POSITIVELY AWARE

HIV TREATMENT, PREVENTION, AND SUPPORT FROM **TPAN**
MAY+JUNE 2019

CROI 2019

CONFERENCE NEWS
FROM SEATTLE

FRESH VIBES

Young people are taking control of their lives, inspiring those around them

MASONIA TRAYLOR

A pharmacy tech by trade, after her diagnosis in 2010, she found ways to connect to others living with HIV: ‘I would disclose to them by saying that I take the same medications they do.’

YOUTH, HIV, HOMELESSNESS —AND RESILIENCE

A PEDIATRICIAN ON HER 30-YEAR HIV CAREER

HELPING CURE RESEARCH AT THE END OF LIFE

IMPORTANT FACTS FOR BIKTARVY®

This is only a brief summary of important information about BIKTARVY and does not replace talking to your healthcare provider about your condition and your treatment.

(bik-TAR-vee)

MOST IMPORTANT INFORMATION ABOUT BIKTARVY

BIKTARVY may cause serious side effects, including:

- **Worsening of Hepatitis B (HBV) infection.** If you have both HIV-1 and HBV, your HBV may suddenly get worse if you stop taking BIKTARVY. Do not stop taking BIKTARVY without first talking to your healthcare provider, as they will need to check your health regularly for several months.

ABOUT BIKTARVY

BIKTARVY is a complete, 1-pill, once-a-day prescription medicine used to treat HIV-1 in adults. It can either be used in people who have never taken HIV-1 medicines before, or people who are replacing their current HIV-1 medicines and whose healthcare provider determines they meet certain requirements.

BIKTARVY does not cure HIV-1 or AIDS. HIV-1 is the virus that causes AIDS.

Do NOT take BIKTARVY if you also take a medicine that contains:

- dofetilide
- rifampin
- any other medicines to treat HIV-1

BEFORE TAKING BIKTARVY

Tell your healthcare provider if you:

- Have or have had any kidney or liver problems, including hepatitis infection.
- Have any other health problems.
- Are pregnant or plan to become pregnant. It is not known if BIKTARVY can harm your unborn baby. Tell your healthcare provider if you become pregnant while taking BIKTARVY.
- Are breastfeeding (nursing) or plan to breastfeed. Do not breastfeed. HIV-1 can be passed to the baby in breast milk.

Tell your healthcare provider about all the medicines you take:

- Keep a list that includes all prescription and over-the-counter medicines, antacids, laxatives, vitamins, and herbal supplements, and show it to your healthcare provider and pharmacist.
- BIKTARVY and other medicines may affect each other. Ask your healthcare provider and pharmacist about medicines that interact with BIKTARVY, and ask if it is safe to take BIKTARVY with all your other medicines.

POSSIBLE SIDE EFFECTS OF BIKTARVY

BIKTARVY may cause serious side effects, including:

- Those in the "Most Important Information About BIKTARVY" section.
- **Changes in your immune system.** Your immune system may get stronger and begin to fight infections. Tell your healthcare provider if you have any new symptoms after you start taking BIKTARVY.
- **Kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys. If you develop new or worse kidney problems, they may tell you to stop taking BIKTARVY.
- **Too much lactic acid in your blood (lactic acidosis)**, which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- **Severe liver problems**, which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.
- **The most common side effects of BIKTARVY** in clinical studies were diarrhea (6%), nausea (6%), and headache (5%).

These are not all the possible side effects of BIKTARVY. Tell your healthcare provider right away if you have any new symptoms while taking BIKTARVY.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.FDA.gov/medwatch, or call 1-800-FDA-1088.

Your healthcare provider will need to do tests to monitor your health before and during treatment with BIKTARVY.

HOW TO TAKE BIKTARVY

Take BIKTARVY 1 time each day with or without food.

GET MORE INFORMATION

- This is only a brief summary of important information about BIKTARVY. Talk to your healthcare provider or pharmacist to learn more.
- Go to BIKTARVY.com or call 1-800-GILEAD-5.
- If you need help paying for your medicine, visit BIKTARVY.com for program information.

Get HIV support by downloading a free app at

MyDailyCharge.com

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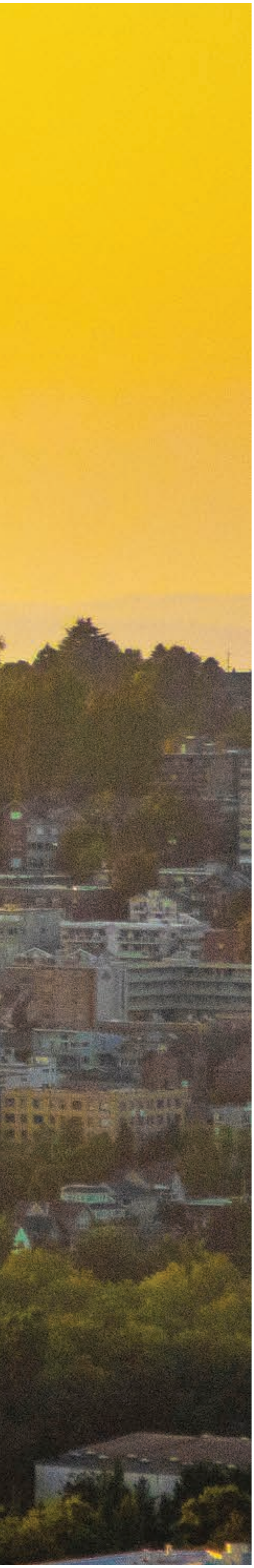
TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission to share accurate, reliable, and timely treatment information with anyone affected by HIV.

THIS YEAR'S CROI CONFERENCE WAS HELD IN SEATTLE, HOME OF THE 605-FOOT SPACE NEEDLE, WHICH WAS BUILT FOR THE 1962 WORLD'S FAIR. A ROUNDUP OF CROI NEWS BEGINS ON PAGE 38.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'GENERATIONS' OF SURVIVORS


THE NEXT GENERATION OF LONG-TERM SURVIVORS

A decade after testing positive, David Durán reflects on his life with HIV

I WAS IN MY DOCTOR'S OFFICE yesterday, looking through the January + February issue, when I came across David Durán's article, "The Next Generation of Long-Term Survivors." I read it with great interest.

David refers to the different "generations" of survivors; I just wanted to say that I am a member of the "original" generation of survivors.

I grew up in Los Angeles and was living in Santa Monica at the time I contracted HIV in 1982. After waiting two weeks for the results of my test, I was absolutely devastated and terrified; at the time, the life expectancy, at most, eighteen months. I had two small children at home at the time; as a single parent I was more than a little concerned.

I was immediately referred by my dentist to Michael Gottlieb, MD, who immediately started me on AZT, as that was the only thing available.

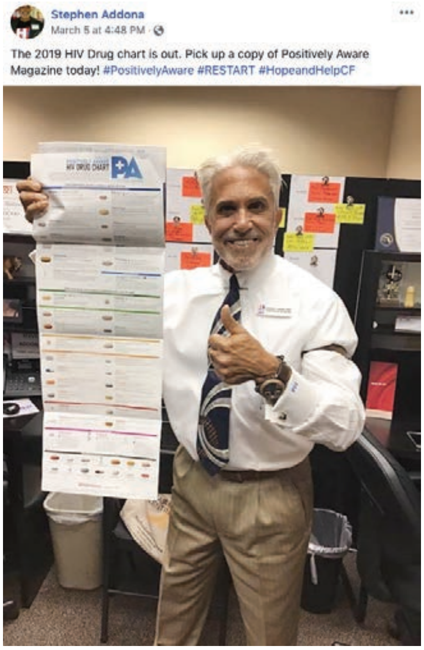
I was 31 at the time; it's been a long and, at times, a very scary 37 years.

I wanted to thank David for his article and for mentioning us "original survivors." I appreciated that nod, because the terror of it back then was almost too much to bear, and was for many who decided to end their lives abruptly.

I am very happy to say, at this time I am nondetectable. My previous T cell count was 1,013; I'm waiting to hear my results from yesterday's test.

So, thank you, David—you're a good man, and I very much appreciate your article.

—**MARK**
JAMESTOWN, TENNESSEE


Stephen Addona
March 5 at 4:48 PM ·

The 2019 HIV Drug chart is out. Pick up a copy of Positively Aware Magazine today! #PositivelyAware #RESTART #HopeandHelpCF

Hello, my name is Gabriel. I was in POSITIVELY AWARE's Golden Years special edition [Summer 2016]. I wanted to share with you my page on HIVMEET. Your magazine and your drug guide have done wonders for a lot of the members on the site. Thank you, and if I could assist in another aging edition, I would welcome the opportunity. Keep up the great work!

—**GABRIEL**

LOOK FOR the Spring 2019 special issue of POSITIVELY AWARE on HIV and Aging.

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PHOTO: JOHN GRESS

EDITOR'S NOTE

JEFF BERRY

Hope for the future

> “When I think about it: AIDS could have killed me. It killed so many friends. Instead, it gave me a vocation and made me who I am.”
>
> — Gregg Gonsalves

After a long day at the recent CROI conference in Seattle and following a late dinner, I was walking back to the hotel and struck up a conversation with two young men standing outside of a restaurant (Seattle is kind of cool that way). Zach and Rusty, who were both probably in their late twenties, asked what I was in town for, and I explained I was attending as media for the one of the biggest HIV/AIDS research conferences in the world, which is held every year in the U.S., usually in Seattle or Boston. Researchers from all over the globe come to present and share their latest findings on HIV and AIDS and related conditions.

At some point the conversation veered toward PrEP, as much of the news coming out of the conference was about advances in prevention. Zach said that he and his girlfriend have talked about HIV and what measures they could take to protect themselves. It was all very nonchalant and matter of fact, and I was extremely heartened by the fact that both Zach and Rusty had a certain level of ease in talking about what, for many, can be a very difficult or awkward conversation. As I turned to leave I said something hokey like “you both give me hope for the future,” but I meant it. Sometimes the messages do break through all the noise, and get distilled down to those who need it most.

In this issue we take a look at some of those who need the information most, and some who are taking their message to the streets, and even to Capitol Hill. According to the CDC, in 2017, youth aged 13 to 24 made up 21% (8,164) of the 38,739 new HIV diagnoses in the United States. Youth with HIV are the least likely of any age group to be linked to care in a timely manner or have a suppressed viral load (undetectable). Addressing HIV in young people will require they have access to information and tools they need to reduce their vulnerability, make healthy decisions, and get treatment and care if they have HIV.

A recent blog post by defeatHIV community advisory board member and AIDS 2020 conference coordinating committee youth representative Manuel Venegas says it best. “More questions than answers remain in the global fight against HIV and AIDS. However, one idea brings consensus from researchers, clinicians, and advocates alike: while young people pose a tremendous challenge in the epidemic, they also offer our greatest opportunity for ending it. When equipped with the right information, skills and tools, adolescents and other young people are uniquely capable of halting the epidemic's progress in its tracks.”

I was extremely heartened by the fact that both Zach and Rusty had a certain level of ease in talking about what, for many, can be a very difficult or awkward conversation.

Which brings me back to Gregg's quote at the top of this page, which was taken from The *New York Times*' “A Conversation With...Gregg Gonsalves Blends Activism and Science.” A leading member of ACT UP who went on to help co-found Treatment Action Group (TAG) and other organizations, Gregg, a recent MacArthur genius award grantee, went back to school at age 44 to get a degree from Yale in epidemiology. “I wanted to gain skills to be more effective. I had worked as an organizer around AIDS issues for almost 30 years and had come to feel that activism alone wasn't enough. I wanted to marry activism to science.” He's now “training a new generation of researchers who, like himself, work across public health and human rights sectors, scholarly research, and activism to correct disparities in global public health.”

In this issue, you'll read about some of the new warriors, including four young women of color who are making a difference in the lives of others, while keeping it real. Service providers themselves grounded in the epidemic who are helping homeless youth. A young man on the road from homelessness to advocacy. A pediatrician looking back and reflecting on 30 years of treating young people living with HIV. And two individuals who are on the front lines, implementing an innovative new program in Chicago for older adults living with HIV.

These are just some of the true heroes in the epidemic, and they all give me hope for the future.

Take care of yourself, and each other.

@PAeditor

ENID VÁZQUEZ @ENIDVAZQUEZPA

BRIEFLY

New two-drug regimen gets FDA approval

The FDA on April 8 approved Dovato, a two-drugs-in-one complete HIV medication regimen. Dual drugs are causing excitement for cutting down the potential for side effects. HIV therapy has been dominated by triple therapy, even if taken as only one pill.

Two years ago, Juluca became the first dual drug single-tablet regimen (STR) on the market. Like Juluca, Dovato contains dolutegravir, an integrase strand transfer inhibitor (INSTI). Unlike Juluca, Dovato is recommended for people taking therapy for the first time. The INSTI medications (except Juluca) are all approved by U.S. HIV treatment guidelines for most people taking antiviral therapy for the first time. The dolutegravir in Dovato is combined with 3TC (or lamivudine), an extremely tolerable HIV drug that's been in use for more than 25 years. Side effects occurring in at least 2% of study participants receiving Dovato included headache, nausea, diarrhea, insomnia, fatigue, and dizziness. Psychiatric disorders have been found with INSTIs. Some individuals (less than 1% of all participants) discontinued study drug for this reason. At this point, a pregnancy test for individuals of childbearing potential is recommended before taking dolutegravir. This is due to a report of a very rare birth defect seen in infants born to mothers who took dolutegravir around the time of conception. More information from that study in Botswana is expected this year. See the Dovato page in POSITIVELY AWARE's HIV Drug Guide at positivelyaware.com.

HIV drug fights inflammation

Brown University reported that generic lamivudine, an HIV medication with practically no side effects, reduced age-related inflammation in old mice. "This holds promise for treating age-associated disorders including Alzheimer's," said John Sedivy, professor of medical science and biology at Brown University, in a press release. "And not just Alzheimer's but many other diseases: Type 2 diabetes, Parkinson's, macular degeneration, arthritis, all of these different things. That's our goal." Age-related inflammation is an important component of age-associated disorders, according to the release. Inflammation, basically a process by which the body breaks down, has long been associated with HIV. Treatment is one way to control that inflammation. The study was published in the February 7 issue of *Nature*.

AIDS United: Protect Medicare Part D

In light of the White House's call to end the HIV epidemic in the United States by 2030, AIDS United responded by urging the federal government to withdraw its proposed Medicare Part D rule.

The proposal would restrict access to HIV medicines, AIDS United reported.

"The six protected classes of Medicare Part D were created to ensure people with serious medical conditions whose health would be severely impacted by any treatment interruption, like HIV and epilepsy, could access the best medicines as prescribed by their doctor," AIDS United said in a press release. "These protections have helped millions and contributed to the significant reductions in new HIV diagnoses across the country. Without the protections afforded to these drugs, insurance companies could potentially interfere in treatment decisions and restrict access to life-saving medications for the more than 250,000 people living with HIV who are currently enrolled in Medicare."

The national advocacy organization created a series of ads urging the government to rescind its proposal. Go to aidsunited.org.

Latino Commission on AIDS: Stigma and transphobia

For the Seventh Annual Latino Health Action Day, held February 26 in New York City, the Latino Commission on AIDS conducted two panel discussions on the effects of stigma, homophobia, transphobia, and xenophobia (fear or hatred of people from other countries).

"After listening to both panels, it's understood that we have much work to do on addressing stigma in our

communities,” said Guillermo Chacón, president of the commission and founder of the Hispanic Health Network, in a press release. “We need to facilitate conversations around many forms of stigma that include HIV status or perceived HIV status, homophobia, transphobia, race/ethnicity, and xenophobia that impact health care access in our communities.”

La Comisión Latina sobre el SIDA: El estigma y el transfobia

Para el Séptimo Día Annual Latino de Acción por la Salud, el 26 de febrero en Nueva York, la Comisión Latina sobre el SIDA presentó dos paneles sobre los efectos del estigma, transfobía, y xenofobia (el miedo o odio a las personas de otros países).

“Después de escuchar ambos paneles, se entiende que **tenemos mucho trabajo que hacer para abordar el estigma en nuestras comunidades**,” declaró Guillermo Chacón, presidente de la Comisión y fundador de la Red de Salud Hispana, en un comunicado del prensa. “Necesitamos conversaciones facilitadas sobre las muchas formas de estigma que incluyen el estado de VIH o estado de VIH percibido, homofobia, transfobia, raza/etnia, y xenofobia que afectan el acceso a la atención médica en nuestras comunidades.”

LGBT elders at inaugural advocacy lobbying day

SAGE, the country’s largest and oldest organization dedicated to LGBT elders, held its first-ever National Day of Advocacy on Capitol Hill, on March 13.

More than 120 SAGE constituents and staff nationwide, from 20 states and Puerto Rico, met with dozens of members of Congress and their staffs, telling their stories and advocating for rights for LGBT elders.

“On top of a tremendously successful National Day of Advocacy, when we joined forces with hundreds of our LGBT pioneers, we also celebrated the introduction of game-changing legislation that will have a major impact on LGBT elders and those living with HIV for years to come,” said SAGE CEO Michael Adams, in a press release. “Through the National Day of Advocacy and SAGE’s ‘Still Out in Front: 50 Years of Pride’ campaign, we will continue to fight to better protect our community’s trailblazers.”

The proposed legislation, known as the Ruthie and Connie LGBT Elder Americans Act, “would ensure that LGBT elders and older people living with HIV have improved access to aging services and supports the Older Americans Act, the country’s largest vehicle for funding and delivering services to older people in the U.S.” It was re-introduced on March 14 by U.S. Representative Suzanne Bonamici and her colleagues Ted Deutch and Charlie Crist.

Ruthie Berman, namesake of the bill, told the audience, “I am beyond proud tonight to be here in this room with SAGE, and leaders in my government. I didn’t come out until I was 40, when I fell in love with Connie. I wish you all the relationship that I had with my beloved Connie. It is extraordinary to come to this point and know that there’s still work to be done. SAGE, you are holding up this country, with the work that you do.”


PÉREZ

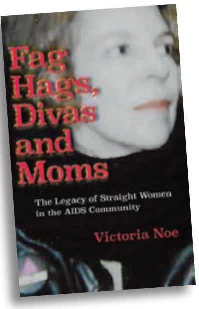
SAGE has launched an online advocacy campaign, generating letters to members of Congress. The organization encourages people to participate by sending letters to their representatives at sageusa.org/still-out.

Transgender filmmaker debuts new documentary

For International Transgender Day of Visibility, March 31, the global streaming network Revry premiered the documentary series *America in Transition*. Transgender filmmaker, educator, and community organizer André Pérez founded the Trans Oral History Project in 2008, motivated by his own sense of isolation growing up in a military family in Virginia. **The series includes a veteran turned activist, an immigrant seeking a home, a woman living with HIV healing from trauma, and a model navigating family life.** “I had questions about everything from health care access to navigating relationships, but I had no one to ask,” said Pérez about growing up. “Without role models or institutional support, I felt like I had to come to the city to find myself.” Go to Revry.tv for more, including community partnerships around the country.

New book celebrates women in the AIDS crisis

HIV activist and writer Victoria Noe has a new book, looking at women who made a difference in the AIDS epidemic. According to a press release, *Fag Hags, Divas and Moms: The Legacy of Straight Women in the AIDS Community*, “shines a light on the courage, defiance, and compassion displayed by heterosexual women who came forth when the AIDS epidemic of the 1980s and ’90s was decimating both the gay community and communities of color across America.” **The book covers both famous and not-so-famous women.** Noe, a longtime author and veteran member of Chicago’s HIV community, said she found that most books on the epidemic were written by white men. She wanted to write something specifically about women’s role in the epidemic as they dealt with ignorance and ridicule.



Project Inform closes

One of the first reliable—and free—sources of information about HIV and hepatitis C has folded

Project Inform, the prominent national organization advocating for HIV and hepatitis C care and services, closed its doors in March.

"We wish to honor and celebrate nearly 35 years of service to people living with and at risk for HIV and a decade-plus service to people at risk for or living with hepatitis C," the staff said in a statement. "Despite the continued success and evolution of our work in HIV and HCV—two of the most stigmatizing diseases in the United States—we have not been able to successfully navigate the current funding environment. We've been proud to work with colleagues who are among the most creative, strategic, committed, and passionate advocates, providers, educators, and decision-makers in the country. We're also deeply grateful to the funders and donors who have so generously supported Project Inform through the years."

Among its efforts, the San Francisco-based agency produced the annual Hepatitis Drug Guide published each year in the July + August issue of POSITIVELY AWARE, and went above and beyond in helping to produce this essential comprehensive resource. Project Inform and its Hepatitis C Education Manager, Andrew Reynolds, simply approached the magazine to collaborate on a similar version of POSITIVELY AWARE's annual HIV Drug Guide.

"When Martin Delaney and Joe Brewer founded Project Inform in 1984, they couldn't have imagined the great changes that would grow out of their urgent desire for people with HIV to be able to take charge of their own health and work toward better health for their peers," the statement continued.

"Thirty-five years hence, life with HIV is counted in decades rather than weeks or months and HIV can't be transmitted when viral suppression is achieved. As well, people wishing to protect themselves from HIV transmission have an additional powerful tool, pre-exposure prophylaxis (PrEP). Hepatitis C is curable and people who use drugs may soon have greater access to services that will keep them alive.

PROJECT INFORM CO-FOUNDER, THE LATE MARTIN DELANEY

"Above all, the millions of pieces of print and electronic publications we've offered people freely, the videos we've disseminated, and the thousands of hours spent counseling individuals on the phone or by chat have helped ensure that people know about these facts and can use them to positively impact their own lives and the lives of the people they love or provide care for," the staff said.

The dedicated and brilliant staff members, including David Evans and Anne Donnelly, will continue to work on behalf of people living with HIV and hepatitis C in new endeavors.

Judge says airmen who are living with HIV can remain in service—for now

Efforts by the U.S. Air Force to discharge two active duty airmen because of their HIV status have been halted for now. U.S. District Judge Leonie Brinkema issued a preliminary injunction, saying that the **Air Force's treatment of personnel who are HIV-positive was "irrational, inconsistent, and at variance with modern science."**

The airmen's case, *Roe and Voe v. Shanahan*, was taken up by Lambda Legal and OutServe-SLDN. Although it applies only to 22 airmen who are HIV-positive, and not to personnel in other branches of the military, Scott Schoettes, Lambda Legal's HIV project director, says that the case could eventually have larger implications for HIV discrimination in the workplace.

For combat reasons, the military is exempted from the Americans with Disabilities Act. However, says Schoettes, one of the arguments in this case is that the Pentagon can't arbitrarily discriminate against one group of people or another.

"The U.S. military is the largest employer in the world," says Schoettes. "When you're suing that entity, you have the potential to make change on a large scope. The next frontier is employment discrimination—it's already been determined there's no risk in food preparation, working for Cirque du Soleil, or as a first responder living with HIV. If you can do the job of soldier, you can do any job without any risk to others."

The judge's ruling was issued in February; while no trial date has yet been set, the case is expected to go to court late this summer or early fall. —**RICK GUASCO**

TRANSPLANTING HOPE: 'I don't want to be anyone's hero. I want to be someone's example, someone's reason to consider donating,' says Nina Martinez

MARTINEZ: SARAH MARIE MAYO

First kidney transplant from a donor living with HIV

Nina Martinez became the world's first HIV-positive to HIV-positive living kidney donor, following a successful transplant of one of her kidneys to a recipient. According to a press release, a multidisciplinary team from Johns Hopkins Medicine completed the living donor HIV-to-HIV kidney transplant on March 25. The doctors say both the donor and the recipient are doing well. During a press conference following the surgery, Nina, who wrote about her journey to becoming a living donor in POSITIVELY AWARE's January + February issue ("Where There's HOPE"), said that one of the unexpected things that came out of the whole experience was that they discovered she had a kidney stone, although it was not enough of an issue to cause concern for the transplantation.

"Some people believe that people living with HIV are 'sick,' or look unwell," says Martinez. "For me, I knew I was in good health. **HIV was no longer a legal barrier to organ donation**, and I never considered HIV to be a medical barrier either. As a policy advocate, I want people to change what they believe they know about HIV. I don't want to be anyone's hero. I want to be someone's example, someone's reason to consider donating."

People living with HIV haven't been able to donate kidneys until now, because there were worries that HIV was too much of a risk factor for kidney disease in the donor. However, Dorry Segev, MD, PhD, professor of surgery at the Johns Hopkins University School of Medicine, and colleagues' recent research on over 40,000 people living with HIV showed that the new antiretroviral drugs are safe for the kidney, and that those with well-controlled HIV have basically the same risks as those without HIV and are healthy enough to donate kidneys.

"This is the first time someone living with HIV has been allowed to donate a kidney, ever, in the world, and that's huge," says Segev. "A disease that was a death sentence in the 1980s has become one so well-controlled that those living with HIV can now save lives with kidney donation—that's incredible." —**JEFF BERRY**

BRIEFLY

ABOVE: Several local and national dignitaries and celebrities joined in cutting the ribbon in front of the Anita May Rosenstein Campus (from left to right): Congressman Adam Schiff; Los Angeles Mayor Eric Garcetti; Los Angeles LGBT Center CEO Lorri L. Jean; lead donor Anita May Rosenstein; David Bailey, capital campaign Chair and co-chair of the Center's board of directors; Los Angeles County Supervisor Sheila Kuehl; philanthropist Ariadne Getty; Los Angeles councilmember David Ryu; and entertainers Lily Tomlin and Kathy Griffin.

Los Angeles LGBT Center opens intergenerational facility

Conceived more than a decade ago, the Los Angeles LGBT Center opened its two-acre Anita May Rosenstein Campus in April. The $141 million, 180,000-square-foot facility will offer housing and social services for youth and seniors in an intergenerational setting.

The new building houses 100 beds for homeless youth, a youth drop-in center, the Ariadne Getty Youth Academy, and a senior community center, and will also serve as the Center's administrative headquarters. The Center is compromised of buildings at several locations in Los Angeles and Hollywood; the current headquarters, at the four-story McDonald/Wright Building, will be transformed entirely into a health center. Plans for the new campus call for 99 units of affordable senior housing and 25 supportive housing apartments for youth to open by mid-2020.

"Let's be clear: this is not my campus, it's our campus," said lead donor Anita May Rosenstein. "Our campus is a beacon of hope and inspiration for people around the world. It is a safe haven for youth experiencing homelessness, and it will become a unique experience for youth and seniors to live together and learn from each other."

The opening of the new campus was celebrated with a day-long block party, and comes as the Los Angeles LGBT Center marks its 50th anniversary. With nearly 700 employees, it is the largest LGBT social services organization in the world. For more information, go to lalgbtcenter.org. —**RICK GUASCO**

PHOTOS COURTESY OF THE LOS ANGELES LGBT CENTER

In the Clinic

All my transgender youth living with HIV acquired it at less than 15 years old by a man 20 years and older. Even the cisgender girls acquired HIV from an older man. My newest patient is a 14-year-old male. His initial description of his situation is that he was in love. But the man was 35 years old. That's not a choice. That man is a pedophile.

—**Laura Hoyt, MD**, of Children's Hospitals and Clinics of Minnesota, is an Assistant Professor of Pediatrics at the University of Minnesota Medical School. She spoke to the speakers at the CROI 2019 symposium "Girls and Boys Just Want to Have Fun: Making Prevention Desirable for Youth." See the symposium at croiconference.org.

SHARE your clinical and medical insights with POSITIVELY AWARE for our *In the Clinic* feature. Send to e.vazquez@tpan.com.

HOYT: ENID VÁZQUEZ

Ask your doctor about once-daily ISENTRESS HD.

What is ISENTRESS HD?

ISENTRESS HD is a prescription HIV medicine used with other antiretroviral medicines to treat human immunodeficiency virus-1 (HIV-1) infection in adults, and in children weighing at least 88 pounds (40 kg). HIV is the virus that causes AIDS (Acquired Immune Deficiency Syndrome).

Important Safety Information

Some people who take ISENTRESS HD develop serious skin reactions and allergic reactions that can be severe, and may be life-threatening or lead to death. If you develop a rash, call your doctor right away. If you develop a rash with any of the following symptoms, stop using ISENTRESS HD and call your doctor or get medical help right away: fever; generally ill feeling; extreme tiredness, muscle or joint aches; blisters or sores in mouth; blisters or peeling of skin; redness or swelling of the eyes; swelling of the mouth, lips, or face; problems breathing.

Sometimes allergic reactions can affect body organs, such as your liver. Call your doctor right away if you have any of the following signs or symptoms of liver problems: yellowing of your skin or whites of your eyes; dark or tea-colored urine; pale-colored stools (bowel movements); nausea or vomiting; loss of appetite; pain, aching, or tenderness on the right side of your stomach area.

Changes in your immune system (Immune Reconstitution Syndrome) can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your doctor right away if you start having new symptoms after starting your HIV-1 medicine.

People taking ISENTRESS HD may still develop infections or other conditions associated with HIV-1 infections.

The most common side effects of ISENTRESS HD include: trouble sleeping, headache, dizziness, nausea, and tiredness. Less common side effects include: depression, hepatitis, genital herpes, herpes zoster including shingles, kidney failure, kidney stones, indigestion or stomach area pain, vomiting, suicidal thoughts and actions, and weakness.

Tell your doctor before you take ISENTRESS HD if you have a history of a muscle disorder called rhabdomyolysis or myopathy or increased levels of creatine kinase in your blood.

Tell your doctor right away if you get unexplained muscle pain, tenderness, or weakness while taking ISENTRESS HD. These may be signs of a rare serious muscle problem that can lead to kidney problems.

These are not all the possible side effects of ISENTRESS HD. For more information, ask your doctor or pharmacist. Tell your doctor if you have any side effect that bothers you or that does not go away.

Tell your doctor about all your medical conditions, including if you have any allergies, are pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed. **Do not breastfeed if you take ISENTRESS HD.** Women with HIV should not breastfeed because their babies could be infected with HIV-1 through their breast milk.

Tell your doctor about all the medicines you take, including, prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines interact with ISENTRESS HD. Do not start taking a new medicine without telling your doctor. Your doctor can tell you if it is safe to take ISENTRESS HD with those other medicines.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call FDA at 1-800-FDA-1088.

Please read the adjacent Patient Information for ISENTRESS HD and discuss it with your healthcare provider.

Talk to your doctor about ISENTRESS HD and visit **isentress.com**

Having trouble paying for your Merck medicine? Merck may be able to help. **www.merckhelps.com**

MERCK INFC-1218547-0007 11/18

Patient Information
ISENTRESS® HD (eye **sen** tris **HD**) (raltegravir) film-coated tablets

Read this Patient Information before you start taking ISENTRESS HD and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is ISENTRESS HD?

ISENTRESS HD is a prescription HIV medicine used with other antiretroviral medicines to treat Human Immunodeficiency Virus-1 (HIV-1) infection in adults, and in children weighing at least 88 pounds (40 kg). HIV is the virus that causes AIDS (Acquired Immune Deficiency Syndrome).

Before you take ISENTRESS HD, tell your doctor about all of your medical conditions, including if you:

- have liver problems
- have a history of a muscle disorder called rhabdomyolysis or myopathy
- have increased levels of creatine kinase in your blood
- receive kidney dialysis treatment
- are pregnant or plan to become pregnant. It is not known if ISENTRESS HD can harm your unborn baby.

Pregnancy Registry: There is a pregnancy registry for women who take antiretroviral medicines during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk to your doctor about how you can take part in this registry.

- are breastfeeding or plan to breastfeed. Do not breastfeed if you take ISENTRESS HD.
  - You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.
  - It is not known if ISENTRESS HD can pass into your breast milk.
  - Talk with your doctor about the best way to feed your baby.

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines interact with ISENTRESS HD.

- **Keep a list of your medicines to show your doctor and pharmacist.**
- You can ask your doctor or pharmacist for a list of medicines that interact with ISENTRESS HD.
- **Do not start taking a new medicine without telling your doctor.** Your doctor can tell you if it is safe to take ISENTRESS HD with other medicines.

How should I take ISENTRESS HD?

- Take ISENTRESS HD exactly as prescribed by your doctor.
- **Do not** change your dose of ISENTRESS HD or stop your treatment without talking with your doctor first.
- Stay under the care of your doctor during treatment with ISENTRESS HD.
- ISENTRESS HD film-coated tablets **must be swallowed whole.**
- **Do not switch between the film-coated tablet, the chewable tablet, or the oral suspension without talking with your doctor first.**
- **Do not** switch between the ISENTRESS® (raltegravir) 400 mg film-coated tablet and the ISENTRESS HD 600 mg film-coated tablet if your prescribed dose is 1200 mg.
- **Do not** run out of ISENTRESS HD. The virus in your blood may increase and the virus may become harder to treat. Get a refill of your ISENTRESS HD from your doctor or pharmacy before you run out.
- Take ISENTRESS HD on a regular dosing schedule as instructed by your doctor. Do not miss doses.
- If you take too much ISENTRESS HD, call your doctor or go to the nearest hospital emergency room right away.

What are the possible side effects of ISENTRESS HD?

ISENTRESS HD can cause serious side effects including:

- **Severe skin reactions and allergic reactions.** Some people who take ISENTRESS HD develop severe skin reactions and allergic reactions that can be serious, and may be life-threatening or lead to death. If you develop a rash call your doctor right away. If you develop a rash with any of the following symptoms, stop using ISENTRESS HD and call your doctor or get medical help right away:
  - fever
  - generally ill feeling
  - extreme tiredness
  - muscle or joint aches
  - blisters or sores in mouth
  - blisters or peeling of the skin
  - redness or swelling of the eyes
  - swelling of the mouth, lips, or face
  - problems breathing

Sometimes allergic reactions can affect body organs, such as your liver. Call your doctor right away if you have any of the following signs or symptoms of liver problems:

  - yellowing of your skin or whites of your eyes
  - dark or tea colored urine
  - pale colored stools (bowel movements)
  - nausea or vomiting
  - loss of appetite
  - pain, aching, or tenderness on the right side of your stomach area

- **Changes in your immune system (Immune Reconstitution Syndrome)** can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your doctor right away if you start having new symptoms after starting your HIV-1 medicine.

The most common side effects of ISENTRESS HD include: trouble sleeping, headache, dizziness, nausea, and tiredness.

Less common side effects of ISENTRESS HD include: depression, hepatitis, genital herpes, herpes zoster including shingles, kidney failure, kidney stones, indigestion or stomach area pain, vomiting, suicidal thoughts and actions, and weakness.

Tell your doctor right away if you get unexplained muscle pain, tenderness, or weakness during treatment with ISENTRESS HD. These may be signs of a rare serious muscle problem that can lead to kidney problems.

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of ISENTRESS HD. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store ISENTRESS HD?

- Store ISENTRESS HD film-coated tablets at room temperature between 68°F to 77°F (20°C to 25°C).
- Store ISENTRESS HD film-coated tablets in the original package with the bottle tightly closed.
- Keep the drying agent (desiccant) in the ISENTRESS HD bottle to protect from moisture.

Keep ISENTRESS HD and all medicines out of the reach of children.

General information about the safe and effective use of ISENTRESS HD

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information Leaflet.

Do not use ISENTRESS HD for a condition for which it was not prescribed. Do not give ISENTRESS HD to other people, even if they have the same symptoms you have. It may harm them. You can ask your doctor or pharmacist for information about ISENTRESS HD that is written for health professionals.

For more information go to www.isentress.com or call 1-800-622-4477.

What are the ingredients in ISENTRESS HD?

ISENTRESS HD 600 mg film-coated tablets:

Active ingredient: raltegravir

Inactive ingredients: croscarmellose sodium, hypromellose 2910, magnesium stearate, microcrystalline cellulose.

The film coating contains: ferrosoferric oxide, hypromellose 2910, iron oxide yellow, lactose monohydrate, triacetin and titanium dioxide.

The tablet may also contain trace amount of carnauba wax.

usppi-mk0518-mf-1711r028
Revised 11/2017

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MERCK

SOCIAL JUSTICE **SHEROES**

United in love, support, and power

BY **OLIVIA G. FORD**

MASONIA TRAYLOR AT THE CENTER FOR CIVIL AND HUMAN RIGHTS MUSEUM IN ATLANTA.

PHOTO: PRECIOUS T PHOTOGRAPHY

My sweethearts... My loves... Boo... Bae... Elders... Legends... Heroes. The genuine affection this group of new advocates has for each other, and for the women whose work has paved their way, is clear in the language they use to refer to one another. Forged at community conferences and grown on social media, their connections run deeper than shared HIV status alone. To them, the HIV community is a family—and they each have their own distinctive ways of fighting for their family's health and freedom. Get to know them and their work; chances are you will be hearing about them for a while.

LaDawn Tate

DETROIT, MICHIGAN

LaDawn Tate has never been one to stay quiet. "HIV is not the only thing that has happened to me in my life," explained the 37-year-old mother of two, "and I've always been open." It's natural for LaDawn to be available to others to lean on, and learn from, during challenging times. When it came to her HIV diagnosis in 2012, she wanted to do the same.

"I acquired HIV and wasn't offered a test because I didn't fit a demographic," she said. "How many other people don't know that they need to ask?" LaDawn was eager to spread the word that anyone could

‘You can just see her

LaDawn Tate

acquire HIV—and live, laugh, and love following their diagnosis. But her partner at the time discouraged her from speaking up, for fear that people would guess his HIV status if they knew hers. She kept silent out of respect for him. “I told him, ‘I feel like I’m not being myself, not being able to talk about this,’” she recalled.

Once the two went their separate ways, LaDawn was free to jump into advocacy. She began sharing her story on social media; she also became part of the Southeastern Michigan HIV/AIDS Council (SEMHAC), after meeting Evelyn Postell-Franklin, one of SEMHAC’s co-chairs and a longtime advocate, at a support group. “Even when she first met me she was like, ‘I see so much for you!’” LaDawn remembered. “I call her the mother of all of us. ...Some of these [programs] that we are part of now, she helped form.”

Postell-Franklin would encourage LaDawn to attend events and sit in on meetings to expand her knowledge. “It was just a pleasure to meet somebody like LaDawn who had all this life and spunk and spark and excitement in her,” she said. LaDawn soon moved into her current role as a linkage to care specialist at UNIFIED, a regional multi-service center. “UNIFIED has given me wonderful opportunities to be on the news, in the newspaper ... places I could never imagine being,” said LaDawn. She has connected and shared resources with other advocates at national gatherings, and engaged in federal advocacy as part of Positive Women’s Network-USA (PWN)’s Policy Fellows program.

She is raising two advocates, as well: Her older son, who is hearing impaired, shares HIV information with his friends in sign language. Her youngest, who just turned 12, corrects teachers who get things wrong about HIV and has become an ally to LGBTQ kids in his middle school. “He’s like, ‘Mom, you taught us not to judge people,’” LaDawn said with pride. “He is not afraid to stand up for you!”

LaDawn talked about being honored to meet and get to know women like Postell-Franklin who have been involved in HIV advocacy for decades. “[They paved the] way for us ,” she said, “we’re just putting a newer spin on it.” In her local area, LaDawn’s unique “spin” has not always been received warmly. “[Older advocates were] like, ‘This girl is wild ... Sexy and HIV don’t go together!’” she remembered. “We had to get to know each other.” Said LaDawn of Postell-Franklin: “She helped people understand me.”

To Postell-Franklin, telling LaDawn and others to simmer down was “a way to keep a lot of our voices muted. I just didn’t want to be a part of that.

“You can just see her beginning to shine; she is really becoming a polished advocate for women in our community,” Postell-Franklin observed. “To bring another one on is a blessing; and honestly, I would like some rest!”

As a linkage to care specialist, one of the key messages LaDawn uses to support her clients’ staying connected to care is U=U: the simple, powerful fact that a person with HIV and an undetectable viral load is unable to transmit HIV through sex. She also names U=U as one of the biggest differences between her generation and that of her mentors. “When you do get diagnosed, and you go through the tears, that’s the next thing you learn: the good outcome,” she said. “That’s what did it for our generation.

“For them not to have that, I can imagine the stigma that they went through. I can understand why they looked at me like, ‘Sexy and HIV in the same sentence?!’

“They were watching their friends die, and we’re helping our friends continue to live.”

Tiffany Marrero

OCALA, FLORIDA

Tiffany Marrero has a way with words that will keep you laughing, but make no mistake: She is serious about pleasure and healing.

“HIV is urgent, but I don’t see the point in us working until burnout,” she said. “When we get to zero, what are we gonna do? Funding gets pulled, the lights go out, and we’re all sitting there with our peer navigation certificates.

“When all this is over [we’ll ask ourselves]: Did you even get to cash in any of that PTO [personal time off]? Did you even get to go home for the holidays? Do you even have sex? ... You got T cells just sitting there!”

A huge concern for Tiffany, in nearly two years in the HIV advocacy community, has been whether HIV advocates are enjoying the lives that they are fighting for. For Tiffany, the goal is liberation, and pleasure must be part of it.

The 2017 U.S. Conference on AIDS (USCA) in Washington, D.C., was a watershed moment for Tiffany. After living with HIV all her life, it was her first conference. One of the providers at the clinic she attends had encouraged her to apply for USCA’s Youth Initiative Scholars program.

“I was having a really difficult time, and I think a lot of my clinic people could see that,” she remembered. “I was a grown woman who didn’t know how to date or make friends or keep relationships ...or cope with my diagnosis, or with life in general. It was kind of boiling over.”

She had gone to college for social work; while in school, “all my topics were on HIV and I kept on flunking all of them. ... I was afraid that if I acted too passionately or I was too correct that they could tell.”

When she stepped into the conference hotel, her life shifted.

“Picture dropping a goldfish back in the water after taking it out,” she said. She was surrounded by mostly black and brown people who embraced, challenged, and believed in her. “Being around people who understand trauma or are trying to work through trauma is such a soothing, peaceful space to be in,” she commented. “After that, I was hooked.”

Tiffany attended numerous events that first year; the following year, when the same opportunities presented themselves, she encouraged other young advocates to apply. “Other folks need that kind of space, too.”

Tiffany refers to the legion of older black women advocates with whom she

beginning to shine; she is really becoming a polished advocate for women in our community.’

has connected as her “Board.” “They keep me from getting arrested by accident at these conferences,” she joked. She also spoke of how proud she is to know them; and they reflect back to her the immense value of what she brings to the community around her.

“Tiffany affirms everything and everybody,” said Kamaria Laffrey, who facilitated the 2017 Youth Initiative Scholars program. In her characteristic exuberant way, Tiffany informed Laffrey that she was going to be Tiffany’s mentor. Laffrey couldn’t have been happier.

“She is so bold, and brave, and completely unapologetic in being herself,” Laffrey said. “She knows the world that she wants to live in; she already operates in the change she is looking for.”

In Tiffany’s world, black and brown advocates living with HIV do not just work hard, but also celebrate that work by enjoying more leisure, more fun, and yes, more sex. Tiffany rarely misses an opportunity to point out connections between pleasure, healing, sex, and liberation.

“I think sex is so big that we downplay it ...sexuality overall, and how powerful it is,” Tiffany said. “When are we [as advocates] going to sit down and decide: What is our stance on sex and sexuality? Are we going to accept that we love sex?”

On social media, at speaking engagements, and in her writings for TheBody.com, she is very open about enjoying as much sex as possible. She is also not naïve about the potential consequences of such a stance in a society that criminalizes the sexuality of people with HIV, sharing in a May 2018 opinion piece that she makes her sex partners sign a form indicating that she disclosed.

“That’s a conversation that I feel we don’t have openly,” Laffrey added. “We may have our little groups where we meet up and huddle and talk about what we enjoy, but I don’t feel there is a platform of sexual freedom when it comes to living with HIV.”


TIFFANY MARRERO

“If we’re not talking out loud about our scars and the shit that we go through, we are never going to heal.” Tiffany is all about bringing about a culture shift in which black and brown advocates are more open about their pleasure as well as their struggles—and she models that shift in herself. “I have people hit me up all the time and say ‘I really love that you’re so blunt,’ ” she said. “It’s not that I’m blunt; I just don’t put on the ‘white filters’ anymore”—referring to the ways people of color are often expected to avoid topics like race for the sake of white people’s comfort.

“If that disrupts someone’s day, I’m sorry; but that’s not why I take these pills every day. That’s not why I survived an epidemic.”

Masonia Traylor

ATLANTA, GEORGIA

“I am young-*ish*; I am not young,” said Masonia Traylor, now 32. She sometimes feels sandwiched between generations: older than those engaged with youth programs she championed, and younger than many others who have been involved as much as she has since becoming an HIV advocate—which, it is easy to forget, was only seven years ago. She was diagnosed with HIV at age 23 when, after requesting an HIV test religiously each year since high school, her results came back positive.

Masonia had envisioned becoming an advocate, though she never thought it would be because she herself was living with a health condition. A pharmacy technician by trade, she had compassion for her clients living with HIV; after her diagnosis in 2010, she felt compelled to share her own status. She tentatively found ways to connect: “I would disclose to them by saying that I take the same medications they do,” she remembered.

Then, in early 2012, she found out via Facebook that a longtime school friend who was living with HIV had passed away. “If he had known that he wasn’t in it by himself, maybe he would still be living.”

Masonia began researching HIV, and learned of the high rates of HIV in Atlanta and across the South.

“Everyone was either complacent about it, or at a standstill where their only approach was ‘Let’s get tested,’ and medicine,” she noticed. “Many of us in the community don’t realize the reason they are testing is because there’s a high rate in those areas.”

By March of that year, Masonia had her first speaking engagement, at Spelman College, and told the first of numerous rooms full of young people that she was living with HIV. She decided to start speaking up because “I would rather others be uncomfortable because I am public with my status than for them to ever make me feel ashamed and uncomfortable with it.”

She also began attending Ryan White Planning Council meetings, and got involved in her state’s planning group. Her reach eventually expanded to national advocacy. She was often the only young person, or the only mother, or the only person living with HIV, in rooms where decisions were being made that would impact the lives of those like her.

“I would listen to what was *not* being said that, if I said it, my friends who would never sit in these rooms would feel the change and be impacted by it.” She would point out gaps and make recommendations based on her experience as a young person living with HIV—and a mom who had gone through prenatal care and given birth

‘I have a lot of different mentors for different things, depending on what people are good at.’

to an HIV-negative daughter. “Whatever was lacking for me that I could not find, I would speak up on those things,” she said.

By her side along the way has been Christopher Ervin, whom she met through a peer counselor. He urged her to take that first speaking engagement at Spelman—at an event he planned while working at Aniz, Inc., serving women living with HIV. Ervin has been her mentor ever since.

“I have always tried to couch all the work she has done centered around the person she is and what she wants to do, and she just happens to be HIV-positive—instead of all her work being because she is HIV-positive,” Ervin said.

“I have a lot of different mentors for different things, depending on what people are good at,” Masonia said. “This mentor guides me like a parent in the direction I am trying to go.”

Nowadays, that direction is toward fostering ongoing support for women regardless of HIV status. She facilitates a private online support group for U.S. women of color living with HIV, and envisions building what she calls “She’s Positive Network,” a sisterhood of women of any HIV status who pledge to support women living with HIV.

“Most of my friends are HIV-negative; they support me and they tear down stigma all the time,” she said. One goal of the network is to cultivate that support on a larger scale, and connect women who are doing it. She and others have already begun using the hashtag #shespositive to tag acts of advocacy on behalf of women living with HIV.

“The thing that I’m enjoying most is seeing her, whether she realizes or not, starting to mentor other people,” Ervin commented.

Masonia is intent on learning from the success, or failure, of other initiatives. For her, there is a gap that needs to be bridged, where newer and more seasoned advocates share what has worked in advocacy and community organizing, and what has not. As Masonia puts it: “We don’t know what they don’t know.”

Wanona (‘Nunu’) Thomas

ATLANTA, GEORGIA
(VIA MILWAUKEE, WISCONSIN)

Living in your truth is Wanona Thomas’ guiding principle. It is the name of the business she is building as a certified life coach and motivational speaker—the Live in Your Truth Foundation (LIYT). Impactful moments that Wanona shares on social media are punctuated with the hashtag #LIYT—and LIYT’s work is not limited to people living with HIV.

“HIV is just one of the truths,” Wanona said. “It could be homelessness, or single motherhood ...I just want people to learn how to embrace the situations that they endure in life.”

When Wanona shared her HIV diagnosis openly for the first time, via Facebook Live video, she began her passionate proclamation with, “I’m making this video today to expose my truth.”

“I am just an outspoken individual,” said Wanona, when asked what led her to be public about living with HIV. She was pregnant with her fourth child when she tested positive in November 2016. In August 2017, she went live. She acknowledges that her awareness of HIV at the time was minimal; before she made the video, she felt she was “hiding within.” She also made the video to head off any rumors or negative attitudes about her diagnosis.

The reach of social media has raised the bar on a person’s ability to quickly, widely, and indelibly inform a massive number of community members of their experience. Wanona’s post spread like

MASONIA TRAYLOR

WANONA ‘NUNU’ THOMAS

wildfire, eventually reaching thousands of viewers.

But, as Masonia Traylor noted, “Once you go public, you can’t take it back.” When Wanona made her video, someone tagged Masonia on the live stream, thinking Wanona might need help that Masonia could offer.

“I am not familiar with ‘going viral,’ but I do know the pressures that come along with being public,” Masonia said, alluding to her involvement in media pieces for CNN on cable TV, and in *Time* and *Essence* magazines, among others. “You need all the support that you can get.”

According to Wanona, she has found that support—not only from family and friends, whom she calls out by name and thanks in her video for their unconditional love. In the wake of the video, the HIV community emerged to embrace her.

“Everyone is so welcoming,” she marveled. “I feel really well connected.”

Organizations began reaching out to her to participate in events and campaigns. Wanona and her mother were part of a beautiful visual storytelling campaign, HIV in Real Life (hivinreallife.wisconsin.gov/real-stories/wanona), through the Wisconsin Department of Health Services, in their native Milwaukee. Wanona became part of the Community Advisory Board of The Well Project, an online resource for women living with HIV, connecting with numerous learning opportunities, as well as an international community of women.

“I give The Well Project so much love, support, and credit,” she said. “They took me right under their wings.”

Participating in conferences and trainings helped her become more informed about HIV so that she could educate others, as a speaker as well as an avid social media influencer with more than 50,000 followers. “[That’s] where I’m able to spread the knowledge that I obtain from trainings or conferences or events to those that are a little bit unreachable to organizations,” she explained.

Wanona has also found that support in Masonia, who was surprised when Wanona identified her as a key mentor. In June 2018, Wanona made a leap of faith and moved her family to Atlanta—a city where she had never been, and knew almost no one.

“I wanted a new beginning,” she said of her adventure. “I knew that HIV was high there, and I figured there was a lot of work that I could help with.”

Masonia checks in regularly with Wanona now that she is in town. “As a young African American woman with children ...I wanted to just be there for her in any way that I could,” said Masonia. “I love what she is trying to do; I am hoping that she can make her mark right here in Atlanta.

“Some people look at this [advocacy] arena as being competitive. The way I see it, it’s more like a family.”

FROM LEFT: MASONIA, WANONA, AND LADAWN WITH FELLOW ADVOCATE LESHIA SCOTT AT POSITIVE WOMEN’S NETWORK-USA’S 2018 SPEAK UP! SUMMIT.

TRAYLOR: PRECIOUS T PHOTOGRAPHY • PWN-USA SUMMIT: COURTESY OF MASONIA TRAYLOR

A TALE OF TWO EPIDEMICS

Youth, HIV, and homelessness

BY **MICHELLE SIMEK** PHOTOGRAPHY BY **SEAN BLACK**

‘I’m a soldier. And wish I had more soldiers to work with me.’
—SPENCER

> “I need housing and a job. We can talk about that other stuff, but this is what I need.”
>
> —A CLIENT AT THE YOUTH EMPOWERED SOCIETY (YES) DROP-IN CENTER

Homeless, HIV-positive youth (ages 13–29, for the purposes of this article) have their priorities, which don’t always include self-care and treating their HIV. Some are looking for a safe place to sleep. Some want to be gainfully employed. Some are looking for their next fix. Some are looking for something—anything—to eat. Some are running from an abusive home life. Some just want clean socks.

According to the Centers for Disease Control and Prevention (CDC), 39,782 people were diagnosed with HIV in the U.S. in 2016. Shockingly, 8,451 of those newly diagnosed were between the ages of 13 and 24. And nearly half of them were young, African American men who have sex with men (MSM). In 2015, an estimated 60,300 youth were living with HIV, but half of them did not know that they were HIV-positive (and may have been unknowingly passing on the virus to others). In fact, 100 young people died of AIDS in that same year. With all the progress that has been made in HIV prevention (PEP, PrEP, U=U, condom distribution), youth remain highly vulnerable—especially when they are also living on the streets.

The California Homeless Youth Project agrees that homeless and unstably housed youth are highly vulnerable to HIV. Many are involved in survival sex (trading sex for food, money, a place to sleep, or all three). Without regular access to food, shelter or jobs, many homeless youth engage in survival sex in order to get their basic needs met. The survival sex is often condomless. And some are living on the street because they have HIV but no family support. Families of positive youth either kicked them out of the home or stigmatized them to the point where they can no longer live at home. Not being able to share utensils or sheets or towels with your family is emotionally painful.

Many young people use alcohol and other drugs to self-medicate their mental health issues and emotional pain. Substance use also numbs physical pain, hunger, and the challenges of life on the street. And, using uppers (meth, cocaine) can mean more than getting high—these drugs help youth stay up through the night to prevent robbery, physical assault, rape, or other crimes.

It’s been proven that stable housing increases access to medical care, treatment, and continuity of care for HIV-positive youth (and anyone of any age living with HIV). Agencies across the U.S. are trying to get HIV-positive youth into housing, link them to care, and provide them with much needed emotional support.

Spencer not for hire

SPENCER IS A FIERCE force to be reckoned with. Six feet three inches of compassion, caring, and straight talk. Even he agrees, “I’m a soldier. And wish I had more soldiers to work with me.” Formerly homeless himself, Spencer currently volunteers for many agencies in Los Angeles, including APLA Health, LA CADA, Black AIDS Institute, AIDS Healthcare Foundation, and Project Engage. But his favorite place to volunteer is Friends La Brea (also known simply as “Friends”). There, he “recruits” people for HIV testing and helps the homeless youth who hang out near Friends in the heart of Hollywood. Many of the youth call him “dad,” and he calls them his “kids, daughters, sons.” He is their unofficial relative, case manager, and counselor. He has been offered positions at many AIDS service organizations (ASOs) around Los Angeles, but doesn’t want to be tied to any one agency. Spencer wants to serve his community *his* way.

He is a recovering meth addict who has been clean and sober for the past seven years. An out gay man who both sold and shot meth, he did time in prison for dealing. He was also a sex worker, and was a “girl at night and a boy in the daytime.” With his long braids he “looked

like Milli Vanilli" walking the streets of L.A. He contracted hepatitis C (and was treated, which was "rough" but he was cured) yet somehow never acquired HIV, even though an ex-boyfriend had AIDS. They had condomless sex and shared needles—both extremely high-risk activities. When asked how he managed to stay HIV-negative, there was a long thoughtful pause in the conversation. He doesn't know. Luck? A miracle? Both? But he does know that he is grateful and that that his mission is to "give back and help the kids."

He "hangs with the kids to see what they are doing." He gets them tested if they need to be. He connects them to services if they want them. And he listens because he has been there. Spencer did not have his own apartment until he was 51 years old, and he tries to inspire others to do the same. "I am in my place. I got my own apartment. You can have a place like mine if you put your mind to it." And Spencer has ideas about how to get HIV-positive youth successfully housed. "We need classes for them. People have been on the streets so long they don't know how to live. I know someone who put a tent up inside her new apartment. She was so used to being on the streets. And they need to be taught "how to keep the house up. Tackle it one room at a time. Do one thing for your new place every day." Who should teach these classes? "Oh, I'd love to teach them!"

The biggest piece of advice he tells his "kids"? "You gotta have patience and follow your dreams. Whatever you want to do. You want to go to school? You can do that. Don't let nobody tell you that you can't do that."

The roots of her forest run deep

SUSAN FORREST IS A TRUE AIDS warrior. She started her career back when the epidemic was raging in the 1990s, when she was the only one out of 20 friends who injected drugs who tested negative for HIV. Her first HIV-related job was TPAN (the publisher of POSITIVELY AWARE) in Chicago, working for the agency's HIV/AIDS hotline and buddy program. Eventually she moved to Los Angeles and worked for AIDS Project Los Angeles in their housing department and then for 20 years at Behavioral Health Services in Hollywood. Flash forward to 2019 where she now runs the Art House Pasadena (AHP), which provides safe and culturally affirming alcohol- and drug-free housing. AHP is funded by the Los Angeles Housing Authority and is a recovery bridge housing program. AHP links clients to services that assist with the recovery process and uses art as part of that process. Approximately 40–50% of their clients are under the age of 29 and approximately 60–70% are HIV-positive.

AHP can house 20 people at a time. Clients can stay for 90 days with the possibility of an additional 90 days, depending on "forward movement" towards housing. "If there is no movement—then the program is not working for them." AHP makes use of a van that takes clients to their medical appointments and has a relationship with an HIV specialty pharmacy that delivers HIV medications "directly to the door of AHP."

Susan freely admits that HIV prevention at AHP is a hard sell. "All of our clients who have found permanent housing were HIV-positive. Our challenge is to get HIV-negative people to stay negative when they see others getting into housing. They have never known anyone to get sick. They haven't lost 30–40 friends to AIDS. One pill per day, and everyone is healthy. It's hard to make a case to stay HIV-negative. An HIV diagnosis is like a safety net. They get a gym, housing, benefits, which other people don't get. 'What's so bad about it?' "

Angels in the City of the Angels

ANDRES E. SANCHEZ MONTOYA (pronouns: they/them) works in the Division of Adolescent & Young Adult Medicine at Children's Hospital Los Angeles (CHLA). They work in CHLA's HIV highly ranked program with HIV-positive youth 16–25 years of age. CHLA is "one of the few adolescent medicine clinics in Los Angeles County," so, many HIV testing sites refer clients directly to them. They also get word-of-mouth referrals. CHLA's HIV program currently has 60 clients, 26% of whom are homeless. Most of their current clients are MSM (men who have sex with men) who acquired HIV through sex. Some acquired HIV perinatally, and one was the victim of a sexual assault.

Adhering to an HIV regimen is a challenge for anyone, but especially for young people. To help with adherence, says Montoya, CHLA "works together with the B3 (Become, Believe, Belong) group. They provide assistance with support groups and individual one-on-one meetings that discuss the HIV lifecycle, medical adherence, social support, and an array of topics around their individual HIV care. It is extremely difficult for youth, especially when they are homeless. They report not remembering to take their meds or just being tired of having to take meds on a daily basis. For some, it's about reliving when they were diagnosed every time they have to take their medication."

Being homeless is a "huge barrier" to HIV medical care and "no living space means no place to store HIV medication." Andres' homeless clients are "couch surfing, living in tents, squatting in abandoned spaces." Some young MSM "are rejected by their families and kicked out of the house. Or, the family is okay with them being gay, but once they are HIV-positive, that creates another family stressor" and the kids get kicked out at that point. For the youth who go to shelters (mainly the Salvation Army or Covenant House), most "have clients check in their meds and encourage them

'FRIENDS' HELPING FRIENDS: FRIENDS JASON (LEFT) AND ANGEL ARE TWO OF THE CLIENTS SERVED BY FRIENDS LA BREA IN LOS ANGELES, WHERE SPENCER VOLUNTEERS.

to take the meds." However, "things get stolen at shelters," including HIV medications.

CHLA has a "good success rate for getting people into housing. And having an advocate for each client helps. It's hard to get a place to live if you don't have a way for a housing agency to contact you. Clients have different phones and different phone numbers every month. Their contact information changes regularly."

One young man had "bad experiences at other places. He had medical and institutional mistrust. He had been let down. He didn't ask for help right away—he waited until things became more complicated and then presented with a challenge. But by then, he had exhausted all his options." Dealing with both mental health and meth abuse, Andres worked with him six to nine months to get him into housing. They went with the client to all of his housing appointments and were his advocate. "But once he got housing, he became overwhelmed with the responsibilities. He found it hard to deal with and left housing after two months." Andres searched for him for a long time but contact was lost. The client has yet to return to Andres and their program.

Conversely, another client was a 15–16 years old male immigrant from Central America. At some point he was in the Los Angeles foster care system (as are many CHLA clients) and eventually became homeless. But "he pushed forward in spite of the barriers. He was not afraid of asking for resources. He went to college and graduated, even while dealing with HIV and homelessness."

Say "yes" to YES!

BLAIR FRANKLIN WORKS at the Youth Empowered Society (YES) Drop-in Center in Baltimore, MD. Born and raised in the city, "Baltimore flows in his blood." YES serves young people who are 14–25 years old. Perhaps the epitome of a grassroots organization, YES was founded by homeless queer/trans youth (with some adult allies) who "recognized and named that there was nowhere for youth to feel safe and get services. And no one was thinking about long-term system changes" for youth without housing. Baltimore has limited housing options for youth—only two youth shelters with eight beds each. "Adult shelters aren't safe for youth," says Franklin. And YES has an ambitious endgame: to end youth homelessness and put themselves out of business.

YES serves 300 homeless youth per year, an estimated 10% of whom are HIV-positive, although Blair suspects that many clients are not disclosing their HIV status. The youth "still don't know about PrEP. The young people focus on their surroundings and how to get through tomorrow." So YES offers sexual health programs, HIV education, harm reduction, and condoms in the bathrooms. Clients "run in, grab condoms, and roll out."

The agency is "first and foremost a drop-in center for youth who are currently experiencing homelessness. We offer showers, laundry facilities, an address for them to use for mail, a place to charge phones and nap." YES offers what they call "rapid rehousing" and they "provide rental assistance for 1–2 years." Their intensive case management helps clients "learn how to sustain an apartment" and provides crucial support during the housing application process.

Jobs are necessary to keep those apartments and YES offers a workforce development program. Most job placement programs don't offer stipends, so the agency "fundraises to make sure kids get paid." And their youth often say, "Why do I even engage or bother when I won't be safe in this [work] environment?" So YES is heavily involved in advocacy and "what it takes to get jobs and equity." They also work on reducing bias in job interviews and how prospective employers should handle "when a client shows up and looks different [or presents as a different gender] than their identification."

The demand for services is so great that they have already outgrown their current physical space. "The hallways are narrow and people bump into each other, which creates conflict. There's no room to breathe." Blair and YES are looking for a new location, "one that is friendly, affirming, central, and not in street gang territory." And the hope is, if they "do well and do right, they don't have to exist."

Dancing as fast as he can

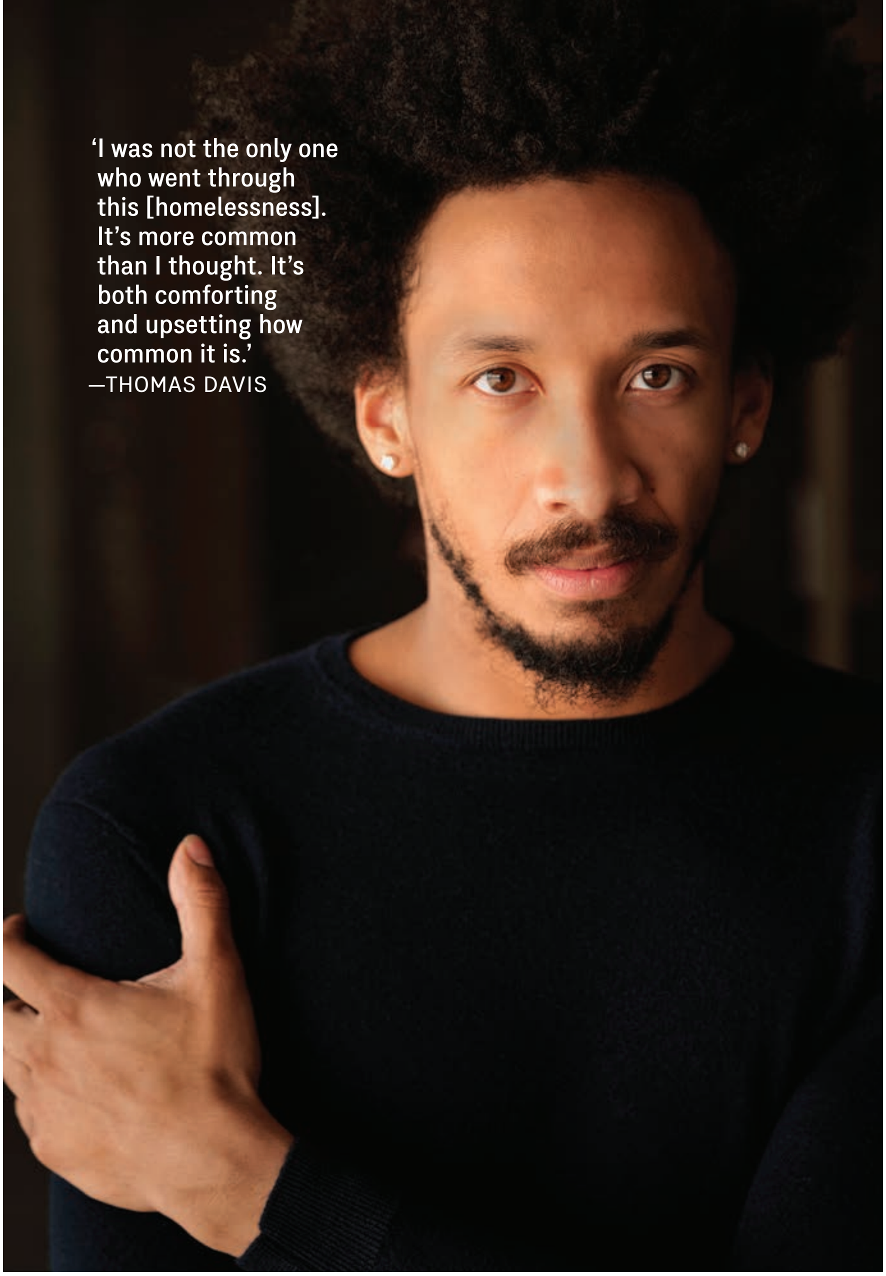
TWENTY-SIX-YEAR-OLD THOMAS DAVIS is a Program Coordinator for Prevention and Care at the Black AIDS Institute in Los Angeles and the creator/founder of The Catharsis Project. A talented dancer from Estes Park, Colorado, he moved to Los Angeles to fulfill his dancing dream and was diagnosed with HIV in 2013. The Catharsis Project started as a film but now uses dance and many kinds of art forms to share stories and experiences about the AIDS epidemic.

The Creative Remedy Education Workshop (CREW) is a one of The Catharsis Project's programs. CREW started in 2017 and is funded by AIDS United and follows the model of Meaningful Involvement of People with AIDS (MIPA). It consists of weekly meetings for HIV-positive millennials (born between 1981 and 1996) of color. CREW is open to anyone, but most members are from the LGBTQ community. Thomas "didn't want CREW to meet at any of the large ASOs [AIDS service organizations] in Los Angeles. We are oversaturated with their content." He also wanted CREW members to avoid the stigma of walking into an ASO. Thanks to his connections in the dance community, CREW meets at the venerable Lulu Washington Dance studio in South Los Angeles, which Thomas calls "an untraditional partnership."

CREW meets every week for two hours. The first hour is full of art and self-expression. Thomas brings in "community professionals" for dance, creative writing, drama, photography, etc. The art hour "creates a safe space and loosens up the group." The outside speakers "offer insight and expertise." The second hour involves food and fellowship. They talk about issues—"sometimes whatever comes up, sometimes the topic is planned." But no matter what they talk about, "HIV always comes up. It is always part of the conversation." CREW usually has 10–15 people at their weekly gatherings and each person has "come more than once. No one-offs, which is big for Los Angeles!" Unfortunately, most CREW clients are homeless or unstably housed.

Although passionate about HIV/AIDS, dance is his true love "and a career in the arts takes some sacrifices. Arts don't pay the most." Thomas is no stranger to homelessness himself and has "experienced homelessness several times, although it is not a regular thing." He has couch surfed and slept in his car. Thomas talks about presenting at a national HIV conference and then flying back to Los Angeles to sleep in his car. Again. Everyone told him he did a "great job" with his presentation, but no one knew where he was actually sleeping.

Now open about his addictions to meth and sex (although Thomas "identifies more as a sex addict" and is "trying to figure out what recovery from sex addiction looks like" for him), he "previously didn't have the vocabulary to deal" with his issues. He had no access to mental health services and "no energy to deal with them." After losing an apartment, he found himself in complicated living situations with so-called "friends." One "friend," who proved to be a predator, let him stay on the couch in the living room. Thomas "woke up with him naked over me one night." He was pressured into survival sex for a place to stay. "I did things I did not want to do." One night he "had it" and moved in with "another friend who was not a friend" and had a meth problem, which was not helpful for Thomas. Fortunately, he has had a safe and stable place to live for the past three years.



'I was not the only one who went through this [homelessness]. It's more common than I thought. It's both comforting and upsetting how common it is.'
—THOMAS DAVIS

Once he started CREW, Thomas realized that "I was not the only one who went through this [homelessness]. It's more common than I thought. It's both comforting and upsetting how common it is." CREW clients talk about housing a lot and about how much harder it was to get housing before their HIV diagnosis. "It's like their diagnosis helped them. Hey! There are programs! What a 'cool' irony!"

CREW's current AIDS United funding ends this October but he is hoping that he will either get refunded or find a grant somewhere else. He is "always looking for ways to keep it going." His dream is to make The Catharsis Project a full-time job for him. That, and to dance.

The tale end

HOW TO END HIV and homelessness in the youth community? Let's follow the example of YES and try to truly end homelessness and not just use Band-Aids. Let's follow CREW's MIPA (Meaningful Involvement of People with AIDS) model and talk about HIV together. Let's get people sober, like Pasadena Art House does, or help create any positive change. Let's create a safe medical home for youth who are HIV-positive, like CHLA. Let's be soldiers like Spencer. With over 8,000 youth acquiring HIV each year, we can't afford not to do this. It's time to bring these tales to an end. PA

MICHELLE SIMEK has worked in HIV/AIDS for over 20 years. She currently works at an HIV clinic in Los Angeles, and is a popular AIDS educator/public speaker both locally and nationally. When not writing for POSITIVELY AWARE, she likes to binge watch BBC shows on Netflix, thrash around while watching punk rock bands, go to the beach under the protection of SPF 4,000, and cuddle with Baxter, her cat and BFF.

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YOU MATTER AND SO DOES YOUR HEALTH

That's why starting and staying on HIV-1 treatment is so important.

WHAT IS DESCOVY®?

DESCOVY is a prescription medicine that is used together with other HIV-1 medicines to treat HIV-1 in people who weigh at least 77 lbs (35kg). DESCOVY is not for use to help reduce the risk of getting HIV-1 infection. DESCOVY combines 2 medicines into 1 pill taken once a day. Because DESCOVY by itself is not a complete treatment for HIV-1, it must be used together with other HIV-1 medicines.

DESCOVY does not cure HIV-1 infection or AIDS.

To control HIV-1 infection and decrease HIV-related illnesses, you must keep taking DESCOVY. Ask your healthcare provider if you have questions about how to reduce the risk of passing HIV-1 to others. Always practice safer sex and use condoms to lower the chance of sexual contact with body fluids. Never reuse or share needles or other items that have body fluids on them.

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about DESCOVY?

DESCOVY may cause serious side effects:

- **Worsening of hepatitis B (HBV) infection.** DESCOVY is not approved to treat HBV. If you have both HIV-1 and HBV and stop taking DESCOVY, your HBV may suddenly get worse. Do not stop taking DESCOVY without first talking to your healthcare provider, as they will need to monitor your health.

What are the other possible side effects of DESCOVY?

Serious side effects of DESCOVY may also include:

- **Changes in your immune system.** Your immune system may get stronger and begin to fight infections. Tell your healthcare provider if you have any new symptoms after you start taking DESCOVY.
- **Kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys. Your healthcare provider may tell you to stop taking DESCOVY if you develop new or worse kidney problems.
- **Too much lactic acid in your blood (lactic acidosis),** which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- **Severe liver problems,** which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of DESCOVY is nausea. Tell your healthcare provider if you have any side effects that bother you or don't go away.

What should I tell my healthcare provider before taking DESCOVY?

- **All your health problems.** Be sure to tell your healthcare provider if you have or have had any kidney or liver problems, including hepatitis virus infection.
- **All the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. Other medicines may affect how DESCOVY works. Keep a list of all your medicines and show it to your healthcare provider and pharmacist. Ask your healthcare provider if it is safe to take DESCOVY with all of your other medicines.
- **If you are pregnant** or plan to become pregnant. It is not known if DESCOVY can harm your unborn baby. Tell your healthcare provider if you become pregnant while taking DESCOVY.
- **If you are breastfeeding** (nursing) or plan to breastfeed. Do not breastfeed. HIV-1 can be passed to the baby in breast milk.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about DESCOVY, including important warnings, on the following page.

Ask your healthcare provider if an HIV-1 treatment that contains DESCOVY® is right for you.

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IMPORTANT FACTS

This is only a brief summary of important information about DESCOVY® and does not replace talking to your healthcare provider about your condition and your treatment.

MOST IMPORTANT INFORMATION ABOUT DESCOVY

DESCOVY may cause serious side effects, including:

- **Worsening of hepatitis B (HBV) infection.** DESCOVY is not approved to treat HBV. If you have both HIV-1 and HBV, your HBV may suddenly get worse if you stop taking DESCOVY. Do not stop taking DESCOVY without first talking to your healthcare provider, as they will need to check your health regularly for several months.

ABOUT DESCOVY

- DESCOVY is a prescription medicine that is used together with other HIV-1 medicines to treat HIV-1 in people who weigh at least 77 lbs (35kg). DESCOVY is **not** for use to help reduce the risk of getting HIV-1 infection.
- **DESCOVY does not cure HIV-1 or AIDS**. Ask your healthcare provider about how to prevent passing HIV-1 to others.

BEFORE TAKING DESCOVY

Tell your healthcare provider if you:

- Have or had any kidney or liver problems, including hepatitis infection.
- Have any other medical condition.
- Are pregnant or plan to become pregnant.
- Are breastfeeding (nursing) or plan to breastfeed. Do not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.

Tell your healthcare provider about all the medicines you take:

- Keep a list that includes all prescription and over-the-counter medicines, vitamins, and herbal supplements, and show it to your healthcare provider and pharmacist.
- Ask your healthcare provider or pharmacist about medicines that should not be taken with DESCOVY.

HOW TO TAKE DESCOVY

- DESCOVY is a one pill, once a day HIV-1 medicine that is taken with other HIV-1 medicines.
- Take DESCOVY with or without food.

POSSIBLE SIDE EFFECTS OF DESCOVY

DESCOVY can cause serious side effects, including:

- Those in the “Most Important Information About DESCOVY” section.
- Changes in your immune system.
- New or worse kidney problems, including kidney failure.
- Too much lactic acid in your blood (lactic acidosis), which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- Severe liver problems, which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark “tea-colored” urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of DESCOVY is nausea.

These are not all the possible side effects of DESCOVY. Tell your healthcare provider right away if you have any new symptoms while taking DESCOVY.

Your healthcare provider will need to do tests to monitor your health before and during treatment with DESCOVY.

GET MORE INFORMATION

- This is only a brief summary of important information about DESCOVY. Talk to your healthcare provider or pharmacist to learn more.
- Go to DESCOVY.com or call 1-800-GILEAD-5
- If you need help paying for your medicine, visit DESCOVY.com for program information.

GILEAD

BRIGHTER PICTURE

Homeless and HIV positive at 23, positive about the future at 24

INTERVIEW BY **ENID VÁZQUEZ**

PHOTO: ENID VÁZQUEZ

LAST YEAR, WHEN HE WAS 23, DANTE'S mother—his best friend—died. "I didn't have a father growing up. It was just me and her against the world." With no other relatives to turn to and unable to afford the rent on his mother's apartment, he began living out of his car. With sporadic part-time and low-paying retail work, he lost even that. That's when he turned to sex work, which allowed him to pay for a motel room for the night. Soon the attractive and intelligent young man with the sparkling personality found a partner who took him in. It was, however, no storybook romance. Yet, through that relationship and all the chaos, Dante emerged from tragedy to a better life. He received life-saving assistance at Howard Brown Health, an LGBTQ health care provider in Chicago, and its Broadway Youth Center. Sitting at BYC, Dante tells his story.

When my mom passed away, I became homeless on the streets of Chicago. I went to doing sex work to be able to get by in hard times. Sex working wasn't something on my list of things I thought I would ever do in my life. I know there was a risk, but I had to take that risk because I didn't have a choice. I also had a little bit of drug abuse with cocaine.

I think a lot of young folks fall for the *okey-doke*. They fall into the trap of, "I don't have a support system, so I'm going to seek it out by any means necessary." And any means necessary sometimes means, you know, maybe sleeping around with people for money, maybe sleeping with somebody so we have a roof over our head. Sleeping with somebody so we could put food in our stomach. These are realistic things that I personally can say that I did. I had to sleep with people to be able to sleep at night. I cried at first. I cried because I felt so used. I was naïve.

I ended up being unable to keep my car. I had someone who would have paid for it, but wanted me to be completely submissive to him. I wanted to be a strong and independent person. I was an only child. I'm used to doing things as a loner.

At the time I did not know about the Broadway Youth Center or any drop-in or shelter. So I just lived on the street, in abandoned buildings or at friends' houses for a time. With sex work, I could get a hotel room for a night, so I had a semi-safe place.

I met my partner through sex work, off Grindr. We were just talking

> **‘We heard about the AIDS crisis,** but for me that was years and years and years ago.’

and I just really liked him. So I took a chance and went out on a date with him. I just explained my whole situation. He’s like, “I just want to move you in with me and we’ll go from there. We’ll try to be really good to each other.” Unfortunately, that wasn’t what happened.

He was older than me and I moved in with him. He was 35. At the time I was 23. And I was dealing with a lot, with losing my mom and feeling alone. So I really looked to him for support during that time. Unfortunately, we were both doing cocaine and that’s where the abuse came in. He would always accuse me of going out and cheating and I wasn’t.

I got really, really sick. I was working as an assistant store manager and I kept having days where I was really fatigued and sick-feeling. Throwing up. I just remember passing out on the floor in the bathroom at work. That’s when I knew there was something wrong in my body.

I didn’t know that he was HIV positive —and neither did he.

I was sick but too scared to go to a hospital because hospitals have a way of treating people [negatively]. I didn’t know what HIV was, really. HIV wasn’t talked about in my community, being a Latinx person, a P.O.C. [person of color—his mother was Italian-American, his father Puerto Rican].

We heard about the AIDS crisis, but for me that was years and years and years ago. I wasn’t even born. I’m a ’94 baby. HIV wasn’t something that was talked about. I wish it was, because I think it would have changed my outlook. Probably would have made me a lot safer and … less trusting with my partners. Or more healthy with my partners, I should say.

It wasn’t until I was really, really sick where I couldn’t get out of bed that one of my friends drove me up here, to Howard Brown. They’re like, “You really just need to go to Howard Brown if you don’t want to go anywhere else.”

I was scared going into Howard Brown. I remember it like it was yesterday. It was like an hour sitting in that waiting room, thinking, “Oh, my God. I hope I don’t have anything.” The doctor was very, very nice to me. He said, “Come on back, we’re going to draw some blood and see what’s going on with you.”

He told me they were going to do a rapid test and from the rapid test I would know if I was positive for HIV or if I wasn’t. I wanted to *leave* at that point. After hearing everything, I really just didn’t want to know the status. Half of me was like, “I don’t think I have it.” I felt invincible at the time.

My partner wasn’t with me. We had gotten into a big fight because I felt like we needed to go get tested together and he didn’t want to do that. He told me he just thought I was cheating, and that he was going to leave and when he came back, I should be gone.

So I had a bag with me when I went to Howard Brown, full of my clothes, my birth certificate, my Social Security card, some other little items, and my mother’s ashes. I was just sitting there looking at people and thinking, “I just don’t know what to do.” I wanted to cry.

They said, “You are HIV positive.” They said, “Everything is going to be fine, *honey*. You’re going to be just great.” They gave me a bottle of juice, water, and a cookie. (Laughs.) I thought it was just the weirdest thing. Because I’m like, *I’m getting cookies and a snack, while I’m finding out I’m HIV positive.*

I just remember crying and crying and crying. Just being like, “Oh, my God. What am I going to do? My life is over.” I think that’s the first thing that goes through your head. I already struggle with depression and anxiety.

So sitting there was like *forever*. It was probably, realistically, two hours I was in the office.

I didn’t go back to Howard Brown. I left out of there. I just didn’t want to deal with it. I didn’t want to believe I heard what I heard.

They set up an appointment for me to come back in and they did reach out to me. I did not follow up with the appointment, at first. And my symptoms were getting worse and worse. It got to the point where I ended up leaving my job because I just physically couldn’t do anything. I couldn’t walk. I was throwing up. I couldn’t keep food down.

My CD4 count was very low and my viral load was very, very high. I don’t even remember the numbers. I didn’t understand what they mean.

Being young, I felt like I’m never going to be able to find a partner. Nobody’s going to want me. I felt like I was damaged goods. I felt like everyone around me, when they looked at me, could see … there’s something different.

Finally, about three weeks in, I went back to Howard Brown. My case manager over there at the time, who was very nice, he was like, “Look, just try to take it slow.”

I remember starting Genvoya and always being in the bathroom on the toilet. I hated it. It was the most terrible feeling. I always had to take the medicine with food. And I was still homeless at the time. And I didn’t have a job. And I felt like I was living with this big secret that nobody else could understand and could relate to. I wasn’t very adherent. One time I just grabbed the whole bottle and threw it [the pills] down the toilet. [He now takes Biktarvy.]

Then I started getting help over at Howard Brown. My case manager put me in support groups, and I still go to these groups. They’re very, very helpful. I started going to the Broadway Youth Center, and the Youth for Youth program for positive folks at the Center on Halsted [Chicago’s LGBTQ center]. I went to UIC [University of Illinois at Chicago] and got-involved in a lot of programs, like TWIST [a program for young people].

At the time I didn’t think I was going to relate to anyone. I thought, “Everyone’s going to be older. They’re not going to be around my age.”

And that wasn’t the case. I found more people who were living with HIV and … *were … young … people*. So they told me pretty much their stories, about how it wasn’t as bad as they thought it was.

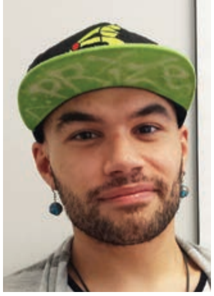
I met someone a little older who told me, “Look, honey, it’s going to be okay. You need to take your medications.” She’s like, “Guess what? You’re not the only one with a secret.” She said, “I’m positive too and I have been for eight years. And it gets better.”

So she really became my rock and my best friend.

It took a lot of energy, a lot of eating right and healthy practices to get my body back to where it should have been. I still struggle with my own self-care. I think self-care is very hard for most people. As a young person, it becomes even harder, especially when you’re homeless.

I’m thankful I’m housed now. But it’s still a struggle, trying to do advocacy work, which is what I do now. I got involved in a lot of advocacy work after

‘**As a 24-year-old,** you don’t really think about your health. Put a Band-Aid on it and we’ll call it a day.’



finding out I was HIV positive. And I want to be an HIV tester, to be there for somebody else, as a support, so they know they’re not going in there alone.

There was one time I was at a friend’s house for dinner. Well, I thought they were a friend at the time. I found out later on that they weren’t. I didn’t tell anyone I was HIV positive at first. I was explaining my whole situation. I’m homeless.

I just had this deep urge ...I felt like I was hiding something. I just wanted to tell somebody, to scream it, to let it out. I had my best friend, but that was just one person. They’re like, “It’s going to be okay.” But then when we sit down to dinner, everybody else had regular silverware and glasses and eating off regular plates. I had a red Solo cup and a paper plate, and plastic utensils. I was wondering, do they not have enough plates? But it made me think, “Wow, is there something wrong with me? Do I have a big sign on my forehead?” I find out they were scared and thought they could contract HIV just by me touching them. Or by drinking behind me or sharing food with me.

I didn’t finish the dinner because I was really upset. I said, “No friend would do what you just did. My mom would never do that. It’s just so insulting.”

I left. I slept on a park bench. And it was cold that night. It was January. There was snow on the ground. People are walking past me giving me weird looks and whatnot. When you’re a homeless person, whether you’re a youth or you’re older, people just don’t treat you very kindly.

I woke up to this very nice older man. He asked me, “Are you okay? Why are you out here—are you homeless?” At the time I didn’t know who he was. I said, “I am. I’m leaving.” I thought he was an officer or something. He said, “Come home with me, if you want to. I would like to feed you, give you some place to sleep. You can stay as many days as you need to until you’re not sick anymore.” He then later told me, “I’m actually HIV positive. I’m just not out.” Months later I ran into him in a support group.

I think fate stepped in a lot of times to help me. I believe in a God. I believe my mom is still with me wherever I’m at. As much turmoil and as many things as I went through, I believe I was looked over by a guardian angel because I couldn’t have made it out of my situation and be here where I’m at. I have a lot to be grateful for and be happy about. And the many people I’ve met through my life now versus my life before being HIV positive—I feel like it’s been so much better.

Now when I do go on Grindr, I’m not ashamed to put down “HIV positive.” It weeds out a lot of effort. It used to bother me that people were very judgmental. But that’s just the way the world is. For me, my status doesn’t mark me as a person. It’s just a health condition that I have to live with. Thank God for the places that give out condoms and lube.

My life is just the same and can be as great as anybody else’s. It took a while to be able to say that.

My mom is the person I really, really yearn to talk to. And it was hard for me to understand at the age of 23, your parent’s gone and it’s you alone in the world. I felt like she would have said, “I still love you. I’ll still be there for you. You’re no different.” When I came out to my mom, it was no different. She never shunned me. She was there for me through a lot of hard things.

At first I didn’t want to have anything to do with HIV. Then I became more mature and understanding what it means to be an HIV-positive person and how that affects me and my community. If I don’t inform people about what’s going on, then I’ll have people who end up like me who *don’t* know what HIV is.

As a 24 year old, you don’t really think about your health. Put a Band-Aid on it and we’ll call it a day.

My mental health has become a lot better. It’s not just the physical aspects of being an HIV-positive person. It’s a mentality as well too. You still live your life to the fullest, but you don’t live it to where you’re going to hurt your body. It’s not fun when I have to go and get my blood drawn, but I have to. These are just responsibilities I have to take for choices that I made. We all make the choice for the dos and don’ts in our life, and these are not always the best choices for us.

ENID VÁZQUEZ: I ask Dante if he really had a choice. Wasn’t it more accurate to say that society didn’t help him? He didn’t choose to be homeless. He didn’t choose to have HIV. It would be better to say he did the best he could.

I suddenly realized that I’ve been working for POSITIVELY AWARE for 23 of his 24 years. I tell him that as long as he’s been alive, when he was a beautiful baby boy and as he grew up, I’ve watched HIV research and development and services. And I saw how they often didn’t reach the people who needed it. One of the things that really got to me was knowing that HIV-negative people could benefit from the magazine, but they won’t read it. Now with PrEP, we can write to HIV-negative people. Even TPAN now has services for people who don’t have HIV. “But there’s still this disconnect,” I tell him.

DANTE: It’s a very big disconnect. The magazine is where I got a lot of my facts. It wasn’t on the internet where I got my facts, it was from the magazine in the doctor’s office, where I could sit there reading it.

Honestly, when I first saw the magazine, I was like, “Oh no. What if someone sees me reading this?” Then I didn’t care. Because I really need to know what’s inside this magazine. For me the biggest thing was the fact that I didn’t have a support group. Youth for Youth was new. I’m very timid about going out and trying new things. A lot of times, we young people focus on the image that we have and what people will think of us. And a lot of times it’s my anxiety too.

So a lot of times having the magazine gave me a nonjudgmental way of accepting my HIV, but also having a way to connect. It was my only outlet before I found other people in my community that I could talk to now on a daily basis that are HIV-positive. Those faces and stories were important to me. I would drift off sometimes in my imaginary world, wondering what would it be like to meet this person. Or what would it be like to do this type of work. If they can do it, I can do it.

It made me realize that further down the line, now that I know what I want to do with my life, which is to be a health educator, that I also want to be an activist for the rights of the LGBTQ community, and also HIV-positive people and people of color. Because there aren’t a lot of people out there in the people of color community who have this knowledge. And if they have this knowledge, it’s scarcely talked about.

LOOKING BACK, LOOKING AHEAD

After more than 30 years of treating young people living with HIV, **Dr. Lisa Henry-Reid** reflects on what more still needs to be done

INTERVIEW BY **ENID VÁZQUEZ**

PHOTO: ENID VÁZQUEZ

Pediatrician Dr. Lisa Henry-Reid began her career in 1986, quickly focusing on children and adolescents living with HIV. After two years at the University of Illinois in Chicago, which was just then beginning to provide pediatric care, she moved to what is now Stroger Hospital of Cook County, in the heart of the city, and in the heart of poverty and more difficult health problems. She rose to become chair of the Division of Adolescent and Young Adult Medicine. As she looks back on her remarkable career in HIV before she moves into retirement, she makes an ironic statement about youth living in an epidemic: "We have a long way to go."

Stigma is still a big, big problem. It's pervasive. There are still people who think you can't drink out of the same cup, eat off the same plate, or wash your clothes in the same washing machine for fear of getting infected. In the African American community we serve, many are still operating under several myths, not knowing how HIV is transmitted. Thinking that if you stand next to someone when they sneeze, you can catch it. Families say you have to eat off paper plates and use plastic forks and spoons, and throw them out yourself.

I think education can help with that. We need to talk together about HIV. I hope knowledge will decrease stigma.

We've had clients who were outed to their family about their sexuality by HIV and were put out of the house.

Most of my patients are African American and Latinx. The one that always stays in my mind is the young man whose father said, ‘We don’t do gay here. You’ve got to go.’ *And he was 17.*

I have a patient who’s been positive seven years and has not disclosed to anyone because they fear they’ll be treated differently. That’s very difficult to live with. Stigma is very difficult to overcome.

It’s like with PrEP.

I feel strongly that PrEP should be marketed to everyone. “This is something that protects all people from HIV and if you have ever had an ‘*oops*,’ this is something that could be for you.”

I believe we need to normalize the message around PrEP: This is a medication you can use to prevent HIV. It’s for anyone at risk—senior citizens, youth, everyone. If we normalize it, PrEP is for anybody who wants to protect their health and we should put it in terms of health only. PrEP is for anyone who’s ever had an *oops* and might have an *oops* in the future. It’s like when you go to your doctor, you get your blood pressure taken.

People say, “This is a medication the government designed to make us sick, to give us HIV.” “We’ve heard if you take PrEP it’s going to increase your risk of getting HIV.”

We hear a lot from youth out in the community: “They call me a PrEP whore. They think I’m getting busy with a whole lot of people. And I don’t want to be perceived that way.”

We need to have a lot of talk.

Now that PrEP is approved for patients weighing 35 kg [77 pounds] and up, we need to increase the legal statute to protect their privacy, so they don’t need parental permission.

The CORE Center [a modern infectious disease clinic that’s part of the county hospital] is seen as a place for people who are HIV-positive, even though we have an STI clinic, where we offer PrEP services. So some of my patients prefer to see me at the hospital clinic. They’re afraid to run into someone they know, from a party or from a ball.

For youth, especially the ones transitioning in their sexuality or don’t know if they are LGBTQ, you have a double stigma—HIV-positive and gay or questioning. And that can be very difficult. Many are not living at home. I think it’s particularly true for LGBT and non-binary youth.

Dr. Sybil Hosek and Dr. Jaime Martinez did a study on mental health in our population years ago. No one was surprised to see that the rates were much higher. There’s a lot of anxiety. Higher than the norm for that population. There is a lot of PTSD. There are housing issues. We find those issues need to be addressed before we can get to the conversation about taking an HIV medication.

There are not enough services for the unmet needs that are out there.

We clearly need to do a better job with HIV testing.

I used to query doctors about why they don’t test for HIV. I don’t know what the problem is. Fear of having a positive test and not knowing what to do?

To me that’s not upholding your Hippocratic Oath at all. What would you prefer? To have your patient come back with AIDS because you weren’t comfortable testing? I used to say, “Well, come to me.”

I think emergency rooms are a key place for testing. Years ago we were funded to do testing in the ER. There was a young man with a sprained ankle. We had someone there asking if people wanted an HIV test and he said sure, and he was positive. He had chlamydia twice. He was openly gay-identified. So the markers for HIV were there. There were at least two opportunities for HIV testing that were missed. And he came in with a sprained ankle. Thank God for that project and that person.

While 51% of people living with HIV are virally suppressed [undetectable], for those 15 to 20 years old, it’s only about 25%.

We need to test, treat, and get virally suppressed so they can also benefit from U=U [Undetectable Equals Untransmittable].

So, they may have elevated viral load and that may be why we see more infections. So we need to test, so we’re not feeding into transmission by the undiagnosed who don’t know what their status is.

There’s a youth risk behavior survey by the CDC every two years. Small towns, large cities, private schools, public schools—everything, 9th through 12th grade. The number ever tested actually decreased between the 2016 and the 2018 data. And it’s only 50%. Even though they also asked, “Have you ever had sex? Have you had sex recently, within 30 days?”

Over 50% say they’ve had sex. Yet 50% haven’t been tested. And if we don’t test them, we can’t identify those with HIV.

Our clinic started for two reasons. Dr. Mardge Cohen, who’s known for her work with women, had a couple of young males she asked us to provide care for.

At the same time, hematologists asked us to take care of hemophilia patients. Initially the majority were hemophiliacs infected by factor [blood products]. There were 40 to 50 young adults around 1990. We knew everybody by name. Now, unfortunately, the epidemic has regularly impacted young adults, so we have close to 200 patients.

We didn’t have the drugs we have now, so you saw the spectrum of the disease. The difference now is that we have medication. The once-a-day tablet, STRs [single-tablet regimens], have been a boon.

Now we have viral load. You can see a lot of things with CD4s at the same level.

The thing about adolescents is they can sense if you’re comfortable or not. And they might generalize that to others. “I’m not going to venture out and seek care.”

I believe we need to normalize the message around PrEP: This is a medication you can use to prevent HIV.

I have quite a few patients turning 25 this year [the age at which pediatric care ends]. One I’ve been taking care of since she was 15.

The good news is there are a lot more providers for this population now. The Lurie [Children’s Hospital] program is largely expanding in a new building on the North Side, with Dr. Rob Garofalo. Advocate [Health Care] had one person, now four. We have more bodies doing the work. The University of Chicago on the South Side, in Woodlawn. We serve the West Side.

That’s good. But again, we have this problem with access. And we have this problem with retention in care. Young people don’t particularly understand the importance of staying on medication. They might take it one week and the next, say they don’t feel like taking it.

There will be more HIV testing. The question of *oops* will be asked and not ignored.

Every 10 years the research would say we’re going to have a cure. I’m hoping this 10-year span will bring some remarkable achievement so we have a vaccine or even a cure.

AIDSWATCH 2019

Photojournalist and advocate **Sean Black** looks at this year's annual effort to lobby Capitol Hill

TEXT AND PHOTOS BY **SEAN BLACK**

“If you missed this year's AIDSWatch then you've missed them all,” said AIDS United CEO Jesse Milan Jr., as he strode out of the Hart Senate Building heading for lunch before his next meeting on Capitol Hill. AIDSWatch is the nation's largest annual constituent-based HIV/AIDS advocacy event committed to ending the epidemic.

Like the famous cherry blossoms in full bloom, AIDSWatch has become a rite of spring in Washington, D.C. Now in its 26th year, AIDSWatch brought advocates together from 40 states as well as the District of Columbia and Puerto Rico, to lobby Congress on issues impacting the rights of the HIV/AIDS community and our ability to access quality and affordable healthcare. Many attendees this year strongly warned that some of the Trump administration's policies undermine progress, such as proposed changes to Medicare Part D.

Milan had just concluded a meeting with Senator John Boozman of Arkansas, a Republican and long-standing member of the HIV Caucus. Milan was joined by colleague Carl Baloney and three of Elizabeth Taylor's grandchildren—Quinn Tivey, Laela Wilding, and Naomi DeLuce Wilding—representatives of The Elizabeth Taylor AIDS Foundation (ETAF). Also present for the first meeting of the day with the Senator was ETAF ambassador Deandre Moore from Texas and foundation staff member Zakkariah Marquez, a native Californian. ETAF ambassadors Kelly Gluckman, Daniel Franzese, and Brian Sims were joined by ETAF staff member John Scott, and attended separate meetings with other lawmakers and their staff.

In the meeting with Milan were Latunja Stockwell and Ashley Young, both HIV advocates and constituents from Boozman's home state, where rates of teen pregnancy and HIV are still among the highest in the country.

Latunja, who works in higher education, shared a deeply personal story of how late into her second trimester she had to hitchhike after her car had broken down in order to get to her scheduled specialist OB-GYN's appointment. Her humbling and eloquent story quieted the room, which was followed by data-driven and researched rebuttals voicing concerns raised by the conservative senator.

The following day's plenary session focused on updates and training. Several arguments erupted during the discussion when Dr. Robert Redfield, director of the Centers for Disease Control and Prevention (CDC) presented. Dr. Redfield attended at the request of Milan to respond to President Trump's pledge during his State of the Union address to end the AIDS epidemic by 2030. The first outburst came over Dr. Redfield's repeated use of the word “infected” in describing people living with HIV, and the second (and more sustainable argument in my opinion, as Redfield has been a clinician for many years) was the issue of patents and profits on Gilead's Truvada, which many in the community argue obstructs widespread access to the drug known as PrEP.

According to a recent article in the New York *Daily News*, Milan asked Redfield, “Will the CDC request a review of the CDC's patents and Gilead's production of Truvada as PrEP in order to obtain possible royalties from Gilead as resources to fund the HIV preventive portfolio and PrEP access?”

TOP ROW: LATUNJA STOCKWELL AND ASHLEY YOUNG; CDC DIRECTOR ROBERT FEDFIELD, MD. **MIDDLE ROW:** KATIE WILLINGHAM; MICHAEL LUCIANO. **BOTTOM ROW:** AIDS UNITED CEO JESSE MILAN, JR., WITH ELIZABETH TAYLOR'S GRANDCHILDREN REPRESENTING THE ELIZABETH TAYLOR AIDS FOUNDATION, NAOMI DELUCE WILDING, QUINN TIVEY, AND LAELA WILDING; ARYAH LESTER, DEPUTY DIRECTOR OF THE TRANSGENDER STRATEGY CENTER.

"Well, I know you are not going to like my answer,'" Redfield responded, sparking further unrest. "I can't comment on any possible negotiations going on with any entity."

An undisclosed source pointed out, in Dr. Redfield's defense, that the issue surrounding patents and royalties would most likely need to be escalated to the U.S. Department of Health and Human Services (HHS), the federal agency that oversees the CDC.

"If anything, the session [with Dr. Robert Redfield] on ending the epidemic demonstrated not only his bravery, but also highlighted how much the government can learn from us and how much it needs to include us," said Aryah Lester, deputy director of the Transgender Strategy Center, who moderated the panel discussion. "From vocabulary to effectively addressing core community issues, the session was, in my opinion, the start of quite a different dialogue than we have had since the beginning of this administration. Community input by those living with HIV is imperative to ending the epidemic and the catalyst to allowing the administration to be educated by those most affected."

I agree with many colleagues that although uncomfortable and heated at times, the discussion never got out of control. Reactions I heard following the session ranged from "disrespectful to the esteemed doctor" to satisfaction over "heckling him off the stage," which I would argue never actually happened. I admire the doctor for allowing the strong criticism and reminding us of his own family experiences connecting him personally with concerns about and commitment to our cause. Dr. Michael Gottlieb, ETAF advisory board member and the doctor who first identified AIDS as a new disease in 1981, spoke in favor of the CDC director: "Bob is a personal friend and a friend to the cause. I don't think we need to beat up our friends."

To help further balance this critical debate, in his press statement following the President's remarks, Jeremiah Johnson of Treatment Action Group highlighted contradictions that greatly alarm the activist community and need to be addressed immediately. "As part of his State of the Union address, President Trump announced a ten-year plan to end HIV as an epidemic in the U.S. by 2030. The Act Now: End AIDS Coalition agrees with the President that we now have the tools to end the U.S. epidemic, even short of a cure or a vaccine, and that this will require prioritizing people and communities who are most affected by HIV infection and who experience poorer HIV-related health outcomes. But to date this administration has targeted these same communities in ways that worsen the U.S. epidemic by proposing drastic budget cuts to HIV research, prevention, and treatment programs domestically and globally; undermining healthcare access through the Affordable Care Act; and attacking sexual and reproductive rights and the human rights, safety, and health of transgender people, communities of color, undocumented immigrants, and other communities disproportionately impacted by HIV."

AIDSWatch, in my opinion, is hands-down the most empowering event an HIV/AIDS advocate could involve themselves in. The power of solidarity for people living with HIV/AIDS is palpable when we come together to hear one another, to debate and constructively challenge one another, and most importantly to resolve differences and leave united in our shared humanity. Dr. Redfield in his leadership position represents the powerful voice we need at this critical time. He must understand our frustrations. Contrary to some accounts of the event, I found his staying on stage demonstration of his resolve to negotiate and fight on our behalf.

"AIDSWatch is our moment to seize this historic opportunity to end this epidemic," said Milan. "We made our voices heard in Congress so that every person has access to the prevention, treatment, and care they need and deserve, so that we finally end new HIV transmissions, while securing the health of those living with HIV."

AIDSWatch is organized by AIDS United, along with the Treatment Access Expansion Project (TAEP) and the United States People Living with HIV Caucus (HIV Caucus). The Elizabeth Taylor AIDS Foundation is presenting sponsor and AIDSWatch is made possible by not only ETAF, but other generous sponsors as well. PA

GET INVOLVED with AIDSWatch 2020; go to aidsunited.org or etaf.org.

SEAN BLACK is a visual artist, college educator, and journalist living with AIDS. Follow him on Twitter: @seanblackphoto.

A next step for adults with HIV who have been undetectable* for at least six months.

*Undetectable means keeping the amount of HIV in the blood at very low levels (less than 50 copies per mL).

Important Facts about JULUCA

This is only a brief summary of important information about JULUCA and does not replace talking to your healthcare provider about your condition and treatment.

What is JULUCA?

- JULUCA is a prescription medicine that is used without other antiretroviral medicines to treat Human Immunodeficiency Virus-1 (HIV-1) infection in adults to replace their current anti-HIV-1 medicines when their healthcare provider determines that they meet certain requirements.
- HIV-1 is the virus that causes Acquired Immune Deficiency Syndrome (AIDS).
- It is not known if JULUCA is safe and effective in children.

How do I take JULUCA?

- **Take JULUCA 1 time a day exactly as your healthcare provider tells you.**
- **Always take JULUCA with a meal.** A protein drink alone does not replace a meal.

Do not take JULUCA if you

- have ever had an allergic reaction to a medicine that contains dolutegravir or rilpivirine.
- are taking any of the following medicines: dofetilide; carbamazepine; oxcarbazepine; phenobarbital; phenytoin; rifampin; rifapentine; proton pump inhibitors (including esomeprazole, lansoprazole, omeprazole, pantoprazole sodium, rabeprazole); St. John's wort (*Hypericum perforatum*); or more than 1 dose of the steroid medicine dexamethasone or dexamethasone sodium phosphate.

Before taking JULUCA

Tell your healthcare provider if you:

- have ever had a severe skin rash or an allergic reaction to medicines that contain dolutegravir or rilpivirine.
- have or have had liver problems, including hepatitis B or C infection.
- have ever had a mental health problem.
- are pregnant or plan to become pregnant. One of the medicines in JULUCA, called dolutegravir, may harm your unborn baby.
    - **You should not take JULUCA at the time of becoming pregnant or during the first 12 weeks of pregnancy.** Your healthcare provider may change your medicine during this time in your pregnancy.
    - If you can become pregnant, your healthcare provider will perform a pregnancy test before you start treatment with JULUCA, and you should consistently use effective birth control (contraception) during treatment with JULUCA.
    - Tell your healthcare provider right away if you are planning to become pregnant, you become pregnant, or think you may be pregnant during treatment with JULUCA.

Before taking JULUCA (cont'd)

Tell your healthcare provider if you (cont'd):

- are breastfeeding or plan to breastfeed. **Do not breastfeed if you take JULUCA.** You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby. It is not known if JULUCA can pass to your baby in your breast milk. Talk with your healthcare provider about the best way to feed your baby.

Tell your healthcare provider about all the medicines you take:

- Keep a list that includes all prescription and over-the-counter medicines, vitamins, and herbal supplements, and show it to your healthcare provider and pharmacist.
- Ask your healthcare provider or pharmacist about medicines that should not be taken with JULUCA.
- Do not start taking a new medicine without telling your healthcare provider.

What are the possible side effects of JULUCA?

JULUCA can cause serious side effects, including:

- **Severe skin rash and allergic reactions.** Call your healthcare provider right away if you develop a rash with JULUCA. **Stop taking JULUCA and get medical help right away if you develop a rash with any of the following signs or symptoms:** fever; generally ill feeling; tiredness; muscle or joint aches; blisters or sores in mouth; blisters or peeling of the skin; redness or swelling of the eyes; swelling of the mouth, face, lips, or tongue; problems breathing.
- **Liver problems.** People with a history of hepatitis B or C virus who have certain liver function test changes may have an increased risk of developing new or worsening changes in certain liver tests during treatment with JULUCA. Liver problems, including liver failure, have also happened in people without history of liver disease or other risk factors. Your healthcare provider may do blood tests to check your liver function. **Call your healthcare provider right away if you develop any of the following signs or symptoms of liver problems:** your skin or the white part of your eyes turns yellow (jaundice); dark or "tea-colored" urine; light-colored stools (bowel movements); nausea or vomiting; loss of appetite; pain, aching, or tenderness on the right side of your stomach area.
- **Depression or mood changes. Tell your healthcare provider right away or get medical help if you have any of the following symptoms:** feeling sad or hopeless; feeling anxious or restless; have thoughts of hurting yourself (suicide) or have tried to hurt yourself.
- **The most common side effects of JULUCA include:** diarrhea and headache.

These are not all the possible side effects of JULUCA. Tell your healthcare provider right away if you have any new symptoms while taking JULUCA. You may report side effects to FDA at 1-800-FDA-1088.

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THE LAST **GIFT**

Taking part in HIV cure research at the end of life

BY **SARA GIANELLA**, **JEFF TAYLOR**, **DAVEY SMITH**, AND **THE LAST GIFT RESEARCH TEAM**

'I'm glad I can provide a voice and maybe open the dialogue for people to talk about mortality, talk about how their lives can benefit others…'

MICHAEL "MAX" DANIELSON (ABOVE, RIGHT, WITH HIS PARTNER MIKE) DONATED HIS BODY TO HIV CURE RESEARCH IN MARCH.

PHOTOS COURTESY OF SARA GIANELLA WEIBEL

> *"When we love and give without expectation, we are at our finest."*
>
> —**PATRICK GRAY,** AUTHOR AND ACTIVIST

Most HIV research today is conducted with blood samples. But to cure HIV, we need a better understanding of how the virus hides in all the tissues. We also need to know if the virus circulating in the blood is the same as (or different from) the virus in the heart, lymph nodes, liver, genital tract, or any other tissues throughout the body.

The Last Gift is an end-of-life HIV research program being performed at the University of California San Diego (UCSD), with the goal of understanding the behavior of HIV throughout the human body. Altruistic people living with HIV who are terminally ill are eligible to participate in the Last Gift study. These people provide: 1) detailed clinical, risk, and socio-demographic information before their death (e.g., use of antiretroviral therapy [ART] and other therapies, surgical procedures, other infections, etc.); 2) regular blood draws while they are alive; and 3) donate their entire bodies after they die for the purpose of a rapid autopsy. So far, eleven people have enrolled, seven of whom have passed away. The Last Gift team was able to successfully perform each autopsy within the six-hour timeframe necessary to optimally preserve the integrity of the virus and tissues collected. These unique samples are invaluable in providing an insight to where the virus hides—so we can find ways to combat it, and hopefully find a cure one day.

Tony (Anthony) Bennett was the initial Last Gift participant. He enrolled in June 2017, after being diagnosed with end-stage Amyotrophic Lateral Sclerosis (ALS, aka Lou Gehrig's disease) and donated his entire body to HIV research after passing away July of the same year. Tony was a smart, kind, and altruistic person who loved dancing and always saw the positive in life. After learning about the end-of-life study, he immediately signed up with the support of his partner, Blake, and the rest of his family. During study interviews, Tony expressed what the study meant to him:

"It was really important to meet you and the Last Gift research team at this moment of my life to talk about your work and to share my story. This program helped me in a large way. Everybody in my family is proud of me and we all gained strength from this experience. I am happy to leave this little piece of myself behind. In this way, I feel that my legacy will not die with me.

"Being able to participate

in Last Gift at this point of my life makes me happy, and I am particularly proud to be number one. It provides me comfort and peace to know my remaining blood and tissues will help somebody else. …As a long-term survivor, I care deeply about the HIV community, and I am thankful for the opportunity to participate and provide this Last Gift to my people."

'As a long-term survivor, I care deeply about the HIV community, and I am thankful for the opportunity to participate and provide this Last Gift to my people.'

TONY BENNETT (ABOVE, SURROUNDED BY HIS PARTNER BLAKE AND A COUSIN) WAS THE FIRST TO TAKE PART IN THE LAST GIFT.

Michael (Max) Danielson was another generous Last Gift participant who donated his body to HIV cure research in March 2019. Like Tony, Michael was a long-term survivor of HIV who had been diagnosed with end-stage ALS. Michael quickly became a passionate advocate for the Last Gift study and a close friend to the entire team. He spent his last months of life maintaining his good spirit, tirelessly raising awareness and funds for HIV and ALS research, and advocating for the End-of-Life Option Act in California, which is currently being disputed in court. Below are a couple of quotes from Michael which exemplify his dedication to the study and HIV research:

"My death will not be in vain. It will allow me to leave a positive legacy and inspire others to give back.

"I believe in the work that is being done. I believe in the study's philosophy."

As a former publicist in Hollywood, Michael, with the help of his friend and award-winning director Terry Parrish, decided to document the last months of his life—including an extraordinary look into the day of his passing. This was part of his personal desire to advocate for greater participation in, understanding about, and support for the causes he championed, including The Last Gift Project. While in the midst of the documentary's production (running title: *Terminal Kindness*) Michael said:

"I'm grateful for the opportunity to do something that is, that will make all this meaningful. …I'm in a unique place to be able to participate in it. So, I'm glad that I can—with this documentary that's being produced—I'm glad I can provide a voice and maybe open the dialogue for people to talk about mortality, talk about how their lives can benefit others, and find meaning in all of this."

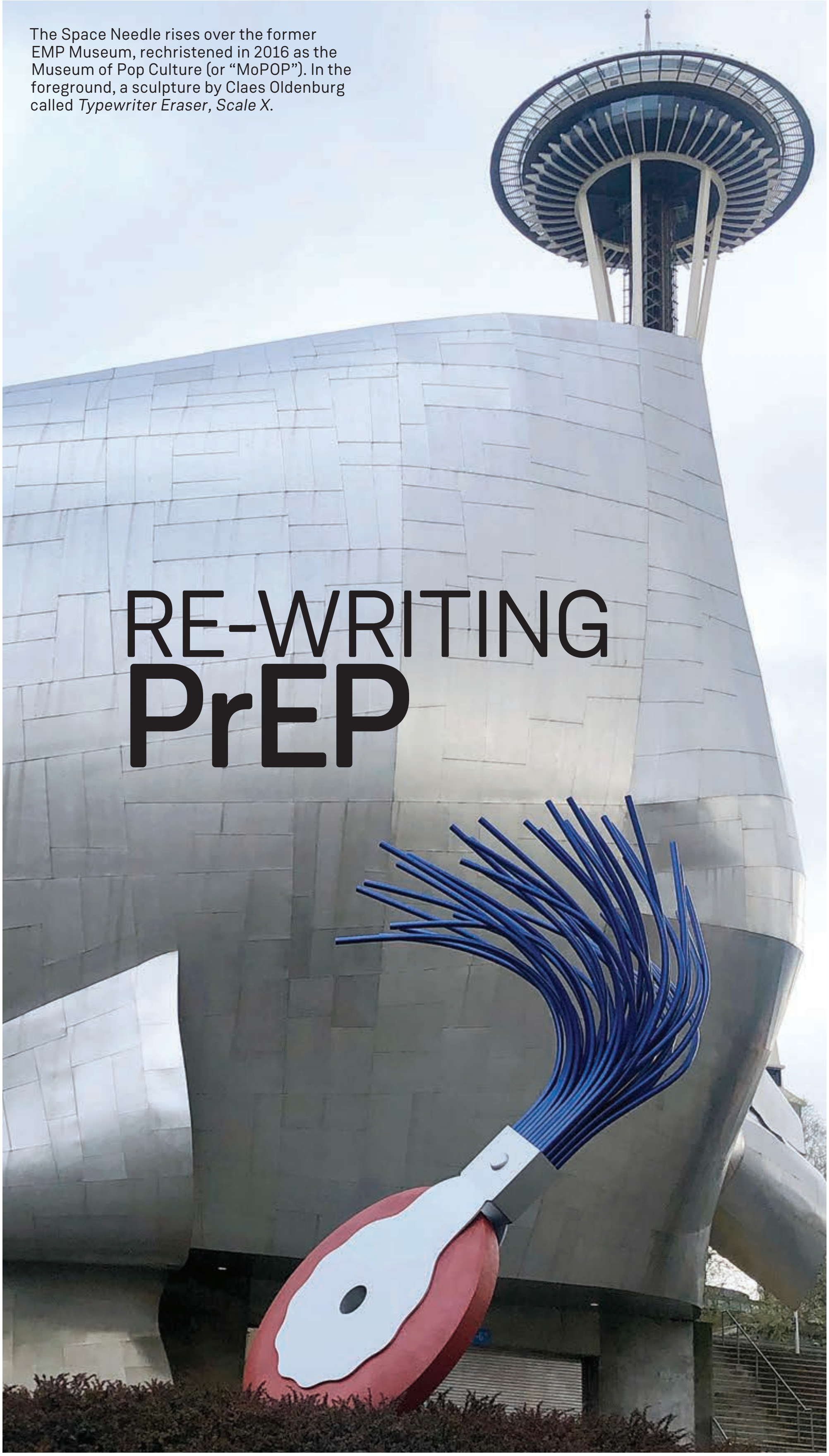
Tony and Michael are two examples of our exceptional cohort of Last Gift study participants. These two men lived with HIV for a long time, and at the end of their life decided to give the ultimate last gift to HIV cure science. Each of our study participants is unique and provides an indispensable piece to the big puzzle of HIV cure research. We hope to be able to further honor their important legacy by contributing to the field of HIV research.

"From our first breath to our last, each of us tells a unique story. Here, we honor our Last Gift participants for their altruism to further research into HIV and the human condition. We take this moment of silence to honor their gifts and express our gratitude for all the discoveries their selfless donations will yield."

—STATEMENT READ BEFORE THE MINUTE OF SILENCE PRECEDING EACH LAST GIFT AUTOPSY

FOR MORE INFORMATION about the Last Gift study, go to lastgift.ucsd.edu.

RE-WRITING PrEP



The Space Needle rises over the former EMP Museum, rechristened in 2016 as the Museum of Pop Culture (or “MoPOP”). In the foreground, a sculpture by Claes Oldenburg called *Typewriter Eraser, Scale X*.

PHOTO: BRIAN K. WELLS

Descovy for PrEP

Will it make much difference for HIV prevention?

BY **ENID VÁZQUEZ**

Now we know for sure—Descovy was found to be just as good as Truvada for preventing HIV.

That’s good to know, but how important is it?

The idea, of course, is that Descovy, the newer and kinder version of Truvada, would be safer to use for HIV PrEP (pre-exposure prophylaxis, or prevention).

Back in 2012, Truvada was a well-established HIV medication when it was approved by the FDA for **preventing** HIV infection in the first place. Today, it is considered 99% effective against HIV when taken as prescribed.

Then in 2016, the FDA approved a newer version of Truvada that’s safer on the kidneys and bones, Descovy. But you couldn’t take Descovy for PrEP, because the research wasn’t there.

The DISCOVER study results presented at CROI showed that of a large number of people put on either Descovy or Truvada for PrEP who were truly at high risk for HIV, almost none became infected with the virus. (See sidebar, “The DISCOVER Trial Data at One Year.”)

When comparing these individuals to a similar group not in the study but who had similar risks, however, you could see how truly effective both drugs are at preventing HIV infection.

Moreover, the high rate of STIs in the study was a clue that way more than 22 people would have become HIV-positive had they not taken the prevention medicine. Half of all individuals in the study had at least one STI, whether they were given Descovy or Truvada.

Does it make a difference now that Descovy can be taken for PrEP instead of Truvada? (In April, Gilead Sciences filed a supplemental New Drug Application [sNDA] with the FDA for Descovy for PrEP. If approved, this would mean a new use—called "indication" in the medical world—for Descovy.)

Yes, said Jenna Wimmer, a nurse practitioner from Howard Brown Health's clinic at TPAN, in Chicago. "For some older patients, who may have renal problems, it makes a difference," she said.

As usual, there are pluses and minuses to using a newer drug.

"Another once-a-day HIV prevention pill that's effective and well-tolerated?" said activist Jim Pickett. "That doesn't make me excited. An effective and well tolerated implant? That makes me excited. An effective and well-tolerated microbicide [inserted vaginally or anally]? That makes me excited." There are a number of ways that HIV PrEP can work, as he pointed out.

In terms of safety, side effects are more important for people using Descovy or Truvada long-term, as with HIV therapy. At this point in time, HIV treatment is meant to be lifelong. So, a small difference in safety may be important for people on HIV therapy.

PrEP, however, is often discussed in terms of "seasons of risk." For example, when someone is in a non-monogamous relationship, or is dating in hopes of finding a committed relationship.

Study presenter Brad Hare, MD, Chief of Infectious Diseases at Kaiser-Permanente, San Francisco, continuously fielded questions about the safety advantage of Descovy for PrEP.

"Our study did not have enough clinical outcomes either in the renal or the bone arenas to identify a difference between the two," he said in a press conference. "Both of those are so uncommon in these young, and in our study population, relatively healthy population. I think it's reassuring to know that both of these drugs actually do pretty well in terms of safety in this population. Whether we'll ever know if there's a clinical difference in outcomes would require a *huge* number of people and a long time of observation."

The difference in drug discontinuation for renal issues or any other adverse event with the two medications was not statistically significant, he said.

'For some older patients, who may have renal problems, it makes a difference.'

Another point to consider is that Truvada is expected to come off patent in another year or so. That means a cheaper generic version can be made available. Insurance payors might even insist on that version being used for PrEP. (A generic has been approved by the FDA, but is not commercially available.)

There may be, however, certain groups for whom Descovy would be preferred. Those with pre-existing kidney or bone problems, for example.

There's a seemingly never-ending search for better options. Just how much better Descovy for PrEP may be over Truvada remains to be seen.

BY THE NUMBERS

DISCOVER trial data at one year

THE DEMOGRAPHICS

- 5,387 individuals enrolled, from the United States (60%), Canada (7%), and Europe (34%). 94 sites from 11 countries participated.
- High risk for sexually acquired HIV required for entry into the study, defined as:
- 2 or more episodes of condomless anal sex in the previous 12 weeks **or**
- 1 episode of syphilis or of rectal infection of gonorrhea or chlamydia in the previous 24 weeks
- Other HIV risk factors included recreational drug use within the past 12 weeks and binge drinking (defined as having at least six drinks on one occasion, every month)
- At least 60 eGFR (estimated glomerular filtration rate), a measure of kidney function, was required for participation
- Ages 18–76 (half were under age 34)
- White (84%), black (9%), Asian (4%), Hispanic or Latinx ethnicity (25%)
- Transgender women: 45 on Descovy (2%); 29 on Truvada (1%); all other participants were men who have sex with men (MSM)

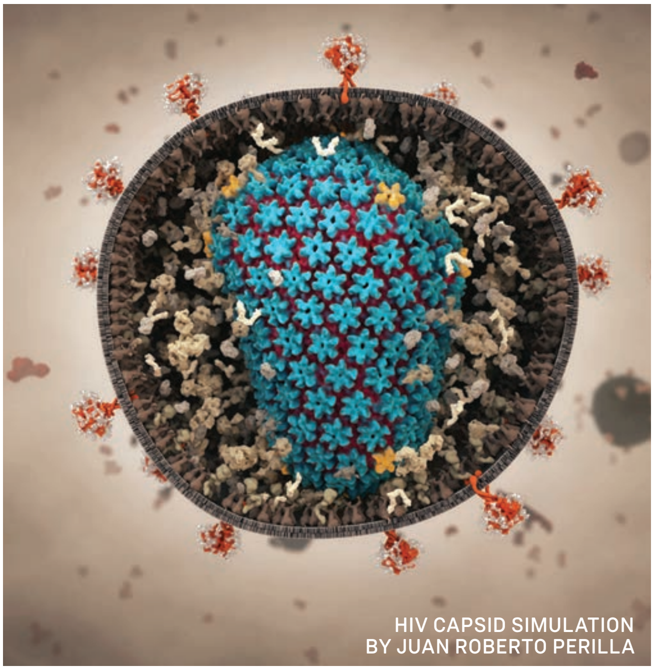
THE STUDY

- 2,694 were put on Descovy (one pill a day)
- 2,693 were put on Truvada (one pill a day)
- All given an extra placebo pill to take so they wouldn't know whether they had been given Descovy or Truvada
- Other prevention services provided included risk reduction counseling, condoms, and lube

THE RESULTS

- At 48 weeks, 2,242 remained on Descovy (83%) and 2,263 remained on Truvada (84%)
- Most frequent reasons for dropping out of the study were: withdrawal of consent; moved; monogamous relationship; reduced sexual risk; and obligations related to work, school, or the military.
- 7 HIV infections on Descovy: 1 suspected infection at baseline; 5 with low levels of medication; 1 with medium level of medication. 15 HIV infections on Truvada: 4 suspected infections at baseline; 10 with low levels of medication; 1 with high level of medication. The difference in infection rate between Truvada and Descovy was not statistically significant.
- Compared to CDC surveillance data on HIV risk for MSM (more details at croiconference.org), the infection rate was:
    - 4.02 per 100 person years (PY) for MSM not on PrEP
    - 0.45 per 100 PY for DISCOVER participants on Truvada
    - 0.08 per 100 PY for DISCOVER participants on Descovy
- Side effects: Both were found to be safe and tolerable. However, two of the individuals taking Descovy and six who were taking Truvada discontinued the medication due to renal issues. One person on Truvada developed Fanconi syndrome (a kidney-related malfunction).

DRUGS IN DEVELOPMENT


HIV CAPSID SIMULATION
BY JUAN ROBERTO PERILLA

Monthly injections plus inhibitors of viral capsid and maturation

BY **ENID VÁZQUEZ**

Switching to a once-monthly treatment: ATLAS and FLAIR at 48 weeks

There were good results from two separate studies of once-monthly injections for HIV.

At one year in the studies, individuals receiving the monthly injections saw similar efficacy compared to those who continued to take oral HIV therapy.

The two injections consisted of long-acting cabotegravir and long-acting rilpivirine, given separately.

In the ATLAS (Antiretroviral Therapy as Long-Acting Suppression) study, 93% of the injection group had undetectable viral loads compared to 95% of the group taking the established and proven pills already on the market. All 616 individuals in the study started out with undetectable viral load on at least six months of oral HIV therapy.

Of the persons receiving the injections, 75% had injection site pain (231 individuals), with 1% (four of them) withdrawing from the study because of it.

The majority of those getting shots (nearly 100%) in both studies, however, reported **a preference for the monthly shots over daily pills**. Not all patients had injection site reactions or had them every time.

Dr. Susan Swindells, who presented the ATLAS results, reported, "My patients [at the University of Nebraska Medical Center in Omaha] say they like not having to take a pill every day and not having to remember their HIV every day." They also felt less stigma with not having to worry about roommates or co-workers finding their pill bottles. "It has surprised me how much people do like it."

In the FLAIR (First Long-Acting Injectable Regimen) study, 93.6% of the individuals given monthly injections had undetectable viral load vs. 93.3% of the pill group. There were 283 persons in each group. While 82% of the injection group had injection site reactions, they were reported as mild to moderate (Grade 1 or 2), with a median duration of three days, and decreasing in frequency over time.

Undetectable viral load was defined as less than 50.

Another study, ATLAS-2M, is looking at dosing every two months.

See Abstracts 139 and 140 LB, which also link to the oral presentations. The two-drug medication, which is expected to receive FDA approval late this year, is listed in PA's 2019 HIV Drug Guide (positivelyaware.com/la-cab-rpv). See also "Built to Last" in the January + February issue of PA.

What is a capsid? New drug on the horizon

Gilead Sciences reported early results with a new type of HIV medication, also given via an injection. **This drug might only need to be taken once every three months.**

The results are so early, this is the first data in humans. And they were so-called "healthy" test subjects, not living with HIV or other disease.

GS-6207 is an HIV capsid inhibitor. Think of a capsule. HIV has a membrane-like envelope around it that's called a "capsid." (This is the first HIV capsid inhibitor ever to go into development.)

Gilead reported GS-6207 was safe and well-tolerated in the 38 individuals who were given one injection. Doses given were 30, 100, 300, or 450 mg. Another two individuals were given a placebo.

The study is ongoing for 20 weeks.

See Abstract 141, which also links to the oral presentation.

Maturation inhibitor

Pharma giant GlaxoSmithKline (GSK) no longer produces HIV medications, but instead puts its HIV drug development into a company off-shoot, ViiV Healthcare. Nevertheless, GSK presented **early data in 33 individuals who were off their HIV therapy and given one of four doses of GSK2838232**. All doses (20, 50, 100, or 200 mg) were boosted by another med, cobicistat, to achieve greater levels in the blood.

The researchers reported that the tolerability and antiviral activity demonstrated over the 10 days of dosing provided proof-of-concept for taking GSK2838232 (or 232 for short) forward in development.

232 is a second-generation maturation inhibitor. It works differently from previous maturation inhibitors that fell to the wayside during research.

Five individuals experienced six adverse events that were considered mild and related to the drug: headache, somnolence (sleepiness or drowsiness), rash, abnormal dream, and pruritus (itching).

See Abstract 142, which also links to the oral presentation.

A proof-of-concept study of a follow-on maturation inhibitor in development, GSK3640254, is open but not yet enrolling as of press time. (ClinicalTrials.gov Identifier: NCT03784079)

GO TO POSITIVELYAWARE.COM to view the illustration, "An ensemble cast," in the 2019 POSITIVELY AWARE HIV Drug Guide to see where the capsid inhibitor, maturation inhibitor, and other antivirals work.

HIV CURE **RESEARCH** HIGHLIGHTS

Has a second person been cured?

BY **KARINE DUBÉ**, **JULIE PATTERSON**, **LIZ BARR**, **DANIELLE M. CAMPBELL**, AND **MICHAEL LOUELLA**

The London Patient: A second case of sustained HIV remission

Of the many HIV cure research-related highlights from CROI this year, perhaps one of the most significant was the announcement of a second case of sustained HIV remission following a stem cell transplant similar to the one received by Timothy Ray Brown, the "Berlin Patient," in 2007.

At this time, **scientists are cautious with the terminology used to describe the case**. It is too early to determine if the London Patient has been "cured" of HIV by clinical standards. His case shows that HIV remission may be possible with a less aggressive approach than the one received by Timothy. However, this cure strategy would only be suitable for people living with HIV who also have a concomitant very serious cancer.

Ravindra K Gupta, from the University College London, described the case of the so-called "London Patient," who was diagnosed with HIV in 2003. Ten years later, the patient developed Stage IVb Hodgkin lymphoma, a cancer of the lymphatic system. The patient received an allogeneic stem cell transplantation from a donor who was homozygous for the CCR5 gene deletion. Individuals with this gene have a natural resistance to HIV infection.

The London Patient has now gone 18 months off ART (antiretroviral therapy) without resurgence of HIV. No detectable virus was found in his blood using a very sensitive assay, called the QVOA (Quantitative Viral Outgrowth Assay). Of note, the London Patient has also been in remission for his lymphoma since December 2017. Watch a webcast of the presentation at: bit.ly/CROInews1.

The study was led by the IciStem consortium, and supported by amfAR, the Foundation for AIDS Research.

Another case, referred to as the "Düsseldorf Patient," who received a similar transplant and has been off ART for four months, was also described during a poster session. bit.ly/CROInews2

For more information

Treatment Action Group: Statement on New HIV Remission Case from Stem Cell Transplantation Study treatmentactiongroup.org/content/treatment-action-group-statement-new-hiv-remission-case-stem-cell-transplantation-study

***POZ* magazine:** A 2nd Man's HIV is in Long-Term Remission, but Is he Cured? poz.com/article/2nd-mans-hiv-longterm-remission-cured

New York Times: HIV is Reported Cured in a Second Patient, A Milestone in the Global AIDS Epidemic nytimes.com/2019/03/04/health/aids-cure-london-patient.html?smid=nytcore-ios-share

2019 Pre-CROI Community HIV Cure Research Workshop Summary

The 2019 pre-CROI community HIV cure workshop took place in Seattle on March 3, bringing together community activists and biomedical scientists to discuss emerging topics in the HIV cure research field. Following are select highlights.

MORNING SESSION

Liz Barr presented a "**Landscape Analysis of HIV Cure-Related Trials**," conducted by the Treatment Action Group (TAG). TAG reported 129 HIV cure-related studies by the end of 2018. Most HIV cure-related studies were conducted in the U.S. and France; 32 of them were found to have an analytical treatment interruption. Based on the small sample of survey respondents who were able to provide information about participants' sex, it appears that the overwhelming majority of participants in HIV cure trials are male (73% male and 27% female) and many HIV cure studies only recruited males. Most common community concerns related to analytical treatment interruptions and HIV drug resistance. TAG is advocating for better completion of clinical trial information found on clinicaltrials.gov, for greater equity in HIV cure research recruitment (with respect to sex/gender and race/ethnicity), and for meaningful community and patient engagement in study design. youtu.be/pTTbWug1MLw

Lynda Dee, Delaney AIDS Research Enterprise (DARE) and amfAR Institute for HIV Cure Research Community Advisory Board, presented the **recommendations for analytical treatment interruptions in HIV cure research**, following a consensus meeting at the Ragon Institute in July 2018. The meeting focused on four key topics: 1) benefits and risks of analytical treatment interruptions, 2) risk mitigation strategies using eligibility criteria, 3) monitoring and ART resumption criteria, and 4) ethical considerations. The detailed outcomes of the consensus meeting was scheduled to be published in *Lancet HIV* in early April 2019. youtu.be/RHAivzIPu80

Michael Louella, defeatHIV Community Advisory Board, and **Karine Dubé**, UNC Gillings School of Global Public Health, discussed **ethical issues in cell and gene therapy research**, following the use of CRISPR-Cas9 technology to edit genes for the HIV co-receptor CCR5 in human embryos in China. He Jiankui made a public announcement of his questionable research in November 2018, generating an international public outcry on the use of germline editing. The risk-to-benefit ratio was unfavorable for this experiment advertised as an "AIDS Vaccine Development Project." Louella and Dubé provided an overview of the many ethical issues that gene therapy research raises and called for community education and engagement as gene therapy research is implemented. They reported that the FDA is strengthening regulations around cell and gene therapies, and that the World Health Organization (WHO) also formed a committee to guide editing of human genes globally. A lively discussion of the issues sparked by this case raised more questions for the attendees to contemplate. youtu.be/f9gm8C8u2us

Josh Schiffer provided an overview of **anti-proliferative therapy for decreasing the HIV reservoir**. Cellular proliferation—or the increase in the number of cells as a result of the natural processes of cell growth and cell division—has been linked to the persistence of HIV in the body while on ART. Dr. Schiffer and

his colleagues believe that continuous, modest reductions in latent cell proliferation would deplete the latent reservoir more rapidly than current kick-and-kill strategies. He explained that this anti-proliferative strategy requires less potency than latency-reversing agents. One anti-proliferative compound being investigated is called mycophenolate mofetil (MMF), which specifically targets B and T cell lymphocytes. MMF may be teratogenic, meaning it can be harmful to a fetus, currently limiting the ability of testing the drug in women of child-bearing potential. A clinical trial is under way at Harborview Medical Center. The investigational drug has been well tolerated so far in four study participants.
youtu.be/LIOYqqMtm6o

AFTERNOON SESSION

Carl Dieffenbach, of NIAID (National Institute of Allergy and Infectious Diseases), provided **a primer on HIV cure research**. Dr. Dieffenbach described the importance of having accurate measurements of the HIV reservoir and shared his hope for a new test developed by the Siliciano laboratory that can accurately capture the number of intact and defective proviruses. If correct in his assessment, this new test may prove as important to the effort to cure HIV as the viral load tests were to our ability to begin to curb the epidemic. Dr. Dieffenbach explained various pathways being investigated towards ART-free HIV remission, including stem cell transplantations (for people living with HIV who have concomitant cancer), cell and gene therapy, therapeutic vaccines, broadly-neutralizing antibodies, and latency-reversing agents. Dr. Dieffenbach's key message was that hints of success are starting to appear in the HIV cure research field.
youtu.be/OiebxDwwwVY

Deborah Persaud, Johns Hopkins School of Medicine, provided **an update on pediatric HIV cure research**. Globally, there are 180,000 new HIV diagnoses among children, and only 52% of them have access to ART. Dr. Persaud explained that we still need to pay attention to perinatal HIV infection in the U.S. The Mississippi baby (2013) is the most famous case of ART-free HIV remission in an infant, but Dr. Persaud also described other less well-known cases of post-treatment control in children and adolescents. She also reviewed two major ongoing pediatric HIV cure trials, including IMPAACT P-1115 (very early intensive treatment) and IMPACT-P-2008 (monoclonal antibody VRC-01).
youtu.be/yTBCaWags2k

Monique Nijhuis, IciStem consortium, presented on **stem cell transplantation as a strategy for curing HIV infection**. People living with HIV have a higher chance of cancers that begin in the cells of blood-forming tissue, such as the bone marrow, or in the cells of the immune system. They also have a lower survival rate after an allogeneic stem cell transplant than matched HIV-negative controls. The IciStem consortium is an international collaboration established to guide and investigate the potential for HIV cure in people living with HIV with cancers that need a stem cell transplant for treatment. The consortium maintains a database of people with the HIV-resistant gene and has identified over 22,000 donors with the gene to date. The two recent announcements of potential HIV cure from CROI 2019, the London Patient and the Düsseldorf Patient, both came through the IciStem consortium's work.
youtu.be/o-qQvPWnkY0

Moses Supercharger, 2017 AVAC fellow, described **African myths and misconceptions around HIV cure**. The African continent currently has over 27 million people living with HIV. A major misconception is that HIV suppression is equivalent to HIV cure. Supercharger thinks we need greater education around HIV reservoirs that remain dormant inside the body, and increased emphasis on ART adherence across the continent. The people of Africa must be welcomed into the work towards a cure for HIV now, while it is still in its infancy, or we will confront the same challenges that currently inhibit the implementation and uptake of ART and PrEP in the parts of the world that could most benefit from them.
youtu.be/_HTi5Mf6vUo

A. Toni Young, BELIEVE Community Advisory Board, led a panel discussion with **Rob Newells**, amfAR Institute for HIV Cure Research Community Advisory Board; **Jeff Taylor**, amfAR Institute for HIV Cure Research and CARE Community Advisory Boards; **Itai Jeffries**, Seattle Indian Health Board; **Tranisha Arzah**, defeatHIV Community Advisory Board; **Danielle Campbell**, DARE Community Advisory Board; and **Laurie Sylla**, defeatHIV Community Advisory Board, on **concepts and perceptions of HIV cure research**. The panel emphasized the need for meaningful community engagement and education at every step of the research process, particularly given the complexity of HIV cure science. This panel spotlighted health equity and social justice as a reminder that we must continue to engage those who are missing from the conversation yet overrepresented in the HIV epidemic, including women, people of trans experience, Black and Latino MSM, and American Indian/Alaska Native people. Researchers and advocates alike must do better to reach all racial/ethnic monitory communities, including those not explicitly listed here. Several participants raised the role of the U = U (Undetectable equals Untransmittable) movement and its relationship to HIV cure research, as effective treatment may contribute to reluctance around participation in cure-related trials.
youtu.be/BzLXeY45qsk

It's a tradition to celebrate the anniversary of a lifesaving bone marrow transplant as a rebirth. With that in mind, the workshop organizers ended the day-long event by celebrating the 12th "birthday" of one of the world's best known transplant survivors: Timothy Brown. On February 7, 2007, Brown underwent a last-ditch effort to cure his life-threatening leukemia. But what makes him different from other transplant survivors worldwide who have been reborn free of leukemia and other blood cancers is that thanks to the donor for his transplant he became the first person in the world to also be cured of HIV. Surviving and thriving to this day, Brown reminds us that we still need to advocate for funding and educate the public about the impact that a cure for HIV would have on society, while understanding the complex ways that a cure would impact people living with the virus.
youtu.be/qovD_s_tgTY


'BIRTHDAY' CELEBRATION

PHOTO COURTESY OF MICHAEL LOUELLA

HEALTHINESS IN HIV

A look in the poster hall

One of the most interesting parts of CROI is the poster exhibition hall. Over 1,000 poster abstracts are displayed over three days, and you can stroll through and speak with the study authors about their findings. Here are just a few that caught my eye. —JEFF BERRY

POSTER 303

Zinc Supplementation and Inflammation in Treated HIV

Many people living with HIV have a zinc deficiency, which has been linked with disease progression and an increased risk of death. Sahera Dirajal-Fargo and colleagues at Case Western Reserve and University and Rainbow Babies and Children's Hospital in Cleveland, Ohio, randomized 52 individuals to receive either zinc gluconate capsules 45 mg (low-dose) or 90 mg (high-dose) elemental zinc daily for 16 weeks. The goal was to evaluate the effect of zinc supplementation on inflammation and monocyte activation in ART-treated HIV. Participants in the low-dose arm were significantly older (54 vs. 47 years). Overall, biomarkers decreased when the arms were combined, and reductions "were meaningful with large effect size" according to study authors. In conclusion they stated that zinc supplementation is safe and effective at increasing zinc levels in participants who are HIV-positive and on effective ART; that it decreases biomarkers known to be abnormally elevated in this group; and "in treated HIV [zinc supplementation] has the potential to be an effective agent in decreasing microbial translocation and improving gut epithelial barrier dysfunction."

POSTER 669

Risk Factors for excess weight gain following switch to integrase inhibitor-based ART

Weight gain following initiation of antiretroviral therapy (ART) occurs with all modern regimens. Recent reports from small studies suggest that integrase strand transfer inhibitor (INSTI)-based ART may be associated with excess weight gain. In a cohort of adults with HIV on suppressive ART and long-term observational follow-up after participation in ACTG interventional trials, participants had to have enrolled in one of two ACTG studies (A5001 or A5332) between 2007 and 2017, switched to INSTI-based ART during follow-up, and then followed up to two years before and after switching to an INSTI in those whose viral load was less than 200 copies/mL at the time of switch.

Study authors concluded that,

- Annual within-person weight gain increased following switch to INSTI-based ART.
- Increases in weight gain following switch to INSTI were most prominent for women, blacks, and persons age 60 or older.
- Compared to pre-switch weight changes on stable suppressive ART, these data suggest post-switch increases in weight/fat mass greater than expected for age.
- Change in rate of weight gain following switch to INSTI appears greater with dolutegravir than elvitegravir or raltegravir.
- Although further studies are needed, choice of NRTI backbone may modify INSTI- associated weight gain.
- The cardiometabolic implications of increased weight gain following switch to INSTI-based ART need to be established."

For more information go to CROIconference.org to view a webcast of a Wednesday, March 6 themed discussion titled, "Weight Gain During ART," or enter "weight gain" into the search bar for more posters on the topic.

POSTER 703

Glycemic Control and Cognition Are Independently Associated with Gait Speed Decline

Another ACTG study, A5322 or HAILO (HIV Infection, Aging, and Immune Function Long-term Observational Study) is a longitudinal, observational study of 1,035 PLWH who were over the age of 40 at the time of enrollment.

Study author MC Masters and colleagues point out that "slow gait speed is an established predictor of functional impairment and mortality in older adults. Persons living with HIV (PLWH) exhibit accelerated decline in physical function and high rates of frailty. The goal of this study was to identity characteristics associated with development of impaired gait speed in older HIV-infected adult HAILO participants."

The study looked at 929 PLWH aged 40 years and older with gait speed and neurocognitive evaluations. Participants were categorized into four groups based on their gait speed over time. PLWH who developed slow gait were compared to those who retained normal gait speed. Participants who entered the study with slow gait speed and improved to normal speed were compared to those whose gait remained slow.

Study authors concluded that "increased levels of hemoglobin A1C, NCI, and black race are associated with gait speed decline among PWH; persons with these characteristics may benefit from early gait speed screening and intervention."

A MEETING OF THE MINDS: Community journalists gather at the CROI Community Reception. From left: Liz Highleyman, Kenyon Farrow, Enid Vázquez, Jeff Berry, Myles Helfand.

New era, new needs

TPAN's new Positively Aging program offers support

BY **ENID VÁZQUEZ**

TWIN POWERS: CHRIS MANVEL (LEFT)) AND CURTIS SANDERS

PHOTO: RICK GUASCO

I call them "the twins" because they started working at TPAN on the same day, and for the same new program, Positively Aging. Plus, they have beautiful matching smiles, and even similar-sounding names.

Together, Chris Manvel and Curtis Sanders offer comprehensive mental health, case management, and outreach services specifically to older adults age 50 and up who are living with HIV.

Positively Aging is the newest program at TPAN, the non-profit organization that publishes POSITIVELY AWARE. PA editor-in-chief Jeff Berry and other TPAN staff members helped create the new initiative.

This new collaboration with The Reunion Project, the national peer-driven support network for long-term survivors, allows TPAN to increase direct services and to create new ones for older persons living with HIV in Chicago. In addition, The Reunion Project will expand its support network through its unique "town hall" programs. Information about the project and issues surrounding aging with HIV will be shared with POSITIVELY AWARE's national audience.

Chris is a mental health specialist. Before coming to TPAN, he served as a chaplain at Chicago's Rush University Medical Center, and as a bereavement counselor for nearly two years at North Shore Hospice, helping the families of terminally ill patients.

"For me, one of the most exciting things about Positively Aging is that this is a new program for a new group with unique needs," says Chris. "It's great that people are living longer, but issues such as isolation, depression, PTSD, and stigma can negatively impact adherence and quality of life. So much more work still needs to be done."

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—CHRIS MANVEL

Curtis has worked 14 years in social services, mostly in HIV prevention. As Positively Aging's community engagement specialist, he coordinates TPAN's wide-ranging services to match his clients' needs, such as housing, case management, and integrated access to the onsite medical clinic run by Howard Brown Health.

"It's a new group in terms of a specific category," he says. "But older adults have already been receiving services." Now, however, there will be services tailored to unmet needs.

He was surprised to learn that most other organizations he's contacted don't have support groups—either for younger or older people.

Positively Aging continues to take shape, responding to feedback from the clients it serves. TPAN's client advisory group has already made suggestions. Areas of need that have been cited include physical health; loneliness and relationships; depression, trauma, and suicide; and practical aspects of aging, such as dealing with health insurance.

For now, Positively Aging is planning at least three educational month-long programs this year, which offer emotional support, under the care of Chris and Curtis. The Reunion Project will coordinate two additional town halls, with the first one taking place in Chicago in June.

At the conclusion of each program, participants will get to choose a social outing, such as going to dinner or seeing a play. They can continue to talk in a monthly support group, with transportation and meals provided. Chris will also provide individual therapy.

As noted in the March + April issue of PA, "the program will incorporate group social activities to address the isolation known to impede access to care for older adults."

When TPAN was founded in 1987, its members formed a social support network intended to help them survive. Today, people are living with HIV longer than imagined back then. Surviving into a new age comes with complications specific to that era. Positively Aging helps people with these new vulnerabilities.

FOR MORE INFORMATION go to tpan.com/positively-aging.

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