for transgender sex workers in 1997. Read the rest of Dzubilo's bio at <https://visualaids.org/artists/chloe-dzubilo>.

I.n. Hafezi was a student of dance, politics, and critical theories of the body at Eugene Lang College. They performed with Katy Pyle and the Ballez Company in *The Firebird: A Ballez* in its premiere and revival runs. They began working with grassroots organization Queerocracy in 2012, with whom they attended satellite events in Washington, D.C. during the 2012 International AIDS Conference, and captained a bus of activists from New York City to Washington, D.C. and back for the WE CAN END AIDS Mobilization and March. I.n. was a writer in the Helix Critical Squad for the Helix Queer Performance Network. They were a student organizer at The New School where they operated with an intersectional trans feminist praxis. Their scholarly interests reached across the disciplines of Performance Studies, Critical Dance Studies, Visual Studies, Trans/gender Studies, and Critical Race and Ethnicity Studies. Their research interests included investigations into the affective registers of dysphoria; the operations of pigmentation politics in the production of self/Other/anOther; and notions of borders/boundaries, and sites of the production of "citizen."

Could I Be A Happy Person? A Conversation between Artists Kairon Liu and Manuel Solano – *Reprint*

Kairon Liu is a photo and installation artist based out of Taiwan whose work provides direct access to people's understanding of their own lives as people with HIV. Through interviews and portraits, the subjects of Liu's work are willing participants in a public reckoning of their lives. In Liu's own understanding of the work, his exhibitions are to be of service to the audience, the subjects, and himself as a way to better understand and know people with HIV.

Manuel Solano is a painter and videomaker living in Mexico City. The lines of Solano's work have, over the years, become bolder, thicker; they are hard-won and emotive renderings on canvas of singer-songwriters, dinosaurs, a favorite aunt, and transgender women. On video, Solano is the primary person on screen, with the ultimate subject becoming the viewer. Bringing the work together is a curiosity about the world through the individual experience of the self. There is nothing flat-footed about Solano's work. A viewer is invited to either surrender or do the emotional and intuitive labor to keep up.

What bonds the seemingly disparate work between Liu and Solano is a deep investment in humanity and ideas of witness. While only Liu could easily be classified as an artist/ethnographer, both he and Solano are using their talents to investigate open heart questions: What is it to experience beauty, to encounter grace, to express loneliness?

While one may be quick to suggest that this common bond is a result of the fact that they are both living with HIV, that would be a crude reduction of their lives. In the interview below, the two artists encounter each other first as strangers, knowing only each other's art work, and end as confidants, bonded by experiences of alienation, talent, and hope. The conversation was originally published in *The HOWLER: Transmitting Art and Activism*, a newspaper created by artists and editors Anthea Black and Jessica Whitbread for the 2018 International AIDS Conference

in Amsterdam. The interview was done over Skype, with Liu in his rented room in Williamsburg, NYC, where he spent the summer on an art residency, and Solano in an art studio in Mexico City. I recorded the conversation, and was present throughout, acting only as grateful witness.

– Theodore (ted) Kerr

Manuel: Kai, you mentioned you felt lonely in Taiwan, but I didn't really gather if it was because of your project or something else...

Kairon: Yeah, because of my project. While I do get funding support for it, all I hear is, "Kai you have to stop because if you keep doing AIDS work, you will narrow your career as an artist."

We don't have an idea of activist in Taiwan. You are either a social worker or an artist. This makes me feel sad because I want to do something, for myself and my other positive friends.

Manuel: Would you say that the situation that you're talking about in Taiwan is a result of social conservatism?

Kairon: I think so. We still have positive people being put in jail.

Manuel: Just for having HIV?

Kairon: If you had sex with someone without telling them your HIV status, the laws can criminalize you just like the US.

Manuel: I know where you are coming from, Kai. Being isolated was something that I definitely was very much afraid of, when I came out, so to speak, as positive, in 2014. I didn't want to become just the guy who went blind from AIDS. I've struggled against that very much, but I think I've overcome it.

I'm happy to say I get less feedback now that my work is about HIV, which it never was. I obviously used an event related to my being positive as a kind of catalyst. I remember an interviewer asking—or basically, saying—that my work was about the virus, but it's about so many other things.

I guess, what I'm trying to say is, Kai, I think my approach when making work about HIV was contrary to yours. It sounds like you have gone the other way. You are directly addressing HIV and how it impacts people's lives.

Kairon: I never thought I would have HIV. I had a belief that only "certain people" got AIDS, and I actually ended

up getting it from my boyfriend. After I recovered and I started learning that anyone can have the virus, the first thing I wanted to do was interview as many positive people as possible. I want to find a way to stay alive and help others. This is how making art is like social work to me, there is a pleasure I get when I make the exhibition and feel my work is actually helping someone. Does that make sense?

Manuel: Yeah, and I think obviously what you're doing is big. It's a burden to normalize the condition of being HIV positive. When I look at your work, I feel relieved and kind of selfish, when comparing my work to yours, because evidently, my work is all about myself.



Kairon Liu, *The Ceremony of Birth and Genius*, 2013. Courtesy of the Artist and Visual AIDS.

Kairon: For me, when I see your work, it's like I'm seeing you, you, you, you, you. I get all of you. And I'm happy. I need to see a person being there, in the world.

Manuel: Okay. Well, I have a question for you. I mean, it is actually from René, my assistant, who is also my best friend, who is also my first boyfriend. He wants to know why there's so many apples in your series. Is it a thing that you add, or is it just that people eat lots of apples?

Kairon: It's a thing I add, for sure. During the interview, the people I photograph and I will exchange our personal life stories. After that, I ask them what objects/

items they use in their daily life. So, besides the apple, everything in the resulting images is what they need and want to maintain their lifestyle. From there, I give them the apples and ask them to choose the meaning of the apple. It can be crime, desire, knowledge, the ability to tell right and wrong... and even the virus itself. They can also choose to show their faces. They are in charge of making up the image with me.

Manuel: René told me that most of them actually cover their faces; the case would be similar if you did the same piece here in Mexico. We are essentially a very conservative society.



Kairon Liu, *Humans As Hosts: 006*, 2018. Courtesy of the Artist and Visual AIDS.

Kairon: I'm surprised. Before I came to North America, I thought it was more progressive here. I actually have a friend who told me: "If you are a New Yorker and you're not positive, it's because then you're not hot enough." After my diagnosis, I became like a suicidal person. When I'm going to sleep with someone, I would tell them, "I am positive. Are you okay with this?" Again, everyone said I shouldn't tell anyone. Friends or even my case manager would say, "Don't tell everybody about your status, you should protect yourself."

But being here now, everything seems different. Whenever I tell someone about my status, they will be surprised and say something like, "Oh, OK! Thanks for telling me. But you're the first one to tell me you are positive." It's quite impressive that people know how to protect themselves and yet, they don't really talk about it.

Manuel: It is not easy. I can't say I told all of my partners early on. I kind of was terrified, and I thought, "Nobody told me, right? So, fuck 'em." Obviously, that's the worst mentality I could have had. Nowadays, I would tell all my partners, if I had partners. But here is the thing, after diagnosis, I was only sexually active for a short time because I became very sick very quickly. During that short time, I would be on Grindr, I would start a conversation and then, eventually when it got to the point of like, actually meeting, I would say, "Hey, I'm positive. Are you okay?" 99% of the times the conversation would die there. A couple times I got insults.

Kairon: In Mexico City?

Manuel: Yes, I was at the art fair here in 2016, I opened up my Grindr and somebody, with no profile pic, sent me a message saying, "If you're positive, why don't you state so in your profile?" Clearly, this was somebody who knew my work or something. I went to settings, I changed my profile to say I was positive and Undetectable as of my last test. Then I went back and said, "I guess for the same reason you don't show your face." I kept my status on my profile and was very open about it. What happened was that nobody would respond when I initiated a conversation. And this silence is in one of the queerest places ever.

Kairon: Do you feel safe living in Mexico?

Manuel: It's a relatively safe place to be queer. But it's not a safe place in general, it's a violent place, but it's not that we're targeted because we're queer. However, my experience of health care after I became positive has

been terrible. I feel like I was being oriented away from retrovirals. I was told I didn't need them for many years, that they are dangerous, bad for kidneys... Doctors systematically lie to positive patients in order to save the government money and nobody acknowledges this.

Kairon: You heard this in 2012?

Manuel: Yes. And then things started to get more confusing with TRUVADA. The medicine that is now being used in the rest of the world to prevent HIV, is the medicine that they are telling us that HIV people shouldn't take, unless it's extremely necessary. Only when we get very sick do they give meds. It's a clash—they tell us that this pill can kill you and they're giving it in other countries to people as if it was Vitamin C.

Kairon: Are antivirals free to citizens there?

Manuel: Yeah.

Kairon: Okay, so maybe it is a way to stay in the budget?

Manuel: Yes, and it cost me my eyesight. From day one after I tested positive, I told the clinic I wanted to get on treatment as soon as possible, and if my wishes had been respected, none of this would have happened. I didn't know the treatment was safe. I didn't know the side effects were so mild. I didn't know that I knew people who had HIV, and I could have asked them questions. It turned out later, after I came out, a lot of people came up to me and like, "Oh, I'm positive," I was like, "Why are you only telling me now?"

Kairon: Yeah, that always happens.

Manuel: I always am left feeling, I wish you told me, I wish we could have been there for each other. Someone I know passed away from AIDS six months ago. We were all shocked that he didn't tell any of us. Only one of his friends knew he was positive. He never sought treatment. It's shocking. He was surrounded by open sex positive diverse people and he never felt safe. He never reached out to me and said, "Hey, I'm positive." It says to me that he was feeling afraid and ashamed. I wish I could do more to stop that.

Kairon: Do you remember what it was like when you tested positive? Did you take action right away?

Manuel: I tested positive, and they told me I needed to go to this other clinic. I went the following morning. This began all the paperwork. It's a lot of bureaucracy that you have to go through. It took me one month to be enrolled into one of the clinics. I did everything as fast as the system allows. I went to the clinic, and said, "I'm here because I'm trying to get on retrovirals as soon as possible," and every time they said, "No. We don't know if you need them yet." They told me that it was them who decided when to start up the treatment. This is wrong. It is the patient that decides.

Kairon: How were you feeling?

Manuel: My health was deteriorating very bad. I lost seven kilos, which was more than 10% of my body mass. I was terrified.

Kairon: Did they do labs? Did they tell you your CD4 count?

Manuel: My CD4 count was okay, but my viral was 1,800,000. But I had no idea what it meant. The doctors said, "Oh, you're very fine. It's a relatively high viral count but you'll be fine. Come back in six months and we'll do another test." I didn't know how bad it was. They lied. Then one day, I needed care for what seemed like an allergic reaction and I ended up in a private hospital. The doctor there was evil. He was very derogatory towards me, in front of his staff and the students. He wouldn't address me, like, wouldn't look at me and wouldn't respond when I spoke to him. One afternoon he yelled and humiliated me in front of my mother, saying, that he had "zero tolerance for my kind." I never knew exactly what he meant by my kind, but after that, I signed myself out of the hospital, and I never wanted



Manuel Solano, *Alanis (diptych)*, from the series *Blind Transgender With AIDS*, 2014, Acrylic on paper 56.5 x 86.5 cm each. Courtesy of the Artist

to see another doctor ever again. But I got very sick and I panicked and fell into the hands of somebody who I thought could help me. But actually, they couldn't. They were very kind and sweet and I thought, "Who knows. Maybe this is my last chance." Looking back, I know that I was scared. I had reached out for help and met so much rejection and shame. And even today I hear similar stories. A friend, who went to one of the same clinics I did, recently tested positive and the person who performed the test said, "I hope you've learned your lesson."

Kairon: Oh, my god.

Manuel: Yeah, and this is the main clinic for the LGBT community in Mexico and still, we're being routinely shamed and threatened and misinformed by our government, and nobody wants to address it. When asked to answer for what they have done wrong, they treat it as something normal. Like, "Oh, the doctor misspoke. Oh, you should have known better." But it is not that. It is like someone in a health office is calculating a way to spend less on retrovirals.

Kairon: Hearing you speak, I can say the medical situation in Taiwan is much better than Mexico. And still, when I am working with someone, I feel like I am providing a service that is missing from the care we receive. There are these people that are like managers, and after I tried six different medications and they didn't work well, the manager asked me, "Are you doing drugs or are you sure you're taking the pills?" I feel like, when you are a patient and you're facing a doctor and the nurse, you are already lower than them, because they actually have a right to control your life. I can often leave the doctor's office feeling like I did something wrong.

Manuel: It's the same here. Whenever I try to talk about my health, I feel like they will try to find any excuse to excuse themselves from addressing themselves as the issue. Like if I complain about an upset stomach, they will ask what I ate, or if I am taking another medication. Unless I bring it up, they will never consider that it could be a result of something they have prescribed me. And when it comes to mental health, it is the same. I was on efavirenz. It makes you very depressed, very anxious, very paranoid. Gives you crazy dreams. It's awful. Every HIV patient that I know in Mexico who takes that drug, every time that they go to their doctor, they give the same complaint, that the side effects are horrible. My other ex-boyfriend is on this pill,

and he's having nightmares and is very unstable emotionally. His doctor, rather than agreeing to change to a better medicine, sent him to a psychiatrist to get anti-depressants.

Kairon: Every time I have a side effect, I would think something like, "Oh, yeah. That's a small price I have to pay to stay alive." It's a way to convince myself, I guess.

Manuel: Yeah, but it shouldn't be.

Kairon: I'm curious, when did you start to go blind?

Manuel: 2014.

Kairon: That is interesting because around that time, the lines of your work become wider, no? Is that actually the way you see things?

Manuel: No. I mean, back then, when I had just become blind, I still had some vision. I was legally blind, but if there was enough contrast, I could see slashes. Which is why I started that series of paintings, the blind transgender with AIDS, I would paint a layer of white on the paper and then add the rest of it because that would increase the contrast. I would start with something black, like the mouth or the eyes, but as I added more elements, I would stop seeing. It just become blurred. I'm even more blind now, and so I have to rely on other things.

Kairon: After you start taking the medicine, the vision should be better? No? It's already damaged?

Manuel: The damage was irreversible.

Kairon: I am sorry. Can I ask another question?

Manuel: Yes.

Kairon: Why are all your models female?

Manuel: It's not a conscious decision. When I paint anything, I'm painting myself. Like, you will see a painting of my aunt, but what you should really imagine is me. It's not that I'm that person or that I wanna be that person or that I have that much in common with that person, but like in this one instant there's something about this attitude that resonates in something about my own self.

Kairon: It's kind of like you share an attitude with them?

Manuel: Yes. But now I have a question for you. You mentioned earlier that each of the people that sits with you for your project selects objects to be photographed with. What would your objects be?

Kairon: I mean, it is a good question, right? Another way I ask is: if I'm going to burn your house down, what object would you grab first?

Manuel: Okay. I need to start conversations like that. But so, if I were to burn your house...

Kairon: Okay. Camera, computer, underwear, pills—of course, each of us will need pills—and if I was back in Taiwan, I would grab all photos.

Manuel: Good list.

Kairon: That is one of the things about the project, people have a chance to consider what you need and want in this life. Like, after diagnosis I forgot what I wanted, how to be selfish in a good way. I think that is why I like your work. As I said earlier, I see you in your work! I see someone who can completely just love themselves. I admire that. It is something lacking in my work. I share things in the process, but it is like I am not there. Or, I am there for them, not for me. We have things in common, and that is good, but....

After the interviews people will say, I have never had a chance to do this before. Even with their boyfriends. We hardly ever are able to talk about our HIV in a meaningful way. We create a bond. Now, some of the people from the project call me when they are depressed. It is good. But I wonder, what about me. So, please, give me some suggestions, some advice.

Manuel: I would say one starting point for you could be the interviews. Like, you just said, you just said it yourself that, while you're interviewing these people you find a lot of things in common. Maybe that could be the subject for another project, like maybe you can focus on what you share with these people and why.

Kairon: When you create art, do you feel like mentally cured after you finish the work?

Manuel: No, no I, no, I feel I'm driving myself crazy.

Kairon: Okay. So the more you paint, the crazier you feel?

Manuel: Yeah, I mean by now I feel very far from the world, very lonely, misunderstood and unseen. The last year I have been working a lot, and getting attention for it, which is nice. But, doing these things that I thought would make me happy, haven't worked. I feel trapped and bored. The last time that I felt at ease was months ago when I went dancing with my friend Johnny.

And my feelings are not just because I am positive, but also because I live far from the center of the city, and my friends live far away, and all my personal relationships are worn out. Like my mother, my brother, René, we're all so tired of being around each other. Like I've been around them non-stop for the past four and a half years, demanding so much of them, taking so much of their time and their assistance and it's just—we all need a break. And I can't get a break so far.

Everything I've done after I became blind is so that I can get away from my family, so that I can become independent, and I still can't. It's so very frustrating. Especially knowing that, if I stay in Mexico, that it's my permanent situation. I'm gonna be dependent on my family and maybe friends, for every single thing. I can't accept that. So, I'm trying hard to change that, but it's also gonna make me even more isolated and lonely.

And my sex life is completely in shambles. I don't have a sex life. And that wears me down. I am constantly surrounded by people who are my age, in my field, we share a lot. Normally you think that I could find some kind of interaction, but I don't. It's almost like I'm separated by something.

Kairon: Do you think it's because you are transgender?

Manuel: No. Most people don't see me as transgender. I don't know what it is anymore. I guess it's a combination of the blindness plus being HIV positive, plus being trans and maybe not being the taste others like. I've never been one to conform to the taste. I've been going to therapy with a sex specialist for a couple of months now, to try to figure these questions out. I will report when we find something.

Kairon: If you need someone to talk with, we are just one call away, you know.

Manuel: Before we go, I want to say, I think it's important work that you are doing.

Kairon: I'm just worried I'm too vulnerable. My family's poor, I'm poor, and I don't think I'm strong enough to do this work without company. Even if there were others, I think I would still feel isolated, and maybe that is the point: to be an artist is to deal with loneliness because you are seeing something that the general people don't. And the price, is the loneliness. Could I be a happy person? I don't know.

Manuel: I guess we just have to stay in touch.

Kairon Liu (b.1992, Taipei, Taiwan) is a visual artist and photographer. Kairon's practice reflects his observations concerning beliefs in human society through the creation of narratives, exploring different issues related to religion, disease, and universal values. Generally, his role in a project would be the activator, in a democratic approach. He would collaborate with the individuals rather than create the images of them. Since 2017, Kairon has started the project "Humans As Hosts" which focuses on understanding the living situation of people with HIV and heightening awareness about HIV/AIDS. In collaboration with social networks, NGOs, and Health Authorities, he recruits HIV-positive individuals to volunteer as participants to join the in-depth interview and photoshoot. The resulting images are to be viewed as the proof/disproof of the stereotypical prejudices and discrimination produced by society. Delivering the rendition of facts that human beings, no matter what field they are in, are subject to or exposed to the virus. We are merely human beings, and now we are all facing an emerging threat

Manuel Solano (b. 1987, Mexico City, MX) completed their BFA at the National School of Painting, Sculpture and Printmaking, La Esmeralda, Mexico City in 2012. Solano was most recently in the New Museum Triennial and is currently in the group exhibition *El Chivo: Expiatorio: SIDA + VIOLENCIA + ACCIÓN* at the Museum of Mexico City. Their work has also been included in solo and group exhibitions at the Portland Institute of Contemporary Art (2017), Museo de Arte Carrillo Gil in Mexico City (2016), and Museo Universitario del Chopo in Mexico City (2014). Upcoming exhibitions include Solano's first US institutional solo exhibi-

tion at the ICA Miami in October of 2018 and group exhibitions at David Lewis Gallery in NY, as well as Peres Projects in Berlin. In May of 2019, Efrain Lopez Gallery, will mount a comprehensive exhibition highlighting the expansive breadth of Solano's practice, which will include painting, video, and performance.

The HIV Howler: Transmitting Art and Activism, is a limited-edition art newspaper focusing on global grassroots HIV art and cultural production. It serves as a forum for dialogue, a demand for aesthetic self-determination, a response to tokenism, and a guide to navigating the vibrational ambiguities between policy, pathology, and community. It is rooted in the understanding that artists have played and continue to play a fundamental role in shaping broader societal understandings of HIV and working within communities that are most impacted by the virus: queer and trans people, people who use drugs, sex workers, people of color, and indigenous peoples. Together *The Howler* reflects the immediacy and urgency of global HIV/AIDS dialogues as well as their historical continuities.

Howler Editor Anthea Black (b. 1981) is a Canadian artist, writer, and cultural worker based in San Francisco and Toronto. Her studio work takes the form of printmaking, drawing, publications, textiles, and performance to address feminist and queer history, collaboration, materiality, and labor. Black has exhibited in Canada, the US, France, Germany, the Netherlands, and Norway, and has circulated collaborative print editions in cities across North America through the artist-curatorial project, *Looking for love in all the wrong places*. Her texts on contemporary art, craft, and performance appear in numerous publications, including *FUSE Magazine* where she was a contributing editor from 2008-2014. Her writing with Nicole Burisch is included in *The Craft Reader* (Bloomsbury, ed. Glenn Adamson) and *Extra/ordinary: Craft and Contemporary Art* (Duke University Press, ed. Maria Elena Buszek). Black is the co-editor of two books, *HANDBOOK: Supporting Queer and Trans Students in Art and Design Education* with Shamina Chherawala (OCAD U Publications, 2017) and *Craft on Demand: The New Politics of the Handmade* with Nicole Burisch (I.B. Tauris, 2017).

Howler Editor Jessica Whitbread is a graduate of the York University Masters of Environmental Studies program, and she has a degree in Building Communities to Ignite Social Change. She is a queer activist and artist who has been working in the HIV movement since shortly after her diagnosis in 2002. She works in the realm of social practice and community art, merging art and activism to engage a diversity of audiences in critical dialogue. Her work includes *LOVE POSITIVE WOMEN* (2012); *Tea Time* (2012); *No Pants No Problem* (2004) and is a co-curator of *POSTERVirus* (2011). In 2014, Jessica published *Tea Time: Mapping Informal Networks of Women Living with HIV*, a photo collection of her Tea Time community arts practice. Jessica was selected as the Wesley Mancini Artist in Residence at the McColl Center for Art + Innovation (2014) and received the Premier's Award from the Government of Ontario (2014) and the Visual AIDS Vanguard Award (2016). In 2016, she birthed twins and advocated to openly breastfeed them in a Canadian context.

Disability, HIV, Art, and Culture

Miuro Michael

In Uganda, HIV and Disability share one thing in common, and that is discrimination and stigma. As much as Uganda has achieved when it comes to awareness about HIV/AIDS, little has been done regarding disabilities. The worst situation is when you are living with a disability and HIV; the community will say that God is not fair who made you suffer twice. HIV is not considered a disability in Uganda, but rather a disease that also causes a disability. This mismatching from the professionals and disability advocates has led to a number of issues: many people with disabilities living with HIV (PWDSLH) are frequently excluded from HIV education, prevention, and support services due to misconceptions that they are not sexually active nor do they inject drugs; healthcare services may be physically inaccessible and lack sign language facilities and other information formats such as Braille; and when access to medication is limited, PWDSLH may be treated as a low priority for services.



Theodore Kerr, *Michael Miuro*, 2017.

Amid the systemic bias, there is a high level of discrimination against PWDSLH by their family and community members. The very people that should be supporting us question our right to be seen as any other human being. There is a failure to see us as people who deserve all the basic rights to life including medication, education, food, shelter, and employment, and to be seen as useful members of the community who are independent and can make decisions about our own lives, families, and community.

A PWDSLH needs to be given a voice to speak for him/herself without being represented by others, because this empowers him/her and best allows him/her to act as a resource and even a mentor for others. Like other social movements throughout history and around the world have shown, self-representation leads to the promotion

of rights, dignity, respect, and meaningful involvement in decision-making on issues concerning HIV/AIDS at all levels.

Often, when it comes to being a PWDSLH, we must wear two hats, attend two sets of meetings, and be spokespeople for two or more communities. As a person living with HIV, I know that:

- The community wants / needs to be sensitized to disabilities, how to handle PWDs, and what language needs to be used while addressing disabilities. This will improve their attitude towards people with disabilities living with HIV; also,
- The community wants to know about PWD lives: where is home, what jobs are being held, what are the everyday challenges and issues being faced? To have this info, we need;
- A disability data revolution to enable disability-inclusive development by including disabilities in data collection and monitoring mechanisms. The lack of data is a significant contributor to the present invisibility of disabilities in national HIV and AIDS programs. We need more in-depth understanding of the multifaceted links between disabilities and HIV to assist decision-makers in prioritizing interventions.

On the other hand, as a person living with a disability, I know that we and our community need:

- Access to equal opportunities to participate in HIV / AIDS planning, budgeting, and implementation;
- Inclusion in community development opportunities to increase household incomes and opportunities; and
- To be free from sexual violence and gender-based violence, which is endemic for people living with disabilities, putting us at higher risk of mental, sexual, and physical health risks.

For many years, through the Masaka Association of Persons with Disabilities Living with HIV & AIDS, many of us have been doing on-the-ground community work and activism. To help us with this work, I have begun to think about the role that art and culture could play.

- Art and culture can be used to sensitize cultural leaders to disabilities and HIV. When they know more, they help to ensure that the community has a positive attitude towards people with disabilities living with HIV.
- Through music, dance, drama, and movies involving PWDSLH, we will be able to push back against the erasure and negative representations that undermine dignity and truth for people living with disabilities and HIV.
- Art and culture could be used as a way of creating employment opportunities and increasing incomes for PWDSLH.

- Because culture is passed down through families, using it to create awareness of PWDSLH will ensure future generations know more, and act better.

All of the abovementioned work is important because in terms of media and cultural representation in TV, movies, visual art, dance, storytelling, books, news, and magazines, people living with a disability have not been lucky in Uganda. We have not been given meaningful coverage; the only time you will read about issues affecting us is if one of us is accused of committing a crime or it is International Disability Day.

Personally, as a disability rights advocate, I feel bad and offended, as media does not think that, despite our disability, we contribute to the social, political, and economic development of our country. It is disturbing because media is one of the most reliable means of sharing information.

There is a need to train the media and those working within the cultural sector to understand disability, the language to be used, basic sign language, and how to portray disability positively. This will enable the public to evolve in the way they treat people living with a disability and HIV, as well as promoting mentors and advocates for people living with a disability within the country. Here is an idea: people working at newspapers, magazines, museums, theaters, movie houses, and dance studios should hire people living with a disability and HIV to help them get the right information out!

PWDSLH are suffering silently from discrimination and limited involvement. In many cases, there are treatments and medicines available to help improve our quality of life. What we don't always have is the political will to help us, or the cultural will to fully see us as people with things to say and the means to contribute. Art and culture are so often responsible for our erasure, or for putting us in a negative or limited light. What would it mean for curators and other art and culture gatekeepers to work with us, and to be part of a transformation in which the rights of all are respected?

Michael Miiro is a Technical Advisor on HIV/AIDS, disability, and sexual and gender-based violence for the Masaka Association of Persons with Disabilities Living with HIV & AIDS (MADIPHA). MADIPHA's mission is to promote access to comprehensive HIV and AIDS services by all Persons with Disabilities (PWDs) through advocacy, mobilization, sensitization, and training. MADIPHA aims to fully incorporate PWDs living with HIV/AIDS into society through advocacy measures that center PWDs while targeting key government agencies, line ministries, and civil society organizations like the Uganda Human Rights Commission. Miiro has trained village health teams, health workers, and police in sign language and held workshops about PWDs who are living with HIV and AIDS, as well as SGBV against PWDs. He worked with the local government on anti-poverty initiatives such as obtaining a grant for PWDs to start village and loan revolving groups, and given PWDs goats, chickens, vegetable seedlings, and coffee seedlings to generate income at the household level. At a regional level, he has worked with other stakeholders to lobby for changing policies that maintain the exclusion and segregation of PWDs from society.

Michael holds a postgraduate diploma in community-based rehabilitation from Kyambogo University-Kampala and a Bachelor of Adult and Community Education from Makerere University-Kampala.

Intersectionality, HIV Justice, and the Future of Our Movement

Cecilia Chung, Olivia Ford, Deon Haywood,
Naina Khanna, Suraj Madoori,
Charles Stephens
– *Reprint*

For World AIDS Day, 2014, AIDS activists from across the US released a statement entitled, *Intersectionality, HIV Justice, and the Future of Our Movement*. Building off work of lawyer Kimberlé Williams Crenshaw, the activists put forward their vision for the future, naming that their “differences in experiences” can be “sources of strength.” What bonds them is their experiences of living with HIV, or being deeply impacted by the ongoing crisis. In this way, like *The Denver Principles*, released 31 years earlier, *Intersectionality, HIV Justice, and the Future of Our Movement* is roadmap for the future made by the people that should be leading the journey.

Threaded through out the document are references to the grounding breaking work of Crenshaw; “Getting to Zero,” a once popular slogan / goal within the AIDS response echoing the UNAIDS vision of achieving “Zero new HIV infections. Zero discrimination. Zero AIDS-related deaths” ; and the death of Michael Brown. At the time of the document’s writing, many communities were early in the process of dealing with the news that the St. Louis County Grand Jury decided to return no bill of indictment against Officer Wilson in the shooting death of Brown, after what Professors Jeffrey Fagan and Bernard E. Harcourt from Columbia Law School referred to as very unusual proceedings leading up to the decision.

Five years since its publication, Crenshaw’s words are as present as ever, Getting to Zero rhetoric has largely been retired, Black Lives Matter activism remains strong, and AIDS-aware communities have galvanized around, *Intersectionality, HIV Justice, and the Future of Our Movement*, ensuring that HIV is part of this historical moment of resistance. The document drags forward powerful paradigms and tactics from the far away and recent past, in pursuit of a just present and future.

– Theodore (ted) Kerr

Intersectionality, HIV Justice, and the Future of Our Movement

“If we aren’t intersectional, some of us, the most vulnerable, are going to fall through the cracks.”

– Kimberlé Williams Crenshaw

HIV thrives in conditions of structural inequity – where the workings of poverty, patriarchy, and other overlapping systems of injustice render community members vulnerable to acquiring HIV. Who is “most vulnerable” and who “falls through the cracks” is not static. We do not all experience these vulnerabilities in exactly the same way. However, the differences in our experiences – the learning edges of power and oppression, privilege and vulnerability – can, for our extraordinarily diverse HIV community, be sources of strength themselves.

Who We Are

We stand together as a group of HIV activists of color. We are Black lesbians. We are Black gay men. We are heterosexual. We are immigrants and descendants of immigrants. We are people living with HIV and people whose lives have been touched by HIV. We are people of transgender experience and non-transgender experience. We are multigenerational, in age as well as HIV movement engagement. We are impacted by trauma in many different and complex ways. We experience intersectional stigmas. We are survivors of a range of health conditions and inequities. We share a vision of social justice and freedom for the communities we serve. In light of the continued impact of the HIV epidemic coupled with, and fueled by, pervasive structural violence facing our communities, this World AIDS Day we call for redefining the path ahead.



Lola Flash, *Charles Long designed Tote Bag for Visual AIDS*, 2019. Courtesy of Visual AIDS.

Origins and Herstories

There are many origins, histories and herstories, genealogies and legacies, that inform and enrich our current HIV activism work. Here we uplift the vision of intersectionality, as articulated by legal scholar and activist Kimberlé Williams Crenshaw and other feminists of color. This frame holds immense potential to build power among our communities and stimulate inclusive visions of liberation, recognizing that a single-issue approach will fail us all.

The Current Landscape

We are encouraged by advances in HIV treatment, prevention, and policy, representative of the scientific innovations that have rejuvenated the field and the advocacy of many of our colleagues. However, we know from experience that vulnerable communities seldom benefit simply from scientific advances.

To that end, we are calling for a centralization and integration of intersectionality in the HIV community, as both a lens and a practice, to guide our efforts and inform our vision. As we write this statement, the appalling and sadly unsurprising verdict in the case of Michael Brown – an unarmed black teenager gunned down by a cop who a grand jury decided last week will not be indicted for this heinous murder – is fresh in the national consciousness. Calls on the streets and on social media that #BlackLivesMatter echo the charges of the most enduring HIV activism: to address structural drivers of the epidemic and of disparities in health outcomes; to promote human rights for people living with and affected by HIV; to assert that our lives matter.

But that assertion cannot stop short of recognizing that those lives may include being unstably housed, or parenting children not biologically their own, or

grappling with the effects of lifetime trauma, or with the criminal injustice system – or a host of other conditions that impact our lives and our advocacy. Our whole lives matter, all at once, and must be addressed with holistic advocacy grounded in an intersectional approach.

Unpacking Intersectionality

Intersectionality begins with the idea that interlocking systems of oppression – for instance, racism, sexism, classism, heterosexism, xenophobia, stigma, transphobia, and state-sanctioned violence in the form of militarism, policing, and criminalization – can be experienced simultaneously based on a person's or group's complex categories of identity. This has significant implications for the HIV community, since many of us who are vulnerable to HIV also experience multiple oppressions. Experiences with intersecting oppressions differ across communities and between individuals; these different experiences of oppressions matter.

Power and Privilege

We all come from different experiences of privilege and oppression. Our privilege is less visible when we're also part of communities that have experienced oppression. For example, a white gay man living with HIV may experience and resist oppression due to his sexual expression and HIV status, while his race and gender privilege remain unaddressed. An undocumented woman of color from a low-income background may experience classism, racism, sexism, and xenophobia, and yet be privileged in many spaces by her identity as a non-transgender woman.

We must commit and be willing to take the risk of exposing and complicating privilege: privilege associated with race, gender, class, sexual orientation, non-transgender experience, and so forth. "Cracks," like those mentioned in the opening of this piece, are allowed to open when we fail to address how our efforts may privilege some individuals in our communities while leaving others behind. Such tactics are toxic to our work.

The framework of intersectionality comes from an understanding that power, privilege, identity, and oppression are intimately linked and cannot be segmented from each other. The fear, ignorance, othering, and complacency that allow for the mass devaluing of so many of our lives endanger all our intersecting communities. We cannot simply draw from narratives of dominant power; we must seek to build a mass movement from shared intersectional narratives in an effort to challenge systems of oppression.

Consequences

If we fail to understand that the systems, structures, and institutions we are collectively fighting are far more pervasive and embedded than the HIV epidemic, we fail as leaders. We will continue to see poor health outcomes, inequitable access across the HIV care continuum, and disparities in death rates. Our community will continue to be plagued by a false sense of victory and strategies that work against each other's interests. We will continue to see divide-and-conquer tactics that hurt the very people we are here to serve and represent – most especially people of color, poor people, and LGBT individuals.

Ultimately, in the fight for a just and equitable world, intersectionality affords us the understanding that no one truly wins until all of us win.

Moving Forward

We are at an unprecedented moment in the history of HIV activism. As we continue to see communities of color disproportionately impacted by HIV and enduring immense structural violence from the criminal injustice system, the medical industrial complex, stigma, economic distress, and other forms of institutional and ideological assault, we also see stunning examples of movement building, collaboration, and transformation.

We are uniquely positioned to hold multiple world-views, which comes from occupying multiple social locations. We also stand to offer service providers and clinicians better tools to engage the communities they serve, to provide more effective and higher quality care. We must confront the intersectional issues faced by vulnerable communities, to build power and healing to help overcome intersecting oppressions.

Rethinking Our Approach to "Get to Zero"

We face a historic and critical opportunity, where we can unite innovations in the scientific realm with greater inclusivity in the community realm. We can model more democratic, participatory, and inclusive models of leadership and continue to disrupt dominant notions, narratives, and practices around who gets to be valued and who doesn't. As we have seen in Ferguson, Mo., and beyond: There is great power in communities, and resistance is alive.

Part Two of this statement will outline concrete examples of work being done in our communities, which serve as guides and inspirations for HIV organizations looking to adopt an intersectional approach. We

must build upon our communities' precious assets, including culture; wield our stories as tools and our differences as strengths; and commit fully to the occasionally uncomfortable yet invaluable work of intersectionality.

In this way, in the US, we may not only "get to zero" in the context of HIV – which we take beyond the public-health paradigm to mean zero structural inequities, zero discrimination, and zero human rights violations that block access to HIV care, treatment, and prevention. We will also build a unified, inclusive, and transformative movement for social justice.

In solidarity,

Cecilia Chung

– *Transgender Law Center, San Francisco, CA*

Olivia Ford

– *Positive Women's Network – USA, Brooklyn, NY*

Deon Haywood

– *Women With a Vision, New Orleans, LA*

Naina Khanna

– *Positive Women's Network – USA, Oakland, CA*

Suraj Madoori

– *HIV Prevention Justice Alliance, Chicago, IL*

Charles Stephens

– *Counter Narrative Project, Atlanta, GA*

Iván Espinoza-Madrigal and Kenyon Farrow

also contributed vital perspectives to the development of this statement.

The **Counter Narrative Project** builds power among black gay men and works in solidarity and coalition with all movements committed to social and racial justice.

The **HIV Prevention Justice Alliance** (HIV PJA) was a diverse, national human rights network at the intersection of HIV/AIDS and economic, racial and social justice. (2007-2018)

Positive Women's Network – USA is a national membership body of women living with HIV and our allies that exists to strengthen the strategic power of all women living with HIV in the United States.

The **Transgender Law Center** is the largest American transgender-led civil rights organization in the United States.

Women With A Vision, Inc. (WWAV) is a community-based non-profit, founded in 1989 by a grassroots collective of African-American women in response to the spread of HIV/AIDS in communities of color.

Drunk At Vogue: The Last Disco

Greg Thorpe

For seven years, my friends and I ran a party named “Drunk At Vogue,” an event that was inspired by our love of 1970s disco, our own contemporary queer performance community in Manchester, and the residue of Manchester’s epic party years of the ‘80s and ‘90s. Our final event took place on World AIDS Day 2017—with perfect synchronicity, since as a collective of queer people we understand the ways HIV/AIDS has shaped our lives and culture.



Drunk At Vogue: The Last Party, Manchester UK, 1 December 2017. Photo by Lee Baxter. Courtesy of the artist.

From my young teens onwards, I was inspired and influenced by New York culture, and as I gradually came into my identity as a gay person, I was able to more fully acknowledge and embrace the queer aspects of this culture, which had and continue to have a huge impact on me. This happened via cinema, fiction, art, biography, documentary, as well as through music and nightlife culture, and eventually led me to the culture that surrounded the early years of the AIDS crisis, so that learning about disco, house, AIDS, and ACT UP happened with simultaneous force in my life.

As I reached my late 30s, surpassing the average life expectancy of many gay men in the peak years of the crisis, I began to think about a responsibility to remember and honour the lives, deaths, and activism of my queer forerunners. As an arts practitioner, I have tried to incorporate this into my creative and curatorial work. For example, my ongoing project “A mile of black paper” is based on an ACT UP demonstration in which the seminal AIDS activist group protested the *New York Times*’ dismal AIDS coverage by jamming their fax machine with black paper in order to get them to pay attention to

AIDS. This work takes the form of a teach-in, presentation, or performance, resulting in collaborative works of art which to date have been displayed at sexual health clinics, galleries, academic conferences, museums, and queer arts festivals.

In 2017, *Drunk At Vogue: The Last Disco* was the climax of Manchester's first *Day With(out) Art*, a programme I curated via my role as coordinator of *Superbia*, the arts and culture project from Manchester Pride. As a collective, *Drunk At Vogue* understands AIDS to be part of disco and house culture, and wherever this culture is referenced, so too should the epidemic be meaningfully remembered. Within the city's contemporary club culture, this rarely happens, and even in our own queer underground (often repped by straight white cis guys) it is rarely factored in. *Drunk at Vogue* has always hoped to be a corrective to this erasure, and our final night gave us the opportunity to go big with this intention. We drew on collective influences to shape an event that would simultaneously celebrate memories; grieve the end of an era (this final disco and all final discos); say thank you to the party faithful; and mark a new era.

Bringing together this cocktail of influences gave us the idea to make it into a "white party," influenced in part from the Pet Shop Boys' song, "Being Boring":

"I came across a cache of old photos
And invitations to teenage parties
'Dress in white' one said, with quotations
From someone's wife, a famous writer
In the nineteen-twenties..."

The white party also references parties of the '70s, in particular those at *The Saint*—"The Saint's Disease," an early euphemism for AIDS—and the subsequent epic Miami AIDS fundraisers. "Being Boring" continues with a painful plaintive refrain on absent friends and lovers:

"All the people I was kissing
Some are here and some are missing
In the nineteen-nineties..."

At the same time, as we were planning our final party, the introduction of PrEP in Manchester had been delayed yet again, and was about to be rolled out in limited trials. Local press had carelessly described PrEP as "controversial," in spite of its universal medical support, thus feeding a damaging narrative of preventative medicines as "lifestyle drugs for promiscuous gays." Around 5,000 people live with HIV in the Greater Manchester region. Access to medication is free, and there are a number of dedicated services supporting and advising people living with HIV, such as the LGBT Foundation and George House Trust, though funding cuts have affected some of the most impactful projects from these organizations. Late diagnosis is an ongoing issue, stigma is rife, preventing people from testing, and making disclosure difficult. These issues are magnified in communities of colour.

Activism and nightlife are not easy bedfellows. Escapism is often the lifeblood of the dancefloor, perhaps more so for queer people than anyone, but I do believe there are always means to creatively engage on a dancefloor, as we have often done with *Drunk At Vogue*, queering venues, putting trans bodies into cis spaces, remembering the epidemic, and so on. In a club setting, a moment of engaged drama is often the most meaningful thing you can reach for, which can then of course resonate for a lifetime. (Man-

chester in some ways has been built on this). Firstly, of course, you have to build your community, another thing clubbing is very effective at.

At The Last Disco we did our best to counter AIDS stigma by making it a place of HIV+ culture. Using literature from the LGBT Foundation, we were able to support and share their U = U campaign materials, as well as raising money for George House Trust throughout the night, and papering our all-gender bathrooms with PrEP literature. Nobody left our event without seeing the U = U message or being asked for donations to support HIV+ people in our community! Midnight arrived, and the club was full of beautiful people dressed in white, a room of both ghosts and friends dancing together, uniting the past and the present. I gave a speech from the balcony while “Being Boring” played, and I looked over our queer family and spoke affectionately of seven years of hedonism, adding:

“Today is World AIDS Day, and we want to pay tribute to the divine artists who we love and who have influenced everything we have done at Drunk At Vogue. We want to big up George House Trust who every day help people in the North West living with HIV. For Manchester’s first Day Without Art and for our Last Disco, let’s remember the pioneers without whom our world would have been a much duller place.”

A digital projector then cast enormous photographs of our roll-call icons across the twenty-foot walls of the venue, as I read aloud these names: “Juan Ramos, Robert Mapplethorpe, Tony De Vit, Leigh Bowery, Liberace, Gia Carangi, Eazy E, Steve Rubell, Cookie Mueller, Klaus Nomi, Derek Jarman, Rudolf Nureyev, David Wojnarowicz, Halston, Arthur Russell, Keith Haring, Freddie Mercury, and Our Queen... Sylvester.” In this way, one era gave way to another, and to another, and as “You Make Me Feel (Mighty Real)” played for the final time, we all danced to mark their passing.

A clever old raver once said, “You can learn a lot more than you think on the dancefloor,” and I believe in nightlife as a meaningful place, of community, influence, and change, while also seeing the limits of what can be achieved under disco lights. As an artist and organizer, I see how in Manchester nightlife can help to sustain a community, which is vital and which makes other things possible, and I can’t wait to see what comes next, who comes next, and what happens when our communities are able to survive and thrive.

Links

- “A mile of black paper”: <http://www.gregthorpe.eu/art-1/#/a-mile-of-black-paper/>
- Day With(out) Art, Manchester, 2017: <http://superbia.org.uk/events/day-without-art-manchester>
- LGBT Foundation on HIV: <http://lgbt.foundation/hiv>
- George House Trust: <https://ght.org.uk/>

Greg Thorpe is a freelance writer, curator, artist, and DJ based in Manchester, UK.

Twenty-One Questions to Consider When Embarking upon AIDS-Related Cultural Production

What Would an HIV Doula Do? and Triple Canopy

In October of 2018 members of What Would an HIV Doula Do? and editors working with Triple Canopy created an event in which community members were invited to engage in conversation around a question: What Would an HIV-Informed Cultural Worker Do?

The twenty-one questions that appear below are a result of that event. A designed version of this text was created by Triple Canopy and distributed on their website.

– Theodore (ted) Kerr



Chris Jennings, *What Would an HIV-Informed Cultural Worker Do?*, 2018. Courtesy of the artist.

In recent years, there has been a resurgence in the creation and dissemination of AIDS-related culture. Vital testimony, memories, tactics, and artifacts, previously in danger of being lost to history, have been shared and preserved; cross-generational dialogue has flourished; and many people who have died with HIV/AIDS have been memorialized. However, there have been problems: gaps in the information being shared and biases around who is being remembered persist within this transmission of history. Artists, curators, and cultural institutions have been put on notice by activists for white-washing the plague, being overly gay-centric, focusing too much on North American coastal metropolises, and ignoring the present by treating the crisis as if it is not ongoing.

In order to think through the current landscape of HIV/AIDS-related art and cultural production, Triple Canopy and What Would an HIV Doula Do? hosted an open conversation on October 14, 2018 entitled “What Would an HIV-Informed Cultural Worker Do?”

The conversation was part of *How We Do Illness*, a day-long symposium that considered how personal narratives shape public perceptions of sickness, and how cultural workers and institutions contribute to the ongoing response to HIV/AIDS. The title was borrowed from the writer Lisa Diedrich, who reminds us that “illness and how we do illness is political.” The symposium was part of *Risk Pool*, an issue of Triple Canopy that asks: How are sickness and wellness defined, and by whom? What are the effects of these definitions, these acts of naming and describing?

Forty artists, administrators, critics, curators, and individuals living with and impacted by HIV/AIDS gathered to share their insights, frustrations, tactics, and experiences with making, seeing, and contemplating AIDS-related culture.

Below is a non-exhaustive series of questions (posing both individual and collective concerns) inspired by the event. These questions are meant to be provocations, and are not put forward with the implication that there are singularly correct answers to any one of them. Hopefully, these can be read as a litany of queries from which a practice of reflection might emerge. And with it, an exhortation to make the best work possible about the intersectional legacy and lived reality of the ongoing response to HIV/AIDS.

1. Are you living with HIV?
2. As cultural producers working on HIV/AIDS, how do we engage with the fact that we are participating in the creation of history?
3. Who are your people? Who are the artists, activists, friends, and lovers that act as both source and recipient of your power, energy, and insight?
4. How do you define inclusion? What does community mean to you?
5. How are we including the ongoingness of HIV/AIDS in our work?
6. How do we best honor the labor of activists, makers, and other people living with HIV?
7. How do sex and drugs figure into current representations of HIV/AIDS? What about: faith, networks of care, and the economy?
8. How do gender, race, class, sexuality, religion, geography, poverty, disability, and other factors of who we are, how we live, and how we are perceived impact how we understand and broadcast HIV/AIDS?
9. What is at risk for you, personally, in creating AIDS-related culture? For the audience?
10. How do we make it clear that any expression of AIDS-related culture is just a sliver of a sliver of larger conversations about HIV/AIDS?
11. How do we factor in the politics of our collaborators and partners?
12. How might we unpack the ways in which the state has factored into our own understanding of the virus?
13. How do we account for the ways in which HIV/AIDS keeps all of our bodies entangled and vulnerable?
14. How are we relating HIV/AIDS to other illnesses and social conditions? How, if at all, are we educating on HIV/AIDS in relation to other illnesses and social conditions?
15. How does our AIDS-related work relate to the people who were diagnosed today? Last year? Last century?
16. What do we consider an AIDS-related archive to be?
17. Is the cultural production of HIV/AIDS-related content a form of activism? Is it always?
18. What are ways in which we can learn, reclaim, and signify loss? Not just of people, but also of ideas, tactics, ways of being, and experiences of living?
19. How can we keep the physicalness of bodies—such as aging with illness—at the forefront of our theorizing and intellectualizing about AIDS-related cultural production?

20. How are we pushing back against the fact that people living with HIV are often positioned as the content of AIDS-related culture but are less frequently shown as the producers of, or even the audience for, that culture?
21. How do we seek out the perspectives and experiences of people and communities living with and impacted by HIV/AIDS who may not already be part of the conversation?

Questions posed and inspired by Jordan Arseneault, Shirlene Cooper, Emily Colucci, Lisa Diedrich, Alex Fialho, Corrine Fitzpatrick, Johnny Guaylupo, Emma Hedditch, Theodore (ted) Kerr, Elizabeth Koke, Carolyn Lazard, Esther McGowan, Fernando Mariscal, Lara Mimoso Montes, Ricardo Montez, Julie Tolentino, and others present in the room who chose not to be named.

What Would the HIV Doula Do? is a collective of artists, activist, academics, chaplains, doulas, health care practitioners, nurses, filmmakers, AIDS Service Organization employees, dancers, community educators, and others from across the movement joined in response to the ongoing AIDS Crisis. We understand a doula as someone in the community who holds space for others during times of transition. For us, HIV is a series of transitions in someone's life that does not start with being tested or getting a diagnosis, nor end with treatment or death. Foundational to our process is asking questions.

Triple Canopy is a magazine based in New York. Since 2007, Triple Canopy has advanced a model for publication that encompasses digital works of art and literature, public conversations, exhibitions, and books. This model hinges on the development of publishing systems that incorporate networked forms of production and circulation. Working closely with artists, writers, technologists, and designers, Triple Canopy produces projects that demand considered reading and viewing. Triple Canopy resists the atomization of culture and, through sustained inquiry and creative research, strives to enrich the public sphere. Triple Canopy is a nonprofit 501(c)(3) organization and has been certified by W.A.G.E.

Imprint
Issue 42

Publisher
 OnCurating.org

Executive Editor
 Dorothee Richter

Editors at Large
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Web Design and Graphic Design Concept
 Biotop 3000

Graphic Design Issue 42
 Volker Schartner, Biotop 3000

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Proofreading
 Stephanie Carwin

OnCurating.org is a non-profit association based in Zurich, Switzerland with a registered identification number.

It runs the OnCurating Journal and an exhibition space in Zurich (oncurating-space.org). The journal is independent with focus on curating both on the web and in print. The publications are openly accessible on the website. It collaborates with different partner institutions.

ISSN 2673-2904 (Online)
 ISSN 2673-2955 (Print)

ONCURATING.org
 Pfingstweidstrasse 96, 8005 Zurich, Switzerland

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PHD in Practice in Curating
Practice-Based Doctoral Programme
Department of Art, University of Reading

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Acknowledgement by the Editor

This issue is dedicated to the power of AIDS,
and everyone living with the virus.

Throughout the making of this issue I thought
countless times of Frank Wagner (1958 - 2016).
He was a curator whose dedication and output
made a positive difference in the lives of artists,
audiences, galleries, and institutions. His scholar-
ship and commitment to artists living with HIV
and impacted by the epidemic was vital and
influential. His exhibitions *LOVE AIDS RIOT SEX*
1 + 2 remain a important touchstones for how
to curate the crisis in the 21st century.

Thank-you to all of the contributors for their bril-
liance, and patience; to Dorothee Richter, Ronald
Kolb, and Volker Schartner for your guidance
and skills; to Stephanie Carwin for your talents and
endurance; to Daniel Brenner, Julie Golia and
everyone at the Brooklyn Historical Society for
the assistance; Corrine Fitzpatrick, Kris Nuzzi,
Heiner Schulze, Amy Scholder, and Liza Zapol
for the information and introductions; to Kyle Croft,
Nancy Chong, Tracy Fenix, Alex Fialho, Esther
McGowan, Amy Sadao, Nelson Santos, and the
whole Visual AIDS crew (past, present, forever)
for being amazing; and to Sam Feder, Amy Fung,
Alexandra Juhasz, Alexander McClelland, Tommaso
Mozzati and Justin Yockel for the support along
the way.

ONCURATING.org is an independent international journal (both web and print) focusing on questions around curatorial practise and theory.

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PHD in Practice in Curating,
cooperation of ZHDK and University of Reading,
supported by swissuniversities

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