



Richmond has one of the highest rates of HIV/AIDS in the United States. In 2014, the city ranked 17th among more than 2,300 localities reporting HIV/AIDS to the Centers for Disease Control and Prevention (CDC). In 2017, the health-mapping website AIDSvu reported that 4,933 individuals were living with HIV in Richmond, of whom 25.4 percent were female and 68 percent were black. The southern states accounted for 52 percent of all new infections in 2017.¹ Today, HIV is regionally concentrated and disproportionately affects people of color. Richmond's HIV crisis is exacerbated by high concentrations of poverty and a lack of sex education in the public schools, as well as the opioid epidemic. Yet outside the public health community, HIV in Richmond has received little attention.

Unseen Faces, Unheard Voices

The books, plays and films that defined a generation's understanding of AIDS, such as Larry Kramer's *The Normal Heart* (1985), Randy Shilt's *And the Band Played On* (1987), Paul Monette's *Borrowed Time: An AIDS Memoir* (1988), and Tony Kushner's *Angels in America* (1991), all focused on white, gay men. Characters played by Tom Hanks, as a lawyer with AIDS in *Philadelphia* (1993), and more recently, Matthew McConaughey in *Dallas Buyers Club* (2013), fit this profile as well. The demographics of those affected by HIV may have changed, but pop-culture representations of the epidemic have not always been up-to-date.

Health activists are now challenging not only these representations but also questioning the lack of diverse voices in the conversations around HIV/AIDS. For example, "Art AIDS America," a 2015 exhibition that originated at the Tacoma Art Museum and has traveled to museums across the nation, drew protests because it includes only four African-Americans among the 107 artists in the exhibition.² This figure is particularly shocking because, while Americans in general have a one in 99 chance of contracting HIV during their lifetimes, black men who have sex with men have a one in two chance of becoming infected with HIV.³ Black women have an infection rate 20 times that of white women.

Voices from Richmond's Hidden Epidemic is an attempt to reveal the faces and to start new conversations around the epidemic. Most of all, it is an effort to center those conversations not on statistics, but on people and their experiences.

"It brought out the best in people and it brought out the worst":

AIDS in Richmond in the 1980s and '90s

Survivors of the AIDS epidemic in the 1980s and '90s offer a picture of devastation – and of a community rallying to support the afflicted. Bill Harrison, now executive director of Diversity Richmond, recalled, "The gay community had just really started to make significant progress, and then we got hit with this. That gave a lot of people permission to hate us again." Yet alongside the hate, there was support from the Catholic and Episcopal Dioceses. Harrison remembers that "recruiting volunteers to work at Fan Free was very easy, because the Fan Free Clinic was the first organization in central Virginia, to create an organized response to HIV. They had a hotline. They had care teams. They had support groups for HIV-positive people, people with AIDS, caregivers. I think there was a support group for straight people with HIV. There would be people lined up to be interviewed sometimes to be volunteers."⁴

While tragic stories were common in the early days when there were no effective treatments – including those of parents turning their backs on their children – the gay community came together. Chris Burnside, Rob Gabriele and Lisa Cumbey, who took care of her brother Alan when he was dying of AIDS, created *Artists for Life*, Richmond's first AIDS fundraiser, in 1988. Performers and

visual artists throughout the city donated their work and time to make the performance and gala a success, and the event raised \$20,000. Jim Beckner, the first executive director of Fan Free Clinic, reflected that “AIDS became an amplifier, it brought out the best in people and it brought out the worst. There were amazing and beautiful unsung heroes during those early days.”

People diagnosed with HIV in the early days had no legal protections and faced tremendous obstacles. Beckner recalled, “They could literally have everything put out on the street in a moment. They lost their family. They lost their friends. They lost their loved ones. They lost their jobs.”⁵ Because funeral homes and cemeteries often refused to accept people who died of AIDS, a supporter donated a plot of land in Goochland County to Fan Free to use as an AIDS cemetery. Funerals could be fraught when families found out for the first time about a child’s sexual orientation or substance abuse. For those whose families had rejected them, funerals hosted by friends and caretakers became outrageous, joyous celebrations of life.

As Bill Harrison said, “I look at how our community responded to that disease and so I know that we can handle anything.” The gay community emerged from those early days with strong support networks and new cultural institutions, such as Richmond Triangle Players, a still-thriving gay theater company formed in response to the AIDS crisis. However, Harrison concluded, “America doesn’t talk about HIV anymore. White, gay men got what we needed. We got the treatments out there. We got a lot of funding. We got the attention. White, gay men with HIV, for the most part, are staying healthy. But the new, diagnosed cases of men of color are astounding.”⁶

“A Hard Pill to Swallow”

It is not surprising that in 2020, most people assume that HIV/AIDS is a disease that mainly affects white, gay men, that it is a thing of the past, and that it is easy to treat. Today, one pill a day can prevent people from acquiring the HIV virus – and another pill can reduce viral loads to undetectable, and untransmittable, levels. As Dr. Sara Monroe, who for more than 30 years treated HIV patients at the VCU AIDS clinic, pointed out, HIV/AIDS could be completely eradicated tomorrow through widespread use of these medications.⁷

PrEP, or pre-exposure prophylaxis, comes in the form of a single pill, Truvada, which contains two kinds of medicine that are also used in combination with other medications to treat HIV. When used daily, PrEP greatly reduces the risk of HIV. However, as Dr. Gonzalo Bearman, director of the Infectious Disease Clinic at VCU Hospitals, told us, “Patients who are white, suburban, with desk jobs, are the ones taking it. The people at highest risk do not ask for it.”⁸

There are complex social dynamics behind this reality. HIV activist Deirdre Johnson noted that “the PrEP pill is an HIV medication, so that when you bring that pill back home to an already stigmatized community, the first thing they’re thinking is not PrEP for preparation, but PrEP for, ‘Oh, no, you’ve got it.’ And now they’re talking about you, family members are pulling away. Kids can’t come over to your house.”

Many interviewees shared that the stigma around HIV can be worse than the medical

For those whose families had rejected them, funerals hosted by friends and caretakers became outrageous, joyous celebrations of life.

effects. That feeling not only inhibits people from taking PrEP – it grows much worse after a diagnosis. For people recently diagnosed with HIV, taking the single pill to suppress the virus can seem like an insuperable challenge. When Yolanda Alexander learned that she had contracted HIV as the result of a rape, “I did not want to live. I did not want to deal with this. I did not want to take all this medicine.”⁹ Her experience was echoed by Zenia Williams: “I didn’t know what to do. I stayed sheltered in my room. I was like, ‘Why take medication? I have a disease; there’s no cure. I’m going to die.’” As she recalled, “I gave up, stopped taking that medicine. And then I’d pick it back up. I would go to the doctor. I would stop going to the doctor. I was going in circles, doing the same thing over and over.”¹⁰

Even when the shock of the diagnosis wears off, for people living with HIV, the decision to take that pill means confronting the circumstances that led to acquiring the virus – whether it was a bad decision to use drugs or have unprotected sex, or whether it was becoming a victim of abuse or rape. Almost every HIV-positive person we interviewed had found her or himself at the brink of death after going off of their medication. Many women we interviewed developed elaborate strategies to make sure they adhered to their pill-taking regiment. For one woman, this meant taking that pill each day in front of a special shelf of family photos.

This past summer, Deirdre Johnson began filming herself each night dancing as she took her pill and then posting the video on Facebook. “Meds make me dance,” she likes to joke, but is deadly serious about providing a light-hearted example of compliance in order to encourage others to do the same. As she and many other women told us, her goal is to prevent even a single infection from taking place, or a single death from AIDS. She is happy when she hears from strangers who are inspired to get back on HIV medication after watching her pill-taking dance.¹¹

Secrecy and Openness: the Ongoing Stigma of HIV

One of our students in the University of Richmond course “HIV in Richmond” noted in her class reflection, “this is a social crisis, almost more than it is a health crisis. The social dynamics are what caused the virus to spread like wildfire: dynamics on the part of politicians, minority communities, health professionals, religious communities, scientific communities It’s crazy to me that this virus attacked people’s emotions and vulnerabilities, sometimes way before it attacked a physical body.”¹²

The decision to share a diagnosis of HIV can be fraught for many reasons. Deirdre Johnson pointed out, “Folks recognize, ‘Well, if I have to tell you I’m HIV-positive, then I also have to tell you that I’m poor. I’m struggling. I may have mental health issues. I might

have housing issues. I might have this issue, that issue, and this issue, and I might be selling a little ass on the street just to make ends meet, and maybe pimping my kids out.’ That’s not great, but it does happen.”¹³

Yet not telling can have real consequences for family relationships. Zenia Williams remembered, “My oldest daughter knew something was wrong, but they told my daughters I had cancer. When they thought that I was not going to make it, in 2014, I had to tell them. I felt bad, because they should have known. My youngest daughter treated me in a whole different way once she found out because I shouldn’t have kept it from her.”¹⁴

According to Eric King, co-chair of the HIV/AIDS Awareness and Prevention Ministry of Nia, Inc. of Greater Richmond, a nonprofit affiliated with St. Paul’s Baptist Church, many of those diagnosed with HIV already have fragile social networks. For those whose housing, employment, and social support are tenuous, disclosing an HIV status can mean risking everything.¹⁵

HIV as a Marker of Inequality

It is impossible to view HIV in isolation from other issues having to do with inequality. VCU physician assistant Bob Higginson, who has worked with HIV patients in Richmond since the epidemic’s start, told us that “For those of us that have more of a middle-class upbringing, you would expect if someone becomes HIV-positive, that’d become their number one concern in their lives. Well, for an awful lot of occasions that’s not it. It’s: Where you gonna sleep tonight? Where you gonna get your food? Are you in a safe environment? HIV sometimes isn’t even in the top five for what their concerns are on a day-to-day basis.”¹⁶

Richmond is a city marked by extreme inequality. It has the nation’s second-highest eviction rates, the nation’s largest food desert, and the highest concentration of public housing south of Baltimore. Average household income in the city’s public housing projects is under \$9,000 annually, and almost 23 percent of Richmonders experience food insecurity.¹⁷

Many of the HIV-positive people we met struggled with homelessness and other issues, leading lives that had an almost unimaginable level of complexity. For example, when we visited one of our interviewees, she met us outside on the porch. It turned out that she had rented a room in the house, and her sister had showed up unexpectedly the night before. Richmond had better public transit than her distant suburb, and this was the day she would get her disability check.

As we further chatted with our interviewee about her children, she mentioned that one of them had been adopted from a next-door neighbor who was constantly having police show up at her door in the middle of the night to bust her for drugs. Our interviewee had taken on one of her children to prevent her from constantly being cycled through Child Protective Services. A second son was the biological child of the woman sleeping inside – not our interviewee’s sister, it turned out, but her best friend – who had had to give him up when he was five, when she and her boyfriend had been convicted of sexually abusing him. When the biological mother had to go to prison for seven years, our

interviewee had stepped in. The son, grown now, referred to them both as his mother – and our interviewee still considered the biological mother her best friend and referred to her as her sister. No matter how unorthodox or even shocking this arrangement might seem to many, this woman had forged lasting social relationships and created a network that made sense for her, which ultimately helped her battle depression and other mental health issues.

Despite the complexity of many interviewees’ lives and the fragility of their social networks, many of the people living with HIV we spoke to also had lives marked by incredible resilience. While several of the HIV-positive women we met cycled in and out of homelessness, this interviewee had started her own non-profit, as did many of the women we worked with. In fact, through our conversations with many HIV-positive Richmonders, we have learned how the diagnosis can become a call to action and a catalyst for deep personal and social change.

All of the HIV-positive women we interviewed were deeply engaged in networking around HIV-related issues. When we were setting up interviews and our cascading book workshop, we found scheduling difficult because many women spent their weekends at conferences or retreats dedicated to HIV advocacy.

Several of the women we interviewed in the St. Paul’s Baptist Church HIV Support and Advocacy Group started their own nonprofits. Tanya “Renée” Brook, a white trans woman, formed a 501(c)3 organization to assist women living with HIV who are experiencing housing insecurity. As she told us, women with HIV have an extremely high rate of homelessness.¹⁸ Yolanda Rawlings is working on getting nonprofit status for her group Just B U Inc., which encourages HIV-positive women to stay on their medications so that the virus becomes undetectable and untransmittable.¹⁹ We first met Deirdre Johnson when she arrived at a cascading book-making workshop, fresh from a speaking tour that took her from Denver to Atlanta and other stops along the way – she hadn’t even had time to stop off at home.

An activist with AIDS Coalition to Unleash Power (ACT UP) 30 years ago might have been taken aback to hear that in 2020, the Black church has moved to the forefront of HIV/AIDS activism. The current activism stands in sharp contrast to the most famous AIDS advocacy during the late 1980s and the 1990s. In 1987, ACT UP was founded in response to an incendiary speech by playwright Larry Kramer, who was enraged by the anemic government response to the crisis. At this point, President Reagan had not once mentioned the term “AIDS,” despite the fact that in the United States alone, more than 50,378 cases of AIDS, primarily among gay men, had been diagnosed, 40,849 had died—and research funding was scarce.²⁰ ACT UP had its first public protest in October

ACT UP is credited by many historians as having made a crucial intervention in the epidemic.

that year at the U. S. Supreme Court. Participants in these events returned home to multiple cities

and formed local ACT UP chapters in Boston, Chicago, Los Angeles, Rhode Island, San Francisco, Washington, D.C. and other locations in the United States and later internationally. ACT UP was incredibly effective, using direct action, civil disobedience, and confrontational tactics,

Cascading Book Project

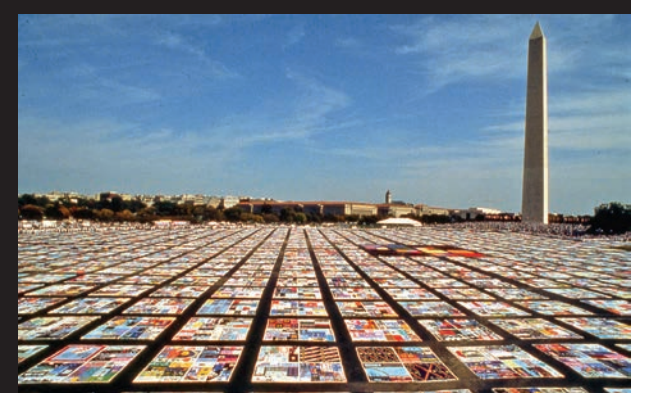


Cascading Books Workshop, University of Richmond Boatwright Library, 2019. Photographs by Michael Simon.

Under the guidance of Jen Thomas, program director of the University of Richmond Boatwright Library Book Arts Studio, members of the St. Paul's Baptist Church, Nia Community Advisory Board collaborated with students in the UR class "HIV in Richmond: A Documentary Theater Project," co-taught by Professors Laura Browder and Patricia Herrera, to create a series of cascading books. Inspired by the AIDS Memorial Quilt, these books reveal the humanity behind the statistics.

While the AIDS Memorial Quilt, a collection of more than 49,000 individual 3-by-6-foot panels sewn by friends, lovers, and family members, commemorates the lives of those who have died from AIDS, the cascading books honor those living with HIV. When the quilt was first unfolded on October 11, 1987 during the second National March on Washington for Gay and Lesbian Rights, it was a powerful visual reminder of how many people have been lost to the disease.

Participants were asked to creatively express how HIV/AIDS has transformed their lives, relationships, advocacy, faith and legacy. These cascading books not only remember those we have lost, but also celebrate the courage, triumph, and resilience of those who are still with us.



AIDS Memorial Quilt exhibit on National Mall, Washington, DC, early 1990s. Photograph by Mark Theissen. Courtesy of The NAMES Project Foundation.

including, most controversially, using the pink triangle that was an emblem of homosexuality in the Nazi death camps. ACT UP is credited by many historians as having made a crucial intervention in the epidemic.²¹

Many of the early ACT UP activists were prominent, wealthy and well-connected individuals. The current HIV activists we met came from very different backgrounds. The orientation of these new activists was in part political and legislative. For example, Deirdre Johnson is working to change laws around informed consent so that people with HIV could no longer be convicted of a felony if accused by a former lover of failure to disclose their HIV status. However, with HIV prevention and treatment medications widely available, the focus of many activists has shifted to reducing the stigma around the diagnosis.

Back in 1992, Virginia Union University political science professor Eric King stood up before 6,000 members of St. Paul's Baptist Church and informed the congregants that he was gay and HIV-positive. As Lindsay Bryant wrote, "Our pastor, Dr. Lance Watson, has been so supportive. I remember the first email I sent him with a list of the things we wanted to do: purchasing condoms for distribution at church, quarterly HIV testing and partnering with the Virginia Department of Health. He responded to the email by saying yes, yes, yes to everything."²² Nia Incorporated of Greater Richmond, a nonprofit founded by the church in 1992 and co-chaired by Lindsay Bryant and Eric King, helps African-American public school students, drug dealers, women, clergy, deacons, ministry leaders, university students, and community organizations to navigate their way through the battle against the pandemic. Lindsay Bryant travelled cross-country to spend a year as a fellow at the Black AIDS Institute at UCLA. Eric King authored "*The Landscape of Our Spiritual Warfare: Ministering in The Face of HIV/AIDS*," a document approved by the Virginia Department of Health Review Board, to help Black congregations formulate their own theology of AIDS Ministry.

Healing Communities

An HIV diagnosis has provided many of the women we interviewed in the St. Paul's Baptist Church, Nia Community Advisory Group

an opportunity for spiritual and emotional renewal. As Sheila Rollé reflected, "Being HIV-positive might have been one of the best things that happened to me, because it allowed me to see who my friends really were, who had my back, and who loved me."²³ Many women talked about how their diagnosis had clarified their relationships for them. Yolanda Rawlings told us, "HIV has given me my purpose and my voice. Until I got diagnosed, I didn't realize that my husband had been doing crack cocaine since 2005. Every time

One thing I told myself is that I would not die for someone else's mess.

he would mess up, I would bail us out. It took HIV to get me to where I could say, 'Wait a minute. I'm not helping him.' Okay, we've been together for all these years. But what's the next 10 years going to look like? One thing I told myself is that I would not die for someone else's mess. And me worrying about what he was doing and how he was killing himself, was killing me."²⁴

Darlene Castro had been a long-term addict until she got her HIV diagnosis. When we worked on the cascading books together, the first thing she added to her page was an article about her successful completion of drug court. Since her diagnosis, "I just continued to be an advocate. I'm just surprised about how so many people want to hear my story. And I'm happy. I'm just trying to live my life and get other people educated."²⁵

HIV has become a sign of the devastating impact of inequality on low-income communities. Yet perhaps because it is now largely invisible outside of the communities it affects, the activism around HIV is primarily focused on preventing new infections rather than structural change. The first wave of HIV activists had specific goals in mind: increasing funding for HIV research and combating the homophobia that had prevented government funders from treating HIV as a health problem along the lines of cancer. Today, HIV activists are dedicating their lives to helping heal their communities and ending the stigma around HIV/AIDS. As Lindsay Bryant said, "The only way that you get rid of a silence, is that you open your mouth and you say something about it. The time is now."²⁶

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4 Bill Harrison interview with Laura Browder, September 1, 2017.

5 Jim Beckner interview with Laura Browder, November 17, 2017.

6 Harrison interview.

7 Sara Monroe interview with Laura Browder, December 1, 2017.

8 Gonzalo Bearman interview with Laura Browder and Patricia Herrera, September 13, 2019.

9 Yolanda Alexander interview with Laura Browder and Patricia Herrera, May 7, 2019.

10 Zenia Williams interview with Laura Browder and Patricia Herrera, May 7, 2019.

11 Deirdre Johnson interview with Laura Browder and Patricia Herrera, October 11, 2019.

12 Anonymous student. "Final reflection." November 27, 2019.

13 Deirdre Johnson interview.

14 Zenia Williams interview.

15 Conversation with Eric King, November 9, 2019.

16 Bob Higginson interview with Laura Browder, September 1, 2017.

17 Tina Griego. "How Did We End Up Here?" *Richmond Magazine*, July 28, 2016. <https://richmondmagazine.com/news/features/creighton-history/>. Accessed December 17, 2019 <https://cura.vcu.edu/ongoing-projects/rva-eviction-lab/>. Accessed December 17, 2019.

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18 Tanya "Renée" Brook interview with Laura Browder and Patricia Herrera, October 1, 2019.

19 Yolanda Rawlings interview with Laura Browder and Patricia Herrera, May 7, 2019.

20 "Thirty Years of HIV/AIDS: Snapshot of an Epidemic." amfAR: the Foundation for AIDS Research. <https://www.amfar.org/thirty-years-of-hiv/aids-snapshots-of-an-epidemic/>. Accessed December 18, 2019.

21 Nurith Aizenman. "How to Demand a Medical Breakthrough: Lessons from the AIDS Fight." *Weekend Edition*, February 9, 2019. <https://www.npr.org/sections/health-shots/2019/02/09/689924838/how-to-demand-a-medical-breakthrough-lessons-from-the-aids-fight>. Accessed December 18, 2019. "The ACT UP Historical Archive: ACT UP Capsule History." <https://www.google.com/search?q=act+up+history&oq=act+up+history&aqs=chrome..69j57j0l6j69j60j6869j0j4&sourceid=chrome&ie=UTF-8>. Accessed December 18, 2019.

22 Lindsay Bryant. "Educating Ministers: Deaconess Lindsay Bryant." *The Black AIDS Institute*. November 24, 2013. <https://blackaids.org/blog/educating-ministers-deacon-lindsay-bryant/>. Accessed December 16, 2019.

23 Sheila Rollé interview with Laura Browder and Patricia Herrera, May 7, 2019.

24 Yolanda Rawlings interview.

25 Darlene Castro interview with Laura Browder and Patricia Herrera, May 7, 2019.

26 Lindsay Bryant interview with Laura Browder and Patricia Herrera, November 16, 2017.



Willnette Cunningham

My name is Willnette Cunningham. I was born in the month of February 1950. I grew up here in Richmond, Virginia.

Sitting there and hearing the doctor say it, I saw myself dying in a matter of months. This was 1991, and people were dropping dead. I started crying, but I'm one of those prayer people. I wiped my tears up, and I left. I got two blocks from there and started crying again.

The day I got my diagnosis, I was about to get in a new relationship. I went straight to his house first and told him my diagnosis. Told him if he didn't want to start a relationship, we didn't have to. He said, "I need to be tested myself." And we were together until he passed in 1997.

It took me two months to get into treatment. Those two months I was really stressed because I just knew I was going to die. But once I got into the treatment and met the doctor I still have today, who said to me, "You can do this," things got better. They had just changed the AZT medications a couple of years before. So the medicine wasn't as strong as it had been, and it didn't affect people's bodies the way it had in the past.

In 1998, I had to choose between food and medication, and then I was diagnosed with AIDS. I tell the world that I am one of the many faces of AIDS. Because when you look at me, you can't tell if I have AIDS, HIV, diabetes, or cancer. I look like everybody else.

Twenty-one years I was celibate because God took away my desire. When he died, there was no desire for sex. I'm in a relationship now, and I told him before we started the relationship. We've been dealing with each other for three years.

I look at every day as a blessing from God. I never said, "Why me?" I always said, "Why not me?" I lived a life where I lived a life. I enjoyed my life. But condoms were not a part of my life. That wasn't in our time period. So nobody was using them. So why not me?

My whole thing is to prevent the spread of this disease. Because it's spreading too rapidly. And it's not stopping—it's increasing. More people need to get on board and get educated and learn about it.

All photos by
Michael Simon

Dana Kuhn

I grew up on Long Island when it was potato fields. I felt the calling to go into ministry and met my future wife at Columbia Bible College in South Carolina. After graduation we got married, and I became a youth minister in Tennessee.

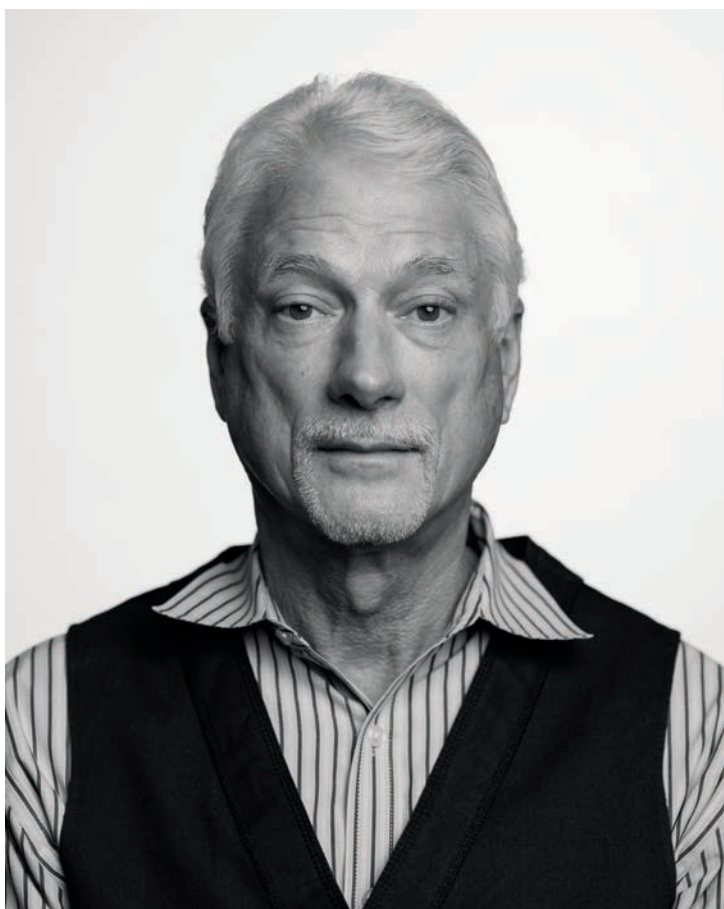
I had mild hemophilia. In 1983, I broke my foot, and it started to swell. Factor VIII, the treatment to stop the bleeding for people with hemophilia, probably pulled blood from 60,000 people. Two days later I had nausea, rash, jaundice. I went to the hospital and they said, "You have non-A, non-B hepatitis, there's nothing more we can do for you." I went home and almost died.

In 1986, an HIV test came out. Mine came back positive. They told me that HIV was sexually transmitted. Eight months later my wife went into the hospital. They said, "We can't figure out what's wrong with her." I said, "You might want to see if she has HIV." They all looked at me like I had four heads.

They transported her to Vanderbilt University in Nashville. Her health started to dwindle – we were waiting for the AZT. I couldn't tell anybody. They would probably oust me out of the church. I didn't want anybody to start persecuting my kids. It was very, very lonely.

The Friends of Nashville, a gay group, came and ministered to me. When I saw them helping me, I said, "God is helping me through people I was prejudiced against."

I had to tell the kids, "Your mom has died," when they were five and three. My parents were here in Richmond. I finished out what I could, and then I came home.



In 1988 I got hired at MCV. Surgeon General C. Everett Koop learned about my counseling people with HIV. He said, "I want you to serve on a committee that's going to put together a curriculum of teaching children about HIV and AIDS." That wasn't a popular subject at that time.

At a Pediatric AIDS conference, I saw a nurse I was very attracted to. At the end of the long weekend, Jan asked me what I was going to do. I had vowed that I would never take a risk of infecting someone. She said to me, "So who the hell do you think you are? God? You can't make that choice for me." In 1990 we got married.

On March 4, 1983, the Centers for Disease Control put out a bulletin: AIDS is in the blood supply that hemophiliacs use. On March 26, I got my infusion. Red Cross and other blood collectors knew they were collecting contaminated blood, giving it to people in transfusions, and processing it into hemophilia factor.

Ravi Perry

I was diagnosed in 2003. I was 21 years old. I was active sexually in college and testing every three months. I spent that summer of 2003 as an undergraduate fellow at UCLA's Summer Humanities Institute in the Department of African American Studies, where they trained undergraduates to prep them for graduate school. I was not on my best behavior in LA, in terms of my sexual health. As the summer program was ending, I got a sore throat that wouldn't go away. When I got back in August on campus [at the University of Michigan] I scheduled a test.

On September 4, I received the results. I was about an hour away from my hometown, and I drove home. I was bawling the entire way there. I had a conversation with my mom, sitting on a garden bench. Her initial response was she thought I was celibate. That was obviously a difficult conversation. I did not tell anyone else in my family until that December.

I don't recall ever having any explicit conversations about HIV and AIDS as a young person. Not with peers, not in any capacity with an adult or a social worker. Not at home. I did not hear about it at church. I did not hear about it at school. I did not hear about it from my doctor. By the time I learned about it I was already sexually active. I think the information I got, I got most



likely at clubs and bars that were few and far between in northwest Ohio, in the late '90s and early 2000s.

After a decade or so of living with the disease, I decided to live more openly with it, and share my story, which has led to my church starting an HIV and AIDS ministry. I'm interested in measuring the actual reduction in HIV infections in Jackson Ward or the improved livable outcomes of those who have the disease. The program will be tailored to black youth because that is the population that needs to be learning about this now.

It has been gratifying to be the recipient of other people's stories that they say they've shared because, for some reason, after hearing or reading mine, they were encouraged to do so. I think the diagnosis of HIV has certainly heightened my understanding of communal life. My openness about my HIV status now has largely motivated my approach to life and humanity and my spiritual compass.



Elaine Martin

I am a child of the North but have lived most of my life in the South. I moved to Richmond in 1986 to go to graduate school. I was planning on getting a Ph.D. and becoming a clinical psychologist but I got waylaid by this public health thing. I needed a job to help pay my way through school, and I saw an ad in the paper for counselors for the AIDS hotline. I knew something about HIV because I had friends in the gay community. I was supposed to work 10 hours a week. My first day they're like, "Can you work 40 hours a week?" The next thing you know it became my career and actually kind of my calling. I never imagined I would be here 31 years later.

Some of our work with gay men has been questioned. A few years ago we were supporting some HIV-related balls for the House & Ball community of black gay men that the CDC [Centers for Disease Control] approved.

Internally it got stopped and they said, "This is not appropriate for the health department to be doing." The community rallied around, and 60 people signed a letter saying, "You should fund this." But we were not able to fund it.

There's still a hole in what's going on education-wise. Kids aren't getting comprehensive sex education, and it's different in every school district. In Northern Virginia you might have really comprehensive Sex Ed. And then in other districts they may be taking an abstinence-only approach.

There were times in the past we weren't allowed to use the word "condoms" in a grant application. So we called them "risk protection devices." As I said, "I'll call them whatever you want as long as I can still do my programs."

Until recently, we have been prohibited from doing syringe services in Virginia. Legislation was passed that became effective in July of 2017. I thought I would end my career and retire without ever seeing syringe services happen in Virginia. But there was the big push because of the opioid epidemic. When I started working in HIV, drug users were probably more than 20 percent of our HIV cases. Now they're down to two or three percent of our HIV cases.

If somebody becomes HIV-positive, we have this whole world of services they can access. They can get mental health. They can get substance abuse services. I think now is the most exciting time. Yes, it is possible. We could see a real end to HIV.



Zenia Williams

I was born in Richmond in 1965. I lost my father when I was nine, and we moved to Highland Park. I had five brothers. I was the only girl. My mother raised us, and she did a wonderful job.

I was diagnosed in 2005. I was a healthy person. I was active. I hung out with my friends. I did wrong in my life, doing drugs. But I changed my life before I had my girls. When I was diagnosed, it just tore me down. I had a best friend I grew up with. I called her my sister. She was there for me when I found out that I had HIV. I didn't want to go home from the hospital. I didn't want to tell my family.

I didn't know where to go. I didn't know what to do. I stayed sheltered in my room. I didn't want to take my medicine, because I was like, "Why take medication? I have a disease. There's no cure. I'm going to die." I didn't go to support groups. I didn't know who to talk to. I gave up, stopped taking that medicine. And then I'd pick it back up. I would go to the doctor. I would

stop going to the doctor. I was going in circles, doing the same thing over and over.

My oldest daughter knew something was wrong, but they told my daughters I had cancer. When they thought that I was not going to make it, in 2014, I had to tell them. I felt bad, because they should have known. My youngest daughter treated me in a whole different way once she found out because I shouldn't have kept it from her.

The community that I lived in – you know, a lot of people talk. I felt ashamed. But for

some odd reason, it never really bothered my daughters. No matter what, it didn't matter. I know they love me and we just got closer.

I met this wonderful woman named Ms. Willnette. Without her help, I would have never known where to go. I thank her today for bringing me into this group with a lot of wonderful women. I listen to their stories, and I see how healthy they are. Today I feel stronger, and I know I can help people in our community get tested. One day I really want to be an advocate, like Ms. Willnette.

I have a granddaughter. She's two years old. She inspires me. When I see her, I'm like, "God is not ready for me yet." I go to the clinic. My doctors are excellent doctors. I feel positive every day. Living with it, I feel good.

Bill Harrison

I grew up on a peanut farm in Emporia, Virginia. A village raised me—grandparents, aunts and uncles, great aunts and uncles, cousins. When I was in the 8th grade, I realized that I was gay. This was back in the late '60s. The times were very different then. I was married to a woman for a few years. My marriage ended. That's when I decided that I was just gonna be honest about who I was. I've been an activist ever since then. I came to Diversity [Richmond] about five years ago. It's a privilege to be here, in the center of it.

AIDS came out of nowhere. We had no instruction. There was no support. We unified, we built community, we responded. People who you did not know in January, you could be making their funeral arrangements in November because you were their closest friend at the time, and their family was absent. It was a very, very difficult time. At the same time, I think that my community showed the world what humanity is all about and how resilient the human soul is, and what love is all about.

Back in the day, every educational campaign featured white, gay men. White, gay men were having cocktail party fundraisers on Monument Avenue. Everybody wanted to be doing something. Over the past 30 years, the face of AIDS has changed. America doesn't talk about HIV anymore.

White, gay men got what we needed. We got the treatments out there. We got a lot of funding. We got the attention. White, gay men with HIV, for the most part, are staying healthy. But the new, diagnosed cases of men of color are astounding.



White, gay men need to step up to the plate again. We need to reinvigorate the community and address this issue because our brothers don't get it, especially the young ones. It's heartbreaking to see the numbers of the young men who are becoming infected. It's not the death sentence that it was, but it alters life tremendously. And it doesn't need to happen.

The Trump administration is a wake-up call for us in a lot of different areas. In some ways, it can be a blessing. It's a call to action. This might be naïve, but I've always believed, this is America. Justice will prevail. It might take a lifetime. It might take two lifetimes. We cannot sit back and be silent. We've got to raise our voices louder than they've been raised in a very long time.

Lindsay Bryant

We must improve relationships with all people, especially those infected and affected by HIV.

My cousin was diagnosed with HIV. I sat beside his bed at the hospital talking to him. He made a hitting-on comment to the nurse. He laughed. I laughed, and the nurse laughed. I said, "Are you hitting on nurses still, while you laying on here in the bed like that?" But he passed.

We had a nurses' ministry at St. Paul's Baptist Church that started the HIV ministry. I was drawn to them. That was 1995.

We said that we wanted to do the prayer that Sunday, recognizing World AIDS Day. We wanted our pastor, Dr. Lance Watson, to preach a sermon on compassion and mercy and healing and giving. We typed that up in an email to Pastor Watson. We said, "We want to give out condoms at church." He said yes to everything we asked for.

One of our members worked at the health department. She helped us to write a grant. We didn't get that first grant. We were standing outside of St. Paul's. We all started crying. You'd have thought somebody had died. But that's been years ago, and we've been funded every year since then. Once we started with the grants, that's where Nia Incorporated of Greater Richmond came from. Nia is Swahili for *purpose*.



I'm a Fellow with the Black AIDS Institute. I'm a member of the Black Treatment Advocate Network that's out of Los Angeles, California. We incorporated what I learned out there into that landscape of spiritual warfare. I'm in the National Baptist Deacons' Convention and will go there to do a class on HIV and AIDS prevention. I'll be one of three women.

The only way that you get rid of a silence is that you open your mouth and you say something about it. The time is now. Everybody can do this. You don't have to be a graduate of anything.

You already know how to listen to someone who may be ill with diabetes, at a critical point with that. It's the same kind of care and compassion to speak with someone who may be HIV-positive and to speak with someone who is HIV-negative to get them to keep a negative status. Not a finger-pointing, and more of a listening to what's going on.



Zakia McKensey

We have so many people outside of our community who've already done a good job of beating us up. I wish we would stop beating up our own folks. Growing up in Richmond, coming out as gay, coming out as trans while being black, was very difficult. I openly came out at 17, began to do hormones, and then came out again at 19 as trans.

My mom didn't accept it at all. Then, there weren't any organizations doing work for black LGBTQ people and specifically not trans people. I really didn't see any people that looked like me until I started going into gay clubs and seeing other transsexuals and performers.

There are many challenges being black and trans in Richmond. The General Assembly just passed a law that protects animals against violence but won't pass laws to protect trans and LGBTQ people. It was sad that a dog has more value than people who identify as LGBTQ.

A really good friend of mine, who was like a mother to me when my family turned their backs on me, was dealing with the virus. They later succumbed to it. I was so young, and I didn't really understand. When they passed away, I felt it was important for me to get knowledge about the disease.

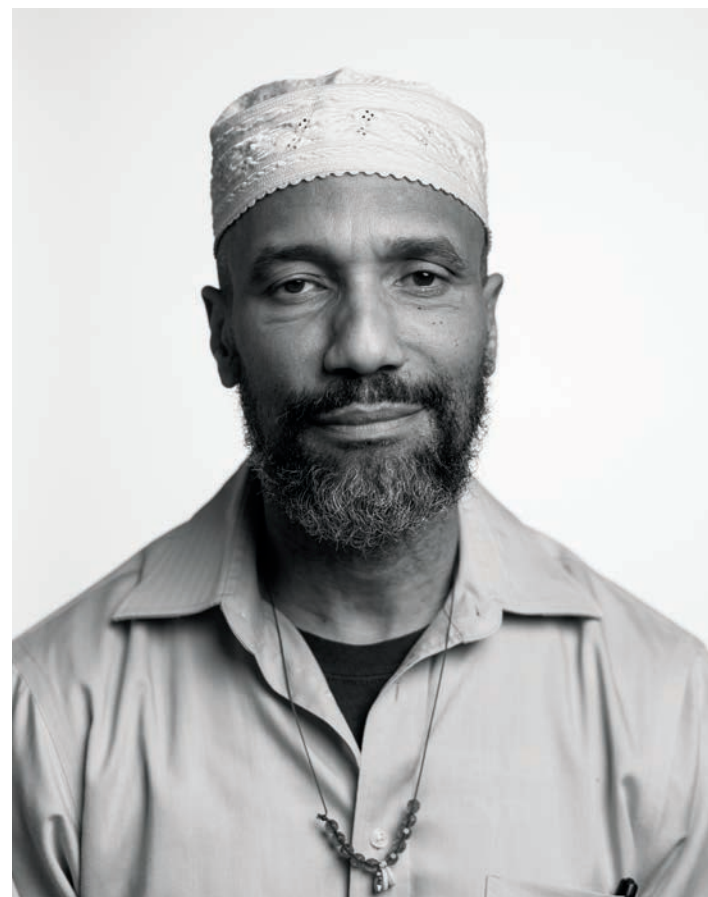
HIV prevention became my mission. When I worked at Fan Free [Clinic], I was able to be instrumental in starting trans health services in Virginia. That model has been duplicated in other organizations like Planned Parenthood. Then I was on their advisory board helping them to implement testing in the club.

I was also a really huge performer in the community and was heavily into pageantry. Me and my cousin started Nationz Pageant to provide education related to HIV prevention. When

ever I would have the microphone in clubs, I would talk about the importance of testing. Then it just got to a point where I told my cousin, "It's more that we need to do to reach people. I want to apply for 501(c)3 [tax exemption status]."

October 24th, 2015, we opened Nationz Foundation. It was a dream of mine to have a mobile van. I know people are not going to just come into this office and get tested. But if we go on Broad Street and Third, people come. We use food as a way to incentivize testing because people are hungry, people are homeless.

One of my friends passed away at 26 years old, and called me grandma, and came to my house every day, and would talk to me about everything except for that because there is so much stigma within our community.



Jihad Abdulmumit

I was 16 years old, in Plainfield, New Jersey, when I joined the Black Panther Party. I was flipping pancakes and bacon and eggs for the kids going to school. We had free clothing drives. We had a food pantry, community education classes, mostly history classes.

Then I became a member of the BLA [Black Liberation Army]. There were different movements in the United States that were trying to carve out five states down South to form a separate government. We started robbing banks to do that. Eventually I got captured doing one of these expropriations and I got a 43-year sentence and did 23 years in prison. I was 20.

People were dying from this thing called AIDS. Myself and Dr. Mutula Shakur, Tupac Shakur's stepfather, we always put our heads together to try to think of

something positive to do with the prison population. So we thought about the HIV/AIDS awareness program. The administration accepted our proposal at Lewisburg [Federal Prison]. They had the Red Cross come in and train us. We started doing peer group sessions with other prisoners. This went on for six or seven years before I was released.

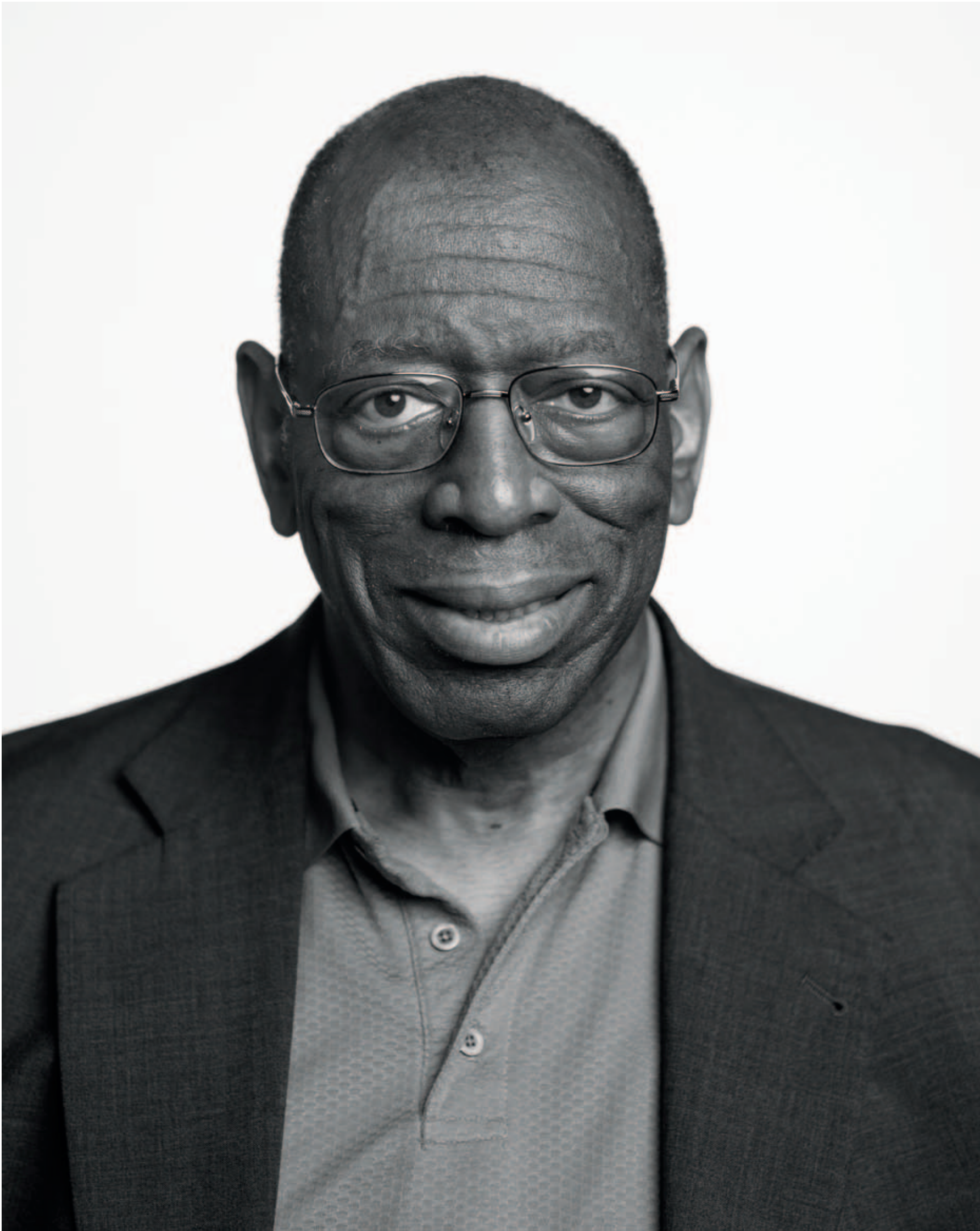
We wrote a play about HIV and AIDS. One guy that was helping me with the class and became a key actor in the performance, I didn't realize until he was on his deathbed that he had AIDS. Because of the stigma. And that stigma exists today still very profoundly in prisons and jails.

I was unemployed for about six months. Around the same time I got married. It was very stressful for me at that time. I read in the paper that the Fan Free Clinic was hiring for an HIV counselor. They hired me almost at the interview, a rare occasion where conviction was a stepping stone instead of a stumbling block. I've

been here 14 years.

HIV rates in prisons and jails are five times higher than in the open communities. We're able to do HIV testing. Somebody tests positive, we can let the administration know that, and then we collaborate to get medical attention for that person – as opposed to hepatitis C.

We don't do hepatitis C testing, even though we do it here at the Health Brigade. Once we test them positive – okay, now what? There's no connecting you with anybody. There's no money for that. The Harvoni treatment alone is phenomenally expensive, almost \$1,000 a pill. And so who's gonna pay for that? Department of Corrections? They'll be broke.



Eric King

I'm originally from Philadelphia. When I was on faculty at Lincoln University, teaching political science, two of my friends who were faculty members died of AIDS.

I went back to Philadelphia to work for the Urban League from 1985 to 1990. In '85, I got my diagnosis. People were dying by the thousands. In Philadelphia, there was a whole network of African-American gay organizations that provided support groups. There were good people who had the same experience that I could talk to, and that was very helpful.

I had fears, stressors, and depression. I didn't know how to negotiate this story with my family. Before I could tell them I was HIV-positive, I had to tell them that I was a gay male. And being gay in the black community was not the best thing at that time. It still isn't.

I didn't know what to expect coming to Richmond in 1993 to teach at Virginia Union University. I knew that Richmond was the capital of a conservative Republican-dominated state.

Fortunately, the Fan Free Clinic welcomed me, embraced me, gave me care. Some friends of mine attended St. Paul's Baptist Church. I heard Reverend Watson preach, and I liked the oratory. I didn't need anybody else.

For about a decade, I had the diagnosis, but I didn't have any evidence that anything was happening, so I would forget. Once the doctor at MCV's Infectious Disease Clinic told me, "Yeah, maybe you should start taking some medication." Then it was more real.

In '95, I identified as a gay black man and came out to my family. I have yet to ever hear the question from any member of my family, "How is your health?" We'll talk about everything else. But nobody wants to directly deal with the issue.

The only thing that has remained consistent was knowing that the Black church had to do more. That year we started doing AIDS ministry, and now we serve as Nia Community Development Corporation of Greater Richmond. My contribution to the education of Black churches was writing the document "The Landscape of Our Spiritual Warfare: Ministering in The Face of HIV/AIDS," which helps Black congregations formulate their own theology of AIDS Ministry. This document was approved by the Virginia Department of Health Review Board.

Ministries take you to some interesting places. I am a licensed minister of this church. Some things that I thought would never come together have come together here. I am grateful to the pastor, Rev. Dr. Lance D. Watson, Sr., for his progressive stance and his support of the community.

Tanya "Renée" Brook

I was born in Norfolk, Virginia, in 1957 in the Navy hospital. I was raised one of three boys. I knew that I was transgender from this big. I found out a long time ago that I have to march to my own drum. When I was 16, I moved to Washington, DC, with my cousin, who was gay. My biological father thought I was gay. I didn't see myself as a man with men. I knew physically that I was a boy, but I knew mentally that I was a girl.

I joined the Navy when I was 19. I stopped taking hormones while I was in the service, and then once I got to a permanent duty station at Bethesda Navy Hospital, I started taking my meds again. When I moved, I started cross-dressing. There was a point when I actually had three wardrobes – a boy's, girl's, and unisex wardrobe. Then, in 1980, I threw away all the boy's and unisex clothes and had one wardrobe. There wasn't any turning back. I legally changed my name to Tania "Renée" Brooke, and it was a rough thing, because in the '70s, I didn't know any transgender people.

While I was in the Navy, I hooked up with a lesbian girl. We lived together to pretend that we were just a couple living together. One of the three times that we were intimate, we conceived a daughter.

In 1997, I had been in a long-term relationship with a guy for seven years. He was bipolar, wouldn't take his medicine, would flip out and do all sorts of crazy stuff. While he was in jail for domestic violence, he put me down as his emergency contact. I got a call that he's in the hospital with pneumonia. I didn't think too much about it. A day or so later I got a call from a social worker. She said, "You need to get tested because he is HIV-positive." I waited a whole year before I got tested. He had been HIV-positive for 15 years. Never told me.

In my first appointment with Bob [Higginson] my viral load was 238,000. Within three months, he had me undetectable. I'm a firm believer in your doctors being aware of all the problems. I drank excessively and was having so many health issues – it was time to quit. HIV-wise, I'm as healthy as a horse. It's all that old age crap that's killing me.



Deirdre Johnson

My parents are from Amelia, which is not too far from here. They're high school sweethearts. They're so cute. They've been married for 44 years. In high school, I did a lot of nerdy stuff. I was a junior class president. I was in the Latin Club. I wanted to be a pediatrician or obstetrician/gynecologist.

I went to James Madison [University] and studied pre-med with a minor in psychology. Started dating one of the star basketball players there, hence then I ended up with my older son.

Two years later, I ended up somehow getting with this person. And from the beginning, it was an abusive situation, and it completely took my self-esteem. August 2000. It was a Wednesday. He says, "Babe, I'll be right back," and he never comes back. He calls me Thursday morning and was like, "Look, they can't find me, but they know where you are." And so that was code for "Get the hell out of Dodge." By Saturday morning, I was on my way to North Carolina and left my older son with my parents, telling them I would come back to get him.

From there, we went to El Paso, Texas. I recognized I was pregnant. That's when I learned I was HIV-positive. On Christmas day, his family had an annual tradition to go to climb this mountain. Once I came down from that mountain, I had a plan. And Zion, my youngest, was the plan to get out.

There are folks in this area that don't tell their HIV status because they're scared still in this day and age – 2019 – of losing their jobs, losing their homes, losing their family, losing their friends. And barricading themselves in their homes and not going out.



Some days it's hard to pick that pill up and put it in my mouth. But I know that there are other people that are struggling too, with the remembrance of the day that you get the diagnosis, and the stigmas that are associated, whether they are implied or not. Knowing that there is a possibility that you could get sick and not recover, all because you took a few minutes out of your day to do something. And whether it was sex, whether it was to use drugs, whether it was something that someone did to you, in the case of abuse or rape.

It takes a minute or two, or 15, 20, 60, 70 if you're lucky, to engage in sexual activity. It takes a moment to make a difference by putting on a condom. So always make sure your minutes, and your moments count to equal the best life you can have.



Rodney Lofton

My junior year at Thomas Jefferson High School, we were reading about this "gay cancer" affecting specifically white gay men. I wasn't white, so it really wasn't an issue for me. We started seeing Haitians. They were people of color. But then I thought, "I've never been to Haiti."

I moved to New York in August of 1992, and I fell in love. Just like anyone who has a heart, I thought this would be the person that I spent the rest of my life with. In September 1993, my mother called and shared with me that one of my high school friends had died from HIV. I told my partner at the time, "Hey, we need to go get tested."

He was a no-show. I went and tested anyway. It was December of 1993. The number assigned to me was 1277597. After we talked about the upcoming Christmas season, the counselor asked for that piece of paper – 1277597. She went to a file cabinet, pulled the

file out, looked at it, closed it, and sat down in front of me. She opened it. She turned it around. It said "Patient has tested HIV antibody positive."

I called my partner, devastated that he didn't show up to be tested a couple weeks earlier. He said, "Thanks for the information," and hung up. I remember going home that evening and getting two packs of Newports and a fifth of Bacardi, drinking myself to sleep.

I was coming back to Richmond to visit my family for Christmas.

I called my cousin. She said, "You need to tell your mom." That was the hardest call I ever had to make. I'm the only child – I let my mom down. I called, and of course, I was drinking. She said, "Are you okay?" I started crying as soon as I heard her voice. I said, "Mom, I tested positive." And I just lost it. Without missing a beat, she said, "We're gonna get through this. Go ahead and get some sleep. You'll be home soon." I weighed 127, soaking wet. I prepared myself to die.

I was connected to the MCV clinic. I met Bob Higginson. Bob said to me, "You're going to be okay. You have to work on everything else. I got this." I walked through life, just marking off every year. Then one morning I woke up and said, "I'm not dead."

Even to this day, there's such a stigma with being HIV-positive in the African-American community. Nobody wants to talk about it. But as my grandmother used to say, "A closed mouth never gets fed." So how can you actually address the issue if you're not really speaking about it?



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Thank you to all the participants for sharing their stories. Your wisdom and lessons learned teaches us how to make a better tomorrow.

the
Valentine