

The Sailor's Daughter: AIDS before AIDS in the Present

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On my flight back to NYC from Oslo I was supposed to sit in 16D, an aisle seat. But upon reaching it, a doe-eyed dad and his daughter looked up at me. A woman reached over from her middle seat across the aisle, asking if I would switch. How could I say no?

I settled into the middle seat. On the aisle was a man in his early 50s. For the hour we waited for take-off he switched between watching *Madame Secretary*, the CBS drama starring Téa Leoni, and checking his Bloomberg portfolio page—an ongoing toggle on his iPad between fantasy and catastrophe. On the other side of me nestled, in the crux of the window, was a younger man, all limbs and big sunglasses. It was an early morning flight and he smelled like a good night: cologne, liquor and cigarettes. An hour later he would wake up, take some pills, order a sandwich—all in a slightly agitated and sleepy state—then eventually relax into his seat, open his laptop, and begin to type, as I was already doing. His skin was a ruddy olive, and his hair the kind that can never really be out of place.

Sitting close, it was impossible not to look at each other's screens. From his, I deciphered he was learning French, behind on a few deadlines, and possibly going to Montreal soon to visit a friend. From mine he gleamed the focus of my work. His first words to me, pointing his head in the direction of my screen without averting his eyes from his, were, "I have that." The "that" being HIV.

After a few jokes about how we had been reading each other's screens, he asked if I was positive. "No," I said, aware this could change the dynamic. But it didn't. Instead, with my laptop screen as jumping off point, Benoit and I dove into a conversation around how intense HIV criminalization was in Nordic countries.¹ He told me how in Sweden there is *informa-*

tionsplikt (information duty), which, when it comes to HIV, puts the burden of the public's health on people living with the virus. "Why is it our responsibility alone to disclose our status to medical staff and people we might have sex with?" he said, "Even if there is no risk of transmission."²

For enforcement, there is the *smittskyddslagen* (Communicable Disease Act)³ that allows for the monitoring of people in Sweden for dangerous behavior. After he was diagnosed, Benoit went to a presentation to learn more. Telling me about it, he said he and others who were there walked away feeling as if they had sat in a room for two hours where strangers yelled at them: "Not only are you sick, but you are criminals in waiting." As a result of this kind of treatment he sees how within poz networks and beyond, there is this idea circulating that the majority of people living with HIV in the Nordic region are immigrants. Regardless of facts, Benoit thinks this is a way white Nords (regardless of their status) can distance themselves from a virus popularly understood as a problem of the past, i.e. not their problem, an illness of the other.

All of this sounded familiar to me, almost in the reverse. I launched into a monologue where I told him how I see the story of HIV in the US and Canada as both whitewashed and pinkwashed, resulting in the erasure of black people, women, people of color, people living in poverty, people who do drugs, and others from both the history of HIV and the ongoing crisis.⁴ In a white su-

membership organization that works with issues involving the violation of human rights for people living with HIV/AIDS. It can be downloaded: <http://hiv-norden.org/Documents/crime%20brochure.pdf>.

[2] Only recently have courts begun taking risk of transmission into consideration. Admissible now in Swedish courts are letters from a positive person's doctor that state their patient has an undetectable viral load and no sexually transmitted illnesses. We both understood this not as a victory, but a stopgap until criminalization was abolished. And, as Benoit explained, it is conditional. If he finds himself with chlamydia for example, then all of the burden is back on him. To see how people living with HIV are criminalized where you live, visit: <http://www.hivjustice.net/site/countries>.

[3] This legislation is currently under review. For some background, visit: <http://www.hivjustice.net/news/sweden-court-of-appeal-acquits-hiv-exposure-case-recognises-national-board-of-health-and-welfare-endorsement-of-swiss-statement/>. To learn more, visit a website from "Sweden's county councils and regions" that provides information on health and wellbeing: <http://www.1177.se/Regler-och-rattigheter/Smittskyddslagen/>. While the page is about infectious diseases in general, HIV is singled out as an illness that can lead to criminalization, along with Hepatitis B or Syphilis.

[4] A lot of activism, art and academic work has been done on the subject of representation, care and HIV/AIDS. In 1993, activists in the US were successful in getting the government to change the definition of AIDS to include women. For the story on how this was done, watch the Women of ACT UP panel: <https://www.youtube.com/watch?v=SLNrFy982vQ>. In the last few years there has been an increased focus on HIV/AIDS and the black community. The CDC reports: "Blacks/African Americans have the most severe burden of HIV of all racial/ethnic groups in the United States.

[1] Recognizing the criminalization of people living with HIV as a growing concern, in 2012 an updated version of the report, "Q & A: HIV and the criminal code in the Nordic countries" was released by HIV-Nordic, a

premacist and patriarchal culture, it is an illness of the unseen other here too, and within that, there is struggle among the oppressed for resources and recognition. I told him about how rare it is for folks other than white gay men to be represented in AIDS discourse. Except when it comes to criminalization, then they are over-represented, with black men and sex workers (of diverse genders and backgrounds)⁵ most often being criminalized for their HIV positive status, frequently in conjunction with other criminal justice system entanglements.

Like Sweden, I explained, in Canada and the US people living with HIV are criminalized and similarly, these laws and high court rulings are inhumane, unjust and increase HIV-related stigma, thus hurting treatment and prevention efforts for those living with HIV and those made most at risk.⁶ But, unlike in Sweden, I pointed out how courts in the US do not usually take into consideration someone's viral load, nor do they consider other medical advancements such as the availability of PrEP (Pre-Exposure Prophylaxis) or PEP (Post-Exposure Prophylaxis). In trying to make sense of the laws, people often say that they were passed at a different time. But as I said to Benoit, "I call bullshit. That kind of thinking fails to remember that people vocally opposed the laws at the time,⁷ and that the laws and rulings have been revisited, updated, and reinforced over the last 10 years."⁸

Compared with other races and ethnicities, African Americans account for a higher proportion of new HIV diagnoses, those living with HIV, and those ever diagnosed with AIDS.⁹ The CDC goes on to state: "In 2014, 44% (19,540) of estimated new HIV diagnoses in the United States were among African Americans, who comprise 12% of the US population." See: <http://www.cdc.gov/hiv/group/racialethnic/africanamericans/>. For more on this, read, "Antiblack Racism and the AIDS Epidemic: State Intimacies" (2016) by Adam Geary.

[5] "Overall, a comparatively greater risk of conviction was observed for black men with female partners and white women overall," is one of the findings available in Trevor Hoppe's paper, "Disparate risks of conviction under Michigan's felony HIV disclosure law," which can be read online: <http://pun.sagepub.com/content/17/1/73.abstract>. More about HIV criminalization related to sex work, see the Williams Institute's report: "HIV Criminalization in California: Penal Implications for People living with HIV/AIDS": <http://williamsinstitute.law.ucla.edu/research/health-and-hiv-aids/hiv-criminalization-in-california-penal-implications-for-people-living-with-hiv-aids/>.

[6] To learn more about the criminalization of people living with HIV in the US, visit: <http://www.hivlawandpolicy.org/>; to learn more about the criminalization of people living with HIV in Canada, visit: <http://www.aidslaw.ca/site/>.

[7] While doing research in St. Louis I came across many news reports indicating the very vocal opposition mounted by citizens against the criminalization of people living with HIV, including anti-criminalization editorials in the mainstream press. I wrote about these findings for *POZ magazine*: <https://www.poz.com/article/theodore-kerr-27923-9019>.

[8] At the 2016 International AIDS Conference in Durban, the HIV Justice Network released the following statement: "HIV criminalization is a growing, global phenomenon that is seldom given the attention it

After we whipped ourselves into a shared righteous frenzy of frustration and anger we sat still for a minute. It is one thing to sit next to someone with whom you have something in common, but it is another to bond with someone within the AIDS movement who is also against criminalization. For reasons I can't understand, it is rare. As we resumed our conversation, we got closer. We closed our laptops, put our trays up and turned our bodies towards each other. When his body passed over mine on his way to the restroom I hoped for turbulence, an opportunity for our bodies to collide in the air.

I went to Oslo to speak at a symposium on art and activism,⁹ and to visit the final resting place of a family who died of AIDS-related complications in 1976. They join Robert Rayford: a teenager born and raised in St. Louis, who died in 1969 of HIV-related causes, in being among the earliest known people to die in the ongoing epidemic.¹⁰ I spent the last summer in St. Louis trying to learn more about Rayford. But without much luck. His mother died in 2011, his brother died in 2007, I could not find any other living family or friends, and his school records were in purgatory due to a real estate deal that involved the building where the Board of Education's archives are stored. What I did have was the address where he grew up. From his birth certificate and an interview his mother and brother gave, I pieced together that the family home was on Delmar, the long-serving dividing line of St. Louis between black and white, between the

deserves considering its impact on both public health and human rights, undermining the HIV response. In many instances, HIV criminalization laws are exceedingly broad – either in their explicit wording, or in the way they have been interpreted and applied – making people living with HIV (and those perceived by authorities to be at risk of HIV) extremely vulnerable to a wide range of human rights violations. Seventy-two countries currently have HIV-specific laws, rising to 101 jurisdictions when individual US states are included. Notably, 30 countries in Africa have such laws, including new overly-broad laws in Uganda (2014) and Nigeria (2015). At least 61 countries have reported HIV-related criminal cases. This total increases to 105 jurisdictions when individual US states and Australian states/territories are counted separately." Learn more: <http://www.hivjustice.net/news/hiv-justice-network-presents-important-new-hiv-criminalisation-data-to-day-at-aids-2016/>.

[9] The First Supper Symposium (FSS) is a Oslo based project of Gidsken Braadlie, Lisa Pacini and Camilla Dahl which began in 2012 that explores issues of art, activism, feminism and politics through public conversation, gatherings and publications. I was invited to participate in 2016 to discuss ideas around the theme of "White Cube vs. Public Space" along with curator Juan Puentes, Professor Mikkel Bolt, and artist Zanele Muholi. Learn more about the project: <http://www.thefirstsuppersymposium.org/index.php/en/>.

[10] Information on Rayford is scarce. There is a 1988 article that confirms his HIV+ status in the *Journal of American Medicine Association*, and a handful of articles including: <http://www.nytimes.com/1987/10/28/us/boy-s-1969-death-suggests-aids-invaded-us-several-times.html>.

under-resourced and the supported.¹¹

The townhouse the Rayford family lived in is gone, replaced by a new one. Walking around the area I did the friendly head nod and exchanged words with young families that lived on the block as they walked from their cars to their homes in the hot August air. I wondered what the area was like more than four decades ago. Now it is a trapped triangle of neglected domesticity with hungry business improvement districts slowly encroaching from all sides. Long after Rayford died, a bathhouse opened up at the end of his street. The patrons, like the families in the area, had not heard of Rayford, nor did they know that the earliest confirmed HIV-related death was in their backyard. Downhill from the house on Delmar is the iconic Gateway Arch, which was built in the years Rayford grew up. I wonder if he and his brother watched it get made from a nearby porch or rooftop.

All this uncertainty around Rayford's life made the journey I had planned in Norway that feel much more urgent. Before the symposium I would travel to Borre, Norway, 77 km outside of Oslo, where the Røed family is buried. They are understood to be the earliest confirmed cases of HIV in Europe. In the 1960s, Arne Vidar Røed, the father, worked as a kitchen-hand on a Norwegian merchant vessel in West Africa and then later as a truck driver in the same region.¹² It is during one of those times he contracted HIV and subsequently returned to Norway where he shared the virus with his wife Solveig Oline Røed and she in turn shared it, in utero, with the youngest of their three daughters, Bente Vivian Røed.

The morning I boarded the train from Oslo the sky was a threatening grey. As I walked the 20 minutes along the highway from Skoppum, where the train stopped, to Borre, I bargained with the sky. I figured all I needed was 30 minutes. I would find the grave, take a picture and sprint back to town where I would catch the train, hopefully all before the rain began. But that was not to be. Instead, as I reached

the city limits of Borre I began to feel drops on my arms. The path ended in an intersection with the sea in front, a church on one side, a historical center on the other, and a fruit stand in the middle. Minding the fruit stand was a young boy who looked up from his phone and smiled at me as I started to get wet. I stood there like a dummy trying to figure out which way to go.

In the research I did before I left, I understood Røed's grave to be part of the Borre Mounds, a historical site where Vikings, kings and others were buried in large mounds along with their earthly trappings ensuring they had what they needed in the afterlife. In my (I guess) biased mind it made sense to me that the first family of HIV in Europe would be buried in such an auspicious place. While I understood that the church would be a logical place to go for information about where someone was buried, I was drawn to the historical center. I ran there from the fruit stand where a grey-haired, strong looking woman greeted me, asking if I needed help.

"Yes, I am hoping you can point in the direction of a specific grave." At the time I thought I was just looking for the father's grave—while his wife and daughter were listed in the literature, it was often just a line or footnote.

The woman looked at me with bemusement in her eyes that I could not track. "Do you have more information?" I pulled out my laptop where I had saved a PDF from the cemetery website that showed a very basic map of where Røed's grave was located. Although it was not clear if he was buried at Field 17, Row 3, Plot 6 or Field 17, Row 3, Plot 7. I was not sure why were two graves marked off?

She pulled out a pair of glasses from her vest pocket and looked at the screen. "He is not here. He died too late." Sensitive to AIDS-related stigma I often can't always hear what people are actually saying. Rather, I hear what I fear they are saying. At first listen I heard her offer a refusal of sorts, rooted in a disbelief that someone living with HIV was buried at her workplace. So in response I said, "I assure you, he is here. He was the first confirmed person to die of HIV in Europe."

Without a beat, she responded, "That very well might be true, but everyone here died centuries before AIDS." Her reply certainly knocked me out of my defensive mindset. She continued: "The place you are looking for is across the way." She pointed behind me. It was then I became aware of the puddle I was leaving on the museum floor, and how strange

[11] In 2012, two years before Michael Brown was murdered by a Ferguson police officer, in a county north of Delmar, the BBC produced a much watched and discussed video that popularized the term, 'the Delmar Divide': <http://www.bbc.com/news/magazine-17361995/>.

[12] Unlike with Rayford, there has been a handful of medical literature produced about the Røed family over the years: Frøland, SS et al., "HIV-1 infection in Norwegian Family before 1970," *Lancet*. 1(8598) (1988): 1344-5.; Hopper, "Sailors and star-bursts, and the arrival of HIV," *BMJ* 315(7123) (1997): 1689-91.; Lindboe CF et al., "Autopsy findings in three family members with a presumably acquired immunodeficiency syndrome of unknown etiology," *Acta Pathol Microbiol Immunol Scand A*. 94(1986):117-23.



Grave plot of Arne and Bente Reed, June 2016, Courtesy of the author.

Borre Kirkegård, felt 017

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Screenshot of research. Accessed July 2016. horten.kirken.no/gravplass

I must have appeared, this little white foreign man speaking a tentative English, coming in looking for a dead man from an epoch beyond his purview, so sure of himself, yet so unaware of his surroundings.

"Thank you." I smiled.

"No problem," she responded, "I will call the church and see if they can help you." And with that, she went into the back. I could hear her speaking in Norwegian. Upon returning she said, "There is no one at the church today. I called the one the next town over. They have no idea what you are talking about but I gave them the grave coordinates you showed me and they said, 'It is on the right hand side of the church when looking at the sea.'"

My planned 30 minutes had long since run out and it was now pouring outside. The woman went back to the office and returned with an umbrella. "People leave these here all the time." With that, I sprinted away from the museum, past the boy on his phone selling fruit and on to the church property, aware that the sea was to my left. I spent the next three hours in the rain in a nearly empty cemetery in a coastal town in Norway looking for the grave of a man I thought was the first confirmed European to die of HIV. I stood in various places near the church with the sea to my right, looking for *Field 17, Row 3, Plot 6 or Field 17, Row 3, Plot 7* with no luck. Spotting a construction worker coming out of a shed near the church I asked for help. He had no English. I had no Norwegian. Seeing people paying respects to loved ones, I waited for the right moment to ask for any insight on how the cemetery was laid out. Like the construction worker before them, they were all very kind but unable to help. The ones who spoke English were unimpressed or unmoved by having such an important figure in AIDS history buried nearby. Maybe to them all dead people were special. Then I tried being more systematic. I walked up and down rows

of graves looking for Røed. But soon this too proved ineffectual, as much of the text on the tombstones had been weathered into indecipherability.

Doubt was dampening my spirits as the rain soaked through my clothes, bag, shoes, and socks. I found reprieve under the overhang of the church roof where I ate a cheese bagel I had bought before I got on the train in Oslo. I wanted to give up. I began to think I should come back on a day with sun and when the church would open. But my time in Norway was short and I wanted to share my findings at the symposium. My sense was that most folks in Norway did not know their country's connection to AIDS history and I wanted to illustrate it with a story and a picture.

Under the church roof I regained my resolve and went back out, deciding this time to look for tombstones I thought were cute, or funny, or gave off an air of allure. This too was unsuccessful. In the end, I found the grave by following a piece of trash. I was kneeling down trying to decipher the name on a tombstone and a black plastic bag skipped past me and got stuck on a twig. I thought about *American Beauty*, laughed and decided to go to the plastic bag,¹³ hoping that the twig was on the grave I was looking for. It wasn't. I was not crestfallen—I was just annoyed and tired. I stuffed the plastic bag in my hand and decided to keep the twig as a memento of the day, a stand-in for the elusiveness of pre-epidemic AIDS. But then I turned around—with the sea to my right—and, as if a joke, as if trailing me one step behind all day, in slightly obscured letters was a tombstone that read RØED on it, not once, but twice: "Arne Vidar Røed, 23 – 7 – 1948 to 24 – 4 – 1976" and "Bente Viviann Røed, 31 – 12 – 1967 to 4 – 1 – 1976." The reason the online map had marked out plot 6 and

[13] In an infamous scene in the film, a young man shows a video recording he made of a plastic bag blowing in the wind as he narrates, "Sometimes there's so much beauty in the world I feel like can't take it." <https://www.youtube.com/watch?v=pGWU4QhJ4L8>.

7 was because the father was not buried alone. He was buried with his daughter, who had died three months earlier than he did. Within a gust of wind I went from not being able to find Mr. Røed's grave to finding the final resting place of he and his daughter (his wife and mother rested in the same row, a few plots down), learning that the first HIV related death in Europe was not the Norwegian sailor, but rather it was the nine year old sailor's daughter.

In previous writings I have addressed the damage I see in the US response to AIDS by the silence that surrounds the life and death of Robert Rayford.¹⁴ It is no accident that the crisis we see manifested early in the life of a black teenager, which then only seemed to garner attention once white men starting to get sick, is still a health issue where for the most part the impacts of a positive HIV diagnosis on a black person is worse than on a white person. The stories we tell and don't tell affect the work that does and doesn't get done.

In my work I come across a lot of people who do not see themselves represented in the stories we tell about HIV. There are underground AIDS movements, intimate in scale and mighty in effectiveness. They include activists raising bail money for sex workers, and Facebook groups where people can crowdsource medication when they run low. They include black youth coming together to demand institutions represent them better, and young women telling their best friends that one of their parents died of HIV. They include people making themselves available to the newly diagnosed so that they don't call the cops on whoever may have shared their virus with them, and people coming together to think about how community can play a renewed role in the ongoing response. When it comes to HIV/AIDS, we have a lot of history but not enough stories. We need more of both, and we need to ensure the stories circulate—because history will always be limited in its reach.

"Can I kiss you?" he asked, as the plane began its descent. A few moments before I had put my hand on his thigh. We had been talking about our dating lives: about me and my new boyfriend, and about how he was dating again after a breakup.

"Yes," I said, not sure it was a good idea, but unwill-

ing to say no. After a few moments we pulled back to look at each other. His face was softer, relaxed. "Now why didn't we do that earlier?" he grinned. We both looked out the window. It was not a smooth landing, but a successful one nonetheless. He insisted that he walk me to my gate. A sweet gesture I accepted by holding out my hand once we deplaned. The mother who had asked me to switch seats caught up to me, her young daughter and husband in tow, eyes still wide. She thanked me. I shook my head, blushed and said, "No, thank you."

When the epidemic was first being recognized, people only had each other. As the response grew, so too did the death toll, and by the time health was being stabilized for many, folks were tired—wanting and needing to move on. There was not a lot of desire to go back and see what was missed, or what was being forgotten. But there is now. There is an opportunity to care for each other and to go back to learn and tell the stories of AIDS before AIDS, and to connect them to the present. In the same way I think that telling people about the life and death of Robert Rayford can effect the work we do when it comes to HIV, perceptions, race and sexuality in the US, I wonder what it would mean to those in Nordic countries living with and deeply impacted by HIV if people spoke about Bente Viviann Røed and her family.

What does it do to the public imagination around HIV to understand that the first confirmed HIV-related death in Europe was a 9 year-old girl? For me, it is not about changing or encouraging new sympathies for people living with HIV per se, rather it is about challenging embedded ideas around what we think we know about HIV, and then looking at how those ideas have calcified into how we think and react to HIV. In mainstream conversation around HIV/AIDS, women and girls are rarely mentioned. Yet, as of 2014, 1,819 women are living with HIV in Norway. What is the quality of their lives? How many have a robust community of support? How many have to manage other people's ignorance upon disclosure? If it is hard for Benoit to hear about criminalization, what is it like for others, such as women living with HIV, to hear? Could the story of Bente Viviann Røed make life better for women living with HIV in Norway and beyond? Make them feel less alone?

Additionally, how could the story of the Røed family impact conversations around innocence, guilt and culpability that Benoit's experiences tell us about? While the Røed's story is rooted in AIDS before AIDS,

[14] I have written about Rayford in relation to representation on three occasions: in an interview for the Visual AIDS blog with writer Joss Barton: <https://www.visualaids.org/blog/detail/ted-kerr-st-louis>; for an article I wrote for Hyperallergic after the Tacoma Action Collective protested the lack of black representation in the exhibition Art AIDS America: <http://hyperallergic.com/264934/a-history-of-erasing-black-artists-and-bodies-from-the-aids-conversation/>; and most recently in the forthcoming AIDS and Memory issue of Drain: <http://drainmag.com>.

it is one that is current in its themes of migrant workers, complex sexual relations, and HIV in the family. Their past makes space for us to talk about the present. It is a tough thing to think about, but in reconciling their deaths, they make possible better futures for those living now. To not consider this is a missed opportunity, and an affront to the dead.

Talking with each other about HIV (past and present), we make space in the public sphere for HIV to be the porous and complex topic that it is. We don't need to sequester it to the past or pretend that it only affects some communities. Decades into the epidemic, we not only have each other, we have the vast sea of the past—waiting to be witnessed, re-witnessed, and welcomed onto the shore of the present.

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