

WINDY CITY TIMES

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AIDS @40



From an ACT UP protest in the late 1980s, downtown Chicago.
Photo by Lisa Howe-Ebright

In this issue, Windy City Times speaks with long-term HIV/AIDS survivors, deals with HIV-positive representation in media, checks in on young activists of today and more!

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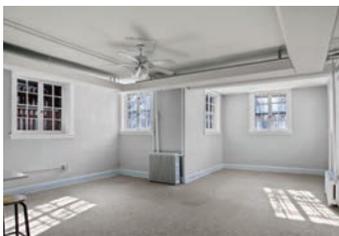
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STILL HERE:

Long-term HIV/AIDS survivors in Chicago reflect on their experiences

BY CARRIE MAXWELL



This article features the stories of survivors (top row, from left) Rae Lewis-Thornton, Jeff Berry, David Ernesto Munar, (bottom row, from left) state Rep. Greg Harris and Peter McLoyd.

Lewis-Thornton photo by Flickr Thornton; Berry photo by John Gress; Munar photo courtesy of Howard Brown Health; Harris photo courtesy of Harris; McLoyd photo courtesy of McLoyd

When the first reported U.S. cases of what later became known as HIV/AIDS were reported in June 1981, a number of physicians and researchers at the Centers for Disease Control (CDC) and elsewhere sought to understand the disease and its origins. This awareness increased over the course of that year, and years going forward, as the media, especially gay media, informed the public of the disease.

According to HIV.gov, “by [the end of 1981] there [was] a cumulative total of 337 reported cases of individuals with severe immune deficiency in the United States, 321 adults/adolescents and 16 children under age 13. Of those cases, 130 are already dead by December 31.”

As the number of HIV/AIDS cases grew over the years, the death toll climbed. By the end of 1984—before then-President Ronald Reagan acknowledged in public that the disease existed—approximately 7,700 cases of HIV were reported in America. Of those people, 3,700 died of the disease, according to Avert.org. This was the year HIV/AIDS became an epidemic.

It was only when a reporter asked Reagan about AIDS on Sept. 17, 1985, that he acknowledged its existence publicly. According to an AIDS.gov timeline report, 30 Years of HIV/AIDS, Reagan’s response to that reporter included “[calling] AIDS ‘a top priority’ and [defending] his administration against criticisms that funding for AIDS research is inadequate.”

By the end of 1989, 117,508 people in the United States were diagnosed with AIDS; of those, 89,343 of them died of the disease, according to amfAR.org. These numbers grew over the course of the next five years with about the same percentages of total AIDS cases reported to the number of total deaths. Meanwhile, researchers were working on drug therapies to mitigate the effects of HIV/AIDS.

In 1995, the FDA approved the first protease inhibitor, otherwise known as the “AIDS cocktail.” According to Avert.org, once this highly active antiretroviral treatment (HAART) “AIDS cocktail” was “incorporated into clinical practice, [it] brought about an immediate decline of between 60-80 percent in rates of AIDS-related deaths and hospitalizations in those countries which could afford it,” including the United States.

According to amfAR.org, “[In 1996] for the first time since the start of the epidemic, the number of Americans dying from AIDS declines, dropping 23 percent from the previous year. The decline is attributed primarily to the success of the new combination therapies.”

“[Then] in September 1997, the FDA approved Combivir, a combination of two antiretroviral drugs, taken as a single daily tablet, making it easier for people living with HIV to take their medication,” according to Avert.org.

These new drugs/therapies, and others developed and put into use since then, have given people living with HIV/AIDS hope that they would not die like many did in those first 16 years.

Among the people diagnosed in the early years of the disease are five Chicagoans—Emmy-winning AIDS activist and ordained minister Rae Lewis-Thornton (diagnosed in 1987), Illinois

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state Rep. and House Majority Leader Greg Harris (diagnosed in 1988), TPAN Director of Publications and Positively Aware Editor-in-Chief Jeff Berry (diagnosed in 1989), Howard Brown Health President and CEO David Ernesto Munar (diagnosed in 1994), and Ruth M. Rothstein CORE Center Consumer Development and Advocacy Coordinator Peter McLoyd (diagnosed in 1997).

Lewis-Thornton, a 57-year-old Black cisgender straight woman, found out from the Red Cross that she was HIV-positive after donating blood. Her memoir *Unprotected*, chronicling this journey, will be released later this year.

"In fact, I organized the blood drive because of blood shortages in Washington D.C., where I lived at the time," said Lewis-Thornton. "People were afraid to donate blood because of HIV/AIDS. I thought it was stupid that people actually thought you could contract HIV from donating blood."

When Lewis-Thornton found out about her HIV-positive status, she said her initial reaction was shock because she did not meet the stereotypes of who could contract HIV. At the time, she said her only solace was that the Red Cross representative told her that she may never contract AIDS; however, in 1992, Lewis-Thornton's HIV-positive status turned into an AIDS diagnosis.

Harris, a 65-year-old white cisgender gay man, was first diagnosed with HIV and then, in 1990, with AIDS.

"My reaction at first was panic, and then deep depression and feeling hopeless watching all my friends get sick and die," said Harris. "I think I coped with that in two ways: throwing myself into volunteering for community organizations and also substance abuse."

Berry, a 62-year-old white cisgender gay man, said that although he was diagnosed with HIV in 1989, he believes he contracted it in the early to mid-1980s.

"When I received my test results, I was scared because many of my friends had already died or were sick at the time," said Berry. "My doctor told me he could not treat me as he did not have any patients with HIV, and referred me to the HIV clinic at Northwestern. I went home and cried."

Munar, a 51-year-old Latinx cisgender gay man and first-generation American whose parents emigrated from Columbia, was in a monogamous relationship at the time of his diagnosis.

"I was completely shocked because I had tested negative six months prior," said Munar. "Because there were no effective treatments at the time, I feared I would not live to see my 35th birthday. Stigma, fear and shame contributed to a deep depression that lasted years, a period when I confided in very few people."

McLoyd, a 68-year-old Black cisgender straight man, found out he was HIV-positive on Valentine's Day, two weeks after being tested at the Chicago Department of Public Health clinic.

"I spent those two weeks knowing that whether the test results were positive or negative, my using days had run its course," said McLoyd. "I was actively using heroin and cocaine and expected the test to return positive, but I was

stunned to learn that I had fewer than 25 CD4 cells, PCP pneumonia and other opportunistic infections."

Lewis-Thornton's treatment began when she enrolled in a National Institutes for Health (NIH) study. She went every six months but did not tell her primary care physician (PCP) about her status. When Lewis-Thornton was put on AZT, she finally told her PCP who had no idea what to do for her and told her to defer to whatever the NIH doctor recommended. Lewis-Thornton said she finally received proper medical care when her HIV converted into AIDS.

"I ended up at the Women and Children HIV Clinic at Cook County Hospital, now the CORE Center, where I continue to receive excellent care to this day," said Lewis-Thornton. "I think, had it not been for the director of the clinic, Dr. Mardge Cohen, I would have died. I came to the right place with the right physician at the right time."

Harris echoed what Lewis-Thornton said in that there was only a small handful of doctors

Hospital and later at the CORE Center, where he, like Lewis-Thornton, still receives care to this day. He is glad that so much more is known today about HIV and the anti-retroviral treatments have been improving over time.

Lewis-Thornton, Harris and Berry were all given AZT at first to treat their HIV. Lewis-Thornton said she was given all the first-generation HIV medications and at one time she had to take 32 pills a day that resulted in "horrible side effects" like fatigue, diarrhea, nausea and headaches but she "kept pressing on." Even today her drug combo is six pills a day along with other medications.

For Harris, the dosing regime was really difficult and complicated to maintain. Like Lewis-Thornton, the side effects were really bad and "often worse than the disease itself, some of which I am still dealing with. The newer drugs are like one or two pills a day and barely any side effects. It is a world of difference, however; they are still very expensive, so accessing them and the diagnostic testing they require are still

cocktail was changed. McLoyd was prescribed the protease inhibitor Indinavir and replaced the AZT with Stavudine.

"There was not as much discussion about racial disparities in healthcare that I recall, but it was disappointing to hear my white peers talk about their three drug regimen when I was only prescribed two," he said.

When asked what she would now tell her younger self, Lewis-Thornton said she wished she had known the language of trauma and the cures to break its cycle, but that did not come until much later.

Harris would tell himself "lots of wise and calming things. But the fear and stigma was so bad back then, I probably would not have listened."

Berry would say that things would be okay, even though it does not seem that way, and that sharing his status with the people closest to him would be "difficult and emotional for you but they will still love and support you just the same."

"Go to support groups, listen and learn from your peers who have more experience and appear to be knowledgeable and doing well with their treatment plans."

—Peter McLoyd

and other medical professionals who knew anything about HIV in the 1980s.

Berry said that the care he received at the Northwestern Memorial HIV clinic at the onset of his diagnosis was "phenomenal." He added that renowned HIV physician and researcher Dr. Rob Murphy became his new doctor and he also received counseling at the clinic to help him deal with the shock of his diagnosis.

"That was life-saving, because it was there, for the first time, that I revealed to another person that I had been sexually abused by my father as a child, and was diagnosed with PTSD."

Munar said the live-saving combination therapies that became available two years after he was diagnosed enabled him to boost his compromised immune system. But he feared the possible side effects and that the therapies might not be effective.

McLoyd began his treatment at Cook County

causing inequities in access."

Berry said that he developed a resistance to each new drug he would take, since his virus was never fully suppressed.

"It was only later when we discovered combination therapy, and that it was the key to suppressing the virus and reducing viral load, that the treatment got better for everyone," said Berry. "But even those first powerful protease inhibitors were difficult to take, requiring handfuls of pills multiple times a day with debilitating side effects, but they kept me and others alive. It was only after 30 years of living with HIV that I was finally able to take one pill, once a day, with virtually no side effects."

McLoyd thought the protease inhibitors that were available would be included in his drug cocktail, but that did not happen. He received two drugs at the time, AZT and Epivir, and it was only after his viral load increased that his drug

Do not be afraid to ask for help and when you give back and help others along the way, you will get so much back in return. Do not ever give up hope."

In Munar's case, he would say "there is hope. The journey is hard but it imparts many valuable lessons."

Munar added that his only desire at that time was to grow older and now he is "eternally grateful" that happened.

For McLoyd, it would include asking questions and speaking up for himself when something did not feel right, which he did not do in the beginning.

"Go to support groups, listen and learn from your peers who have more experience and appear to be knowledgeable and doing well with their treatment plans," he added.

Speaking with other long-term HIV/AIDS survivors, Harris said he is most struck by when they

speak about their fears of growing old and being alone, which is something they never thought they would have to do. They also speak frequently of grieving the loss of friends and having survivor's guilt.

Lewis-Thornton said that the most important thing she has heard from other survivors is that "we have survived a period where it was expected that we would die. We never made any long-term plans back then so in a lot of ways we had to begin to think about our lives in a different way. It became almost a re-definition of who we were, especially those of us who were AIDS activists; [it] had become the sum total of our lives. Later on, we had to reimagine our lives and, for me, that meant going to seminary and expanding my activism beyond HIV to women's issues."

Berry said he is "continually amazed by the inspiring stories of resilience and strength I have heard from other long-term survivors, and while some may be different than my story, and each story is unique, there is a common thread of humanity and perseverance woven through all their stories that resonate with me."

"There is a shared experience of fear and dread among those of us who lived through the years when treatments were not available and infections and death continued to spike," said Munar.

McLloyd said that it is a "mixed bag" and it "makes a big difference" to have people to talk to about one's HIV/AIDS status. He added that with the emergence of COVID-19, for himself and "other long-term survivors, HIV is no longer at the top of their list of concerns."

As for how comfortable they are in talking about their HIV/AIDS status, at first Lewis-Thornton did not share it with all but a handful of people until she thought she was dying, and now, due to speaking out, she became the first Black woman to tell her story nationally when she appeared on the cover of Essence magazine. She said her "life is an open book."

For Harris, being public about his status was never in question, however; he said that even today it surprises him "how many people tell me they still think it is a courageous act to openly talk about it. It makes me sad to think that after all this time; there is still fear and stigma not only in the broader community, but also within the LGBT community."

Berry said that working at TPAN for the past 28 years and being involved in HIV advocacy has given him the freedom to speak about his status, thanks to the support he received from his family, friends and co-workers. He added that many people do not have that option due to a variety of factors.

Munar said "no and yes" and that he is more comfortable in his body and it has taken time to unlearn "HIV shame and blame. I also reject the notion that I am the disease; it is part of me but I am so much more than just my serostatus."

"I have always felt comfortable talking about my HIV status—speaking at universities, high schools and other venues, McLloyd said. "It is a norm, but not something I relish doing, as I once did."

In terms of how they see the current COVID-19 pandemic in relation to the HIV/AIDS pandemic, there are similarities and differences. They all

recognize the disparities in treatment on a variety of fronts for those who contract COVID-19 whether they are due to ones race or socioeconomic status or where they reside. This also continues to happen for those who contract HIV.

Lewis-Thornton said that unlike with HIV, she believes the medical community and politicians recognize the disparities and "are doing what they can to help reduce the numbers in Black and Brown communities."

"People do not believe they can contract COVID-19, that is until it happens to them, just like HIV," said Lewis-Thornton. "People do not do the simple things to keep themselves safe, like wear a mask, like use a condom."

Harris said that, in many ways, history is repeating itself due to "slow and incompetent action by the federal government along with weird conspiracy theories, outright denial and scapegoating by both President Reagan and Trump, and other high officials." He added that stigma and distrust of the medical community are the same now as they were during the early days of the HIV pandemic.

"We see many of the same disparities now that existed and still exist in the HIV pandemic, but in today's 24/7 news cycle, the internet and digital technology it is revealed in real time," said Berry. "I think there is an opportunity for us to use what we have hopefully learned from the past, to address these disparities in innovative ways, such as opening up vaccination centers in Black and Latinx communities, and providing education to address issues like medical distrust."

McLloyd pointed to the CDC data that show, like those with HIV/AIDS, "there are more COVID-19 cases, severe illnesses and deaths in minority communities nationwide. Many of us live in locations and conditions that negatively affect many health concerns including COVID-19."

Munar said that at Howard Brown, staff members are using their "three decades of experience in fighting HIV to inform our response to COVID-19. It comes down to establishing a trusting relationship and providing scientifically valid tools for the community to use in their context."

Troy Johnson, MSW, LCSW Licensed Psychotherapist



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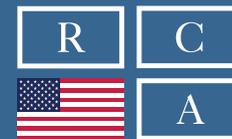
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HIV at 40

Sean Strub (center) getting arrested at a 1987 protest at the White House. Photo courtesy of Strub



Long-term AIDS survivor Sean Strub on his diagnosis, being a mayor and Larry Kramer

BY ANDREW DAVIS

To say Sean Strub is a fighter is almost the supreme understatement.

He was diagnosed with HIV/AIDS in the mid-1980s—when having the disease was almost certainly a death sentence. (Even the doctor who diagnosed him passed away a couple years later.) In the mid-'90s—after becoming the first openly HIV-positive person to run for Congress, and well into a career as an activist—Strub's mortality seemed to be nearing an end after he founded POZ magazine, as his body was covered with advanced systems like Kaposi's sarcoma (a form of cancer).

However, things turned around for Strub, as antiretroviral therapy appeared on the scene, helping him immensely. And he didn't just survive; he thrived: Strub (and partner Xavier Morales) moved to Milford, Pennsylvania, where he purchased a hotel and, in 2017, became mayor of the city—which voted overwhelmingly for Donald Trump in 2016.

Windy City Times: Did you think we'd be 40 years in and not have a cure?

Sean Strub: Well, first of all, I didn't think I'd be 40 years in. But did I think we'd be 40 years in and not have a cure? Well, it depends on how one defines "cure." We have a treatment that's basically a functional cure. I was never that optimistic about something that would eradicate the

virus from the body, just because it doesn't work that way with viruses—so, in that sense, I'm not surprised.

In 1985, I was more concerned about making it to next year. In 2000—and in 2021—yeah, I thought things would get better, but I didn't necessarily expect a cure.

WCT: The very first time you heard of AIDS, was it called GRID [gay-related immune deficiency]?

SS: Actually, it was before that. The first thing I heard was a strange cancer affecting gay men in May of 1981, as a New York native. Then, over the summer, it started being called gay cancer and then gay-related immune deficiency.

WCT: I know you've talked about your journey in the book *Body Counts*, but I'm wondering if you could take us back to the day you were told you were positive?

SS: Sure. The day I was actually told, it wasn't an enormous surprise. Whatever this thing was, I thought I had it for several years. The late summer of 1985 was when I had a really bad case of shingles, and so the doctor said it could be AIDS-related complex (ARC); I was tested and had to go back two weeks later to get the results. I was still semi-shocked when I found it; it's life-changing news. The doctor said, "Look, Sean: These days, people have two years left."

I walked out of his office, and it was a beautiful day. I walked down the sidewalk and everything seemed surreal; every dream and aspiration, and

my friends and family were swirling around in my head. Yet the rest of the world was walking by, unaware and going about their lives. Then I was walking south along Broadway, heading toward Lincoln Center, and I was looking at the faces of people passing me on the sidewalk—and I was wondering what their lives were like. I wondered if they were going through this incredible existential drama in their heads, like I was.

That evening I saw my boyfriend and told him. He didn't want to get tested, and he had already exhibited symptoms. We didn't have cellphones or emails then, and I didn't call anyone on the pay phone with urgent news.

WCT: And from there, you became an activist. What compelled you to do so?

SS: I think it's a lot of things. First of all, having the time to engage in activism is a privilege, but there's also a sensibility. I grew up in a university town where people were protesting was common. I was already a political activist, so being a gay-rights activist was a logical extension.

Also, I didn't have a lot of shame about the diagnosis; I had more shame about coming out and being gay. So without that burden of shame, I felt free to learn more about what was going on around me—and to protest the injustices around me so things could be better. A lot of people were afraid of losing their jobs or families; I didn't have a wife and children, so I didn't have a secret to protect. So all those things helped me become an activist.

WCT: A lot of people were justifiably very upset with then-President Ronald Reagan and his very slow response to HIV/AIDS. However, you also criticized then-President Bill Clinton. Why was that?

SS: When Clinton was elected, in 1992, that was the first time the LGBT vote played an active role in a presidential race. And it became apparent to me that—and I don't want to say this in a critical way—that a whole lot of community leadership became part of the Clinton administration. Once you become part of the administration, you lose the latitude to criticize. Those in the administration wanted those on the outside to criticize.

Queer people were happy to be part of the administration; it was like pixie dust, if you will—but it also distracted from the clear-eyed approach the administration was or was not doing. And the administration was horrific when it came to syringe exchange. The science was absolutely clear that syringe exchange dramatically reduced transmission—and the Clinton administration continued to question the science. They were trying to obfuscate what scientists said, which was utterly ridiculous. That made a lot of us angry.

WCT: I talked with [writer] Edmund White once, and he told me that he went to hundreds of funerals for friends who died of AIDS.

SS: I actually didn't go to that many funerals; I went to memorial services and celebrations of life. I suspect Edmund was encompassing all of those when he said "funerals." But in terms of them, I didn't go to hundreds although I may have gone to a hundred. There were certainly many more that I knew about, although I remember going to two in one day—and there was a third I could've gone to.

WCT: Regarding the LGBTQ community, do you think there's a more cavalier attitude toward HIV/AIDS these days?

SS: Well, yes, but the consequences of getting HIV/AIDS are not as dire as they were years ago. Having said that, do I think people are too casual about it? Yes—we're still getting a lot of transmission, but I think that has to do with who has access to healthcare as well as what type of relationship they might have with the criminal-justice system.

The challenges in reducing HIV transmission today are not so much singular to the virus as they are related to a broader set of circumstances in people's lives and structural elements in their lives.

WCT: Another giant of the HIV/AIDS community, Larry Kramer, passed away last year. Could you talk about the impact he had?

SS: Larry was one of several people who had an enormous impact on the epidemic globally. Larry's contributions could be looked at in two important ways. One, he helped us to find our voice. He helped us to find the anger against the injustice perpetrated against people with HIV. You know, Harriet Tubman freed slaves and she said, "I could have freed a thousand more if only they knew they were slaves." And Larry helped a lot of queer people understand they were oppressed. In that sense, Larry was the megaphone who showed us how effective anger could be. He gave us permission to express the anger smolder-

ing within us.

Larry also believed that queer people were better than others. I don't know if queer people are better, but there are certainly ways we contribute to society. I once had dinner with Harry Hay, founder of Radical Faeries and the Mattachine Society. I was wearing a suit and tie, and he made fun of me because of that, saying that I was an assimilationist. He said that we're different from heterosexuals in that what we contribute to society is unique. And Larry really celebrated and loved gay people—and helped us to love ourselves.

But there are others. [Recently,] we lost someone who was just as much as giant: [physician] Joseph Sonnabend. Not only did he really invent safer sex—probably the most important contribution to prevention in the history of the epidemic—but he advocated for the aggressive treatment of opportunistic infections, including prophylactically, changed millions of lives. In the 1980s, when PCP [pneumocystis pneumonia] was the number-one killer of people with AIDS, he prescribed sulfa drugs for people with impaired immune systems. Yet it took the federal government years to issue an advisory, even though the science had been behind it and Joe had been prescribing it for years. A delegation of people had gone to Washington to beg [Dr. Anthony] Fauci to issue an advisory; during those years, 17,000 people died of pneumonia—overwhelmingly, gay men.

Joe was phenomenal, and he advocated for patients' rights. He was influential in saving so

many lives. He was more private, as Larry was more public, though. Losing someone like Larry hurts because so many people identified with him.

WCT: Let's talk about your politics. I saw the movie *My Friend, the Mayor* [which chronicles Strub's mayoral win in Milford, Pennsylvania]. Did your win later give you hope regarding the 2020 presidential election?

SS: That's an interesting question. It gave me hope for the democracy. There was an opportunity to show, on a local level, that democracy can prevail if people participate. The role of money on the national level can be dispiriting and prevent people from participating. Our campaign showed that democracy works. So, at a time when it clear democracy was under assault—more so since that election—here we were demonstrating that it could work. And it also reinforced my belief that if we could get past this partisan divide, things could work. Things have to change from the ground up—how we relate to our neighbors, how we engage with others.

On the day that the Supreme Court gave George Bush the White House, in 2000, Gore Vidal wrote me a letter and he said, "Oh, well. [The country is] 224 years old. She's had a good run, but all good things must come to an end." He had been predicting the end of the American democratic experiment. Gore has died but I wish he were alive to see the film and see that, yeah, there's still some life here.

WCT: Interestingly, we seem to be at a point where we can't even agree on the actual

facts—whereas, previously, we had different opinions about facts.

SS: Maybe it's my imagination, but I've looked at a local Facebook pages, but there seems to be a lot less of the QAnon items and equally ridiculous things. I don't know if that's because of what social media has imposed, but you know what? I think some people have learned to be a little more skeptical; if something sounds outrageous, they should check things. Maybe it's peaked.

But I think something that has made us vulnerable is the degradation of our public-school system. Over the last 40 years, it's significantly declined in quality. The teachers haven't gotten worse, but they have fewer resources and bigger classes. People don't have the same capacity for critical thinking, for reading, and for absorbing and processing information. We need to rebuild our public-school system.

WCT: Do you ever see yourself running for Congress again?

SS: No. Maybe if there's some dramatic change to the system. I have so much empathy for people in Congress because they have to spend so much time fundraising. It detracts from the quality of the governance we get. I think it's degrading to public servants—people we want to act in our best interest. As Barney Frank used to say, "It's the only job in the world where you're supposed to be elected and follow your conscience and do what's right—but you spend half your time begging for money from people who want you to do something else."

WCT: What's the most important thing you've learned about yourself?

SS: The most important thing is how much I have to learn. I've learned that no one has all the answers. I've learned my own weaknesses and I've learned how important it is to be close to people you love and who love you back.

I've also learned—through decades of political, human-rights and social-justice work—how fragile our gains are and how quickly people take the progress of the generation before them for granted. And that's across the board: You can look at reproductive rights and women's health, the civil-rights movement and AIDS. Progress is fragile and [involves] a never-ending commitment to keep and expand those rights.

WCT: Yes; progress can be lost in buckets and gained in drops.

SS: It is. We've seen, in all sorts of ways with the LGBT community, many countries going backward—and things could get much worse. When people in some faraway country are losing rights, we better pay attention because we could be next.

WCT: What would you like your legacy to be?

SS: When I wrote the book, I told my story to that point. What come to mind are young people I'd like to inspire. I love it when I hear from people who've read *Body Counts* and seen the film. I want as much of my life as possible to be an inspiring example. That's the legacy I most treasure.

The logo for SQUIRT.org, featuring the word "SQUIRT" in a bold, white, sans-serif font with a red dot over the 'i', and ".org" in a smaller, white, sans-serif font below it, all set against a red rectangular background.

Real Men. Real Community.

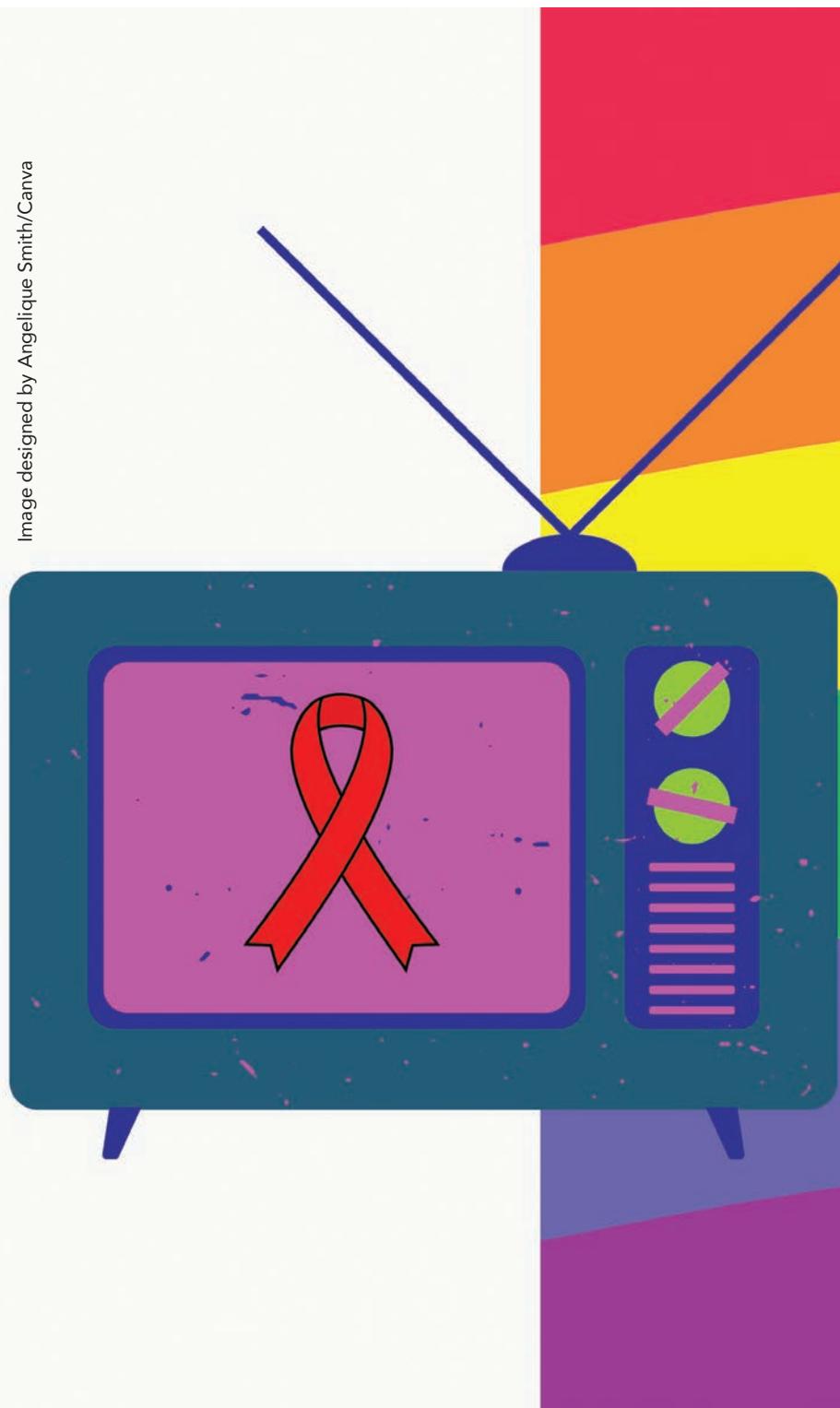
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Forty years later, still a call for accurate HIV-positive REPRESENTATION

BY ANGELIQUE SMITH

Image designed by Angelique Smith/Canva



*"I can look back at a show like *Girlfriends* and see how they dramatized living with HIV; how the character made a quick appearance and then died. For the time that it came out in the early 2000s, the reality of living with HIV had already started to change. I haven't really seen anything today on TV that presents a modern way of looking at living with the virus or anything that reflects my own reality." Isaiah*, a 41-year old, African-American gay man who has been living with HIV for 16 years.*

Forty years after the first reported cases of HIV, and at a time when nearly six in 10 Americans wrongfully think that "it is important to be careful around people living with HIV to avoid catching it," with 89% agreeing that there is still a stigma around HIV (GLAAD and Gilead's State of HIV Stigma survey, 2020), the populace remains in dire need of both education about and positive representation of those living with HIV in television, film and media.

Television and film can be used as an important communications tool and have a lasting impact. A study found that a statistic mentioned on *Grey's Anatomy*—that HIV-positive mothers receiving treatment have a 98% chance of having a healthy baby—both educated and was retained by viewers almost two months later (Television as a Health Educator: A Case Study of *Grey's Anatomy*, The Henry J. Kaiser Family Foundation, 2008).

Early representation of HIV-positive characters came with the 1985 film *Buddies* and the made-for-TV movie *An Early Frost*, months later, which is often seen as a precursor to *Philadelphia*. While other network shows and soap operas have introduced HIV-positive characters over the years, currently, there are only three regular characters who are living with HIV on television in the 2020-2021 season across broadcast, cable and streaming services—and all three are on FX's *Pose* (GLAAD's *Where Are We On TV* report, 2020).

Windy City Times spoke with two Chicago residents living with HIV, in addition to a medical professional, local cultural scholars, and an executive from GLAAD about the state of HIV-positive character representation.

Windy City Times: Understanding the importance of accurate representation for HIV-positive characters, are there any pivotal moments in queer cinema or on television that did the job of driving greater acceptance?

Dr. Jennifer Brier, director and professor of gender and women's studies and history, UIC: *Philadelphia* was a key film. The history of the representation of LGBT characters—and, particularly, people who are living with HIV/AIDS who may, at the time, have been called "AIDS victims"—involves a change in nomenclature that has always been complicated. While visibility is critical, actually seeing accurate and empathetic representation of human struggle and experience is deeply important and one of the ways that change happens.

Rich Ferraro, chief communications officer, GLAAD: You can't look at *Philadelphia* without looking at the context of the time it was released. Having Tom Hanks play that role brought the discussion of people living with HIV to broad

mainstream America at a time when people living with HIV in mainstream storylines were all but invisible. If you look at shows like *Noah's Arc*, that highlight the nuances of living with HIV and the intersection of living with HIV, being queer and being Black in America today, that's one thing that we see in shows like *Pose*, as well. These characters are not just speaking about living with HIV, they're speaking about being trans, being Black and about intersectional issues.

Mack*, a person of color who's been HIV-positive for almost two decades: Even before I was diagnosed, I remember watching *ER* and the African-American female doctor [Gloria Reuben's Jeanie Boulet] was diagnosed with HIV. I was surprised because she's wasn't gay. I had to do research to understand that this is not a gay disease and it's not a male disease. Straight women can have it.

Brier: *Philadelphia* had a really important and powerful effect on U.S. culture, but it also showed things in a very particular way. Which is a way that we know has been much more of a myth than a reality. You see a white, gay man dying of AIDS and Tom Hanks was certainly not gay, not infected with HIV, not dying of AIDS, and so it's part of the performance of that. But it also served to reiterate through the representation the idea that AIDS was a white, gay male disease. Those are myths that, unfortunately, have real currency.

Mack: From everything I saw [on TV and in film], I thought that HIV worked really, really fast. I thought, "Do I have a week? Do I have two weeks? Do I have a month?" That was my first concern: the timing of the disease and how quickly it can take hold of you.

Dr. Maya Green, regional medical director, Howard Brown: When people I see have a story that's related to something they saw in movies, we sometimes get *Dallas Buyer's Club*, especially with medicines. Some people are still on it, but it was kind of rough to take. The main thing I tell them is, "Whatever that person's truth is, it spoke to a time when we didn't have medical technology to develop medicines that helped people living with HIV to live a long, healthy life." Then I usually show a chart of all these medicines that usually work, and let them know that we do have to customize them to individual needs. I tell them, "The medicine and the medical technology is updated, but a lot of times, not only in the community, but in the health care industry, we haven't updated the conversation."

Brier: You see a TV show like *Pose*, where the characters are much more racially diverse, the actors are trans and queer people of color. They're talking about the same moment in time as *Philadelphia*, but it's a totally different representation of what survival looked like, how communities managed to create possibilities for freedom, survival and care for one another. They were made 20+ years apart, so you see how historical thinking has evolved about AIDS, but also how we've tried to unpack the idea that AIDS was once a white, gay male disease. AIDS has always been an illness that is structured by both sexuality and race.

WCT: How has HIV-positive representation changed over the last four decades? Any notable trends?

Ferraro: If you look back to a lot of the LGBTQ-inclusive content from the '80s and '90s, ... *The Hours*, *Angels in America* and *Rent* really opened up people's eyes to what living with HIV was like and reinforced the importance of talking about HIV prevention. Then if you look at the late '90s to the 2000s, there were shows like *Queer As Folk* and, more recently, *How to Get Away with Murder*, that included HIV as part of the narrative when speaking about LGBTQ lives, and showcased characters leading long and healthy lives. HIV was a part of their story, but not the center of their story.

Dr. Nick Davis, associate professor, English and gender and sexuality studies, Northwestern: One surprising trend in film is that there aren't more HIV/AIDS narratives that don't feel like they have to be returned to the moment of initial response in the '80s. I think that our portraits of activism and community impact in the early to late '80s get more textured and inclusive as time goes on. I'm just surprised there are not more stories of people living with and managing HIV now; that's something that still feels pretty under-exploited.

Brier: I would argue, as a historian of AIDS, *Pose* is probably one of the most positive representations of what it means to survive, what it takes to survive, and what it means to have a community that helps you survive of any [television shows] I've ever seen in the last 25 years of doing this work. What I love about *Pose* in many ways is that it's about why communities of color were the leaders in thinking about systems of care when the state was not interested in that.

Davis: I also do appreciate that I remember the first years of seeing characters who were conveyed to me as having AIDS were always dying from it. It's refreshing to feel like not every character with HIV/AIDS is medicalized in the same way as it was in the past, or presented using all the tropes that used to be so common—it's not all about Kaposi sarcoma, or being on a deathbed. We've gotten better at not limiting ourselves to that archive of images, but I would love to see a more robust idea of what we're doing instead.

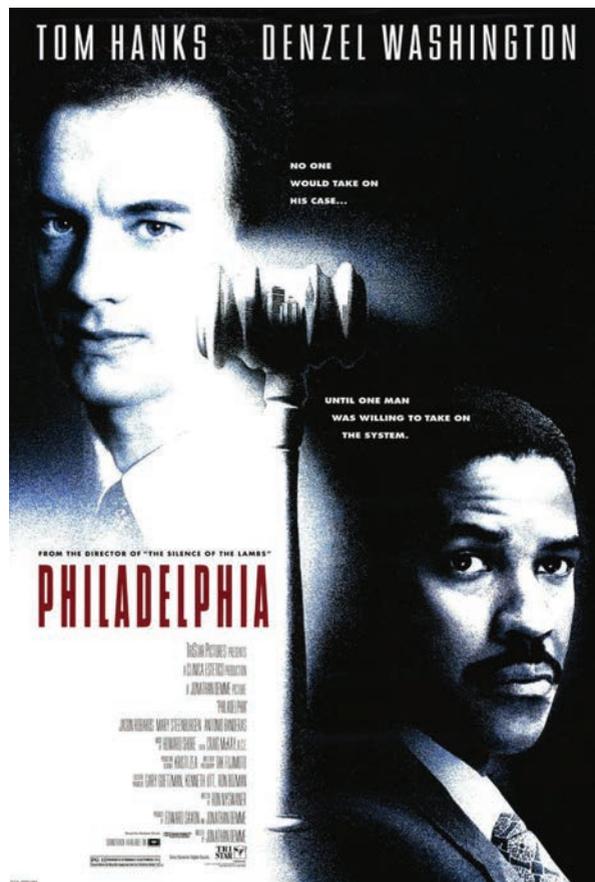
WCT: What are your thoughts on whether it's Hollywood's responsibility to educate viewers? And what are good solutions to the problem of accurate portrayals?

Ferraro: I think Hollywood can play a big role, but Hollywood can't and should not do it alone. National and local LGBTQ organizations need to continue to prioritize sharing stories about people living with HIV, speaking about HIV treatment and prevention. But also starting to introduce discussions around PrEP and HIV testing because those are discussions that queer people should be having more of.

Brier: I think it's all of our responsibilities. I think we need more representation of HIV-positive people in literature, in poetry, not just popular culture. We need it in scholarship and to be seen as scholarship, we need it in real comprehensive sex and health education. We need it in adult education where we actually talk about the ways that we love and are in relationship with one another. We need it in health care if we're going to talk about what it means to be healthy.

Green: The best place to update narratives and the conversation is in the community. A patient is with me 15 minutes. They're going to be with their community, their family, their loved ones for 23 hours and 45 minutes out of the day. When a person is seeing [negative stereotypes about HIV on TV], it helps to have a support group they can trust to help while they unpack that. Unfortunately, the fear of living with HIV is what people recall from the media when people show up in the office. You have some [television] shows that are doing the work of updating that narrative, which is great, but in the health care industry we also have to update the narrative.

Ferraro: Hollywood had been a leader in telling HIV stories in the early '90s and now is suffering from nearly complete invisibility of people living with HIV. So, our commitment was released earlier this year with the "Where We Are on TV" report: We're challenging Hollywood to add characters living with HIV storylines.



In 1993, *Philadelphia* (right) brought HIV issues to the big screen.

Poster courtesy of TriStar Pictures

That commitment will turn into a community working group later this year made up of HIV advocates, people who work in HIV prevention, especially across the U.S. South, and people working in Hollywood who have a deep understanding of HIV and how to create storylines with HIV that are fair and accurate.

Green: Stigma is an infectious disease of the mind and it kills more people than HIV ever could. I say this every chance that I get: to kill the stigma, we vaccinate with education. We have to fight stigmas by leading with facts, and facts are, if you get screened early, and you start on medicine early, you can live a long, healthy life.

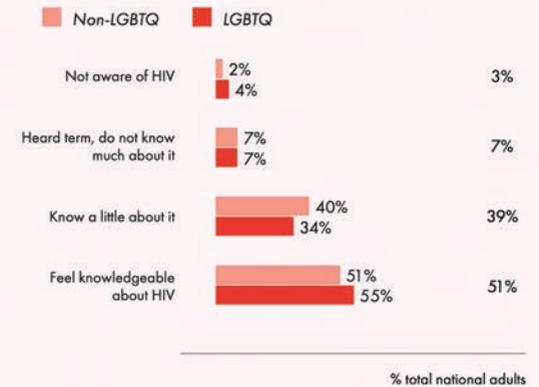
Dr. Jennifer Brier is the author of *Infectious Ideas: US Political Responses to the AIDS Crisis*, and the recently launched "I'm Still Surviving," an online exhibit of the oral histories of women living with HIV, at StillSurviving.net. Rich Ferraro is the chief communications officer for GLAAD and executive producer of the GLAAD Media Awards. Dr. Maya Green is the regional medical director for the south and west regions of Howard Brown. Dr. Nick Davis is the author of *The Desiring-Image: Gilles Deleuze and Contemporary Queer Cinema*.

*Names have been changed at the request of the interviewees.

Infographics provided by GLAAD. ⇨

1 How Informed are Americans About HIV?

Only 55% of LGBTQ Americans versus 51% of non-LGBTQ Americans reported feeling knowledgeable about HIV.



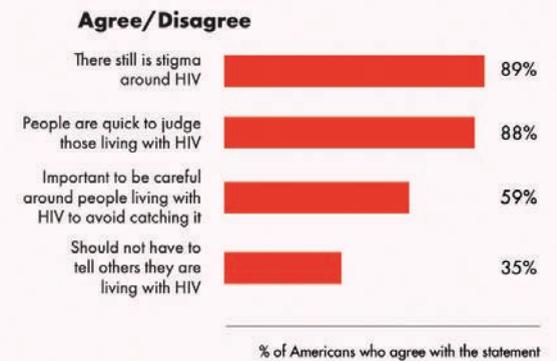
2 How Visible Are People Living With HIV?

A higher percentage of LGBTQ people (61%) than non-LGBTQ people (52%) report having seen any stories about people living with HIV in the media.



3 High Stigma Towards People Living With HIV Remains

The vast majority of Americans acknowledge that there is stigma around living with HIV, with 89% agreeing that "there still is stigma around HIV," and 88% agreeing "people are quick to judge those with HIV." However, over half of Americans (59%) agree with the stigma-reinforcing statement that it is "important to be careful around people living with HIV to avoid catching it" and only 35% of Americans agree that people living with HIV should not have to disclose their status.



TANIA UNZUETA



Tania Unzueta (on microphone).
Photo by Ervin Lopez

Fighting for justice, one cause at a time

BY MELISSA WASSERMAN

LGBTQ, immigration and political activist Tania Unzueta has spent the last three years living in Georgia involved in political and electoral organizing. She returned to Chicago in January with her partner.

Unzueta came to Chicago from Mexico City with her parents and sister when she was 10. Her family members are immigration and labor rights activists—as a child, Unzueta went to rallies and protests for various causes.

“I’ve always seen organizing as an option,” Unzueta said.

A teenage Unzueta, who was undocumented, was faced with the issue of her immigration status for the first time when she was in high school and getting ready to apply for colleges. This, she said, was her first experience of activism for herself and her community.

She went on to earn a bachelor’s degree in gender studies and a graduate degree from the Latin American and Latino Studies program from University of Illinois at Chicago (UIC).

Around 2010 she did a lot of organizing around undocumented youth and that is when she decided to lean into it. Among her many experiences, she was a volunteer with a national group of young people fighting for the DREAM Act, co-founded the Immigrant Youth Justice League, worked on different campaigns including

the Not One More campaign, Jesús “Chuy” García’s mayoral campaign in 2015, and she worked on Stacey Abrams’ gubernatorial campaign in Georgia. Additionally, she is a former journalist and public radio producer.

Unzueta, who identifies as queer, is the political director and co-founder of Mijente—a hub for Latinx and Chicax people to build campaigns and connect around racial, economic, gender and climate justice.

She is also co-founder and on the board of directors at Organized Communities Against Deportations (OCHAD).

“Part of our values as an organization and why I’m at Mijente is we believe in local people making decisions for themselves,” she said, explaining Mijente always partners with local organizations.

She said when she started Mijente she was coming out of immigrants’ rights organizing, particularly around deportation defense, but she had an interest in getting into electoral and political work.

She observed, when she went to work for the Garcia campaign in 2015, that the biggest problem reported in Chicago was that Latinos did not vote, so turnout was always low.

“So we have the problem where Latinos were the majority of our constituency and everyone was afraid the vote wouldn’t happen,” said Unzueta. “So, I feel like I’ve been spending the

last five years at Mijente really thinking through what’s missing in political organizing, what needs to happen differently, what do we know from grassroots organizing that could help political work?”

“I just think there’s people who aren’t excited about electoral politics and what we’re trying to do within the organization is talk about the different strategies that it takes to create change and that includes outside the state, within the state, and non-electoral grassroots work as well as political work,” Unzueta said.

Over the last year, Unzueta has run the entire political program at Mijente, and her roles included supervising teams in Arizona, North Carolina and Georgia for the general election, supporting local candidates and campaigning against Donald Trump. For the U.S. Senate runoff elections in Georgia that took place this past January, she ran the organization’s political campaign in that state for the Democratic candidates. Unzueta explained that her responsibilities covered designing the plan, figuring out who to target and why, choosing the messaging, recruiting people on the ground and making decisions about payment for canvassers, among other things.

In Georgia, particularly for the runoffs, Unzueta said that she and her team succeeded in reaching every Latino voter in the state.

“I feel like it’s part of why the political parties and candidates don’t choose to invest in Latino

communities because it takes a lot of resources to get us there and it’s also why it needs to be done different than the way it is,” said Unzueta. “It’s worth it to invest in these people to be able to allow our voices to be heard.”

As for the successes in this political work, Unzueta said that being able to reach every single Latino person in Georgia for the runoffs is something that has never been done in the state before.

“So we did a lot of microtargeting, for example, and the targeted messages for the community—and I think that was a huge success,” said Unzueta. “I feel like having an independent political vehicle that’s progressive, that’s organizing Latinos nationally is important. Being able to participate for the first time in a presidential election is a win for Mijente.”

When asked about efforts for future elections, Unzueta explained it is about figuring out how to support people who are interested in mobilizing in their own states.

“None of the work in Arizona and Georgia or North Carolina would’ve happened without people being really invested in it,” she said.

“It doesn’t mean the only way of participating has to be voting or has to be doing political work,” she said. “I think there’s a diversity of work that we could be doing and people just need to be involved in some way.”

Unzueta said she is driven by the idea that that things can get better in time.

“I got into organizing because I was seeing the different ways in which my life was being impacted by being undocumented for most of my life and the only way that I was able to figure out how to get into school or how to find resources, how to find people who were telling me I couldn’t do stuff, is to organize and so I feel like when I see injustices in my community and in my family,” she said. “My experience has been by coming together and making a plan and figuring out how to leverage your power.”

Unzueta said an important lesson from her years of organizing is to not just criticize, but to propose solutions.

“I think we spend a lot of time as organizers talking about what’s wrong and don’t often have answers for what is the thing that we are suggesting,” said Unzueta. “So, I feel like that’s part of the challenge for us this year too, like even if we have criticisms of the Biden administration, it’s not about saying what they’re doing wrong, but actually being able to figure out what can work and what are we actually proposing going forward.”

Chicago Latinx, LGBTQ activist and Mijente member Emmanuel Garcia has been friends with Unzueta for about 15 years. They met working at a radio station.

“Tania’s fearless,” said Garcia.

Saying she inspires constructiveness in activism work and finding solutions, he described her as “an incredible organizer,” a storyteller and someone who also works behind the scenes, as well as someone who would coach and motivate others to get their point across.

“It wasn’t just that Latinx people are left out of electoral politics, it’s like but what are we going to do about that and so you can see clearly

“I think that there’s a diversity of work that we could be doing and people just need to be involved in some way.”

—Tania Unzueta

what the outcome of that was for her in Georgia and all the places that she’s been to,” he pointed out. “For me that’s the reminder; what are the solutions and how are we being more proactive about what we’re building.”

For future generations, Unzueta insisted that institutions can change. She shared a piece of advice she said she personally learned early in her activism: “Just because something is against the law, just because something is set in the institutions’ rules, doesn’t mean it can’t change. I think the history of immigration and the history of the LGBTQ community are great examples of that. To think just because an institution, a government, an organization has a way of doing things, I actually think our experience and our organizing and all of the ways in which we come together can change those things.”

To continue organizing efforts, Unzueta suggested staying safe, being forgiving—and being patient.

“Understand that some things are going to take longer or be less efficient or just less clear and that’s okay,” she said. “Maybe be creative. ... It’s a time where we need new strategies and new ways of doing things.”

Justice might not take breaks, but Unzueta understands and practices work-life balance.

She believes that life varies and is not always 50/50. Sometimes the organizing requires a 15-hour work day or an all-nighter, but it is necessary to take a vacation.

“We shouldn’t punish ourselves when that happens,” she explained. “We should take the time on all of that to do what needs to be done and at the same time there’s times when actually that’s not needed. There’s times when we can say no because we can. There’s times when we need the vacation. When you have to step back, other people have to step forward. I think that’s a thing to keep in mind.”

For more information, visit mijente.net.



Tania Unzueta (center).
Photo by Sarah Ji-Rhee

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PrEP options likely to change following Truvada patent expiration

BY MATT SIMONETTE

Among the myriad challenges facing HIV/AIDS advocates and healthcare providers has been increasing use of pre-exposure prophylaxis, or PrEP, among persons at risk for HIV transmission. A PrEP intervention, which usually consists of taking the oral medication Truvada, has been shown to decrease the risk of transmission by more than 90 percent.

Truvada was approved for PrEP use by the Food and Drug Administration in 2012 and, since then, has been widely prescribed by physicians to help at-risk patients prevent HIV transmission (it was earlier used to treat persons living with HIV). But Truvada's patent expiration in 2020 means both generic options for consumers are forthcoming and that a competing drug, Descovy, by the same manufacturer, is already on the market.

Some advocates are looking forward to having lower-cost options available. AIDS Foundation of Chicago (AFC) Senior Director of Prevention Advocacy and Gay Men's Health Jim Pickett suspects that "lower drug costs will lower the cost of access and alleviate some pressure on the system."

He added, "With PrEP, the costs are not just about the drug. There are costs affiliated with seeing your doctor, having blood work done, being tested for HIV and STI's. It's important to remember that services that come along with PrEP are part of the program—PrEP isn't just a prescription. If our system can spend less on the drug, there's arguably more money to cover those other things which can be prohibitive for people."

The cost of Truvada—which is a combination of the drugs known generically as tenofovir disoproxil fumarate and emtricitabine—has indeed been a key deterrent to widespread PrEP implementation. A month's supply of the medication is often \$1,500-2,000. Nevertheless, many insurers cover Truvada in their formularies, and the medication's manufacturer, Foster City, California-based Gilead Sciences, provides consumer assistance for monthly co-payments their plans require.

Various public health agencies have also made PrEP access a central component to long-term strategies that eliminate new HIV transmissions, such as the Getting to Zero initiative launched

in Illinois in late 2018. The federal government announced a similar program with PrEP interventions playing a central role in early 2019.

Nevertheless, PrEP adoption numbers remain far behind where advocates and providers want to see them. Getting the message about PrEP to white gay men has been a relatively minimal challenge, but communicating that same message to diverse audiences at risk, such as transgender women or young Black men, remains problematic. Usage in the southern United States, where a large number of new HIV transmissions take place, is also low.

In late 2019, Gilead announced it would donate a five-year supply of Truvada to 200,000 people. Their Truvada patent expired in late 2020. The company reached an exclusivity agreement for six months Israeli pharmaceutical manufacturer Teva for a generic version of tenofovir disoproxil fumarate and emtricitabine. Starting in spring 2021, Teva's exclusivity window expires and any manufacturer can produce a generic version of tenofovir disoproxil fumarate and emtricitabine.

Gilead still intends to remain a player in manufacturing and distributing medications for PrEP, however. In 2019, it received approval for use of Descovy as a PrEP intervention and has aggressively marketed the new drug as a replacement for Truvada. Google users who search "Truvada generic" will likely spot an advertisement for Descovy toward the top of their results.

Among the advantages of Descovy, according to Gilead, are reduced chances of complications to kidneys or bone density, which are stated side-effects to Truvada. But Descovy shares the same high cost as Truvada, about \$16,600-20,000 a year, according to aidsmap.com.

Many advocates and providers say that there is no need for a "mass exodus" from Truvada to Descovy for PrEP users, Pickett said.

"In terms of prescribing for PrEP, the vast majority of people using Truvada for PrEP have absolutely zero clinical need to switch over to Descovy," he added. "The only clinical reason to switch would be if you have some underlying kidney or bone disease, or if Truvada is giving your kidneys a hard time."

Gilead could not provide a spokesperson to comment on Descovy by this article's deadline.



Photo by Matt Simonette

Shortly after Descovy was approved for PrEP in October 2019, Daniel O'Day, Gilead's chairman and CEO, said the new medication nevertheless "provides a new HIV prevention option that matches Truvada's high efficacy with statistically significant improvements in renal and bone safety, which can be an important consideration as people at risk increasingly use PrEP for longer periods of time."

Prior to her appointment as director of the Centers for Disease Control and Prevention, Rochelle Walensky, MD, was lead author on a March 2020 Annals of Internal Medicine study which concluded that mitigating for Truvada's side-effects with a new medication was outweighed by the benefits of a lower-cost generic substitute for Truvada. Other researchers also have expressed concern that Descovy has not been tested on as diverse a population as Truvada has been.

"We already are seeing insurance companies pointing people to the generic alternative—when you are prescribed PrEP, the insurance company might cover the generic form of Truvada," Pickett said. "They may or may not be inclined to cover Truvada itself. We are also seeing insurance companies put in utilization-management for Descovy, so if you are prescribed Descovy, the doctor has to show clinical need."

Gilead has also been involved in extensive litigation with the federal government regarding the PrEP-related patents. The CDC sued the company in 2019, maintaining that it had not been properly compensated for federal researchers' contri-

butions to Truvada and Descovy's development. In January 2021, a federal judge rejected the Justice Department's motion to dismiss Gilead's counterclaims that the federal government had been in breach of key contracts, so the litigation will continue.

But for now, a key challenge for stakeholders remains getting the costs under control. Using PrEP represents a collective commitment of time and money for patients, providers and insurers.

In the years ahead, the PrEP landscape will likely change even further. An injectable version of the intervention has proven to be as effective as oral applications. In such a scenario, the medication cabotegravir could be injected and offer two months' worth of protection for patients who don't wish to take a pill every day.

Pickett said he didn't foresee injectable PrEP completely replacing pills however, noting that compliance challenges might only shift for some consumers. While the injection saves the patient from the responsibility of taking a pill, they'd still need a bimonthly appointment to receive it.

"I don't see it as replacing [oral medication]—I see it as being additive," Pickett said. "I see it drawing in people who struggle with PrEP because it is a pill, or aren't interested because it's a pill. Overall, if we do it right and create support systems that make it easy for people to get their shots—imagine being able to do it at Walgreens—I'll be super-excited about it. It means people having more options and more protection."

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