POSITIVELY AWARE

HIV TREATMENT, PREVENTION AND HEALTH FROM **TPAN**
NOV+DEC 2021

4:31 PM:
PHILADELPHIA,
PENNSYLVANIA
"Living, loving,
and playing."
—ANDRENA INGRAM

A DAY

EVERYDAY MOMENTS IN EX

FRONT COVER(S) BACKSTORY

ONE ISSUE, FOUR COVERS. POSITIVELY AWARE's annual anti-stigma campaign portrays 24 hours in the lives of people affected by HIV. On September 22, 2021, people photographed a moment of their day, posted the pictures to their social media and shared their stories with the hashtag #adaywithhiv. In addition to a selection of photos appearing on pages 37–42, there are four versions of this issue's foldout cover. An online gallery is also on view at adaywithhiv.com.

4:31 PM: PHILADELPHIA, PENNSYLVANIA
"Living, loving, and playing." —**Andrena Ingram**

9:55 AM: PHOENIX, ARIZONA
"Being transgender, gay, and HIV-positive are all parts of me but they aren't the whole of what defines me. I am a leader, a healer, a therapist, a friend, a trailblazer, an entertainer, and a role model. A day with HIV is just another day to make a difference in this life." —**Elijah Palles**

9:48 AM: PHILADELPHIA, PENNSYLVANIA
"Who would have thought I would give birth to a baby? That was one of the first questions I asked when I was diagnosed 13 years ago. My baby was born today." —**Ciarra Covin**

3:00 PM: STOKE-ON-TRENT, UNITED KINGDOM
"Celebrating my 80th birthday. HIV-positive for over 37 years. A Day with HIV is another chance to enjoy life to the full and do something useful." —**Maurice Greenham**

12:21 PM: NAIROBI, KENYA
"Find yourself in those things that make you human."
—**Ruele Okeyo**

7:12 PM: AUSTIN, TEXAS
"Advocating against voter suppression to ensure Texas Black women and other women of color maintain the fundamental right to vote at every level of government."
—**Michelle Anderson**

8:30 AM: WESTPUNT, CURAÇAO
"Grateful to make it to my 40th year here on planet Earth. Ready to be seen." —**Christian Kelly**

8:00 PM: SACRAMENTO, CALIFORNIA
"Picking 200 pounds of tomatoes at a local farm to can for food security." —**Irene**

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TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals living with HIV 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.

NOV+DEC 2021

POSITIVELY AWARE • VOLUME 31 NUMBER 7 • positivelyaware.com • @posaware

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A SPECIAL MESSAGE

You can make an impact

"POSITIVELY AWARE saved my life." We've heard that from readers more than once over the years, but each time it affirms for us that the work we do makes a difference. When you support POSITIVELY AWARE (PA) as an Impact Member, you help TPAN deliver critical HIV health news, treatment information, peer stories, and inspirational profiles to people affected by HIV. With every issue, we serve more than 100,000 readers—including long-term survivors of HIV, individuals living in isolation who turn to PA as their confidential, go-to health resource, and care providers working to better serve our HIV-affected communities.

"Over the past 18 months we've learned the effect that mis-information and dis-information can have during a pandemic," says TPAN CEO Kara Eastman. "It is now more important than ever that there are trustworthy resources such as POSITIVELY AWARE to inform, educate, and uplift the communities we serve."

Our readers consistently tell us that they turn to PA to help make sound, informed decisions about their health. "The more I learn, the better equipped I am to teach," one health educator said.

Readers also tell us that PA uplifts and inspires. "I am an HIV advocate and love to read POSITIVELY AWARE!"

Because of subscribing members and supporters like you, we tackle important issues and help individuals living with or vulnerable to HIV on their journey. Many readers express concern about aging well with HIV. One asked, "How am I going to survive financially in retirement? I did not plan on living this long."

When you subscribe and donate as a PA Impact Member, you are an integral part of our mission. You help make sure that PA reaches more readers who need us and PA's trusted resource of accurate, up-to-date treatment information and important news for people living with HIV/AIDS as well as our advocates. Every issue, PA arrives in mailboxes, non-profit and health care settings, and readers' hands around the country and the world, reaching some of our most isolated peers and community members. Most notably, POSITIVELY AWARE is free to anyone who is living with HIV or unable to pay. This is our mission.

Go to our website at www.positivelyaware.com/impact or contact us using the information below to make a monthly recurring gift of $5 or more to become a PA Impact Member. Your support not only carries membership benefits for you, it helps us uplift all communities affected by HIV.

Impact Membership includes:

- An annual subscription to PA's print edition (6 issues per year, mailed discreetly to you)
- PA's annual HIV Drug Guide. Your handbook to the medications prescribed for HIV, along with the latest HIV treatment news
- A subscription to PA Update, our bi-monthly digital newsletter, alerting you to the latest issues and stories

Make your monthly recurring PA Impact Member contribution today, or a one-time donation, by texting **ISupportPA** to 44-321 or go to www.positivelyaware.com/impact. Your support will make a difference in the lives of those living with and affected by HIV—and you may help save a life.

In gratitude,

Jeff Berry
EDITOR-IN-CHIEF

IMPACT MEMBER PA POSITIVELY AWARE

Help POSITIVELY AWARE make a difference in the lives of people affected by HIV

EDITOR'S NOTE

JEFF BERRY
@PAeditor

Communities left behind

Aging is hard. And not for the reasons I used to think when I was younger. I'm not talking (necessarily) about the skin tags or body changes, the lapses in memory, or the (sometimes) decreased sex drive. I'll save those for another column.

No, the hard part of aging for me lately has been the loss of friends and acquaintances, or the anticipated loss. In the last few months, several people I know and am close to are experiencing serious health challenges. The rational part of my brain says that some of this is just a natural part of aging, which I guess it is, if you are lucky enough to have survived into your sixties, with or without HIV. But the emotional part of me is, well, emotional at times. Add to that an entire generation of gay men of a certain age, like me, as well as many straight folks, many of whom never had children, and it's downright scary. Who will care for us as we age?

We need an HIV and aging infrastructure plan. Many of our community-based organizations and AIDS service organizations are aging and ailing themselves, and in dire need of an infusion of funding, expertise, and innovative ways of thinking and approaching the many challenges we face as a community. COVID has permanently altered the landscape, in ways that we are only just beginning to see and understand. One example is telehealth and telemedicine—we talk about hybrid services but are ill-equipped individually, as organizations, and as a community to plan, design, and deliver quality services that combine in-person appointments, meetings, and events with technology that will enhance those experiences. There are varying levels of comfort among people with meeting in person, and some of us have realized that we can be just as productive, if not more so, working remotely and using technology as being in an office every day. But there is nothing like coming together and interacting socially with each other and in groups in certain instances. How do we find a way to use technology to our advantage, and at an affordable price, rather than wait passively until technology finds a way to use us (Facebook algorithms anyone?).

Aging has never been prioritized by the policies we put in place or by the culture we live in, and yet it's what we all strive for, right? To make it to a point where we can look back and reflect, and take time for ourselves to do the things we enjoy. *To discover the wisdom that comes with age.* At least that's what's been drilled into us for most of our lives. What if, *what if*, we did something radical, like look inward and reflect *now*, and take the time to do the things we enjoy most *now*. To tell the people we love and care for the things we appreciate and love about them most, and what they truly mean to us. As life shows us, and this latest pandemic has taught us all, nothing in life is guaranteed. Take nothing and no one for granted—our time here is short.

Just as the aging community has in many ways been left behind, there are entire communities that have been left behind and overlooked in our fight against HIV. In this issue you'll learn about four people who are straight who have overcome immense odds to live a better life with HIV, even when there weren't always services geared toward them. People involved with the criminal justice system are often left out of the conversation, and the Prison Journalism Project is working to change that. You'll read about some amazing women of trans experience, and why it's necessary to have people with lived experience leading the efforts to end the epidemic in their communities. If we are ever going to end the HIV epidemic, we will need to employ (literally) those who are most disproportionately affected.

> Just as the aging community has in many ways been left behind, there are entire communities that have been left behind and overlooked in our fight against HIV.

This issue also features POSITIVELY AWARE's annual *A Day with HIV* anti-stigma campaign, now in its 12th year. The idea is to take a photo and include a caption that captures a moment in one day to show what it means to live in a world with HIV, and once again it inspired hundreds of submissions from around the globe. Among the four different covers created for this issue, one is special to me, and makes me smile. It's the one featuring Baby Zuri, who was born on September 22, 2021, A Day with HIV. Zuri is pictured in her crib, swaddled in a blanket and cute cap, on one of the four foldout covers alongside Maurice Greenham, celebrating his 80th birthday as a 37-year long-term survivor.

Wow, how far we have come, and yet how far we have to go. But through sharing our stories of survival, resilience, and rebirth, we will get through this, together—and will be better for it.

Take care of yourself, and each other.

P.S. This issue also highlights POSITIVELY AWARE's annual appeal, and this year there is a new way to give! Just text `ISupportPA` to 44-321, and enter the amount you'd like to donate along with your credit card information. Your support will help enable us to continue to share inspiring stories like these for many years to come.

ENID VÁZQUEZ @ENIDVAZQUEZPA

Briefly

Long-acting PrEP with cabotegravir could be around the corner

HIV prevention with just one injection a month could be here soon.

The U.S. Food and Drug Administration (FDA) has granted priority review to a New Drug Application (NDA) for the long-acting medication cabotegravir to be used once a month as prevention against HIV. **The FDA has set a target approval date of January 24, 2022.**

“In the United States, fewer than 25% of those who could benefit from PrEP [pre-exposure prophylaxis] are currently taking it, which points to the need for additional HIV prevention options. We believe new options like investigational cabotegravir long-acting for PrEP will help play a significant role in our collective efforts to end the HIV epidemic,” said Kimberly Smith, MD, MPH, head of Research & Development for ViiV Healthcare, in a company press release September 28, the day that the FDA granted the priority review.

The NDA was based on good results from studies HPTN 083 and HPTN 084. Those studies demonstrated safety and also declared superiority in preventing HIV compared with a daily tablet of Truvada for PrEP. (See page 23.)

Long-acting cabotegravir is currently used for the treatment of HIV, in combination with another long-acting injectable medication (LA rilpivirine). The two injections are taken once monthly. There are hopes of being able to use the combination every other month for the treatment of HIV.

ANCHOR study: Stopping anal cancer in its tracks in HIV

Treating pre-cancerous anal lesions is better at preventing anal cancer than aggressive monitoring, according to a large, Phase 3 multi-center study in people living with HIV.

“ANCHOR data show for the first time that, like cervical cancer, **anal cancer can be prevented even in high-risk populations**, such as people living with HIV, who often have HSIL [high-grade squamous intraepithelial lesions] that can be difficult to treat,” said lead investigator Joel Palefsky, MD, a professor of medicine at the University of California San Francisco, in a press statement. “Although the study was performed in people living with HIV, the results suggest that anal cancer prevention could be similarly possible in other groups known to be at increased risk of anal cancer, including women with a history of vulvar or cervical cancer, men who have sex with men who are HIV-negative, and men and women who have immunosuppression for reasons other than HIV infection.”

The study results were released early, in October, because of their public health importance. There were 4,446 participants in the ANCHOR study (Anal Cancer/HSIL Outcomes Research study).

ANCHOR was conducted through the AIDS Malignancy Consortium through the National Cancer Institute.

Volunteers sought for clinical studies

The UCLA Center for Clinical AIDS Research and Education (CARE) is currently seeking volunteers for these research studies:

A5359—This study is investigating if long-acting injectable antiretroviral therapy (ART) as a monthly shot will be more successful for people who have trouble taking daily, oral HIV medication.

A5391—The Do IT Study is looking for people living with HIV who have experienced weight gain from taking a treatment regimen that contains both an integrase inhibitor (such as bictegravir, dolutegravir, or raltegravir) and “new” tenofovir (TAF, tenofovir alafenamide). This study will assess whether the new combinations reduce weight gain or possibly reverses the weight gain over 48 weeks compared to people who remain on their current ART.

CARE provides primary HIV care and HIV prevention clinical services and conducts DAIDS network sponsored research in HIV treatment and prevention.

For more information, **GO TO** uclahealth.org/care-center or contact the UCLA study team at (310) 843-2015 or careoutreach@mednet.ucla.edu.

Other sites around the country, including Northwestern Universityin Chicago and the University of Pittsburg, are also conducting these trials. **GO TO** actgnetwork.org/studies/a5359-the-latitude-study and to actgnetwork.org/studies/a5391-doravirine-for-persons-with-excessive-weight-gain-on-integrase-inhibitors-and-tenofovir-alafenamide-the-do-it-study.

Home HIV testing program reaches out to Black, Latinx LGBTQ folk

The Human Rights Campaign (HRC) Foundation in August announced **the first national home HIV testing program focused on reaching Black and Latinx gay and bisexual men and transgender women of color**.

The foundation is working in partnership with Us Helping Us, in Washington, DC, an organization founded in 1985 as a Black-led, community-based HIV services organization.

“Today, Black and Latinx gay men and transgender people are still dying of HIV and dying at disproportionately high rates,” said HRC president Alphonso David in a press release. “Although we have made significant advances in addressing HIV, some of our communities remain ravaged by it.”

HRC is the largest LGBTQ civil rights

organization in the country, and the foundation represents its educational arm.

The home testing kits, supported by HIV drug maker Gilead Sciences, are part of the *My Body, My Health* education campaign. The 5,000 kits will include the OraQuick oral swab, condoms and lubricant, a referral to providers for HIV prevention medicine, and an online services page for local HIV prevention and treatment services.

Home HIV testing kits can be ordered at mybodymyhealth.org.

Making sure that insurers, providers know that PrEP is free

As of last year, preventing HIV with the use of PrEP (pre-exposure prophylaxis) should be covered by insurers without co-pays or any other cost-sharing. But **some medical groups may not understand that this also includes the services associated with the HIV prevention pills** (Descovy and Truvada). These services, for example, include testing for hepatitis B and C and screening for STIs. To clarify these issues, three government departments (Labor, Health and Human Services, and the Treasury) issued an FAQs (frequently asked questions) document in August. Aimed at service providers, the document is technical. The points made include the fact that insurance companies can request that generic Truvada be used in order for the PrEP to be cost-free to the individual. **GO TO** bit.ly/dol-FAQ-ACA-part47.

New infections down globally, but not enough

The World Health Organization (WHO) reported that a decline in new HIV infections across the globe from 2010 to 2020 was smaller than expected, and downward movement has actually stalled.

While declines were greatest in sub-Saharan Africa and the Caribbean, "too few" countries were using a combination of structural, behavioral, and biomedical interventions focused on groups of people with the greatest risk as needed for greater declines.

According to the announcement, "While the global rollout of HIV treatment has saved millions of lives, efforts to prevent new infections have been less successful. **The annual number of new HIV infections among adults globally has hardly changed over the last four years**, and total new infections have declined by just 31% since 2010, far short of the 75% target for 2020 that was set by the United Nations General Assembly in 2016."

READ the September report at bit.ly/UNreportSEP2021.

HIV information *en español*

POZ magazine, a national publication that, like POSITIVELY AWARE, is devoted to serving people living with HIV and their allies, has **added posters in Spanish to its repertoire of information** in that language. Started in 1994, *POZ* produced its first issue in Spanish in 1997. Since then, *POZ* has continued to add more information in Spanish, both online and in print. *POZ Basics in Spanish*, for example, was rolled out in 2006. There is also a Spanish language sister site, *Tu Salud* (*Your Health*), which is devoted to health care in general and produces bilingual issues. This year, *Tu Salud* issued a new digital issue specifically on sexual health. The *POZ* Health Information Posters come in silver frames, and are meant

CONTINUED ON PAGE 10 >>

TPAN welcomes Kara Eastman as its new CEO


EASTMAN

Kara Eastman, Chicago native and former Democratic nominee for Nebraska's Second Congressional District, joined TPAN, publisher of POSITIVELY AWARE, **as its new CEO in August. "The TPAN board and management team is very excited to welcome Kara Eastman as our new CEO," says board chair Michael Murphy. "Her experience and leadership are exactly suited to lead TPAN today and into the future."**

"I'm honored to work with such an important organization, and will do everything I can to widen its reach and continue to promote TPAN's mission of self-empowerment," says Eastman. "One of the things that impresses me most about TPAN is its legacy of community outreach. TPAN began with a mailing list and a meeting, with small groups coming together to organize and share information. Today, TPAN has grown and adapted holistic measures for its clients, as HIV and its treatment have changed, affecting people in myriad different ways. I'm excited to begin this new chapter in my hometown."

Eastman, who has a master's degree in Social Work from Loyola University of Chicago, has over 20 years of experience leading non-profit organizations in Chicago, Omaha, and beyond.

TPAN, founded in 1987, provides direct services for people living with and affected by HIV, and publishes POSITIVELY AWARE, **the leading U.S. HIV magazine published by a non-profit, which also spearheads the annual "A Day With HIV" anti-stigma campaign.**

TPAN partnered with Morten Group LLC, a national consulting group, for an extensive search.

>> CONTINUED FROM PAGE 7

to “empower your clients with the information they need to actively engage in their health care.” **GO TO** poz.com/posters. *¡Googlelealo!*

Latinx LGBTQ health series debuts online

Latino Alternative TV (LATV) in October kicked off an online digital series for the LGBTQ+ community, *My Health Agenda*. The October 6 premiere featured Erick Velasco from *The Homo Homie* podcast. Others **telling their stories in the series through the month of November** include trans recovery advocate Jennifer Rodriguez; influencer Curly Velasquez; and artist, filmmaker, and HIV activist Vasilios Papapitsios. Dr. Ariel Ourian, a plastic surgeon who works with many individuals in the LGBTQ+ community, leads the conversations with the featured guests. In addition to talking about their journeys, they also address myths, stigmas, and fears around health.

The series, part of LATV’s *Proud* initiative, takes a creative approach with artwork from members of the LGBTQ+ community, including illustrator Tevy Khou and trans visual artist Ledesma Vazquez.

The series began airing in October to coincide with Hispanic Heritage Month and in observance of National Latinx AIDS Awareness Day on October 15. It aims to help people “feel seen and empowered,” especially to take steps towards their own vision of health, according to a press release from LATV.

“We empowered incredibly talented creators from our community to bring a unique series to life that gives visibility and representation to members of our community who make us proud in a way that is genuine, creative, and original,” said Andres Palencia, creator and director of *My Health Agenda*, in the release. “As Latinos, it can be difficult to bring up health-related conversations for a number of reasons. We decided to create this series as a loving and creative ‘ice breaker’ of sorts so we can normalize health-related conversations for LGBTQ+ people—especially Latinos.”

Vaya. **GO TO** latv.com.

LOVE

Black playwright living with HIV creates prize to support new talent

Donja R. Love, an African American playwright living with HIV, has **expanded his *Write It Out!* program for other positive playwrights to include award money**.

On his Facebook page, Love wrote, “With the support of Billy Porter and GLAAD, I’ve created a new prize for playwrights living with HIV. I’m actually about to cry! On top of the 10-week playwright’s course, *Write It Out!* now has a prize which consists of $5,000 and a year of dramaturgical support. Our lives and our stories matter!”

Love is also the creator of *Youth Write Now* for LGBTQ youth ages 14–18, and *Learning to Love*, which pairs playwrights ages 18–35 with an older playwright.

Love, writer of *Sugar in Our Wounds*, *Fireflies*, *soft*, *one in two*, and *The Trade*, won the 2021 Terrence McNally Award for *What Will Happen to All That Beauty?* from the Philadelphia Theatre Company. The company reported, “A Philly native, his work examines the forced absurdity of life for those who identify as Black, Queer, and HIV-positive—a diverse intersection filled with eloquent stories that challenge the white supremacist, heteronormative structures that exist in American culture.”

Documentary shows positive pilot achieving his dream

James Bushe only ever wanted one career—to be a pilot. Then HIV discrimination changed his course. Bushe, from Stoke-on-Trent, England, discusses his journey in the new short documentary, *The Tyranny of Petty Things*.

“**The only thing I could think about was, *This is the only thing you’ve ever wanted to do. You cannot let this go***,” Bushe says in the film.

BUSHE

“All of the evidence—all of the medical evidence—that was used to justify the authorities’ position on HIV at the time was outdated,” he continued. “And it didn’t know, or didn’t recognize, that somebody that’s on successful treatment had the virus suppressed in the body so you weren’t going to become incapacitated at any point in time. There was blatant discrimination based on somebody’s HIV status and ... that didn’t make any sense to me ... and it needed to be challenged.”

His success at changing the regulations, with the support of the news media, community, and politicians, came with scars, and he also confronted self-stigma. In January 2020, he became the first HIV-positive commercial pilot in Europe, based in Glasgow, Scotland, and flying for Loganair.

“Flying, to me, has always felt very therapeutic,” said Bushe.

Terrence Higgins Trust, a British charity that provides services related to HIV and sexual health, premiered the film August 17 as part of its *Life Really Changed* campaign. Said Chief Executive Ian Green, “The incredible

LOVE: AHRON R. FOSTER BUSHE: LOGANAIR

progress we've made in the fight against HIV means a diagnosis doesn't have to be a barrier to success."

"There's no place for discrimination based on status in 2021," he added. "Tell everyone."

The film was directed and produced by Cameron Nicoll. **READ** the story and watch the film at tht.org.uk/news/pilot-launches-film-about-his-campaign-overturn-hiv-training-ban.

Stories of recovery told in new National AIDS Memorial documentary

The National AIDS Memorial in August released another in its series of mini-documentaries, *Surviving Voices*.

In *Substance Users, the Recovery Community & AIDS*, several **members of the LGBTQ community who are living with HIV tell their stories**. They talk about how they started using drugs, how they suffered from that, and how they got better. They examine fears, stigma, and resilience. Insights from professionals working in the field are also included.

"People who use drugs have been integral to the fight against AIDS," says one person.

"Being sober is not always fun and pretty, pink skies," another person admits.

The National AIDS Memorial said its multi-year oral history was created to "ensure the myriad stories and lessons of the epidemic are captured, curated, and retained for current and future generations."

Other mini-documentaries from *Surviving Voices* include *The Transgender Community & AIDS*, *The A&PI Community & AIDS*, *Women & AIDS*, *The National Hemophilia Community & AIDS*, and *The San Francisco Leather Community & AIDS*. The films are produced and directed by Jörg Fockele and funded through a grant by Chevron, a long-standing partner of the National AIDS Memorial. Community partners include the San Francisco AIDS Foundation, The Elizabeth Taylor 50-Plus Network, Stonewall Project, and the Castro Country Club.

"We believe in the power of storytelling and the lessons it can teach current and future generations," said Huma Abbasi, general manager, Health & Medical at Chevron, in a press release from the memorial.

GO TO aidsmemorial.org/surviving-voices. Other oral history sites collecting stories from the epidemic are listed.

Boston Planning Council unveils anti-stigma video

Boston's Ryan White HIV Planning Council unveiled a short video as part of an anti-stigma campaign, *Someone You Know and Love*. In the film, **council members talk about a diagnosis, and the conversations they've had with parents, children, partners, and friends**. They discuss experiences of living with HIV, both personal and within the overall epidemic.

Catherine Joseph talks about the experiences of her partner, Shirley, who appears in the video. "They didn't invite us to the house anymore," she says of some family members.

"People are afraid of what they don't know," council member Larry Day says in the video, "and most folks didn't really know, didn't really understand, what HIV was [in the beginning of the epidemic]."

At the video's debut in August, the city's Chief of Health and Human Services, Marty Martinez, formerly of the Boston AIDS Consortium, said, "The fact that there is this video related to stigma and wanting to break down stigma, especially at a time like now, is remarkable, and important." He said there's a need for creating access to care and services by breaking down barriers, to help people "not just survive but to thrive," as council committee chair Tim Young proclaims.

GO TO youtube.com/watch?v=_lL0-vtGodw.

New podcasts from International AIDS Society, NMAC

"We now live in a world where AIDS has become old news: the forgotten pandemic," said the International AIDS Society (IAS) of the **podcast it debuted earlier this year, *HIV unmuted***.

Speakers lending their voice and expertise to shake that up start with Dr. Anthony Fauci, director of the U.S. National Institute of Allergy and Infectious Diseases (NIAID), with *Back to the beginning: AIDS and the elusive vaccine*.

Others speaking with Femi Oke, British television presenter and journalist, and podcast host, include Michael Gottlieb, MD, who reported the first case of HIV in the U.S., and longtime activist and epidemiologist Gregg Gonsalves, PhD. Advocates discussing vaccine research and

MATT CAMERON (LEFT) GETS WET WITH DAMON JACOBS.

Tub Talks with Damon Jacobs

HIV prevention advocate Damon L. Jacobs, founder of the Facebook page *PrEP Facts*, shows a fun side to serious conversation with *Tub Talks*, which he started uploading in September to his YouTube channel. In *Tub Talks*, **Jacobs has a one-on-one conversation with men working in HIV treatment and prevention, and other interesting work—while they're in a bathtub together**. Think of bubbles as part of a celebration of life and add love of self and community. Jacobs is a licensed marriage and family therapist in New York state and author of *Absolutely Should-less: The Secret to Living the Stress-Free Life You Deserve*. **GO TO** youtube.com/user/DamonLJacobs/videos?app=desktop.

Corrections

In **Children's Research Continues to Grow Up** (September+October), Ben Banks' age was given incorrectly. He is 42, and he was 12 when he learned of his HIV diagnosis. He speaks to medical students at George Washington University, not Georgetown. Dr. Rohan Hazra oversees studies throughout the Eunice Kennedy Shriver National Institute of Child Health and Development (NICHD), not the entire National Institutes of Health. POSITIVELY AWARE apologizes for the errors.

vaccine myths are Vincent Basajja (Uganda), Udom Likhitwonnawut (Thailand), and Maureen Luba (Malawi).

In the second podcast, French virologist Francoise Barre-Sinoussi talks about her co-discovery of HIV back in 1983. Also speaking up are Australia's health minister Neal Blewett; long-term survivor and Pacific Islander Vince Crisostomo on facing fear and stigma; and Vuyiseka Dubula, of South Africa, on the myths that led her to activism.

Subscribe to *HIV unmuted* for free wherever you listen to podcasts. "Join us as we journey through four decades marked by resilience in the face of adversity," IAS said in September with a release of its first three episodes.

NMAC (formerly the National Minority AIDS Council) has launched its own podcast, *Real Talk with NMAC*. The first episode introduced the podcast's hosts. The second episode observes National Latinx AIDS Awareness Day featuring NMAC's treatment manager Damián Cabrera, and is entirely in Spanish. The podcast is available at nmac.org/resource-library/podcasts and through Apple Podcasts, Google Podcasts and Spotify.

Young TV producer publicly discloses his HIV status

ABC news producer Tony Morrison writes about living with HIV on the eighth anniversary of his diagnosis, on the *Good Morning, America* website. He was only 23 when he learned of his status. Morrison writes about being overwhelmed with negative emotions, some of them resulting from comments by people around him, not by living with the virus. It made living fully more difficult. He writes about feeling alone, until his doctor explained that he was not alone, and that he could look forward to a long and normal life. She also explained U=U—telling him that his undetectable viral load means "there would be virtually no risk of me passing the virus to anybody else."

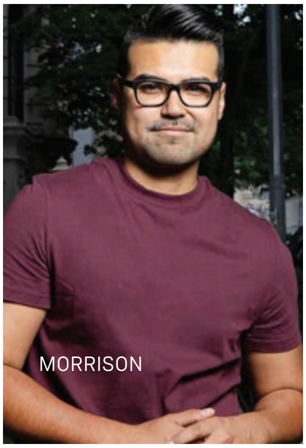
"**My reality is that I am not only alive, I am thriving**," Morrison writes.

"But learning to thrive has been and continues to be a process.

"And thriving, I've found too, is a choice."

He concludes, "I've found that living is a duty. I'm choosing to celebrate life as long as I have life to live."

READ THE ESSAY: good-morningamerica.com/living/story/personal-essay-learned-living-hiv-secret-years-79392051.


MORRISON

Artists living with HIV say 'no' to stigma with Paris exhibit


L'ART DE RUE BONAPARTE, FROM THE ARTPOSITIVE EXHIBIT

Artists from across Europe who are living with HIV worked together to fight stigma and discrimination with ArtPositive, an exhibit held in Paris in September at the Galerie Marie Holmsky.

"Although science has made great strides, discrimination against people living with HIV has largely remained," they write in an artist statement. "Fear and prejudice are deeply rooted in people for no good reason. However, some people with HIV also self-stigmatize and many cannot, because of public pressure, reveal their status.

"ArtPositive is an artistic project, the culmination of which will be an international exhibition by visual artists living with HIV.

"**The objective of this initiative is to combat, through art**, the stigma, discrimination, and isolation some people still face living with the virus.

"We are HIV-positive artists from different countries and we want to say NO to HIV stigma! We want to show through our artistic creations, exhibited in a high-class art gallery (located in the artistic epicenter of Paris, the Saint-Germain-des-Pres quartier), that we are people and artists like all the others in the world.

"The virus in the blood is apparently easier to eliminate than stigma in the mind.

"We want people to know that everyone has the same rights, duties, and opportunities whether you live with or without HIV."

The statement is signed by the four artists: Nacho Hernandez Alvarez, of Barcelona, Spain; Bóre Ivanoff, of Paris, France and Bulgaria; Adrienne Seed, of Manchester, UK; and Philipp Spiegel, of Vienna, Austria.

In an email to POSITIVELY AWARE, Ivanoff wrote that visibility and popularity "will be a great help and encouragement to fight HIV-related stigma and discrimination and to encourage other people living with HIV to organize similar activities, to go out in public and not be ashamed of HIV."

ArtPositive was produced in partnership with Elus Locaux Contre le SIDA; EACS (European AIDS Clinical Society), Brussels; Visual AIDS, New York City; and Forum Culturel Autrichien, Paris.

MORRISON: HEIDI GUTMAN-ABC · L'ART DE RUE BONAPARTE COURTESY OF BÓRE IVANOFF

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FACING COVID IN PRISON WHILE LIVING WITH HIV

A recently released inmate looks at the effects of quarantine—and stigma

BY **ROBERT EHRENBERG**

At 6:30 a.m. the bell rings in my cellblock. I swing my legs to the floor and think, *F**k, I'm still in a cage*. Going on 29 years with no hope of ever reentering the real world in sight, I'm now facing an invisible enemy that has no regard for human life—COVID-19.

I endure another standing count. I realize I'm considered nothing more than a prisoner identification number occupying space. I wonder when the misery of confinement will end. Perhaps it will be cut short by this potentially deadly virus, resulting in my passing without ever having a chance at redemption.

Nearly three decades ago, I committed a horrific crime. A robbery gone wrong resulted in felony murder and devastating grief for both a family and a community. My penalty was 50 years to life, a death-by-incarceration sentence. But now a clear and present danger had reared its ugly head and my fear of never applying my skills in a real world setting is almost tangible, especially considering I was diagnosed with HIV 35 years ago.

Living with HIV in prison is a challenge. Physical activity is regulated and inconvenient, which means it's limited. Nutrition is subpar and insufficient. But the most frightening aspect is the stigma associated with the disease.

Support for immunologically compromised prisoners is often ignored, and many of us are ostracized in prison. I am U=U (undetectable equals untransmittable), and I still get mixed reactions from my peers all the time. So when the first group of prisoners to be vaccinated included the elderly and those with underlying medical conditions including HIV,

Over time, the infection rate abated and some restrictions were lifted just as in the outside world. A sense of normalcy returned as religious gatherings, programs, and college classes resumed. But how long will it be until we rid ourselves of this mutating threat completely?

many HIV-positive men made false excuses to disguise why they were among them.

In the beginning, COVID-19 was taken mostly as a joke in this prison. After all, we lived in a communal setting. The occasional cough or sneeze was followed by a lighthearted "COVID!" exclamation by inmates and staff alike.

Then reality struck.

The virus's spread was sporadic. There was a case in one cellblock, then another. Mask requirements were imposed. Eventually, the virus infected the B-Block housing unit, where 12 cases were confirmed. Inmates of varying age groups were infected. Some had mild symptoms, others required hospitalization. Known cases were immediately sent to quarantine units, but some people hid their illness and continued their jobs, including in food services. Visions of Typhoid Mary weren't inconceivable. It's almost impossible to practice social distancing in prison.

Soon, medical staff shut down B-Block entirely. Suiting up with gear that looked like something out of a science fiction movie, nursing staff descended on the cellblock and began taking temperatures. Potentially-infected inmates with symptoms were monitored for blood oxygen levels. All other inmates were confined to their cells.

Eight inmates at a time were allotted one-hour time slots for phone and kiosk use, showers, and recreation at any given time. Family reunion programs were put on hold along with visitation privileges. Inmate programs, including college and religious gatherings, were shut down.

As people came down with the coronavirus, unfair and uncompassionate labeling emerged along with the spread of the disease. People were referred to as being "sick" or having "the monster." This was particularly painful for those with HIV who already accepted a certain level of disgrace. This kind of stigmatization, regardless of sexual identity, should not be tolerated in any class of society today.

Over time, the infection rate abated and some restrictions were lifted just as in the outside world. A sense of normalcy returned as religious gatherings, programs, and college classes resumed. But how long will it be until we rid ourselves of this mutating threat completely?

It is now September. Governor Andrew Cuomo granted me clemency before he left office, and I'm expected to be released soon. But as I sit in my cell waiting for that day to arrive, I face the third wave of the virus—the delta variant. Although fully vaccinated with the Moderna vaccine, I can't help but wonder whether I'm playing Russian roulette with an undeniable foe every time I leave my cell. The fear is back.

ROBERT EHRENBERG, 62, is a recent college graduate and holds an associate degree in humanities and a bachelor's degree in social science. He was serving his sentence at Sullivan Correctional Facility in New York before Governor Cuomo granted him clemency on August 23, 2021. He left prison on September 16.

Ehrenberg wrote this article for POSITIVELY AWARE through the Prison Journalism Project.

A reader reaches out through the bars

I wanted to tell you how grateful I am to receive the September+October issue (*The Basics: Living Your Best Life with HIV*), so informative with topics I think about daily. Every article was amazing and well-worded. We don't have access to the web to get information or enjoy the links. And the only way to receive information on being positive or having hepatitis is through the mail. There is no information being shared in prison and no support groups. We're just in the dark on changes in the community. I've been a subscriber for well over 20 years, and I enjoy every issue like it's the last. "Aging with HIV," I think I will see a cure sooner than I thought when I was first diagnosed. I am U=U. And, I enjoyed "A Day With HIV" POSITIVELY AWARE! Thank you.

—READER IN HOUTZDALE STATE CORRECTIONAL INSTITUTION,
ST. PETERSBURG, FLORIDA

THE PRISON JOURNALISM PROJECT is an independent, nonprofit, nonpartisan national initiative training incarcerated writers and people affected by incarceration in the tools of journalism to help them reach a wide audience through the project's publication and collaborations with other publications. The initiative believes that "the deep reforms that are necessary to fix the criminal justice system can only happen by shifting the narrative. Intentional, responsible, and well-crafted journalism from within the incarcerated community can break stereotypes, increase transparency, and drive change." The project welcomes essays, articles, and poetry from first-time and experienced writers who are incarcerated, formerly incarcerated, family members, corrections officers, prison educators, and people involved in the criminal justice system or who are affected by the experience of prison or jail. Go to prisonjournalismproject.org for more information or write to PJP, 2093 Philadelphia Pike #1054, Claymont, DE 19703 to request a submissions information packet free of charge (do not send a SASE, as they cannot be processed).

VOLODYMYR SHTUN-ISTOCKPHOTO

Straight, living with HIV, and invisible

BY **MICHELLE SIMEK**

> *“HIV don’t care if you are black or white, or straight or gay.”*
>
> —EUNICE MARSHALL

Anyone can get HIV, including straight men and women. In 2019, heterosexual people made up 23% of all new HIV diagnoses in the United States. Straight men accounted for seven percent of those new diagnoses and straight women accounted for 16%, according to HIV.gov. Yet HIV prevention and care programs for the heterosexual community are sorely lacking. And straight people who are living with HIV are severely stigmatized and often hide in the shadows. The general public thinks that they are gay and hiding it, have a history of injecting drugs, or have been promiscuous. Following are stories from straight men and women living with HIV in the U.S. South and Southeast. They used to be invisible but have grown to become fierce advocates for their communities.

Love is love

KALVIN & EUNICE MARSHALL

Kalvin and Eunice Marshall live in Houston, Texas. They went to high school together and married in 1984. Twenty-three years later, in 2007, HIV/AIDS entered and changed their lives.

Kalvin was diagnosed first. He was working as a training cook for Denny’s. He trained staff on new menu items and taught new hires how to cook. He had a stroke in 2006 and became sicker in 2007. Kalvin was exhausted and was confined to a wheelchair. He “stopped eating and lost control of bodily functions,” says Eunice. He also lost the job that he enjoyed. Kalvin tried to get an appointment with his doctor, but one was never available. The couple spent an entire day in the doctor’s waiting room, only to be told that the doctor was on sabbatical, so they went home. Meanwhile, Eunice was experiencing chronic yeast infections.

Later that year, Kalvin ended up in the emergency room. Unbeknownst to him, he was part of a pilot project to find people living with HIV in emergency room settings and he was tested for the virus without his consent. The HIV test was positive, but Kalvin did not know that. He was admitted to the hospital where one of the doctors finally told him, “You have HIV. You need to tell your wife.” Kalvin insisted that he did not have HIV and an argument ensued between him and his doctor. When the nurse entered his room, she told him he had advanced HIV disease. Kalvin immediately had a heart attack.

When he awoke, he was in a different room, didn’t know that he was in the hospital, and didn’t know his HIV diagnosis. Kalvin asked the nurse what pills he was being given. “You know what they are,” said the nurse. “How could you do that to your wife? Put her at risk like that. Doing those things you did.” Kalvin was discharged to a skilled nursing facility (SNF) and faced the same stigma there. When he insisted that he wasn’t gay, he was told, “but we can’t help you until you are totally honest with us. This is a judgement-free place.” From his nursing home bed, he heard a staff member say, “I don’t know why he won’t come clean. We can help him if he comes clean!” No one believed that he was straight.

Meanwhile, Eunice was consumed with worry about her husband and her own HIV status. “I saw what the virus did to Kalvin and how the staff treated him.” She was tested by a worker from the local public health department in February 2007. Health department staff were supposed to meet Eunice at Kalvin’s SNF in March to provide the results, but they didn’t show up. The appointment was rescheduled for a few days before Easter, but again the staff no-showed. Eunice finally received her HIV test results on April 17, more than two months later. “I was given no resources, no help, no support.” She was laid off from her job and they both stayed at home for a year, thinking they were going to die. The couple didn’t go see an HIV specialist. “No one told us to,” she said.

They eventually had a relationship discussion and decided not to play the blame game. No one had strayed outside of the relationship and they agreed that one of them contracted HIV prior to their 1984 wedding. “It’s not about pointing fingers,” said Eunice. Kalvin and Eunice made the important decision to stay together.

In 2008, the Marshalls sent a letter to their families about their mutual diagnosis. “You’re either for us or against us and we want to know which way you are.” Their families chose not to discuss it. And at the next family function, Kalvin and Eunice were served food on paper plates and given plastic utensils to use.

The Marshalls became activists. They

DI TUBBS PHOTOGRAPHY

enrolled in Project Leap, a 17-week program at the now defunct Houston Center for AIDS. Upon graduation, they were the first couple to serve jointly on the local Ryan White Planning Council. In the council's third year, the group wanted to focus solely on women and children. Kalvin and Eunice decided "to stir the pot" and asked, "What about heterosexual people? What about straight men?" They also wanted support for couples like themselves and were told "if you want it, you start it." So, they did. Three years later, the group had eight couples in the support group.

Currently, Eunice is a member of both the Houston and Texas chapters of Positive Women's Network - USA. Kalvin is active in the Bow Tie Movement Campaign, a Facebook group for straight men living with HIV and the people who support them. And their marriage remains as strong as ever. "If you love each other, stay together. Work it out."

A girl like her

MARISSA GONZALEZ

Originally from New Jersey, Marissa Gonzalez is a 32-year-old Latina living in southwest Florida who is "considered a 'baby' when it comes to the HIV diagnosis." She learned about her HIV status in 2016 and went very public with her diagnosis in a Facebook post in 2018. Currently, she is an active writer for The Well Project's blog, *A Girl Like Me*, and also serves on their community advisory board (CAB). She is an ambassador for both Youth Across Borders and Greater than AIDS—all while holding down a full-time job. Her journey from 2016 to 2021 has been tumultuous but powerful.

In 2016, she ended a "toxic relationship" and moved back in with her parents, brother, and niece. "At the time, I was in a one-sided monogamous relationship—he was not monogamous." In May, Marissa went to her long-time OB-GYN, Dr. Deirdre Fisher, for a Pap smear and sexually transmitted infections (STIs) tests, just to be on the safe side. "To me, if the penis was clean, [sex] was okay with me." She had very little sexual health education, and HIV/AIDS was not on her mind. "This won't happen to me." Much to her and Dr. Fisher's shock, Marissa's HIV test was positive. "I'm not sure who took it harder, her or me."

As she describes the events of that day, Marissa was waiting for her ex-boyfriend to stop by and "pick up his shit," when she received a call from Dr. Fisher's staff stating that the doctor wanted to speak with her. She knew that call meant that something was wrong. When her ex arrived, Marissa was running out the door to the clinic and asked, "What the fuck did you give me?" Marissa spent an agonizing amount of time waiting for Dr. Fisher to finish with her regularly scheduled patients and "Googling different STIs." The doctor knew Marissa very well and believed her to be low-risk. She asked the lab to re-run the confirmatory HIV test several times. Each time the result was the same. Dr. Fisher said, "I don't know how to tell you this," and told Marissa that she had HIV. Marissa "curled into herself and started crying in the exam room like a baby. It was 'instant depression.'" Three days after her diagnosis, Marissa attempted suicide with alcohol and pills, but fortunately recovered in the psychiatric ward of the hospital.

Her best friend had been pushing her to disclose to her family. She was feeling shaky and vulnerable and told her mother the day before the suicide

MARISSA GONZALEZ:
LEARNED ABOUT HER HIV STATUS IN 2016 AND WENT VERY PUBLIC WITH HER DIAGNOSIS IN A FACEBOOK POST IN 2018.

attempt. Her mother immediately said, “We need to tell the family.” The rest of her family found out as the ambulance came to take her to the hospital. In hindsight, Marissa wishes she had “taken more time” before disclosing. “This felt rushed to me.”

Once she was released from the hospital, Marissa returned to her family’s home. She went back to work at her events job and coincidentally started working on a youth HIV/AIDS awareness program for the McGregor Clinic in Fort Meyers, Florida, where she eventually became a client. This was only seven months after her own diagnosis. She worked hard to make this event happen, but chose not to disclose her own status. Marissa was invisible at her own event. “I tied a lot of HIV events back to my work, so they couldn’t be tied back to me personally. [As far as they were concerned], I was doing it for the youth of my community.”

In 2017, she organized “Ribbons and Tiaras,” an HIV awareness event for women and girls. “While I was very visible while wearing my organizer hat, I was very much invisible as the girl living with HIV. I used the opportunity to educate the community but hid behind my title.” In 2018, she shared her HIV status on Facebook and was pleasantly surprised by the reactions. Most of the responses to her post were supportive. “It was nice and different to see.”

She began working at the McGregor clinic and desperately wanted to attend the 2019 U.S. Conference on HIV/AIDS (USCHA) but could not as she was a new hire and other staff had priority. And then COVID hit in 2020. As of the writing of this article, Marissa has yet to meet another woman living with HIV in person. She has only met them online. She is eager for live, in-person conferences to happen again. How will you find her at the next conference? “I’ll be wearing a t-shirt that says ‘hug me.’”

Not all heroes wear capes

SHAWN MARK

Shawn Marks is originally from Florida but currently lives in Nashville, Tennessee. He acquired HIV at birth (known as perinatal or vertical transmission), and was “within three weeks of turning three” when he was taken in by a foster family. “They were the first set of people I did stigma work on.” The family already had 12 foster children and didn’t want to take on another but they accepted him once they learned of his HIV diagnosis. He had been living with his biological mother up to that point. He does not know who his biological father is; there was no name on the birth certificate.

Shawn was six years old when his foster mother took him aside and explained HIV. “It was a cool disclosure. She doodled what T cells and the virus looked like”. But she also told him, “Don’t let your blood touch other people’s blood and don’t share this information with anyone.” Six-year-old Shawn decided that his HIV made him a “superhero, like [Spider-Man’s alter ego] Peter Parker.”

But even superheroes can experience stigma. “On paper, I sound like a terrible person.” In kindergarten, he nipped another boy when they almost collided in line. The nip didn’t break the skin and Shawn was merely “being a little boy.” But he was suspended for a week. In third grade, he was suspended again for another week. During his art class, he was playing a game of thumb war with a friend. The other boy dug his thumb into Shawn’s hand and Shawn bit him in response to the pain. He attributes both suspensions to HIV-related fear. After that, he was assigned a special aide which resulted in him getting bullied by the other students.

Then, his foster parents decided to enroll him into private school. “It was at a church and was like being home schooled, but under a church roof.” There were only 36 students in the entire school. His foster parents were Southern Baptist but the church school was Pentecostal. That was a big difference.

Shawn “wasn’t allowed to play contact sports, so I filled my extracurriculars with other things” like real life work experience and music. “I overheard that I was supposed to have died already, my attitude was, *do what you can*. Tomorrow may not happen. I probably wouldn’t live long enough to go to college.” He worked as a bag boy at a local grocery store and helped his foster father with his plumbing company. He was also a DJ for the local roller rink, Skate Station.

VISUALS BY FRAME

SHAWN MARK:
‘I CAME TO TERMS WITH HIV AT 30… THE ONLY WAY TO BE OKAY, IS TO BE OKAY.’

LAVALLE WHITT

While he DJ’d, “no one knew that I was freaking out in private.”

He doesn’t really know when he started HIV treatment. When he was a little boy, he had to take “cough syrup” that he assumes was AZT. “It tasted disgusting.” His foster father once tried his liquid Norvir and said it “tasted like gasoline and pennies” while crying at the dinner table. “We’ve got to get Shawn off of this,” he said.

As Shawn got older, he says he became interested in girls and wanted to start dating, but was instructed by his foster parents not to “get caught up in a future partner or wife.” He wasn’t expected to live long enough for relationships. But when he was 15, “there was a pretty redhead in church. We courted for a few months and then dated for a few months.” His parents knew he was dating, and his girlfriend and her parents knew about his HIV status, but he didn’t know that they knew. Consequently, they were all waiting for him to disclose his HIV status to her. “She was tired of me not telling her, so she ghosted me before that was even a thing.” Shawn tried to commit suicide after she vanished and was institutionalized in the pediatric wing. “I felt bad. I felt terrible. I stopped taking my [HIV] meds then. I figured I would just fade away.” This was one of several suicide attempts.

Shawn’s relationship with HIV medications was already complicated. “I got in the habit of not taking them. I’d only take them occasionally. Out of sight, out of mind.” Eventually, he became resistant to many HIV medications. He describes his drug-resistant HIV “like a king cobra that eats other snakes.”

When he was discharged from the psychiatric institution, he returned to the Pentecostal school where the congregation and students were encouraged to speak in tongues. As a Baptist, Shawn did not want to do that, so he offered to help behind the scenes with sound during the services. This eventually led to sound mixing which led to roadie gigs across the country with rock bands, including two years with the Drive-By Truckers.

But the rock and roll lifestyle intensified Shawn’s teenage experimentation with alcohol. He started drinking at 18, but now hard drugs were easily accessible. “If someone asked me if I wanted drugs, I would say ‘yes.’” But when he had sex, “it was always protected. And that’s because I was that superhero. I had a responsibility that I didn’t ask for.” He also had many “discussions with God. *Why this? Why me?*”

He was running away from himself and his HIV and moved to different cities and states, drinking and using drugs. As he bounced across the U.S., he experienced homelessness and was arrested. Finally, he got very sick and was admitted to a hospital. He was “24 years old and only had six T cells.” The doctor told him that he had AIDS. Shawn’s response? “No I don’t. I have HIV.”

Shawn took a Greyhound bus to Nashville from Melbourne, Florida. He landed at Nashville Cares, a local AIDS service organization (ASO), “ready to kill myself.” He became a client of Nashville Cares and started going to 12-step meetings. “I dug deep into the Alcoholic Anonymous (AA) rooms.” Relatively new to the recovery community, there was a chairperson opening in his group. He thought this only involved “setting up and taking down chairs” before and after every meeting. It turned out there was more responsibility involved! (A chairperson describes the program for newcomers, and introduces speakers who share their personal stories.)

Once he got clean and sober, he decided to be out about his HIV status. “I came to terms with HIV at 30 [years of age]. I had to pull the trigger on it. The only way to be okay, is to be okay.” And “U=U [undetectable equals untransmittable] was life-changing.” Shawn says he learned about it “on my deathbed but it didn’t register,” but it “registered” two short years later. He even listed his HIV status on his Facebook dating profile. His current girlfriend knew his status before they met, and it didn’t dissuade her from getting involved. She is taking pre-exposure prophylaxis (PrEP).

The former client of Nashville Cares is now a member of its staff. He is also heavily involved in several local HIV/AIDS committees, including the Ryan White Part A Planning Council, and describes himself as a “queer ally.” His HIV status led to many people assuming that he was gay. But “every time I got in trouble, someone from the queer community saved me.” Shawn plans to continue his work in HIV at his ASO as part of the Healthy University Program. He wants to speak at conferences about his lived experiences.

And he will continue to be a superhero to all. PA

……

MICHELLE SIMEK has worked in HIV/AIDS for more than 20 years. She works at the UCLA Center for Clinical AIDS Research and Education (C.A.R.E.) in Los Angeles and is a popular HIV/AIDS educator, both locally and nationally. In her spare time, she is an actor, fiction writer, avid reader, and enthusiastic cat mom.

PrEPared?

As long-acting treatment and prevention begins to enter communities, we must move toward dismantling systemic racism

BY ABRAHAM JOHNSON, MPH

WILD PIXEL-ISTOCKPHOTO

The announcement that HIV Prevention Trials Network (HPTN) had two successful studies on long-acting technologies (LAT) to prevent HIV—HPTN 083 and 084—came with much excitement. Populations most impacted by HIV could possibly have an even greater opportunity to prevent HIV. LATs provide for potentially easier adherence, fewer side effects, and are less noticeable, which creates more privacy for users than pre-exposure prophylaxis (PrEP) in pill form. Yet, as the prevention toolbox continues to grow, there are still uncertainties on the effectiveness, cost, accessibility, and other structural barriers of long-acting technologies. This raises the question: just how prepared are we really for long-acting technologies? Ending the HIV epidemic requires everyone to have access to LATs regardless of race, geographic location, gender identity, income, and immigration status—ensuring that communities everywhere have the same chance of reducing their likelihood of contracting HIV. We spoke with some leading voices in HIV prevention to get their take on what we need to do to prepare for LATs.

Establishing trust within communities

PROGRESS TOWARD increasing LAT access starts with building trust. As we have seen with the development of the COVID-19 vaccine, mistrust influenced vaccine hesitancy among underserved communities, particularly among Black people living with HIV. Before LATs are available, medical providers must foster trust within communities. Medical providers must provide community members with accurate and accessible information about LATs, including side effects and possible challenges that come with their use. For communities to believe in and feel comfortable with accessing LATs, researchers and manufacturers must do a better job at being transparent and trustworthy. In a recent interview with *TAGline*, Sarit Golub, a professor at City University of New York said: “In order to build trust, we need to act trustworthy.” Lessons learned from the roll-out of once-daily oral dosage of PrEP show that, to date, uptake of PrEP in marginalized communities in the South is low.

“We need to get rid of the assumption that we continue to do business as usual. We must start by meeting and educating people around their options in the role that these options can play in the context of their lives,” Matthew Rose, the Director of the U.S. Policy and Advocacy at Health GAP, said in an interview. “Injectables will meet the same fate as everything else if we don’t roll out a new way of engaging people.”

No matter how effective LATs are, researchers must intentionally engage with community members who

stand to benefit the most from using LATs. Sarrit Golub notes, “We should see community members as ‘targets’ of our public health system. We need to recognize they are ‘agents’ of their own health and that an agentic [an individual’s power to control his or her own goals, actions, and destiny] mindset is one that centers community power and autonomy.”

No population left behind in research

BIOMEDICAL PREVENTION research has historically excluded populations such as cis-gender and transgender women. Black women are consistently excluded when it comes to biomedical prevention. From the moment PrEP was introduced, Black women were left out. “Today, Black women are the least

CONTINUED ON PAGE 24 >>

The challenge of diagnosing HIV in people on long-acting PrEP

BY **RICHARD JEFFERYS**

Impressive results from two efficacy trials of a long-acting form of the integrase inhibitor cabotegravir (CAB LA) have boosted prospects for long-acting HIV pre-exposure prophylaxis (PrEP). In both cases, CAB LA proved superior to oral Truvada PrEP (see table below).

Analyses of the trial data have also revealed a wrinkle associated with the approach: among the small number of HIV acquisition events that occurred, the capacity of CAB LA to suppress viral replication masked the presence of the virus by reducing viral load and preventing seroconversion to HIV antibody positive (delaying HIV diagnosis). In most cases, these HIV acquisition events had occurred either immediately prior to PrEP initiation or during windows of suboptimal LA CAB levels associated with delayed (or lack of) receipt of scheduled drug doses. In two trial participants who acquired HIV despite adequate drug levels, the virus had mutations associated with resistance to CAB LA.

The researchers identified these masked HIV acquisition events retrospectively by testing stored blood samples for low levels of HIV viral load. Once identified, antiretroviral treatment (ART) regimens were successfully initiated. In a few cases, HIV had developed CAB LA resistance due to the trial participants having spent an extended period on monotherapy after acquiring HIV, rather than appropriate combination ART.

The potential occurrence of masked HIV acquisition events in users of LA PrEP raises the question of how best to diagnose HIV in future studies and when LA PrEP becomes available on the market. (ViiV Healthcare announced the submission of a new drug application to the U.S. Food and Drug Administration on May 4, 2021. See page 6.)

Currently, it appears that monitoring for HIV will require intermittent use of sensitive viral load tests. This approach is under evaluation in the open label extension phases of HPTN 083 and 084. The researchers are assessing a variety of point-of-care and rapid viral load tests to better understand whether their use in the context of LA PrEP can identify incident HIV acquisition events sooner and prevent the emergence of drug resistance.

Another idea in development that might offer enhanced convenience is home viral load testing. For example, the pharmaceutical company Merck is collaborating with researchers at the BEAT-HIV Martin Delaney Collaboratory in Philadelphia to assess whether a system that allows an individual to draw blood at home and mail for testing can be used to monitor for HIV viral load rebound in clinical trials involving an ART interruption. The National Institutes of Health is also supporting research into finger-prick viral load tests that could be self-administered at home.

Before these tests could become HIV diagnostics for people on LA PrEP, they would need to overcome an important hurdle: the need for very low thresholds of viral load detection (e.g., 20 copies/mL of HIV RNA). Currently the Merck at-home testing technology has a lower cut-off of 1,000 copies/mL; in the ART interruption trial in which it’s being evaluated, 1,000 copies/mL or greater is the viral load level that triggers restarting treatment. There is hope, however, that this lower limit of viral load detection can be improved.

As long-acting approaches to HIV prevention become more widely used, attention will also need to be paid to developing appropriate tools for diagnosing HIV among recipients. The issue highlights how new and successful interventions can sometimes create novel challenges that need to be addressed for optimal implementation.

STUDY	HPTN 083	HPTN 084
Participants	4,566 cisgender men and transgender women who have sex with men	3,223 cisgender women
HIV acquisition endpoints (CAB LA / Truvada)	12 / 39	3 / 36
HIV incidence per 100 person-years (CAB LA / Truvada)	0.37 / 1.22	0.15 / 1.85
Incidence reduction (CAB LA vs. Truvada)	68%	92%

In his current role as TAG’s Basic Science, Vaccines and Cure Project Director, **RICHARD JEFFERYS** is particularly focused on HIV cure research, education, and advocacy. Richard began working in HIV in 1994 at the AIDS Treatment Data Network in NYC, helped establish the Health GAP Coalition in 1999, and has written for a wide range of publications, including POSITIVELY AWARE.

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>> CONTINUED FROM PAGE 23

likely to take PrEP. This can't be the case with long-acting technologies. We must make sure the language speaks to women. Women must see themselves in this from the beginning," Gina Brown, Director of Strategic Partnerships and Community Engagement (SPaCE), said. "The same efforts that have been put into engaging Black gay, bisexual, and same-gender-loving men in prevention have to be replicated with Black women."

Although HPTN 084 avoided the missteps made by Gilead with F/TAF for PrEP—for which no research was done in cisgender women and transgender men at the time of U.S. Food and Drug Administration approval—we must ensure that efficacy trials for LATs continue to cover all of the major HIV exposure risks. We must include people with current or a history of injection drug use in efficacy trials. For real-world effectiveness studies and demonstration projects, we must make it the norm to immediately and fully scale-up studies that intentionally look at the unique barriers to access for all major vulnerable populations, including transgender and gender-nonconforming individuals, people of color, cisgender women, and people who use drugs.

We also cannot forget about the rural South. There is a difference between the HIV epidemic and health care access in urban cities in the South—such as Atlanta, Houston, Dallas, and Miami—that distinctly differs from access in the rural South. Non-urban counties in the South have higher rates of new HIV infections compared to non-urban counties in other regions. Rural residents have limited access to PrEP, although the need for PrEP providers is evident because the South has the highest proportion regionally of PrEP-eligible persons living a 60-minute drive away from the nearest PrEP provider. Rural populations in the U.S. are generally underserved by HIV prevention services that offer HIV and sexually transmitted infections (STI) testing, don't get a sufficient supply of free condoms or individual prevention services, and are less likely to have PrEP providers than those in urban cities. Even with the implementation of PrEP, the South has still felt the burden of the HIV epidemic for years. Integrating LATs in both the urban and rural South successfully will require a collaborative effort among key stakeholders, health departments, and other service providers.

Preparing for challenges through clear communication

LIKE MOST new innovations, long-acting technologies will have their challenges. On a community level, one challenge is ensuring that health information is provided in a way that is understandable. Generally, knowledge on PrEP is low in underserved communities. Therefore, the marketing of LA injectable PrEP must be creative. Perhaps this means veering away from the biomedical term "PrEP" to something more comprehensible. When developing materials, health communication specialists must tailor the medical information for low-literacy settings. The lead-in phase required before starting long-acting cabotegravir (LA-CAB) injections bears a challenge for people using this specific treatment. Although LA-CAB proved more effective than emtricitabine/tenofovir DF (Truvada) in preventing HIV infection, users must take oral cabotegravir for five weeks and then start their injections. The delay in starting injections may be a challenge for people who struggle with taking their medication daily as prescribed.

Concern also surrounds the effectiveness of the injection once drug levels begin to wane; a few participants in a study acquired HIV after delayed injections. We will need to walk the fine line with overinflating the challenges of any prevention modality to the point of discouraging uptake, a mistake made often by healthcare professionals with oral PrEP. Healthcare professionals downplayed their significance to the point of losing community trust. We must be prepared to mitigate unintended negative outcomes.

While some clinics are known for providing quality services to patients—particularly those owned and led by members from the most vulnerable communities—this is not the reality for all. Racism and provider bias have negatively impacted community members' experiences with accessing PrEP. Implementation of LATs require follow-up visits, ongoing health education, and culturally humble providers who can clearly communicate about potential side effects. Providers should allow patients to make informed decisions about whether LATs are the right choice for them.

'What we can do is we can try to ensure equity by shifting the paradigm—putting people of color in decision-making authority over the roll-out and program generation.'

Creating an equity framework

LATs MUST be affordable and accessible to all communities. For this to happen, funders and policymakers must address inequitable LAT distribution head-on. In an interview, Sarit Golub said, "Funders must hold implementers accountable for equity metrics, not just volume metrics. In other words, any measure of quality or success in outcomes must examine not just how many new individuals are adopting a new prevention strategy, but whether adoption patterns are substantially reducing inequitable distribution in biomedical prevention adoption overall at an agency-, health system-, or jurisdictional-level."

Dismantling systemic racism

2020 TAUGHT us many lessons, underscoring that systemic racism is a public health issue. "There is literally no way that long-acting injectables enter the world and not be part of the racist system. The system is pervasive. It has long been part of our society," Matthew Rose said. "What we can do is we can try to ensure equity by shifting the paradigm—putting people of color in decision-making authority over the roll-out and program generation." All communities must have access to LATs, and policymakers have an obligation to make sure of this.

As LATs begin to enter communities, we must move toward dismantling systemic racism. Healthcare facilities need to offer cultural sensitivity training to doctors that provide services to Black, Indigenous, and People of Color [communities]. Additionally, senate leaders need to directly infuse resources to communities of color, including local community-based organizations. In keeping with the Denver Principles and the rallying cry, "Nothing about us without us," more people of color should be in leadership positions to make decisions for their communities.

ABRAHAM JOHNSON, MPH, is the HIV Community Engagement Officer of Treatment Action Group (TAG).

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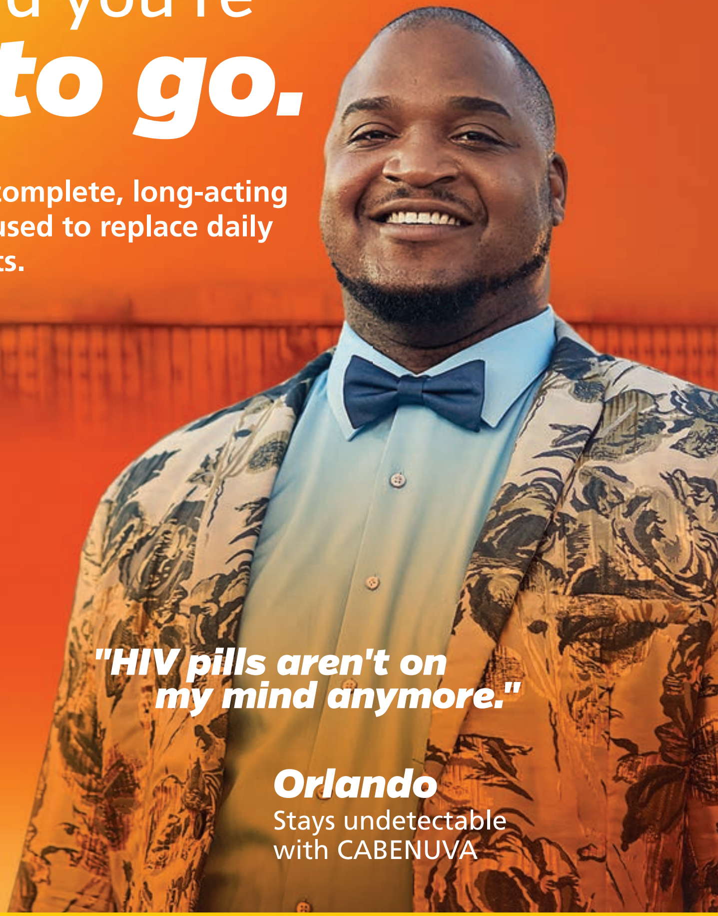
CABENUVA is the only complete, long-acting prescription injectable used to replace daily HIV pills in certain adults.

CABENUVA is given as two injections monthly by a healthcare provider, after taking about a month of once-daily starter pills. It's important to attend all appointments.

> ***It's a long-acting injectable that works continuously to keep you undetectable for an entire month.****



Ask your doctor about CABENUVA

*Undetectable means the amount of HIV in the blood is below the level that can be measured by a lab test. Results may vary.

Orlando has been compensated by ViiV Healthcare.

Important Facts About CABENUVA

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

(kab' en ue vah)

ABOUT CABENUVA

CABENUVA is a complete prescription regimen used to treat HIV-1 infection in adults as a replacement for their current HIV-1 treatment when their healthcare provider determines that they meet certain requirements.

HIV-1 is the virus that causes Acquired Immune Deficiency Syndrome (AIDS).

CABENUVA contains 2 different medicines:

- cabotegravir
- rilpivirine

It is not known if CABENUVA is safe and effective in children.

DO NOT RECEIVE CABENUVA IF YOU

- have ever had an allergic reaction to cabotegravir or rilpivirine.
- are taking certain medicines:
  - carbamazepine
  - oxcarbazepine
  - phenobarbital
  - phenytoin
  - rifabutin
  - rifampin
  - rifapentine
  - dexamethasone (more than a single-dose treatment), and/or
  - St John's wort (*Hypericum perforatum*)

BEFORE RECEIVING CABENUVA

Tell your healthcare provider about all your medical conditions, including if you:

- have ever had a skin rash or an allergic reaction to medicines that contain cabotegravir or rilpivirine.
- have or have had liver problems, including hepatitis B or C infection.
- have ever had mental health problems.
- are pregnant or plan to become pregnant. It is not known if CABENUVA will harm your unborn baby. CABENUVA can remain in your body for up to 12 months or longer after the last injection.

Please see additional Important Facts About CABENUVA on the following page.

CABENUVA
cabotegravir 200 mg/mL; rilpivirine 300 mg/mL
extended-release injectable suspensions

CABENUVA
cabotegravir 200 mg/mL; rilpivirine 300 mg/mL
extended-release injectable suspensions

CABENUVA.com

Important Facts About CABENUVA (cont'd)

BEFORE RECEIVING CABENUVA (cont'd)

Tell your healthcare provider about all your medical conditions, including if you: (cont'd)

- are breastfeeding or plan to breastfeed. **Do not breastfeed if you take CABENUVA.**
  - 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 CABENUVA can pass to your baby in your breast milk.
  - Talk with your healthcare provider about the best way to feed your baby during treatment with CABENUVA.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines interact with CABENUVA. Keep a list of your medicines and show it to your healthcare provider and pharmacist when you get a new medicine. You can ask your healthcare provider or pharmacist for a list of medicines that interact with CABENUVA.

Do not start taking a new medicine without telling your healthcare provider. Your healthcare provider can tell you if it is safe to take CABENUVA with other medicines.

POSSIBLE SIDE EFFECTS OF CABENUVA

CABENUVA may cause serious side effects, including:

- **Allergic reactions.** Call your healthcare provider right away if you develop a rash with CABENUVA. **Stop receiving CABENUVA 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
  - trouble breathing
  - blisters or sores in mouth
  - blisters
  - redness or swelling of the eyes
  - swelling of the mouth, face, lips, or tongue
- **Post-injection reactions** have happened within minutes in some people after receiving their rilpivirine injection. Most symptoms resolved within a few minutes after the injection. Symptoms may include:
  - trouble breathing
  - stomach cramps
  - sweating
  - numbness of your mouth
  - feeling anxious
  - feeling warm
  - feeling light-headed or feeling like you are going to pass out (faint)
  - blood pressure changes

POSSIBLE SIDE EFFECTS OF CABENUVA (cont'd)

CABENUVA may cause serious side effects, including: (cont'd)

- **Liver problems.** People with a history of hepatitis B or C virus or people who have certain liver function test changes may have an increased risk of developing new or worsening changes in certain liver tests during CABENUVA treatment. Liver problems have also happened in people without history of liver problems 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 or tenderness on the right side of your stomach area
  - itching
- **Depression or mood changes. Call your healthcare provider or get emergency medical help right away 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 CABENUVA include:

- pain, tenderness, hardened mass or lump, swelling, redness, itching, bruising, and warmth at the injection site
- fever
- tiredness
- headache
- muscle or bone pain
- nausea
- sleep problems
- dizziness
- rash

These are not all the possible side effects of CABENUVA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

GET MORE INFORMATION

- Talk to your healthcare provider or pharmacist.
- Go to CABENUVA.com or call 1-877-844-8872, where you can also get FDA-approved labeling.

January 2021 CBN:1PIL

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ViiV Healthcare

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‘Folks who need the most should get the most’

PACHA appointee Tori Cooper discusses the needs of the transgender community with PA associate editor **Enid Vázquez**

PHOTOS COURTESY OF TORI COOPER

In August, longtime community advocate **Tori Cooper** *became the first Black transgender woman appointed to the President’s Advisory Council on HIV/AIDS (PACHA). Cooper is Director of Community Engagement for the Transgender Justice Initiative at the Human Rights Campaign, the nation’s largest LGBTQ+ advocacy and lobbying organization.*

ENID VAZQUEZ: We’ve been telling our readers for years how the statistics for the transgender community are disproportionally bad. What do you think is important now about HIV in the transgender community, and where do we need to go?

TORI COOPER: One of the reasons why we’re still having these discussions is because we still need these discussions.

There are healthcare systems that are not inclusive of trans people. There are treatment modalities that are not inclusive of trans people. When you think about HIV, you don’t just think about treating people living with it, but also about prevention. And the fact that one of the newest prevention methods actually says in its advertising that it hasn’t been tested on people who were assigned female at birth leaves out transgender men, trans masculine folks, and non-binary folks, folks who simply because of who they are

and who they have sex with are at greater risk for HIV.

So the fact that there are all of these different systems that are not inclusive, and some that are actually even anti-trans, means we have to still have these conversations.

It's important to incorporate new voices into the conversation as well, not just the voices who are always speaking the loudest. As public health professionals, we have to take much more of an intersectional approach to our work.

Intersectional doesn't just mean listening to people. It means listening and implementing new policies and procedures, with a DEI focus—more diversity, equity, and inclusion.

But it also means having a more diverse set of providers—folks who are providing the services, folks who come and represent a bunch of different communities—because our waiting rooms don't just look like all of one thing. So in turn, providers should not just represent one community as well.

EV: There's stigma in clinics. If young trans girls know they're going to be looked at funny, why the heck would they even go in for treatment?

TC: That's one of the many reasons that people who are neither White, nor cisgender, nor gay, nor male identified are falling so behind when it comes to treatment.

And, especially when folks are new to an HIV diagnosis, if you have to go to a place where "AIDS" is part of the name of the clinic, you're probably going to be less inclined to go to that place for treatment. It may be because of your own stigma, or because of the stigma of other people. We are also underutilizing peers in the fight against HIV. Folks who represent different communities.

Peer is one of those catchphrases that has both negative and positive connotations. One of the negative connotations, from a public health perspective, is that any time you have *peer* in the title, it's a kind of outing. You know, if you are a trans peer coordinator, that means you're a trans person who works with other trans people.

But some of the positives that are associated with *peer* is that peers have that lived experience. And that's really, really underutilized. Most providers of HIV services are not people living with HIV. And so utilizing and empowering peers and peer-to-peer interactions is one of the best ways to incorporate lived experience into treatment. It is one of the best ways to use subject matter experts who sometimes may not be degreed. But it's a way to use that lived experience and acknowledge that folks are subject matter experts in their own lives. And there's a lot of value that comes with that.

When we talk about empowerment, I think a message that really gets missed is that we—as a healthcare system, as providers of services—have failed to empower people who are living with HIV to take a greater part in their own health care. What I mean by that is, if every person who's living with HIV achieved viral suppression and maintained it, there would be no new HIV infections, which is essentially an end to the HIV epidemic, right?

However, that's not the model that we use. We don't address many of the factors that in public health are referred to as *social determinants of health*. We don't address the factors that keep people from becoming virally suppressed. We don't properly address homelessness. We don't properly address mental health. We don't properly address wage equity, employment, or education for people who are living with HIV.

There's been this model that was set up. Through the years, there was a time when you got an HIV diagnosis, you got a disability check, because you'd be dead in six months or a year. Since that's no longer the case, how are we empowering people who are living with HIV to live their best lives? What are we doing that's helping folks to live healthfully between doctor appointments?

EV: It seems like you've already answered this question, but where do we need to go from here?

TC: I use the term *CED*: community economic development. Cede power back to the community.

> **‘It’s important to incorporate new voices into the conversation as well, not just the voices who are always speaking the loudest. As public health professionals, we have to take much more of an intersectional approach to our work.’**

The HIV healthcare system really was created when the community, which at the time essentially was a bunch of gay, White cisgender men of a certain socioeconomic status, created it. And that’s wonderful. That’s also why White gay men aren’t dying from AIDS the way that they were 40 years ago, because they created a system that works for them. And it’s wonderful. Because of their advocacy, we got highly active antiretroviral therapies, which were the first HIV cocktails. Because of them, we have programs like the Ryan White CARE Act.

But because HIV doesn’t look like that today, we have to perhaps dismantle the system in order to create a new one that’s much more inclusive of a lot of different identities and experiences. We need to have policies, procedures, and programs that are much more inclusive of all kinds of different folks. The fact that there are HIV medicines being prescribed that in their research didn’t include Black bodies, that’s problematic.

And so at all levels of HIV engagement—research, of course, and doctors and medical providers, but also evaluators of programs, and statisticians, and folks who work at the CDC—we need to have many more Black and Brown people. It’s also because we share community. I can’t tell anybody that’s White what it means to be Black in America, so that they fully get it. But another Black person understands it. A Spanish-speaking person whose first language is Spanish can articulate that better than someone who took a year of Spanish in middle school. And so, we have to add more value to these lived experiences, and really incorporate them much, much more across the board in how we tackle HIV, pre-diagnosis and post-diagnosis.

Here’s an interesting thing that I think some non-trans folks don’t get yet. Trans people don’t have to just do trans jobs.

At my first job in HIV, I was like, *Don’t put trans in my title*. Now, in hindsight, I’m glad that they did. But I fought against having *trans* in my title simply because I didn’t want to limit the work that I do. And I didn’t want folks who are by definition trans but who may not live their life as openly trans people to feel left out. You know, Black women are working in aeronautics and in auto mechanics, and they are teachers and professors, and firefighters. But none of those terms have the word “Black” or “woman” attached.

EV: It’s a journey. One of the reasons I wanted to write about you was a conversation we had a couple of years ago. I thought “cis-gender” sounded weird and didn’t like being called a “cis-gender woman.” And you said, “Well, I don’t like being called a transgender woman.” Oh! Of course not. It was a lightbulb moment.

TC: Let me add some context to that. My trans identity is simply a part of me. And what I tell people is, if we’re picking fruit at my local grocery store, I don’t expect anybody to identify me as that trans woman. It doesn’t mean that I’m not proud of who I am. But it doesn’t matter. At that point, we’re both just two people who want to spend our money on some melon. And until we get to a point that people are just people and we’re all sharing this earth together, how we got to where we are in our adulthood, how we describe our journey and how we got there is less important than how we all share the space. Until that day, you are cis and I am trans.

EV: If you have trans people in a program, but you want to say they’re like anybody else, how do the trans kids know there are trans people there?

TC: Right now, in a lot of organizations, it feels like you’re just ticking boxes. And the truth is, we may have to tick boxes in the spirit of intentional inclusion, until we no longer have to tick boxes. When folks are hired simply because they’re the best person for the job, regardless of the agenda items, of their race, their age and physical ability or disability. Until we get to that point, we do have to tick boxes. We have to make sure that we cover a whole bunch of bases. But that’s what essential inclusion looks like, until we no longer have to do it.

It also goes to why we’re giving pronouns, and we are identifying ourselves, at the start of every Zoom meeting and even in the medical office. It’s one of the reasons why, in my opinion, that should just become common practice. We’re modeling good behavior. Because if we only do it when we think somebody is trans, then we missed out on an opportunity to engage someone who’s trans and we don’t know. And we also missed out on a lot of educational opportunities for people who are not trans.

EV: What do you want to tell our readers, most of them living with HIV?

TC: I want to make sure that people understand that everybody’s lived experience is as valid as everybody else’s. And then, as a community of human beings, it is important to validate other people’s experiences, and honor those experiences, especially when they’re different from our own.

One more thing I’d like to add: Folks who need the most should get the most.


ARIANNA LINT

TRANSFORMING POWER

The transgender community takes the reins

BY ENID VÁZQUEZ

“You cannot end the HIV epidemic against all without working with the transgender community,” says Arianna Lint, founder and director of Arianna’s Center in Fort Lauderdale.

The discrimination against transgender people is well recognized, as well as the resulting greater risk of HIV infection. That script can be flipped with greater empowerment of the community, says Lint and other transgender advocates.

“We are not the problem. We are the solution,” Lint says. “And we have proved that. Casa Rubia in Washington is one of the best examples of housing for transgender individuals. TransLatina Coalition, based in Los Angeles, is one of the best examples for advocacy and working with state laws and policies to change them for the better for the transgender community. My organization can provide help in working together to make changes happen.”

Arianna’s Center provides a wide range of services. There is help with education, employment, health care, and immigration. Lint herself is an immigrant from Peru. The center uses an integrated case management model that tailors the services to the needs of the individual.

Then there’s also political advocacy and assistance with data collection, important components in wielding power and creating change.

Or as the center’s website breaks it down: “helping individuals thrive” and “building community power.”

Getting the data

At the International AIDS Society conference this year (IAS 2021), transgender activists and allies issued a manifesto that included a push for greater research participation.

“The *No Data No More* manifesto, written and informed by trans and gender-diverse (TGD) advocates from Cape Town to Cologne, with support and solidarity from AVAC [a U.S.-based HIV prevention advocacy group], offers practical and essential priorities to manifest meaningful change,” the team wrote. “We believe the future must include peer-led HIV prevention research with true ownership, acceptability, and viability in TGD communities.”

The Transgender Law Center, located in Oakland, California, saw—and met—the need from its inception. Founded in 2002, the center not only works for legal rights and changes, led by a transgender staff, but has also collected data of its own.

Earlier this year, the center issued a report, The Roots of Anti-Trans Violence, presenting data and stories from Louisiana, New York, Texas, and Puerto Rico. As early as 2006, it reported the results of an economic survey of transgender people living in the Bay Area.

And the center’s Positively Trans project paired up with Arianna’s Center for a 2018 needs assessment of transgender and gender non-conforming people living with HIV in the Miami and Fort Lauderdale areas. Among other things, that report found high rates of housing and employment discrimination reported by transgender and gender non-conforming survey respondents, particularly those who were African American.

“I think one of the biggest problems for the transgender community, especially in the South, is the lack of official data for transgender individuals,” says Lint. “That’s why my organization advocates for data. We made the first needs assessment for transgender individuals living with HIV in Broward County and Miami-Dade County. I worked closely with the Transgender Law Center on the study titled, *Our Knowledge is Our Power*. And that is true.

“Transgender individuals and people living with HIV are experts on issues that affect them,” Lint says. “We need to ensure that decisions being made place an emphasis on the input and lived experiences of the people they most affect. It’s our time to make sure our knowledge is seen and heard and make the powerful decisions that impact our lives.”

That impact showed with another research project this year. “We just finished a project with a school of social work in Puerto

ARIANNA LINT: CARINA MASK

Rico surveying the transgender community," she says. "Only 120 respondents were needed. But they partnered with the transgender community and got 350 respondents. ... It's so important to have data and prioritize the needs."

That report will be presented as this issue is released in November, which is also the month in which Transgender Awareness Week (November 13–19) takes place.

Getting the power

Lint looks at needs particularly in the face of obstacles.

"It's more of a danger living in the South if you are a transgender individual. That's why it's so important for me to highlight the good work, the teamwork, and the leadership of the transgender community, because that's how changes are being made. Bambi Saucedo. Ruby Corado. Cecilia Chung. Other amazing leaders. Tori [Cooper's] appointment [to PACHA, see page 27]—that is very empowered.

"Just last week we celebrated our sixth anniversary," says Lint. "It's important to show the talents of trans-led organizations, of trans-led advocacy."

CDC analysis

Earlier this year, the U.S. Centers for Disease Control and Prevention (CDC) issued a report on HIV in the transgender community. Among the findings in *HIV Prevalence Among Transgender Women in 7 U.S. Cities, 2019-2020*, 42% of the women overall were living with HIV. This compares with less than half of one percent (< 0.50) of the U.S. population.

As with previous HIV surveillance reports, however, the CDC found racial and ethnic differences for the groups of women surveyed:

- 62% of the Black or African American transgender women were living with HIV
- 35% of the Hispanic or Latina transgender women were doing so
- 17% of the White transgender women were positive

Another growing movement in the transgender community is addressing the need for gender affirmation and gender-affirming care.

According to the CDC report, 18% of the women reported "having seriously thought about suicide." This number was lower for the women living with HIV, 12% vs. 22% for those who were HIV-negative. The CDC pointed to a previous report, however, showing that 40% of transgender people attempted suicide in their lifetime (the 2015 U.S. Transgender Survey, from the National Center for Transgender Equality).

> **'Transgender individuals and people living with HIV are experts on issues that affect them.'**

The CDC report went on to say that, "Gender affirmation may lower suicidality among transgender women. A study found that gender affirmation was significantly associated with lower odds of past-year suicidal ideation and psychological distress; gender affirmation also mitigated the association between discrimination and past-year suicidal ideation."

Gender-affirming care

Lisa Spedalle, RN, of the Visiting Nurses Society of New York (VNSNY), places gender affirmation front and center in her work with women undergoing post-operative transgender care, along with emotional support and medical expertise. She has spent the last two of her 20 years with VNSNY working in its Gender Affirmation Program (GAP). VNSNY is one of the largest nonprofit home- and community-based health care organizations in the U.S., and has received the SAGECare Platinum level LGBT cultural competency credential from the national nonprofit organization SAGE.

Because VNSNY works in people's homes, it's important to know the partners as well as the family members who are involved. The partners are also going through an emotional situation, says Spedalle, and they have experienced stigma and discrimination as well. The stress of post-operative care is hard for all caregivers, she notes.

"It's extremely important that as soon as I walk in there, they know I am non-judgmental, and I respect them," Spedalle says. "First of all, it's very important to get the pronouns correct. And if you don't, apologize and start over, but it's extremely important."

"Every patient has spoken to me about discrimination they face from healthcare providers," says Spedalle. This included programs specifically for transgender people. "They say lack of education is the biggest problem, and finding that people are judgmental. They say people are not as knowledgeable as they could be or should be. So I can feel their relief and their gratitude for the extensive training and knowledge that we provide."

As a nurse who's passionate about helping her patients, she's troubled by the poor healthcare experiences they've shared with her.

"Your primary care physician—that relationship with your PCP is like your relationship with your mom and dad. If they don't know something, they should figure it out. If not, that's incompetency," she says.

There's a need for health care workers and other service providers to promote the supportive care shown by Spedalle and the VNSNY. In addition to the leadership of the transgender community.

Leading the way

Says Arianna Lint, "Empowerment is central to our mission at Arianna's Center. But I strongly believe that effective empowerment means centering the leadership of transgender individuals and those living with HIV. While the input of our allies is essential, it is the example that is set from within our community that leads to true empowerment."

GO TO ariannas-center.org and transgenderlawcenter.org. **SEE** cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-special-report-number-27.pdf.

TRANSGENDER MEN AND HIV

A recent article in *Medical News Today* examines *What to know about HIV and transgender men*. Transgender men who have sex with men may be at greater risk for HIV, but the article also looks at HIV prevention for transmen. GO TO medicalnewstoday.com/articles/hiv-and-transgender-men#-summary. SEE ALSO Safer Sex and Sexual Health for Trans Masculine People at tht.org.uk/hiv-and-sexual-health/sexual-health/trans-people/trans-masculine/safer-sex.

Measuring isolation and loneliness

There are a number of ways to look at support

BY ENID VÁZQUEZ

RYAN ORR

The growing focus on aging with HIV, especially for people over 50, has led to a closer examination of *isolation*. The concept of isolation has long been a concern in geriatrics because it's known to have a negative effect on health. Well, it turns out that there are actually ways to measure isolation.

For example, do you have someone you can talk to openly about your problems? Who can help you if you get sick? Who can lend you money, or cook and clean for you when you need it?

The measurements vary, depending on who's doing the measuring. There's a difference between the number of contacts vs. a lack of *desired* contacts. A spouse may be viewed differently—count more—than another family member or a friend. Do you have more than six people to turn to, for example, or are you satisfied with the number of helpful people in your life?

"Isolation" is not the same thing as "loneliness." *Isolation* is basically a separation from others, whereas *loneliness* is a negative emotion. It's a perceived lack of connection when you want it.

Different groups of people may have different networks of support.

"Certain populations, such as low-income, minority, and lesbian, gay, bisexual, and transgender elders, may be disproportionately affected by the social determinants of health," according to a 2020 report from the National Academies of Sciences, Engineering, and Medicine, funded by AARP. The authors add, "It is critical to have assessment tools for social isolation and loneliness that do not further exacerbate inequalities between minority or at-risk groups and the general population."

The report, *Social Isolation and Loneliness in Older Adults:*

Opportunities for the Health Care System, is available as a free download online or for sale as a book.

The De Jong Gierveld Loneliness Scale asks you to consider such statements as *There is always someone I can talk to about my day-to-day problems; I find my circle of friends and acquaintances too limited; and I can call on my friends whenever I need them.*

The National Institutes of Health (NIH) lays out definitions and measurements of social support, social distress, and companionship, across various ages

The Berkman-Syme Social Network Index asks how many times you talk on the phone with family or friends in a typical week, and how often you get together with them. It also asks how often you attend church or club meetings.

The Duke [University] Social Support and Stress Scale (DUSOCS) measures both the support and the stress from people in your life. According to the questionnaire, "*A supportive person* is one who is helpful, who will listen to you, or who will back you up when you are in trouble. A person who *stresses* you is one who causes problems for you or makes your life more difficult." Then you get a list of people to check off as providing support or causing stress, including a spouse or significant other, children and grandchildren, neighbors, church members, and co-workers. You might want to bust out the calculator, because these helpers and stressors get measured according to a point system. (GO TO fmch.duke.edu/sites/cfm.duke.edu/files/cfm/Research/HealthMeasures/DUSOCS.pdf.)

The National Institutes of Health (NIH) lays out definitions and measurements of social support, social distress, and companionship, across various ages in its Social Relationship Assessment Battery, part of a larger "toolbox" of looking at how people function. Look for those three subheads at ncbi.nlm.nih.gov/pmc/articles/PMC3759525. For example, under "companionship," the article says that, "*Intimacy* refers to the availability of people with whom one feels emotionally close or connected."

There is even a Campaign to End Loneliness, by a non-profit organization of the same name based in London. The campaign, which also considers all age groups, has provided three simple measurements for loneliness: *I am content with my friendships and relationships. I have enough people I feel comfortable asking for help at any time. My relationships are as satisfying as I would want them to be.* Their report, *The Psychology of Loneliness: Why It Matters and What We Can Do*, available free online, dives into suggestions for change, such as looking at your thinking patterns. According to the organization, "Nobody should be lonely in older age. We believe that loneliness is not inevitable. People of all ages need connections that matter."

Creating your own survey

For several definitions and measures of isolation and loneliness from a number of researchers, GO TO ncbi.nlm.nih.gov/books/NBK537897.

With all the different ways of looking at isolation and loneliness, what may be most important is what matters the most to you. After that, it may be a matter of keeping track of your progress in getting and maintaining the support that you want or need—or feel that you need.

Video

In March, the National Institute of Aging uploaded a YouTube video exploring social isolation and loneliness during the COVID-19 quarantine: "Many older adults feel socially isolated and lonely, which leaves them vulnerable to related health problems such as cognitive decline, depression, and heart disease." The speakers address health issues and how to stay connected during and after the COVID-19 pandemic. WATCH youtube.com/watch?v=WBJclABlg_U. GO TO nia.nih.gov.

In and out of isolation

"Thanks for turning me on to POSITIVELY AWARE about 30 years ago," said the message on my voice mail at work.

It was a reader from San Francisco now living in Oregon. I had just written the above piece for Positively Aging and hadn't considered POSITIVELY AWARE as a resource that helps people with isolation. I called Eduardo back.

"It's so hard to find something that reflects the issues that we deal with," he told me, "so the magazine really helps, even if you don't meet the person in the story."

He got a number of clinics and hospitals to subscribe as well over the years. He loves the annual HIV drug guide. Recently, he had to pull out the drug guide to show a hospital staff member that she was giving him the wrong medication. The woman got very angry. He also said he needed to take his HIV pill with food, but it wasn't dinnertime. So she wrote on his chart, "Refused medication."

"It's like an Alice in Wonderland environment sometimes," Eduardo said. He added, "It's amazing how many drugs there are and how many combinations exist."

In San Francisco, his relationship of 10 years broke up shortly before his move two years ago. He couldn't afford to stay in the city on his own. "She's come up a couple of times to visit," he said.

He was now out in the middle of nowhere, but with his beloved German Shepherd, Kogi. Then Kogi got sick and he made the heartbreaking decision to put Kogi to sleep. "It was the hardest thing I've ever done. But he was starting to suffer. There was nothing that could help. So not only was I out here in the boonies, but I lost my best friend. It put me in extreme depression. I actually stopped taking meds for three months. I'm back on meds now and undetectable."

Now he's living in a convalescent hospital where he's recovering from minor brain surgery for hydrocephalus. "It's locked down because of COVID. I can't go anywhere except medical appointments. People can't see me. My case manager couldn't get an appointment."

He gave me the new address for his subscription.

—ENID VÁZQUEZ

The stories behind the images

The idea behind *A Day with HIV*, POSITIVELY AWARE’s anti-stigma campaign, is to depict a single 24-hour period in the lives of people affected by HIV. On Wednesday, September 22, 2021, people—regardless of their HIV status—were encouraged to capture a moment of their day, and post the picture with a caption to their social media, accompanied by the hashtag #adaywithhiv. About 250 pictures were posted. It’s an opportunity for people to share their stories. But for some, sharing their photo led to the next chapter of life with HIV.

7:16 AM: DAVENPORT, FLORIDA
“At my home work station, doing some editing for my AIDS musical, *Open Discussion*, before signing on to my daily 12-Step Zoom call at 8 AM.”
—**Harry C. S. Wingfield**

“I had two people message me to thank me for just being me,” said Thom Bland, a long-term survivor of HIV. “One had held his status secret for 16 years and needed release, the other was 10 years living with HIV and was happy to know a friend he could reach out to. This *Day* is bigger than the sum of our parts.”

“My sister wasn’t aware of how many meds I take each day and she asked me a lot of questions,” said Rose McCloud. “I didn’t share my status with anyone in my family beyond my children until two years ago, although I have been positive for 28 years and counting. I had heard enough negative and absolutely horrible jokes about people living with HIV from family members over the years to know that I should keep it to myself. But the picture I posted of my meds opened the door for open honest conversation with a few family members.”

Sascha Rex was only diagnosed with HIV last year. “Taking part in *A Day with HIV* was one of my best decisions,” he said. “I got surprising messages and warmhearted reactions. Friends and colleagues reading my post were supporting my fight against stigma of people living with HIV, and were proud of how openly I handle my status being HIV-positive.”

The annual campaign started in 2010. A number of HIV advocates regularly take part, while others have taken pictures, documenting their journey over the years.

“I love seeing all the people living with HIV in their daily lives, living largely ‘normal’ lives,” said transgender HIV activist Katie Willingham. “If I had seen something like this when I was diagnosed, I wouldn’t have spent so many years waiting to die. I would have seen hope that life goes on, even while living with HIV. So, I turn in my picture every year for this campaign in hopes of giving others hope, because this is a campaign of hope.”

9:10 AM: TUSCUMBIA, ALABAMA
“Getting my blood drawn for my annual labs, because it’s so important to keep your healthcare appointments and maintain your health by always knowing your status.”
—**Katie Willingham**

“I felt an overwhelming sense of community, both from the other posters and from my family and friends on Facebook and Instagram,” said Harry C.S. Wingfield, a long-term survivor.

“I loved seeing so many people celebrating life,“ said Anthony Johnson. “It was wonderful seeing people out and proud of who they are. It was great seeing some who were originally scared to share their stories kick shame and stigma to the curb. It was like they finally freed themselves of their chains.”

“It’s a really sweet and simple way to pause for a few minutes and share with others what you’re doing or feeling as a person living with this shared commonality,” said Tranisha Darlene Arzah. “I really appreciate it, and to witness what living with HIV looks like on that day for this unique community is very inspiring, and builds a sense of gratefulness that we all get to share these moments together. Thank you!”

9:10 AM: WILTON MANORS, FLORIDA
“Fifty-one years old, 27-year HIV survivor. Living out loud and proud.”
—**Anthony Johnson**

10:43 AM: NEW ORLEANS, LOUISIANA
“So much to be grateful and thankful for this year! I celebrate my one-year anniversary of living in the extraordinary city of New Orleans, 31 years of thriving with HIV, and my first Mabon celebration with my spiritual community as we begin the autumnal equinox.”
—**Tranisha D Arzah**

THE FOLLOWING SIX PAGES of this issue feature pictures from *A Day with HIV*. Some captions have been edited for brevity and space. An online gallery is on display at adaywithhiv.com. Search for images using the hashtag #adaywithhiv on Facebook, Instagram, and Twitter.

<< 6:05 AM: JOHANNESBURG, SOUTH AFRICA

"Diagnosed in 1997, that's 24 years ago. Living a healthy life at age of 62. Treatment has given me the ability to live without fear. Every day is an opportunity to make a difference."
—**Alan Brand**

< 7:00 AM: LARKANA, PAKISTAN

"Children living with HIV and their caregivers in District Larkana, Sindh, Pakistan, have powered through the HIV outbreak of 2019. Challenging stigma and calling out discriminatory acts is what they require from their communal allies. Embrace #Sujaag, break stigma!"
—**HIV Sujaag**

<< 7:25 AM: CHEYENNE, WYOMING

"I was diagnosed HIV-positive eight years ago last week. It has inspired me to take better care of myself. I started running. I have completed multiple 5Ks, 10Ks, half marathons, and three full marathons. At the age of 47, my diagnosis will not get the best of me!" —**Dennis**

< 8:00 AM: LEXINGTON, KENTUCKY

"Spending 32 years of my life with HIV has given me much time for reflection. This is me with my husband, volunteering for Dining Out For Life Bluegrass in Lexington. We're a 22-year serodiscordant couple trying to spread kindness and love."
—**Steven C. Burch**

<< 8:30 AM: WASHINGTON, D.C.

"After hours of insomnia, I started planning my day, and practiced piano once the hour seemed reasonable. Life can be challenging and life can also be quite amazing. One thing inspiring me is learning new things like piano as a grownup, for example."
—**Julio J. Fonseca**

< 8:30 AM: PARADISE, GUYANA

"HIV does not define who I am. In the war for 17 years. It is bad enough that people are dying of AIDS, but no one should die of ignorance. I am an HIV-positive strong, active, and beautiful woman. HIV is not a crime. Face us, not our status, but our story." —**Risanna**

8:30 AM: BONN, GERMANY >
"I tested HIV-positive last year. The first months were full of fear, shame, and self-stigma. But I've come to understand that I can live a long and healthy life thanks to modern therapy. Today I am a happy positive man who fights stigma, and talks about #UequalsU! @aidshilfe_de" —**Sascha Rex**

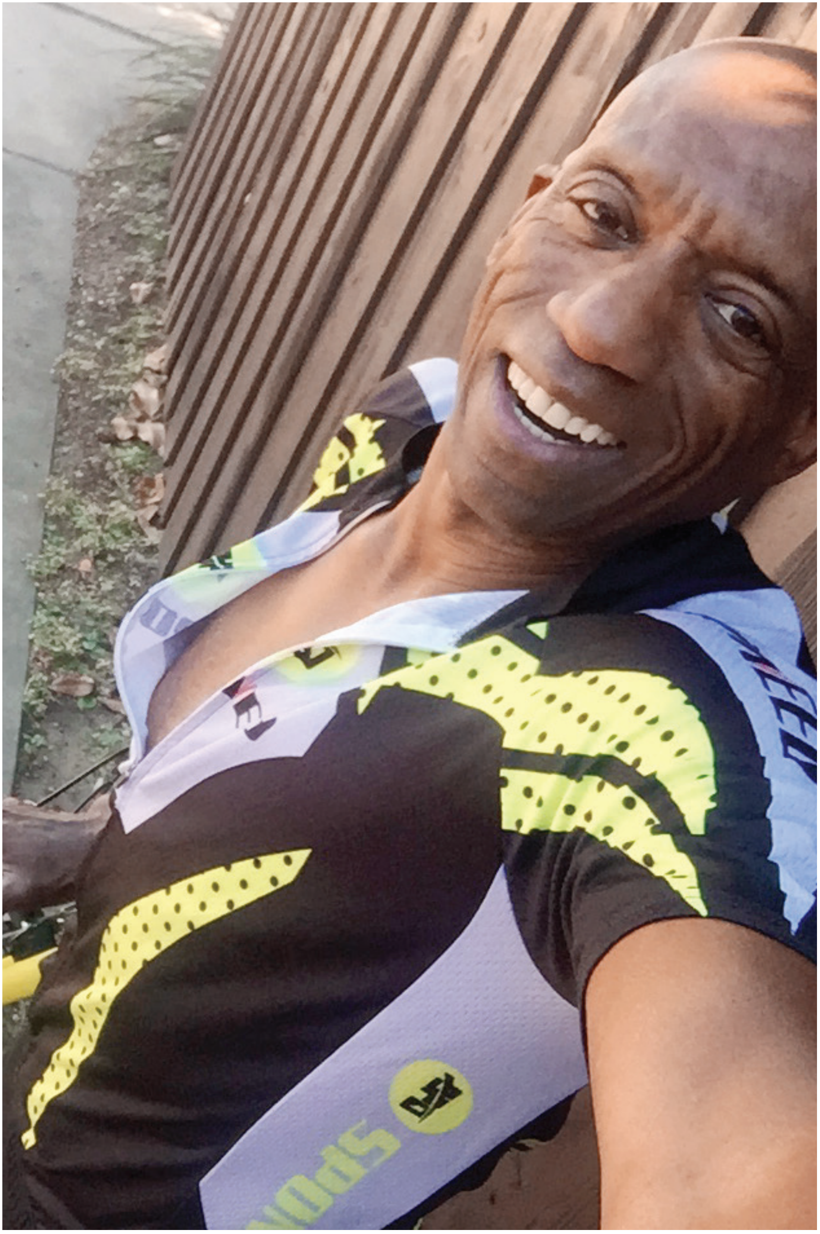
8:39 AM: LONDON, UNITED KINGDOM >>
"I wanted to capture my reality as a woman who has lived with HIV for 30 years. I am not feeling well today and this photo captures me shortly after I woke up. I sleep in wrist splints due to inflammatory arthritis and peripheral neuropathy in my wrists and hands." —**Emma Cole**

9:45 AM: DENVER, COLORADO >
"Another day with HIV is another beautiful day! Grateful for every minute. Picking my grapes to make jam. Just turned 70!" —**Debora**

10:00 AM: STROUDSBURG, PENNSYLVANIA >>
"Wish I had a better picture for today, but not feeling too good. Not every day with HIV is perfect, but that's life. This, too, shall pass, Thirty-six years positive." —**Marci Egel-Guzowski**

10:08 AM: ARLINGTON, VIRGINIA >
"Over 35 years ago, I was diagnosed as someone living with HIV and not expected to live another eight years. Today, I am a parent. I am a husband. I am a teacher. I am an activist. I am hope. And, these are not destinations. All of these have become just a part of my life's journey." —**Larry Bryant**

10:10 AM: ALAMEDA, CALIFORNIA >>
Honoring Our Experience. I think there's over 100 years of living with HIV in this photo. I've known these two amazing humans for decades, and they've lived lives of love-filled service forever—Paul Aguilar and Harry Breaux, along with our ally Diana Sciarretta [not pictured]." —**Gregg Casin**



<<< 10:48 AM: ARLINGTON HEIGHTS, ILLINOIS

"I have been HIV-positive since 2/28/17. It changed my life and made me take my health seriously. Luckily, my status hasn't stopped me from meeting an amazing partner who supports me and even attends my doctors appointments with me." —**Michael**

<< 10:50 AM: PHILADELPHIA, PENNSYLVANIA

"Stretching after my regular Wednesday virtual training. No matter what your medical condition, it's important to stay as active as possible to improve your quality of life." —**Asha Molock**

< 11:00 AM: NEW YORK, NEW YORK

"I am a person who has been living—more like thriving—with HIV for 32 years. I love softball. I pitch and I catch and my number is 69. LOLOL!"
—**Enrique Menendez**

<< 11:00 AM: OAKLAND, CALIFORNIA

"LHIVing with HIV for 28 years—half of my life. It has been a journey. At first I thought I would die, but it actually taught me to live. I was scared, ashamed. I thought I was afraid of what others thought, but finally realized it was what I thought of someone with HIV. My thoughts were negative, so my challenge was to change my thoughts. Through depression, through drug abuse...to a leader, a proud King."
—**Jesse Brooks**

< 11:53 AM: IRVING, TEXAS

"Wednesday, it's time for biking. Part of my fitness routine in addition to weights and swimming. HIV-positive 33 years, by the grace of God. Undetectable."
—**Gabe Sims**

<< 11:30 AM: NEATH, UNITED KINGDOM

"Having bloods done for diabetes, I was offered, and accepted, a flu vaccination, 'since you're here.' The silver ribbon badge was made by the National Long-Term Survivors Group (now known as HIVitality) in the 1990s."
—**Steve Craftman**

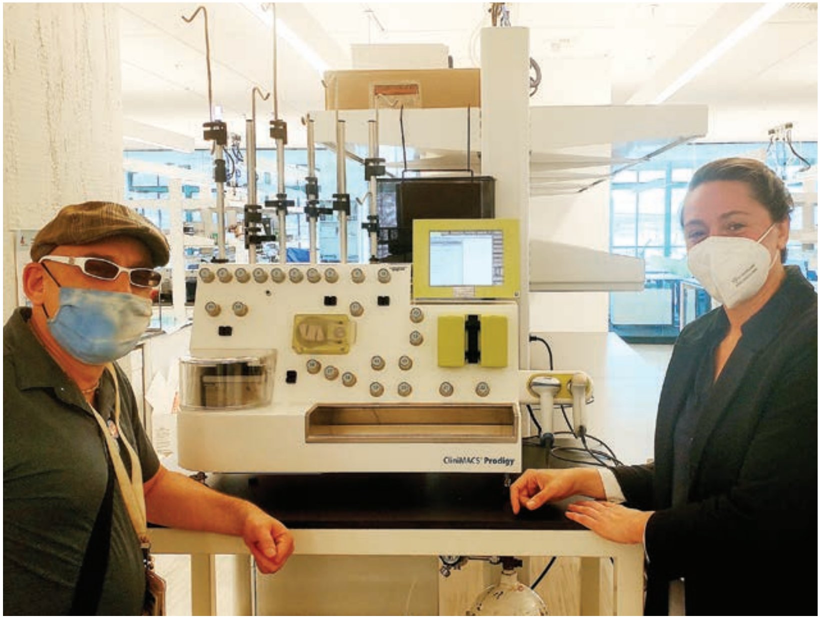
12:10 PM: DENVER, COLORADO > "Collecting the morning eggs from my hens. I'm a mom to seven kids, a wife, a friend, an advocate, and an ally for people living with HIV here in the U.S. and around the world." —**Jess Wiederholt**

1:12 PM: JUANA DÍAZ, PUERTO RICO >> "When I was diagnosed with HIV in 2018 in a hospital, I thought my life was over. Now, I am undetectable and living a full life." —**Eddie Martinez**

1:44 PM: HARARE, ZIMBABWE >>> "A day in the office celebrating 20 years of healthy living!" —**Sharon Mashamba**

2:10 PM: WILTON MANORS, FLORIDA > "Having known my HIV status since the mid-1980s, I'd have never guessed that in 1993 with the diagnosis of non-Hodgkins lymphoma and given seven years to live, that I'd leave living on disability to work full-time helping people to get care, access support, and gain a fuller life. Being a Care Guide (Ryan White case manager) with a large HIV-focused organization is amazing. My transgender non-HIV-positive girlfriend supports all I do, as I do her. This is just another fabulous day with HIV." —**Robert Hadley**

2:30 PM: SEATTLE, WASHINGTON > "At Fred Hutch, Dr. Jennifer Adair shows me her 'gene therapy in a box' technology that will make it possible to bring cell and gene therapy research for an HIV cure to Uganda and India by 2024. Jen and I work with the Global Gene Therapy Initiative, an alliance of key stakeholders including clinicians, scientists, engineers, advocates, and community members who seek to enable access and implementation of gene therapies as curative approaches to sickle cell disease and HIV in low- and middle-income countries." —**Michael Louella**



2:35 PM: PEORIA, ILLINOIS >> "Thirty-one years living with HIV, and I get to do what I love—Ryan White case management!" —**Bruce Broughton**

<< 2:36 PM: HARARE, ZIMBABWE
“Today is a beautiful day. We celebrate all living with and affected by HIV. BIG LOVE.”
—**Haatsari Lorreen Chinyanga**

< 3:51 PM: BOSTON, MASSACHUSETTS
“Heading home after spending the day at the largest HIV community center in Boston, the Boston Living Center. Providing meals, peer support, case management.... all life-saving services to me!”
—**Jo Ann Coull**

<< 4:17 PM: VERO BEACH, FLORIDA
“Spending A Day with HIV with my new husband and loving life.”
—**Sherie and Bob**

< 4:21 PM: ALBANY, NEW YORK
“It’s been 17 years since being diagnosed with HIV. As a Black Woman of Trans experience living a healthy and productive life, I’m thriving and achieving my goals. Heading to school!” —**La’Mia**

<< 4:30 PM: VENICE BEACH, CALIFORNIA
“Finding joy in the little things.”
—**Robin Barkins**

< 5:28 PM: HAMILTON, ONTARIO, CANADA
“My favourite part of the day is picking up my daughter from daycare! Living with HIV, I never thought I’d have a child, but here we are! U=U.”
—**Breklyn Bertozzi**

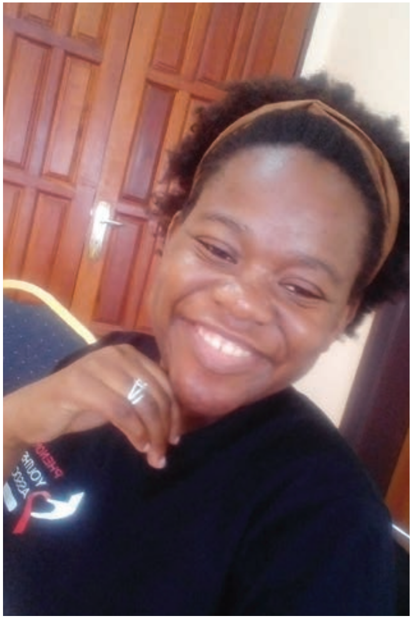
5:35 PM: ARVADA, COLORADO >
"My birthday, celebrating 55 years on this planet. We were on our way to dinner. I was diagnosed in November 2011. During the past 9+ years I have experienced depression and mental breakdowns due to my addiction to methamphetamine. Today, I celebrate one year and 11 days in recovery, and now see the light at the end of a very dark tunnel. I am so grateful to all my friends and family who stuck by me, even through my dark days." —**Mary Jane Maestas**

6:23 PM: SITGES, SPAIN >>
"Running HIV testing for locals and tourists at Colors Sitges Link LGBTI organisation." —**Simon Randerson**

6:49 PM: PORTLAND, OREGON >
"Yá'át'ééh shi Dine'é, shi'kéh, dóó táhanołtso! Shi'eiya Lorne James yinishyę́. 'Áshįįhí nishłį́, dóó Kinyaa'áanii báshíshchiin. Tódích'íi'nii dashíchei dóó Kinyaa'áanii dashínáłí."
TRANSLATION:
"I am **Lorne James**, 2005 is when I learned I was HIV-positive. I was born for my mother's clan, The Salt People ('Áshįįhí) and into my father's mother's clan, The Towering House People (Kinyaa'áanii). In Diné [Navajo] culture, every person has four clans: the mother's first clan, the father's first clan, the maternal grandfather's first clan, and the paternal grandfather's first clan. The clan system was Changing Woman's way of telling the Diné People that this will allow you to be who you are."

8:00 PM: SAN ANTONIO, TEXAS >>
"I'm living proof that treatment works! I was born HIV-positive 33 years ago. My adopted family and medical team didn't expect me to live to graduate high school. I'm currently attending Texas A&M University to earn a Bachelor's Degree in Psychology." —**Katina Adcock**

8:01 PM: LUSAKA, ZAMBIA >
"Another year, another day, every day living with HIV. I always remember it's my health, my life, my responsibility to take my ARVs every day." —**Precious Mwewa Chisenga**



RESILIENCE OVER STIGMA:

STORIES FROM A DAY WITH HIV

An event honoring World AIDS Day

Join a celebration of the personal stories shared for A Day with HIV, POSITIVELY AWARE magazine's anti-stigma campaign.

FEATURING

Charles Sanchez
CONTRIBUTING EDITOR,
THEBODY.COM

Davina Conner Otalor
PREVENTION ACCESS
CAMPAIGN

David "Jax" Kelly
LET'S KICK ASS
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BEING BRIDGETTE

BRIDGETTE PICOU

As a woman

As a woman, I know what it feels like to be invisible. As a Black woman that feeling is sometimes intensified. It gets juxtaposed with occasionally being the person everyone is looking at, but not really seeing. In a time of “racial reckoning” such as what’s currently going on in the world right now, the need to be seen, and heard, is more important than ever if we expect to elicit change.

Being seen and heard in this space can be complicated. It’s a double-edged sword of wanting someone to understand and comfort your insecurities, but at the same time not wanting to open yourself up to hurt.

Being a minority woman living with HIV comes with a bit of invisibility. Forgive my bluntness, but I imagine being anything other than a gay man living with HIV is a little like that. I’m trying not to be offensive—only to live my truth by saying that, but the truth always seems to offend someone these days. My truth is that I am a Black woman living with HIV, and sometimes I struggle to be both seen and heard. I struggled at the beginning of my diagnosis to find faces that looked like mine. Voices that sounded like mine. Struggled to find services that considered my femininity and the unique experience of being a woman, let alone a Black woman. I struggle now to see regular representation in literature, research, and media of our presence and place in the big picture.

According to UNAIDS, in 2020 53% of people living with HIV were women and girls. Black folks, both male and female, are disproportionately affected by HIV. Yet, Black men, Black women, and really, women of any race, have never been seen as a face of what HIV could look like. Through no fault of their own, White gay men became “the face” of HIV/AIDS in the beginning of the epidemic. There are a lot of women’s organizations focusing on women and fighting for a seat at the table, but it shouldn’t be a fight. Women have always contributed to caring for those living and dying with HIV. At the same time, they have often been left out of study trials. Even though strides and advancements have been made in treatments, life expectancy, and quality of life, too many old stigmas and old prejudices persist. With statistics like the ones above, women need to be seen.

No matter who you are, in a crisis, identifying with others like you gives you the starting point for goals and boundaries and your journey to overcoming. Being seen and heard in this space can be complicated. It’s a double-edged sword of wanting someone to understand and comfort your insecurities, but at the same time not wanting to open yourself up to hurt. You want to be seen but not stigmatized. You want to be heard, but you don’t want someone else to tell your story or your truth in a way that doesn’t honor you. When you’re living with HIV there are levels of acceptance and peace. I think that for me the most important thing is that people with HIV learn to see themselves as they want to be first so that whether or not someone else sees you in a positive light (pun intended), it won’t matter because you see yourself as who you are and it’s enough for you. There is power in just being enough until you get to abundance. I will forever believe that stigma will persist and therefore so will new infections, until we normalize what people consider abnormal. That means everyone needs to be seen and heard, so people can see themselves, and let go of shame and fear and get real about risk and testing.

Be well. You matter.

BRIDGETTE PICOU is a licensed vocational nurse in Palm Springs, California. She uses her voice to speak for others as a member of the Board of Directors for HIV & Aging Research Project-Palm Springs (HARP-PS) and as a Community Advisory Board Member for The Well Project-HIV and Women. She is also an active HIV blogger and member of ANAC, the Association of Nurses in AIDS Care, Greater Palm Springs Chapter. Finding a voice in advocacy and activism is a natural progression, since she feels that every time she fights for someone else, she affirms her own life.

PICOU: CHAD SAIN • IMAGE: ISTOCK

If you are living with HIV, ask yourself the following questions:

Have I lost weight?

- ☐ Have I lost weight without trying?
- ☐ Does the change in my weight impact how I feel about myself or my health?
- ☐ Is my clothing looser than before because I have lost weight without trying?
- ☐ Have those I know mentioned that my appearance has changed?

Do I have less energy?

- ☐ Are any of my usual activities more difficult to perform?
- ☐ Am I exercising less than in the past?
- ☐ Do I need to take a break more often?
- ☐ Do I tire more easily after certain activities?

If you answered "yes" to any of these questions, take this questionnaire to your next appointment with your healthcare provider to start a conversation about HIV-associated wasting and to inquire about treatment. Together you can discuss next steps. To learn more about HIV-associated wasting, visit: **IsItWasting.com**

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