POSITIVELY AWARE
FEB+MAR 2024

1:23 PM: PRINCETON, NEW JERSEY

"At the HealtheVoices 2023 conference. Following our passion as HIV advocates."
—**KAMARIA LAFFREY, JAHLOVE SERRANO, BRADY DALE ETZKORM-MORRIS, JESUS HEBERTO GUILLEN SOLIS, TIMOTHY S JACKSON, BRYANT O'DONNELL, ROBERT BREINING, DANIEL G. LEWIS, OCTAVIA YAZ-MINE LEWIS** and **MYCAH ARELLANO**

ONE OF THREE
SPECIAL EDITION
FOLDOUT COVERS

A DAY WITH HIV

EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

POSITIVELY AWARE
FEB+MAR 2024

ONE OF FOUR
SPECIAL EDITION
FOLDOUT COVERS

1:00 PM:
PHILADELPHIA,
PENNSYLVANIA

"Diagnosed 2003 at age 16. Twenty years—TWENTY YEARS POSITIVE!!!—later with a few stories to tell and a few scars, physically and emotionally. But today I'm fitter, happier and healthier than ever. Fight HIV shame and stigma! Act up!Fight back!"
—**NATHANIEL J. HALL**

A DAY WITH HIV

EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

6:00 PM:
PHILADELPHIA, PENNSYLVANIA

"Celebrating my birthday today with my daughter. The love and support of family is important when living with HIV."
—**ASHA MOLOCK**

ONE OF FOUR
SPECIAL EDITION
FOLDOUT COVERS

POSITIVELY AWARE

FEB+MAR 2024

6:13 PM: MBALE, UGANDA

"As a young person living with HIV, I advocate for HIV prevention measures, U=U, elimination of mother to child transmission and an end to stigma among adolescents and young people living with HIV. As a change champion, I want to create change in my community and country."
—**GLORIACLARA**

A DAY WITH HIV

EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

11:30 AM: LOS ANGELES, CALIFORNIA

"I am more than a long-term survivor… I am a thriver."
—**ROBERTO**

POSITIVELY AWARE
FEB+MAR 2024

ONE OF FOUR
SPECIAL EDITION
FOLDOUT COVERS

1:55 PM: MONTGOMERY, ALABAMA

"Enjoying the beautiful rays of sunlight on my couch. The sunlight reminds me of the warm love I have for all mankind. Before any HIV diagnosis, we were human first! Recognizing the human first is the true path to the eradication of HIV!"
—**MARCO MAYS**

A DAY WITH HIV

EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

6:14 PM: DALLAS, TEXAS

"'Cuz I'm grown and I like being outside!"
—**MICHELLE ANDERSON**

FEB+MAR 2024

POSITIVELY AWARE · VOLUME 34 NUMBER 1 · positivelyaware.com · @posaware

FEATURES

EVERY ISSUE

THIS ISSUE

POSITIVELY AWARE

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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.

BE GREEN.
SHARE OR RECYCLE
THIS MAGAZINE.

BEHIND THE COVERS

ONE ISSUE, FOUR FOLDOUT COVERS. The issue features four versions of the foldout cover, each with photos from **A Day with HIV**, POSITIVELY AWARE's annual anti-stigma campaign. A Day with HIV portrays 24 hours in the lives of people affected by HIV. On September 23, 2023, people around the world photographed a moment of their day, posted the picture to their social media and shared their story using the hashtag #adaywithhiv. An online gallery is on view at adaywithhiv.com.

1:23 PM: PRINCETON, NEW JERSEY
"Following our passion as HIV advocates, we are spending the day at HealtheVoices 2023"
—**KAMARIA LAFFREY, JAHLOVE SERRANO, BRADY DALE ETZKORM-MORRIS, JESUS HEBERTO GUILLEN SOLIS, TIMOTHY S JACKSON, BRYANT O'DONNELL, ROBERT BREINING, DANIEL G. LEWIS, OCTAVIA YAZ-MINE LEWIS AND MYCAH ARELLANO**

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"'Cuz I'm grown and I like being outside!"
—**MICHELLE ANDERSON**

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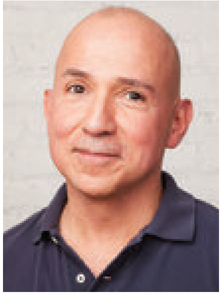


EDITOR'S NOTE

Rick Guasco
@rickguasco

Mosaics

People sometimes think a community must be made up of members who are all the same, as if they were cookie cutter identical to each other. I think of communities as mosaics, made up of many faces, different experiences and an incredible assortment of lives.

This issue offers a collection of mosaics, starting with the photos taken on A Day with HIV, the magazine's anti-stigma campaign that portrays 24 hours in the lives of people affected by HIV. On the first day of autumn every year since 2010, people everywhere photograph a moment of their day and share it on their social media with a caption that tells the time and location of their picture and what inspired them to take it, accompanied by the hashtag #adaywithhiv. This past year, dozens of photos were posted from across the U.S. and from 15 other countries around the world. Some of the pictures are featured on four different versions of the foldout cover and a special eight-page section inside.

These selfies are a mosaic of resilience. Together, they make the statement, *There is life with HIV.*

You'll find families of all kinds spending time together, people attending concerts, having a normal day as they go grocery shopping and reflecting on how far they've come. A Day with HIV isn't all smiles and sunshine, though, as Jeffery Parks in Fort Worth, Texas admits he's having a rough day with his picture on page 34: "That's the intent of this campaign, to capture an ordinary day in the life of people affected by HIV—both the negative and the positive."

This issue also presents a mosaic of experiences. Writer Larry Buhl looks at a simple but effective educational presentation by Steven Cardenas, a nurse practitioner and instructor in Florida, that gives healthcare workers a better understanding of the stigma faced by transgender folk in medical care settings (page 36). This, in a state that has one of the most extreme bans on gender-affirming care in the country.

"The biggest challenge for trans patients is fear of rejection by providers," Cardenas says. "This fear prevents trans people from seeking health care."

In a powerful commentary, Katie Willingham speaks to that fear and writes about her experience as a transgender woman living with HIV in today's political environment (page 38). She points to the growing number of proposed anti-trans laws being considered in state capitals across the country—467 so far this year, she reports according to the trans legislative tracker website translegislation.com, and counting.

"It seems that conservatives are determined to erase my community by any means available, including denying our right to health care," Katie says. Still, she is determined. "We must remain vigilant in these times; unite across race, gender and sexual orientation; and fight against unjust legislation, discrimination and hate."

HIV activists in Uganda and Ghana are also pushing back against government-backed hate while providing access to HIV care and preventive services in their home countries, writes Pascal Akahome in, "A sliver of hope" (page 19). Helen is a 28-year-old trans woman who founded one of the few trans-led and trans-focused HIV service organizations in Uganda before fleeing the country for safety. A law passed in May 2023, one of the harshest on the continent, that has criminalized being gay, mandates the death penalty for LGBTQ+ people and outlaws organizations that serve gay people.

A similar law is being reviewed by the supreme court in Ghana; the country's president has said he will sign it if the court rules it is constitutional. Yet, Kizza, another woman Pascal spoke with, maintains a sliver of hope. "Some clinicians can be sympathetic to our cause; we can only hope that we find a way of building a connection with them so they can help our people," she says.

Pascal transcends communities, if not worlds. Born in Nigeria and currently living in Canada, he is a pharmacist, researcher, a fellow of the Advocacy for Cure Academy of the International AIDS Society (IAS) and the director of the Antiretroviral Improved Access Initiative (AIAI), a local advocacy network based in Nigeria.

Our community transcends boundaries, labels and definitions that are imposed on us and ones we sometimes put on ourselves. Let these mosaics remind us of the variety of our community, and of the variety that exists within each of us.

You are not alone.

Rick

GUASCO: JOHN GRESS • MOSAIC IMAGES: A DAY WITH HIV, ISTOCK

Briefly

ENID VÁZQUEZ @enidvazquezpa

VIIV HEALTHCARE

Dovato now available in new packaging option

The single-tablet regimen Dovato is now available in a new blister pack option, announced the drug's maker, ViiV Healthcare.

Designed to be small and discreet, the new packaging is perforated and measures about the size of a credit card. A 30-count box contains five sheets of tablets. The sheets allow people who are taking Dovato to view the number of pills they have left and track their doses.

"The Dovato blister pack is designed to help address some of the challenges we hear from the HIV community, which include stigma and convenience, and offers a discreet package which may fit more seamlessly into people's daily routines," said Lynn Baxter, head of ViiV's North American operations.

The FDA approved Dovato's blister pack on Nov. 23, 2023. It is available now in the U.S. and will be offered in some European markets later this year. Dovato will continue to be available in a 30-pill bottle.

Dovato is a once-daily, single-pill, two-drug combination of dolutegravir, an integrase strand transfer inhibitor (INSTI) and lamivudine, a nucleoside analog reverse transcriptase inhibitor (NRTI).

ViiV is majority owned by pharmaceutical company GSK, with Pfizer and Shionogi as shareholders.

—RICK GUASCO

New guidelines protect positive hearts

The large, international REPRIEVE study found a 35% reduction in major adverse cardiovascular events for people living with HIV (PLWH) who used pitavastatin compared to the individuals who took a placebo (fake pill). It is now recommended that PLWH ages 40–75 with a low-to-intermediate 10-year risk of atherosclerotic cardiovascular disease (ASCVD) start "at least moderate-intensity statin therapy" consisting of:

1. pitavastatin 4 mg once daily (AI recommendation—the highest available in the guidelines) or
2. atorvastatin 20 mg once daily (AI) or
3. rosuvastatin 10 mg once daily (AII)

The updated HIV treatment guidelines from the U.S. Department of Health and Human Services (HHS) were published as this issue went to press. **GO TO** bit.ly/3Pi2CsD.

Biktarvy FDA-approved for common type of drug resistance

The U.S. Food and Drug Administration (FDA) has approved a new, expanded usage (indication) for Biktarvy to include people who are virally suppressed (a viral load of less than 50 copies/mL, often known as "undetectable") with a confirmed or suspected form of drug resistance known as M184V/I.

One of the most common, the M184V/I resistance mutation has been found in a range (22–63%) of people living with HIV (PLWH) having a pre-existing resistance to nucleoside reverse transcriptase inhibitors (NRTIs) across various HIV subtypes, including one of the two in Biktarvy.

The label update is based on week 48 data from Study 4030, which evaluated the efficacy, safety and tolerability of Biktarvy in a broad range of people living with HIV-1 (the most common HIV type in the U.S.) with or without pre-existing NRTI resistance, including M184V/I resistance.

In the phase 3, randomized, double-blind trial, participants were on a baseline regimen of dolutegravir (DTG + either emtricitabine/tenofovir alafenamide [FTC/TAF] or emtricitabine/tenofovir disoproxil fumarate [FTC/TDF]). They were then randomly switched—284 participants onto Biktarvy and 281 onto DTG+FTC/TAF.

Out of the Biktarvy group, 47 had HIV with pre-existing M184V/I resistance. The primary endpoint included the proportion of individuals with HIV RNA greater than or equal to 50 copies/mL at week 48. About 89% remained suppressed and 11% did not have virologic data at week 48, according to the results.

No one with M184V/I who received Biktarvy and had virologic data had HIV RNA of 50/mL or greater. There were also no cases of treatment-emergent resistance to Biktarvy, regardless of known or suspected pre-existing M184V/I resistance in the final analysis population.

Overall, the safety profile in virologically suppressed participants in Study 4030 was similar to other studies of Biktarvy in people who are

TOP OF THE NEWS

➤ Dovato now available in new packaging option ➤ New guidelines protect positive hearts ➤ Stopping HIV in the streets ➤ Acting director Fanfair becomes permanent head of CDC’s Division of HIV Prevention ➤ Long-acting injectable superior to daily pills, study says ➤ Helping women envision PrEP ➤ Special issue on LGBTQ+ aging ➤ Remembering Hydeia Broadbent

treatment naïve (individuals taking HIV antivirals for the first time).

“This label update builds on the established high resistance barrier of Biktarvy by showing that it’s effective in [PLWH] who may have certain forms of pre-existing resistance or a history of past treatment failure,” said Paul E. Sax, MD, clinical director of the Division of Infectious Diseases at Brigham and Women’s Hospital and a professor of medicine at Harvard Medical School.

Approved by the FDA in 2018, Biktarvy is now the first and only integrase strand transfer inhibitor-(INSTI-) based single-tablet regimen that is FDA approved and recommended by the U.S. Department of Health and Human Services (HHS) for PLWH who are undetectable and have M184V/I resistance.

—RICK GUASCO

Stopping HIV in the streets

The success of the Boston Health Care for the Homeless Program in pushing back against HIV was detailed in an interview with the city’s public radio station in January.

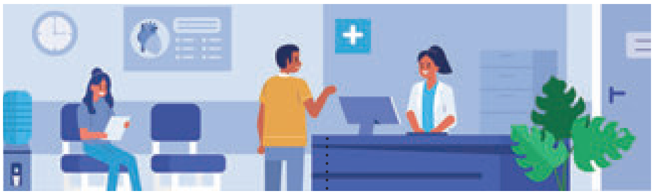
The Boston Department of Public Health reported a rise in new HIV cases beginning in 2019 for people who experienced homelessness, especially among people who also used injection drugs. By early 2022, there were nearly 170 new cases in this group.

Working with the homeless agency, however, there were 20 new cases for all of 2022 and five in 2023.

What helped? Among other things, simple testing and treating. The treatment of HIV, which prevents transmission to other people when it’s successful, was often innovative in that **medications were taken out to individuals instead of having them go to a clinic**. There was also respectful support and fighting the stigma that the group constantly faces.

Preventing transmission by bringing down HIV viral load to undetectable levels with medication is called Treatment as Prevention (TasP) or U = U (Undetectable Equals Untransmissable).

Hear Jennifer Brody, MD, MPH, director of HIV services at Boston Health Care for the Homeless Program, talk about the city’s outbreak and its response, in conversation with host Arun Rath on WGBH during NPR’s *All Things Considered* afternoon news show; **GO TO** bit.ly/49QPy5m. A transcript is available.



IRINA_STRELNIKOVA - ISTOCK

Using hospitals to prescribe PrEP

For many years now, prevention advocates have pointed to the limited promotion of HIV pre-exposure prophylaxis (PrEP), medication that can stop the virus in its tracks.

At the University of California-San Francisco (UCSF) hospital, Sarah Flynn, MD, MPhil, and colleagues took an innovative approach to addressing the problem. Noting that PrEP information in the health field (such as it is) is mainly provided to outpatients, they set up a study program for people being admitted to the hospital. Their institution is San Francisco’s “main safety-net hospital,” they wrote, with many patients experiencing one or more factors that may expose them to HIV.

Through the study, **providers were educated about HIV PrEP and becoming comfortable with screening for HIV, providing prevention counselling and prescribing PrEP**. In the first nine months of the initiative, 14 hospital patients were started on PrEP during their admission. In the year following their discharge from the hospital, six of them (42.9%) continued on PrEP prescriptions through their outpatient care providers.

Interventions at the hospital included new workflows for staff to start PrEP inquiry, counseling and prescription.

“PrEP was initiated in particularly vulnerable populations: 85% of patients were experiencing homelessness and 64% injected drugs. … This project required a substantial culture change since PrEP initiation was considered an outpatient intervention in our healthcare system,” Dr. Flynn and colleagues wrote in their journal paper published in the Volume 13, Issue 1 online *BMJ Journals*.

GO TO bit.ly/3v84OMv.

Cancer now leading cause of death in HIV

The American Cancer Society (ACS) reported that cancer is now the leading cause of death among people living with HIV.

The organization’s report, *Cancer Facts and Figures 2024*, notes that **while the virus does not cause cancer, it contributes to a greater chance for it to occur**. Ironically, it states that successful HIV treatment allows people to live longer and thus become more likely to develop cancer as they age. Several cancers are especially more likely with HIV, including cancer of the liver, lungs and cervix.

Released in January, the report is produced in conjunction with *Cancer Statistics 2024*, and is published in ACS’s journal, *CA: A Cancer Journal for Clinicians*.

The report includes a special section addressing the LGBTQ+ community. The report notes that CancerCare.org, which helps provide emotional, physical and financial resources, has an LGBTQ+ section; **GO TO** cancercare.org/tagged/lgbtq+. It also directs people to the National LGBT Cancer Network; **GO TO** cancer-network.org.

ACS also reported that cancer diagnoses in 2024 are expected to climb above 2 million in the United States, a record high.

To read the ACS report, **GO TO** amercancer.co/cff24.

Acting director Capt. Robyn Fanfair, MD, MPH, becomes permanent head of CDC's HIV prevention division

CAPT. ROBYN NEBLETT FANFAIR, MD, MPH

CPAN SCREENSHOT

Having served as acting director since August 2022, Capt. Robyn Neblett Fanfair, MD, MPH, has been named the permanent director of the Division of HIV Prevention (DHP) of the National Center for HIV, Viral Hepatitis, STD and Tuberculosis Prevention (NCHHSTP) of the Centers for Disease Control and Prevention (CDC). The DHP oversees much of the CDC's HIV prevention efforts; its mission is to prevent HIV and to reduce HIV-related illness and death.

"During her time as acting director, **Dr. Fanfair demonstrated her dedication to collaborating with the HIV workforce to gain a better understanding of suggested solutions and strategies for HIV prevention**," said Leisha McKinley-Beach, founder and CEO of the Black Public Health Academy. "While we commemorate her deserving appointment, it's important to recognize that she is navigating a system with its own obstacles related to racism and discrimination. Nonetheless, Robyn shines as an exceptional guiding light, a catalyst for change, and as a woman committed to positively impacting the lives of others."

Dr. Fanfair began her career in Baltimore as an HIV prevention researcher, clinician and public health worker. She served as a primary care provider for people living with HIV (PLWH) at the Moore Clinic of Johns Hopkins Hospital. She was a clinical research track fellow at Hopkins' Division of General Internal Medicine, conducting research into sexual networks and HIV and aging. A board-certified internist, she is also a primary care provider at the Atlanta VA Medical Center for veterans living with HIV.

In 2012, she joined NCHHSTP as a medical epidemiologist in the Division of STD Prevention, working on projects focused on syphilis, mycoplasma and herpes. She joined DHP in 2015, leading a randomized clinical trial to assess a collaborative data-to-care model to improve HIV care continuum outcomes. Becoming team lead of the DHP's Treatment Research Team in 2018, she led research efforts to improve engagement and retention in HIV care, increase viral suppression and improve health and life equity for PLWH. She also led DHP's Treatment pillar workgroup, supporting the Ending the HIV Epidemic in the U.S. initiative (EHE). She was named DHP's principal deputy director in November 2021, becoming acting division director the following August.

Dr. Fanfair is also a captain in the U.S. Public Health Service (USPHS), active in emergency preparedness and response, deploying to provide support for efforts around Ebola, Zika, COVID-19 and hurricanes Irma and Maria.

She received her bachelor's degree from Brown University, her Doctor of Medicine from NYU and her master's in public health from Johns Hopkins. She trained at Cornell-New York Presbyterian Hospital in internal medicine.

Announcement of Dr. Fanfair's permanent position was made Feb. 12 by Jonathan H. Mermin, MD, MPH, director of the NCHHSTP.

—**RICK GUASCO**

New report: Transwomen and HIV

The first report of the National HIV Behavioral Surveillance Among Transgender Women (NHBS-Trans) was released in January.

NHBS-Trans was established in 2017 by the U.S. Centers for Disease Control and Prevention (CDC). The agency noted that **while transgender women experience HIV out of proportion to their numbers in the country, there has been no HIV surveillance research devoted to them**.

NHBS-Trans focuses on three areas:

- Behavioral risk factors
- Prevention usage
- HIV prevalence

Surveys were conducted in seven urban areas—Atlanta, Los Angeles, New Orleans, New York City, Philadelphia, San Francisco and Seattle.

Nevertheless, the comprehensive 73-page report for 2019–2020 data covers wide territory, including reports from many research studies that have included transgender people.

Of the 1,608 women who participated in the survey:

- 902 were HIV-negative
- 706 were living with HIV

"The disproportionate effect of HIV infection among transgender women is the result of a complex layering of syndemics," the CDC noted, "and more remains to be understood. NHBS-Trans highlights the social and economic factors that are contributing to this disparity." The report explains that, "Syndemic theory posits that epidemics are produced by both diseases and social conditions. The theory emphasizes how structural factors (e.g., experiencing homelessness and incarceration) and psychosocial factors (e.g., sexual violence and polydrug use) jointly increase risk for HIV acquisition and transmission."

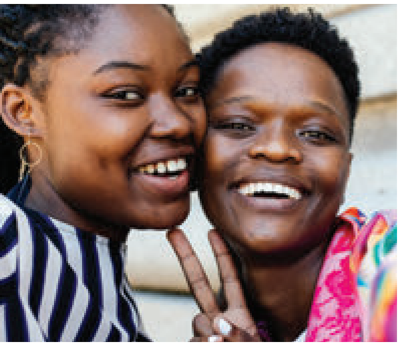
Syndemics specifically examined in the report are

- structural and psychosocial syndemic conditions and condomless anal intercourse
- nonprescription hormone use
- homelessness
- discrimination and employment discrimination as it relates to health-care access
- social support and the association between certain forms of violence and harassment and suicidal ideation

In a separate section on the use of pre-exposure prophylaxis (PrEP) for the medical prevention of HIV, the CDC reports that half of the HIV-negative women had discussed PrEP with their provider during the past year and a third had used it.

According to the report, "Although transgender women who reported sexual behaviors that are associated with HIV acquisition were more likely to have PrEP discussions with their healthcare provider and use PrEP, many who could benefit from PrEP were not using it. Because transgender women are one of the groups most affected by HIV, providing access to PrEP is critical to reducing HIV acquisition risk among transgender women and to reaching the goals for Ending the HIV Epidemic in the United States. Use of gender-affirming care was associated with having discussions about PrEP with a healthcare provider and PrEP use. Improving access to gender-affirming care for transgender women and training healthcare providers that serve transgender women to incorporate HIV prevention, including PrEP, into their services are strategies that might help increase PrEP use among transgender women."

TO SEE the report published in the January 25 issue of the CDC's *Morbidity and Mortality Weekly Report* (MMWR), **GO TO** cdc.gov/mmwr/volumes/73/su/pdfs/su7301-H.pdf.



IANA MIROSHNICHENKO-ISTOCK
GALLO IMAGES/GETTY IMAGES

Helping women envision PrEP

The MOSAIC project has issued a strategy brief sharing its findings on how to communicate HIV biomedical prevention to young women in Africa.

Communicating the PrEP Category to Adolescent Girls and Young Women (AGYW) reports on **insights the project has gained from talking with girls and young women**. For example, they don't want the facts around taking PrEP to be sugar coated and they don't want to be dictated to. In this last insight, "Prescriptive instructions are less effective than personal stories, examples and honest conversations."

In another insight, "AGYW don't want to feel that they are being singled out or stigmatized." An action

Long-acting injectable is superior to daily pills, study says

Data from a phase 3 clinical trial show that, for people who have challenges with adherence, monthly injections of the HIV medication Cabenuva are superior to a daily pill regimen.

Comprised of the anti-HIV drugs cabotegravir and rilpivirine, Cabenuva is a long-acting injectable antiretroviral therapy (ART) that is administered every four or eight weeks.

The finding came during a regularly scheduled interim review by an independent Data and Safety Monitoring Board (DSMB) looking at data from the ongoing LATITUDE study.

"The interim data indicating **the superiority of long-acting therapy compared to daily oral therapy in individuals who have difficulty taking pills for HIV every day is a remarkable outcome**," said Kimberly Smith, MD, MPH, head of research and development at drug maker ViiV Healthcare. "There are many reasons why people may find it challenging to stay on daily oral treatment and the LATITUDE study shows cabotegravir and rilpivirine injectable treatment can help them keep their virus suppressed, which benefits their overall health. Optimizing therapy for all people living with HIV, including those with adherence challenges, is critical to the effort to end the HIV epidemic."

LATITUDE (Long-Acting Therapy to Improve Treatment Success in Daily Life) is an ongoing study at 31 sites across the United States including Puerto Rico. It focuses on people who have challenges with adhering to a daily oral regimen. Participants were tested to ensure the HIV in their blood was not resistant to the study drugs. They then underwent "comprehensive and incentivized adherence support" using daily oral HIV meds to achieve viral suppression—that is, their viral load was too low to be measured by most tests. Participants were then randomized into two groups, either continuing daily meds or receiving the long-acting injectable medication.

After reaching its finding on February 12, the DSMB recommended that study participants be offered the opportunity to switch to Cabenuva. All participants will be monitored for another year.

While there are other long-acting injectable HIV medications, Cabenuva is the only FDA-approved long-acting complete regimen. For now, it is approved only for people whose viral load is undetectable. About 70% of people living with HIV in the United States who take oral ART are virally suppressed, according to the Centers for Disease Control and Prevention (CDC).

The two-drug injectable combo was approved by the FDA in 2021. Cabotegravir is an integrase strand transfer inhibitor (INSTI), which inhibits HIV replication by preventing the virus's DNA from integrating into the genetic material of human immune cells (T cells). Rilpivirine, a non-nucleoside reverse transcriptase inhibitor (NNRTI), interferes with an enzyme, reverse transcriptase, that the virus uses to multiply.

LATITUDE was launched in 2019 by the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health, and is conducted by Advancing Clinical Therapeutics Globally for HIV/AIDS and Other Infections (ACTG), the world's largest HIV clinical trials network. Additional support was provided by the National Institute of Mental Health, the National Institute on Drug Abuse and by cabotegravir maker ViiV Healthcare and the Janssen Pharmaceutical Companies of Johnson & Johnson, manufacturer of rilpivirine.

—**RICK GUASCO**

step states, “Even though the focus is on supporting AGYW’s PrEP use, include images of people of all ages, genders and ethnicities so the communities around them know that PrEP is for everyone.” As the report notes elsewhere, “This is not a story about HIV. This is a story about young women in Africa.”

To “brand” PrEP—promote it—MOSAIC reports that “PrEP is a way for young women to prioritize their physical health and mental well-being, to live a life uninterrupted by HIV. It affirms that self-love is strength.” It should also be noted as a source of peace of mind and something that provides the girls and women with a measure of control.

MOSAIC—*Maximizing Options to Advance Informed Choice for HIV Prevention*—is a five-year (2021–2026) global project funded by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development (USAID) to help AGYW and other women prevent HIV acquisition by accelerating introduction and scale-up of new and emerging biomedical prevention products.

Published in November 2023, the report notes that PrEP now includes oral (pill) options, an injectable and the dapivirine vaginal ring, with more choices on the way. The full-color report contains many beautiful photos and the extensive graphic design work belies its clinical title. MOSAIC has other beautiful and comprehensive reports to its credit.

TO SEE the seven-page brief, **GO TO** bit.ly/3uQOkbj.

Special issue on LGBTQ+ aging

The American Society on Aging (ASA) has devoted a special issue of its *Generations Journal* to topics related to the LGBTQ+ community.

The ASA worked with SAGE, a national organization devoted to improving the lives of LGBTQ+ elders.

“Our essay collection analyzes ageism as a systemic bias—like racism and sexism—and explores its deep links to ableism, given that bias about age is often linked to bias about disability,” writes SAGE CEO Michael Adams. “The essays reflect a reality that is often overlooked: that **aging, ageism and ableism affect different socio-economic groups differently**. That’s why organizations like ours exist.”

Other articles include one on women with HIV; “The Power and Limits of Law to Fight Structural Ageism, Ableism and Racism” by Gelila Selassie and Denny Chan and “With Age, Blacks Fall Into Poverty as Their Health Worsens,” by Rodney A. Brooks.

TO READ the special edition of *Generations Journal 2023*, **GO TO** bit.ly/3UZTH2M.

Keeping people on Medicaid

An online hub showing Medicaid renewal requirements state-by-state was created early this year by the U.S. Department of Health and Human Services (DHHS). The intention is to **help people figure out how to maintain their Medicaid coverage**. The resource is available in Spanish, Chinese and Tagalog among additional languages. **GO TO** hiv.gov/blog/hhs-launches-new-medicaid-chip-resource-hub-help-keep-people-covered.

DHHS also created a blog post addressing HIV service organizations and others working with the community about helping people living with HIV maintain their Medicaid coverage. **GO TO** hiv.gov/blog/the-medicaid-unwinding-period-a-message-for-the-hiv-community-09-01-2023. The post also contains links to information for pediatrics and people living with hemophilia.

Positive Women’s Network welcomes new executive team

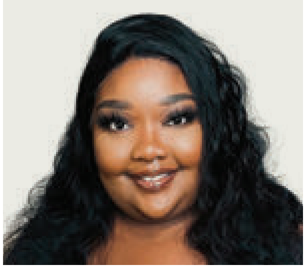
The Positive Women’s Network-USA (PWN-USA) announced a new leadership team—**Keiva Lei Cadena and Marnina Miller became joint executive directors** in January.

“We can’t imagine a better team to lead PWN-USA into its bright future,” said board of directors co-chairs LaTrischa Miles and Pat Migliore in a press release. “Keiva Lei and Marnina have been a part of the PWN family for many years and are talented, brilliant and emotionally intelligent leaders; this represents a natural next step in PWN herstory.”

KEIVA LEI CADENA

Keiva Lei Cadena is a nationally recognized advocate, activist, speaker and a Native Hawaiian cultural practitioner with extensive experience in HIV services, harm reduction and transgender rights. She is a graduate of PWN’s R.I.S.E. (Resist, Inspire, Sustain through Education) Gender Justice Training Academy, and was later welcomed back as faculty in the same program.

“It’s such a privilege to join PWN’s staff as co-director; this network played a role in my understanding the importance and power of having BIPOC trans women living with HIV advocating for ourselves fearlessly—the effects impact our entire community,” said Cadena. “I’m so proud to be a Native Hawaiian woman of trans experience holding this type of role at the national level. We don’t often see Native people lifted up in this way. PWN continues to be groundbreaking in our efforts to empower our communities. I will continue to strive for the dignity and quality of life we deserve, with the best group of sisters by my side.”



MARNINA MILLER

Marnina “the Queen” Miller is a highly accomplished human rights activist, speaker, trainer and social media strategist with “a profound commitment to

MILLER: © THE WELL PROJECT · LEI CADENA: ©TRANSGENDER LAW CENTER · SUBKONTR - ISTOCK

fostering positive change in society.” She has been part of PWN’s Greater Houston Area chapter and has served on PWN-USA’s Board of Directors since 2018.

“I am honored to co-lead PWN as a young Black woman living with HIV, keeping in minds and hearts our shared values of sisterhood, solidarity and meaningful involvement of people living with HIV,” Miller said. “In this unique journey, let us forge pathways of change, shatter barriers and create a future where our voices not only matter but shape policies that support and empower every woman living with HIV.”

Cadena and Miller follow on the heels of founding director Naina Khanna, who stayed on to help them during a transition period.

Under Khanna’s leadership, PWN-USA grew from a group of 28 founding members to a national organization with seven regional chapters and an organizing presence in more than a dozen states over the past sixteen years. PWN declared in a press release that it has “successfully advanced demands to uplift human rights and dignity for people living with HIV—from changes to the National HIV/AIDS Strategy to increasing the focus on gender responsive services and programs to protecting abortion access and reproductive justice at the ballot box.”

“Keiva Lei and Marnina jointly bring years of community organizing and advocacy, grounded in PWN’s values of Black liberation, trans liberation and meaningful involvement of communities impacted by HIV,” said Khanna, who is pursuing a PhD in medical sociology at the University of California-San Francisco. “Their brilliance, courage, conviction and compassion are urgently needed in this political and cultural moment and will serve as a beacon to the whole HIV field.”

READ MORE about Cadena and Millerat bit.ly/3OV9lZl.

HYDEIA BROADBENT (LEFT) APPEARED WITH JURNEE SMOLLETT IN A 2016 HIV AWARENESS CAMPAIGN.

Remembering Hydeia Broadbent

Hydeia Broadbent was a young child when she began speaking on behalf of people living with HIV, but especially on behalf of children like herself who were born with HIV. She died in her home in Las Vegas February 20 at the age of 39. Her father, Loren Broadbent, announced, “With great sadness, I must inform you that our beloved friend, mentor and daughter Hydeia, passed away today after living with AIDS since birth. Despite facing numerous challenges throughout her life, **Hydeia remained determined to spread hope and positivity through education about HIV/AIDS**.” Cause of death was not immediately given.

In her extensive work on behalf of people living with HIV, Broadbent made many TV appearances. At age 7, she participated in a Nickelodeon special with Magic Johnson. At age 11, she discussed her AIDS status on the Oprah show. She appeared in an episode of the ABC show *20/20* and on *Good Morning America* as well as other TV shows. She was presented with an award by Mariah Carey in an Essence Awards ceremony and she won a Black Achievement Award from *Jet* magazine. Broadbent spoke at the 1996 Republican National Convention. She made appearances through the Elizabeth Glaser Pediatric AIDS Foundation. Broadbent also worked with the *Let’s Stop HIV Together* campaign of the Centers for Disease Control and Prevention (CDC) and started the Hydeia Broadbent Foundation. Again and again she raised awareness around HIV and spoke out against stigma.

Patricia and Loren Broadbent adopted Hydeia when she was a baby. Born in 1984, she had been left at a hospital by her birth mother. It wasn’t until age 3 that she was found to have HIV and doctors predicted she would not live past age 5. The family wrote her story in a book, *You Get Past the Tears*.

Hydeia Broadbent lived her life succeeding beautifully against the odds.

THE CATEGORY IS

REFILLS

Interruption of a prescription refill can be a major worry for people living with HIV. POSITIVELY AWARE put the question to its social media followers:

Have you ever had difficulty getting a refill of your HIV meds? If so, what happened and how was it resolved?

COMPILED BY **RICK GUASCO**

"I had this pharmacy about 10 years ago that was recommended by my HIV clinic. They only did mail order for HIV medications and were always five days late. I switched to another pharmacy in West Hollywood, which I still use today.

"My new pharmacy has been a godsend. The staff are what I like to call my Rescue Rangers. They are never late and always call before they ship anything to me. I have not had a single snafu with them in the last nine years, not a single hiccup. I'd like to give them a shout out: Community Pharmacy, in West Hollywood. They are my superheroes.

"I'm a 38-year thriver with HIV. I was diagnosed on April 18, 1986. As a 23-year-old gay boy, I was told that I had a virus that was going to kill me in six months. I had 19 T cells. Who would have believed that that young man would live to see his 62nd birthday, which is only days from now."

—LEE RAND

"My problem is that my insurance provider, UHC/Optum, bought The Polyclinic [a physician-owned multi-specialty clinic with several locations in the Seattle area purchased by UHC in 2018] and renewal of scripts has become a nightmare: My pharmacy contacts the clinic, the clinic now routinely ignores these requests until I contact my physician's office. Every time. This was elevated by supply chain issues. My husband recently went for over a week without his HIV meds because of the runaround at our clinic."

—DUINE AR BITH

"I've not had any problems. Living in the UK, medication is picked up from a hospital pharmacy. I did receive an email regarding people not picking up their medication in good time. This costs the service [England's national healthcare system, the National Health Service, known as the NHS] money. With a polite reminder for people to pick up their medication or inform the service if they are unable to get it when it is ready. I think they hold it for a week."

—MATHEW LONG-SMITH

"I had a monster of a problem this week. I was down to five Biktarvy pills. I keep a stash of 10 pills but didn't think I would ever really need it, so I called my pharmacy and asked why they still hadn't delivered the refill. They said it was on backorder and they didn't expect to get any for at least a month. I was livid and asked when they were planning to tell me. I reached out on social media to my HIV community and they offered a few suggestions. By Thursday I was able to reach my case manager, who found a nearby pharmacy that delivers. I have mobility issues and need a wheelchair to go more than 20 feet. Pharmacies that deliver are a godsend. I tell folks all the time that social media has connected us and other groups of people who would otherwise be alone and have little or no support. Thank you all for being there for me, if only to listen."

—ROSE McCLOUD

"I was living in a small town and no pharmacy carried Biktarvy when I was diagnosed. I had to wait about to start ARVs and my CD4 count was down to 15. It was scary."

—ADRIAN FLINT

"Over 10 years ago, my union's health plan changed our prescription plan (it had always been separate from other health coverage). What they did not say was that HIV meds would now be considered 'specialty' and would have to be filled by their own mail-order pharmacy, meaning my local specialty pharmacy could no longer provide them. Of course, I did not find this out until I needed a refill. Fortunately, the administrator of our overall health plan was able to get an exception for me for that one drug that time, but I still needed to get all future fills changed."

—JEFFREY FRANKLIN JENNE

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VADIM SAZHNIEV - ISTOCK

RIPPLE EFFECT

How counterfeit drugs and PBMs threaten people living with HIV

BY **TRAVIS MANINT**

THE INFILTRATION of counterfeit drugs into the legitimate pharmaceutical supply chain poses a significant risk to patient health and safety, particularly for people living with HIV (PLWH). While counterfeit drugs are nothing new, the criminals threatening our safety have a surprising new ally: Pharmacy Benefit Managers (PBMs). A report by the Partnership for Safe Medicines unveils how criminal entities exploit vulnerabilities in the supply chain, made worse by PBMs, whose reimbursement policies often leave pharmacies on the edge of financial viability.

The fight against HIV/AIDS is significantly hindered by the infiltration of counterfeit medications into the pharmaceutical supply chain, an issue that transcends mere regulatory challenges or financial losses. It directly impacts the health and safety of people living with HIV (PLWH), undermining the global effort to manage and eventually end the epidemic.

A striking example of the severity of this issue is the investigation conducted by Gilead Sciences Inc., which was extensively covered by *The Wall Street Journal*. This investigation uncovered that over two years, a staggering 85,247 counterfeit bottles of Gilead's HIV medications Biktarvy and Descovy, valued at more than $250 million, had been distributed within pharmacies. These counterfeit products, the result of sophisticated criminal networks exploiting supply chain vulnerabilities, ranged from being filled with harmless over-the-counter painkillers to dangerous antipsychotic drugs, posing significant health risks to unsuspecting patients. "Harmless" is relatively qualified here because when PLWH are not receiving necessary antiretroviral medications, conditions can develop quickly with deadly consequences, medication resistance can bloom and new transmissions can occur.

Counterfeit medications not only endanger the lives of PLWH but also severely erode trust within communities, particularly those that are already marginalized and financially strained. The breach in the supply chain security caused by these counterfeit drugs highlights a critical public health issue that demands immediate and concerted action from all sectors involved in healthcare delivery.

Addressing the challenges posed by pharmacy benefit managers and under-reimbursement

PBMs are at the heart of growing scrutiny for practices exacerbating healthcare system challenges, notably impacting the economic viability of pharmacies, and facilitating the entry of counterfeit drugs into the supply chain.

Their primary role is to negotiate drug prices and manage prescription drug benefits on behalf of health insurers, under the guise of controlling costs and streamlining the prescription process. The reality is, PBMs do not necessarily pass on "savings" to patients or plan sponsors and have, in truth, become a self-dealing entity working hard to maximize the profits of insurance company shareholders. PBMs often implement reimbursement policies that pay pharmacies less than the actual cost of acquiring and dispensing medications when those pharmacies are not owned by the PBM itself. This under-reimbursement pressures pharmacies, especially independent ones, to find ways to sustain their operations amidst shrinking margins. In other instances, PBMs offer higher reimbursement rates to their mail-order pharmacy and work hard to steer patients away from independent pharmacies.

This economic squeeze leads to a consequential gap in the market: the demand for medications that the legitimate supply chain cannot adequately supply at the prices set by PBMs. Counterfeiters exploit this gap, introducing fake or substandard medications into the supply chain and offering the fakes at a lower acquisition cost than legitimate wholesalers. The cycle perpetuated by PBM under-reimbursement practices not only undermines the financial stability of pharmacies but also compromises patient safety. Pharmacies, caught in the vise of financial pressures, may unknowingly procure medications from less reputable sources, inadvertently becoming conduits for counterfeit drugs. This situation is exacerbated in rural and underserved communities, where pharmacies are often the sole healthcare providers, making the impact of counterfeit medications even more devastating. These counterfeit drugs find their way into pharmacies struggling to balance financial viability with the provision of quality care. The allure of lower cost options in the face of under-reimbursement makes counterfeit products dangerously appealing for pharmacists seeking to meet patient needs.

The financial strain on independent pharmacies due to PBM policies is further highlighted by the National Community Pharmacists Association's (NCPA) support for a class action lawsuit against Express Scripts. This legal action accuses Express Scripts, one of the "Big Three" pharmacy benefits management companies, and several smaller PBMs of colluding to manipulate reimbursement rates and impose higher fees on pharmacies.

> **Together, we have the power to reshape the landscape of drug affordability and access, guaranteeing that all people receive the comprehensive care and medications they deserve.**

American Pharmacy Cooperative, Inc. (APCI)'s initiative to engage Vanguard Inc., a significant investor in the conglomerates owning the "Big 3" PBMs—Caremark (CVS Health), Express Scripts (Cigna), and OptumRx (UnitedHealth Group)—exemplifies the urgent need for systemic reform. This effort, celebrated by Pharmacists United for Truth & Transparency (PUTT), emphasizes the necessity of reforms that ensure transparency, fair reimbursement, and ethical conduct to safeguard the pharmaceutical supply chain.

Prescription drug affordability boards (PDABs) and their impact

Prescription Drug Affordability Boards (PDABs) are quickly gaining popularity among states, being sold as an attempt to make health care more affordable. These boards, armed with the authority to scrutinize and cap drug prices, aim to shield the public from the soaring costs of essential medications. However, there's concern that these actions might limit access to medications for marginalized communities and create more challenges for pharmacies.

A recent webinar hosted by the National Minority Quality Forum (NMQF) brought to light the challenges PDABs face in balancing drug affordability with healthcare equity. Jen Laws, president and CEO of the Community Access National Network (CANN), voiced a critical perspective, highlighting the limitations of PDABs' current toolkit, which primarily revolves around setting upper payment limits. "The only tool that the PDABs have been provided is an upper payment limit, and they are not being encouraged to explore other tools or learn how to make investments into issues of health equity and access," Laws said. "When we take money out of systems, the people not represented lose out first." Few of these boards have patients appointed to them. This insight underscores the complexity of ensuring drug affordability does not come at the expense of access, particularly for people in marginalized communities.

Echoing this sentiment, Gretchen C. Wartman, vice president for Policy and Program and director of the Institute for Equity in Health Policy and Practice at NMQF, emphasized the need for PDABs to broaden their approach. "We must pursue efforts to ensure that PDABs are improving access to medicines, rather than constraining that access in the interest of financial risk mitigation," Wartman said, advocating for a more holistic strategy that aligns drug affordability with comprehensive access to care.

The discussions surrounding PDABs, particularly highlighted in the NMQF webinar and CANN's blog, reveal a critical need for a nuanced approach to drug affordability that doesn't inadvertently compromise access or exacerbate vulnerabilities in the pharmaceutical supply chain. By focusing narrowly on upper payment limits (UPLs) as a primary tool for cost containment, there's a real risk of creating gaps in the medication supply that counterfeiters could exploit, further endangering patient safety and public health. This scenario underscores the importance of developing comprehensive strategies that not only address the immediate issue of drug costs but also consider the broader implications for healthcare equity, pharmacy viability, and the integrity of the medication supply chain. Policymakers and stakeholders must work collaboratively to ensure that efforts to control drug prices do not inadvertently introduce new risks, particularly for marginalized communities and the pharmacies that serve them.

A legislative response: Florida's Prescription Drug Reform Act

The Florida Prescription Drug Reform Act stands as a major legislative response to the pressing issues within the pharmaceutical supply chain, particularly addressing the detrimental practices of Pharmacy Benefit Managers (PBMs) that contribute to pharmacy under-reimbursement and indirectly foster an environment ripe for counterfeit drugs.

Focused provisions:

- **Regulating PBM operations:** The Act mandates PBMs to obtain a certificate of authority, introducing a layer of accountability and transparency previously absent. This requirement aims to scrutinize and regulate PBM practices more closely, ensuring they operate in a manner that supports rather than undermines pharmacy financial stability.
- **Prohibiting harmful practices:** Specifically targeting practices that have strained pharmacies, the Act prohibits PBMs from engaging in retroactive fee recoupments and spread pricing strategies. Such practices have historically placed pharmacies in precarious financial positions, making the supply chain vulnerable to counterfeit medications as pharmacies seek cost-saving measures.
- **Ensuring fair reimbursement:** By enforcing a pass-through pricing model, the Act ensures that pharmacies are reimbursed the actual cost paid by the health plan to the PBM for medications. This approach directly addresses the issue of under-reimbursement, reducing the financial pressures that can lead pharmacies to inadvertently engage with dubious suppliers.

Implications for supply chain security:

These targeted reforms within the Florida Prescription Drug Reform Act are designed to directly impact the economic pressures pharmacies face due to PBM policies. By ensuring more equitable and transparent reimbursement practices, the Act mitigates one of the key factors that have made the pharmaceutical supply chain susceptible to counterfeit drugs. It represents a significant step towards safeguarding pharmacies from the financial instability that can compromise patient safety and healthcare integrity.

In essence, the Act provides a comprehensive framework for other states and federal entities to consider, highlighting the importance of addressing PBM practices as a critical component of enhancing supply chain security and protecting patient health.

Advocating for change: Strategic policy reforms and mobilization

The challenges posed by PBMs, PDABs, and drug affordability impact not just the healthcare industry and policymakers but directly affect people seeking affordable, safe medications. This underscores the urgency for a unified advocacy movement towards systemic reform. Drawing on the initiatives of groups like PUTT and APCI, as well as the framework set by Florida's Prescription Drug Reform Act, we have a clear path to advocate for transparency, equity, and patient access across health care.

Calls to advocacy

1. **Broadened engagement with policymakers, investors and the public:** Advocacy efforts must expand to encompass not just policymakers but also investors and the broader public. Echoing APCI's engagement with Vanguard Inc., it's critical to advocate for investor responsibility in healthcare practices. Moreover, by leveraging the legislative model of Florida's Prescription Drug Reform Act, advocates can champion similar transparency and regulatory measures nationwide. This expanded advocacy should also include a focus on ensuring PDABs operate with a mandate that balances drug affordability with the need for access to innovative treatments.
2. **Unified support for legislative and regulatory reforms:** Stakeholders are encouraged to unite in supporting and proposing legislative initiatives that tackle the foundational issues of PBM reform and the effective operation of PDABs. Advocacy should push for laws that not only enhance drug pricing transparency and regulate PBM reimbursement rates but also ensure PDABs do not inadvertently limit access to essential medications for marginalized communities.
3. **Active participation in rulemaking processes with strategic alliances:** Stakeholders should actively participate in the rulemaking process, forming strategic alliances to influence the regulations governing PBMs and PDABs. This collective action is vital in shaping policies that promote fair reimbursement practices, safeguard pharmacy access, and ensure PDABs contribute positively to healthcare equity.
4. **Comprehensive educational campaigns to foster awareness and action:** Initiating educational campaigns that explain the roles and impacts of PBMs and PDABs in the healthcare system is essential. By incorporating success stories from state and federal legislative achievements and insights from advocacy efforts, these campaigns can underscore the benefits of reform for pharmacies, patients, and the healthcare system at large. The goal is to inform the public, inspire support for reform efforts, and motivate active participation in advocacy initiatives.

> When we take money out of systems, **the people not represented lose out first.**

The path toward meaningful reform in pharmacy benefit management, drug pricing and the equitable implementation of PDABs is fraught with challenges. Yet, the successes achieved in regions like Florida provide hope that meaningful reform is possible. By rallying for targeted policy reforms and engaging in proactive advocacy, we can drive systemic changes that ensure the pharmaceutical supply chain operates with transparency, equity, and a steadfast commitment to patient health. Together, we have the power to reshape the landscape of drug affordability and access, guaranteeing that all people receive the comprehensive care and medications they deserve.

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TRAVIS MANINT is vice president of the board at Connect Northshore, an LGBTQ+ advocacy organization. An advocate for LGBTQ+ rights, he is driven by personal experiences with HIV and substance use disorder.

‘A sliver of hope’

The unyielding struggle for health and human rights in Africa

BY **PASCAL AKAHOME**

Helen quietly escaped from her apartment in Kampala, Uganda’s capital, on a moonless night. Save for the darkness of the lonely night and a veil, there was not much else to rely on for refuge from detection. Her flight to safety required abandoning her home and traveling 700 kilometers (about 435 miles) to Burundi to stay alive. Had she waited another night in Kampala, the transphobic mob that laid siege to her house might not have spared her life. It would be several months before the 28-year-old founder of one of the few remaining trans-led and -focused institutions providing HIV care and prevention services could return to her country. Earlier that day, a blogger had posted Helen’s personal information on social media, exposing her identity as a transwoman living in the city, leaving her open to the dangers of transphobic neighbors. Her attackers, encouraged by news of an anti-gay law in the final stages of parliamentary approval, went from house to house, searching for members of the LGBTQ+ community to harm.

Yuwore Museveni, Uganda’s homophobic president who has ruled the country since 1986, had vowed to criminalize same-sex relationships. In May 2023, he made his threats a reality by signing into law the harshest anti-homosexuality bill ever seen on the continent. With passage of this law, Uganda has joined the list of 65 countries that have criminalized being gay. It prescribes the death penalty for LGBTQ+ people while criminalizing belonging to or registering an organization that provides services to gay people. To Museveni watchers, this law comes as no surprise, as Museveni gained global notoriety by describing gay people as “disgusting” in a CNN interview.

With the stroke of his pen, Museveni rolled back years of gains made in the fight against HIV in Uganda. “Before the law, we provided follow-up services for people on antiretrovirals and PrEP. Now, our clients are too scared to attend appointments,” Helen told me. The situation is dire, as the organization she leads has begun to see increased rates of new diagnoses. Helen’s return to Kampala meant seeking accommodation elsewhere, far removed from her previous apartment and running her organization secretly. Considering the prevailing security situation, the alternative to not being extra careful could be fatal. “If they catch me,” she said, “I risk going to jail. No one is safe providing the services we do, but we have to find a way.”

The situation is equally dangerous for people who access preventive services. Helen said that in the month following the passing of the law, two gay men living together were reported to Ugandan police by their neighbors, suspected of “aggravated homosexuality.” At night, while they slept, their house was broken into by the police, who illegally searched their apartment, confiscating condoms and lubricants as material evidence of homosexuality. The men were led away amid jeers by neighbors and have not been heard from since.

The United States ambassador to Uganda said that Uganda’s HIV rate is still one of the highest in the world. “Evidence shows that laws and policies, such as the criminalization of HIV transmission and same-sex relationships, hamper HIV response and people’s access to stigma-free sexual and reproductive health services,” said ambassador William S. Popp last November.

ON FEBRUARY 28, the Ghanaian parliament passed an equally insidious anti-gay bill. The country’s two major political parties in a rare show of bipartisan unity passed the act, which imposes a three-year prison sentence for anyone convicted of identifying as LGBTQ+, and 10 years for running or funding LGBTQ+ groups or organizations. While the president, Nana Akufo Addo, is expected to sign it into law, this piece of legislation already has far-reaching consequences.

I spoke with Sam, a gay man who works in the Ghanaian municipal government, to understand the current attitudes of healthcare providers. He said that violence against queer people has noticeably increased in the last few months, and access to HIV services has suffered. Some organizations providing HIV services to the LGBTQ+ community in Accra, Ghana’s capital, have been raided by angry mobs who accuse them of recruiting people into homosexuality, forcing them to close shop.

Accessing health care from the government hospital is not seamless for gay people. Sam said that at any regular government facility, the default assumption is that you are heterosexual, and your treatment and diagnosis are based on this flawed premise.

“Some doctors and nurses in these hospitals are sympathetic to us,” Sam said. “However, they are primarily worried about their own safety and prefer not to help us access quality and queer-friendly health services on many occasions. HIV centers are supposed to be queer-friendly, but they are not in this country.”

Both countries are at risk of going the way of Nigeria, which passed its own Same-Sex Marriage Prohibition Law, a blanket law that criminalizes gay expression and equal rights, in 2014. The effect of the law on access to queer-focused health care, mainly HIV services, was instant. After the law was passed, preliminary reports suggested that it

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limited access to HIV care, as gay people reported being increasingly stigmatized in public health facilities, making them reluctant to access treatment and prevention services.

I SPOKE WITH Kizza, a clinical service associate at one of Uganda's remaining LGBTQ+-led and -focused NGOs (non-governmental organizations, known in the U.S. as non-profit agencies). According to Kizza, they are lucky to stay active despite the continuous raids and evictions of similar organizations by the police in Uganda. Kizza's clinic remains one of the few places in Kampala where members of the LGBTQ+ community can access testing, PrEP and other related services in a safe space. However, they have had to adapt to the hostile environment by switching to online services, offering consultations with clinicians. They found this easy because they already had the virtual consulting option set up before the law was passed, so it was a case of simply switching their walk-ins to virtual clients.

However, this option has its shortfalls. Kizza said that online consultations were less effective than in-person visits. "You have to understand," she said, "that most of our clients are young adults living with their parents. To speak on the phone with us, they inadvertently would say something that would identify them as gay or living with HIV. They are usually not out to their families, and they risk being outed by anyone listening to their conversation. The physical clinic was a safe space for them, and now they no longer have that."

I asked Kizza if members of her community could not simply access HIV services at government hospitals. She said that while on paper, the government had put out a circular to the effect that no one should be denied health services irrespective of the provisions of the law, the reality is quite different. It is significantly worse for masculine-presenting women and feminine-presenting men. In her experience, there have been cases where healthcare workers in government hospitals deny services to people who present this way. Usually, the targets of this neglect would rather sit at home and wait out whatever symptoms they are experiencing instead of going to the government hospital. In many cases, the disease progression rate is relatively high.

"The government does not even recognize the existence of other sexual and gender identities," she said. "In official documents, they prefer to use *men who have sex with men* (MSM) rather than *gay men*, and *female sex workers* (FSW) to refer to lesbian or bisexual women. You do not expect a government that does not recognize your existence to make space for you," she said.

ANOTHER CHALLENGE affecting the ability to provide services is brain drain. Several peer educators in various organizations have sought asylum to escape the oppressive regime. "In our organization alone, five of the seven peer educators we had are out of the country on asylum," Kizza said. "We cannot be sure that the remaining will not do the same. How are we supposed to operate in a situation like this?"

Bad as the situation may be, the air of optimism about the future displayed by each person I spoke with was unnerving. And there is cause to hold out hope. A group of activists, law professors and two legislators from Museveni's political party filed suit to overturn the law in Uganda's constitutional court, and the hearing began in December. On the part of the healthcare providers, Kizza said there is a need to find a way to collaborate with government health services. "Some clinicians can be sympathetic to our cause; we can only hope that we find a way of building a connection with them so they can help our people," she said. Asked if she was sure that could work, she said, "We can only hope. It would seem that despite the country's situation, the people still have a sliver of hope."

EDITOR'S NOTE: All names have been changed to protect the safety of the interviewees.

PASCAL AKAHOME (he, him) is a pharmacist, researcher and writer who uses the power of words to advocate for improved HIV treatment and prevention services access to marginalized groups in the global south. His writings also explore the intersection between policy at a macro level and healthcare access. He is a fellow of the Advocacy for Cure Academy of the International AIDS Society (IAS) and the director of Antiretroviral Improved Access Initiative (AIAI), a local advocacy network based in Nigeria. He often speaks on HIV scientific and advocacy panels.

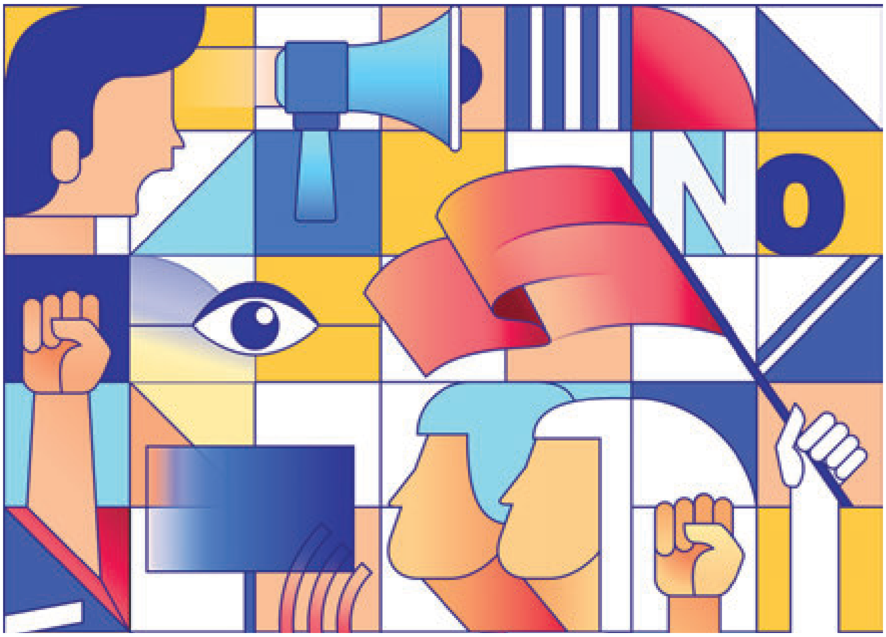
THE 2023 ANTI-HOMOSEXUALITY ACT OF UGANDA is not the first piece of legislation targeting gay people. The 1950 Penal Code carried the punishment of life imprisonment for "carnal knowledge against the order of nature" and seven years' imprisonment for violations of the law.

THE NEW LAW PROHIBITS "AGGRAVATED HOMOSEXUALITY," which it refers to as same-sex acts where HIV is transmitted or where one participant has a mental illness or disability. Aggravated homosexuality carries the death penalty upon multiple convictions.

UNDER THE LAW, a friend who allows a same-sex couple to use their apartment to have sex or a landlord who rents property to an LGBTQ+ advocacy organization could be found guilty of promoting homosexuality.

FAILURE TO REPORT SOMEONE suspected of homosexuality carries jail time of up to five years. Same-sex sexual acts carry a penalty of life imprisonment, while attempts to engage in same-sex sexual acts can lead to 10 years in prison.

> 'You do not expect a government that does not recognize your existence to make space for you.'



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A call to end stigmatizing language in HIV research

BY **RICK GUASCO**

It all started with a recruitment flyer for an HIV cure clinical trial. Calling for volunteers, the flyer said, "You may be eligible if you are HIV-1 infected."

The flyer had been posted in the lobby of National Institutes of Health (NIH) headquarters in Bethesda, Maryland. It was seen by HIV activists attending a meeting of the community advisory board (CAB) of the Martin Delaney Collaboratories, an interdisciplinary group of advocates and medical researchers who work on developing HIV cure strategies. This was after a number of NIH presentations during the meeting that had included similar language.

As a result, a coalition of HIV activists and about 60 organizations sent a letter to the National Institute of Allergy and Infectious Diseases (NIAID), calling on the agency to require the use of non-stigmatizing language in HIV research.

The letter asks for changes in HIV-related language policy to be established across the agency, removing stigmatizing and dehumanizing terms such as HIV-infected, populations and subjects when referring to people living with HIV.

The letter states that stigmatizing HIV language generally takes three forms:

- marking or labeling someone as "other"
- assigning responsibility or blame
- invoking danger or peril

Acknowledging that the use of such language is not intentional, the letter continued, "Many people do not realize many terms are offensive and stigmatizing to people with HIV and affected communities and use old terms out of habit."

Activists have for years promoted the use of people-first (or person-first) language, which prioritizes the individual over their condition. It's why saying someone "is HIV-positive" is generally no longer considered acceptable; instead, it is preferable to say a person "is living with HIV." Similarly, rather than calling someone "a diabetic," people-first language would identify them as "a person with diabetes."

Yet, the NIH website includes a style guide to person-first and destigmatizing language; NIAID has its own HIV Language Guide, produced in July 2020.

"It just didn't seem like the NIH was familiar with its own language guide around HIV," said Michael W. Louella, manager of the Office of Community Engagement at the University of Washington/Fred Hutch Center for AIDS Research. "Hearing the language was sort of triggering, combined with the sudden appearance of this flyer in the lobby."

Louella added, "It's not so much about being right or wrong, it's about becoming better communicators. I think it's language that separates us, and it's language that can also unite us."

Another Martin Delaney Collaboratory CAB member, Jeff Taylor from the HIV+Aging Research Project-Palm Springs (HARP-PS), acknowledged that clinical wording is "ingrained" in researchers' heads. "It's been used in research over many years; they see it in the [medical journals] all the time," he said. "Even though they know that people don't like it, it's really hard to break those habits. So, we thought it was important to go to [NIAID] and say, *Remove this language, let people know that it cannot be used.*"

If NIAID adopts such a policy, it would apply to researchers' grant applications, study papers and presentations.

Another term the activists take exception to is *sterilizing cure*, referring to a therapy that would *eradicate* the virus or lead to *viral clearance*—terms that are not as triggering while remaining medically accurate, said Louella.

Controlling how scientists talk to each other is not the goal, Louella, who uses the pronouns they and them, added. "We are talking about when you were talking to a broader audience, where there is a likely chance that there are more than just scientists in the room. I also think it's a good practice for scientists anyway, even if there are no other people in the room, because it's hard to code switch," shifting from impersonal vocabulary to person-first language.

"It doesn't hurt for someone to learn how to speak about HIV without needing to use *HIV-infected* or to use certain terms that people find triggering," they said. "It would be nice to see researchers take this idea on and for them to work among themselves, reminding each other, so it's not just put on the shoulders of community members who have always had to fight for dignity."

Among the organizations adding their names to the letter are AIDS United, BABES Network, SAGE, The Well Project and The Center for HIV Law and Policy).

As one of the 27 agencies within the NIH, NIAID conducts and provides federal funding for research on infectious diseases, including HIV. The proposal would apply to all NIAID-published documents, including grant applications, materials for clinical trials and NIAID-funded research papers.

TO DOWNLOAD the NIAID HIV Language Guide, go to bit.ly/niad-hiv-language-guide. **GO TO** bit.ly/nih-person-first-style-guide for the NIH's style guide to person-first and destigmatizing language.

Recipients and donors living with HIV

Transplanting HOPE

BY **CHRISTIAN KILEY**

Al Morales lives in Chicago with his partner, Reed Benedict. They met in 2009, and neither could have anticipated that one of Benedict's kidneys would give Morales a chance to survive end-stage kidney disease (ESKD). Diagnosed in 2017, Morales would become the second person in the United States to receive a life-saving kidney donation from someone living with HIV.

Life-saving organ transplants have become a standard of care, and people living with HIV (PLWH) are finally joining the party, at least in some cities.

How did we get here? Life-saving organ transplantation has, historically, not been available to anyone and everyone who needs it. Imagine a donor organ like a ticket to see Beyoncé in concert. There are only so many of these opportunities in a given span of time. In 1984, Congress passed the National Organ Transplant Act, which did two notable things.

First, it made it illegal to buy or sell organs in favor of a more equitable wait list-based approach. Next, it made it illegal to transplant organs from donors with HIV.

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Even for people without HIV, there have never been enough donors to match the need. Many people (with and without HIV) died before a potentially life-saving organ became available. A disproportionate number of patients living with HIV were pushed down already long wait lists during the difficult years preceding antiretroviral therapies because they were deemed too ill to save. And so taken in context, both the medicine and politics of organ transplantation have improved immeasurably since 1984.

Thirty years in the making, the HIV Organ Policy Equity (HOPE) Act allows organ transplants from donors with HIV to recipients with HIV. Until 2013, donors identified as HIV-positive were prohibited. Advocates who pushed for the legislation campaigned on the fact that people living with HIV are more likely than people without HIV to develop end-stage kidney and liver disease.

HOPE Act-authorized research protocols mean people living with HIV and end-stage liver or kidney disease may not wait as long for a transplant if an organ from a donor with HIV is available. The protocols also mean that people with HIV may now sign up to become organ donors.

Since passage of the HOPE Act, the lives of hundreds of people have been saved. One of them, the first person to receive a kidney under the HOPE Act, has remained anonymous, but their living donor, Nina Martinez, has become a leading advocate. Her efforts to bring awareness to stakeholders in the HIV transplant field, from lawmakers and medical researchers to doctors and patients, have been painstaking. Martinez is quick to point out that "...the mortality rate among kidney transplant candidates living with HIV is nearly twice that reported for candidates not living with HIV. There are many ethical issues surrounding the ranking of wait list candidates, and the length of the wait list disproportionately affects many vulnerable populations. While HIV status does not give a transplant candidate priority status, the HOPE Act increases equity on the wait list by providing a donor pool specifically for people living with HIV."

Shortly after Morales' ESKD diagnosis, Benedict offered to undergo testing to determine whether he was a potential donor. The two were a match.

Nearly three years later in 2020, the procedure was a success. Both were up and walking around within a few hours of their surgery, with relatively few complications since. Morales is on immunosuppressant treatments to prevent rejection, and other than adjustments to his ART regimen, his experience isn't much different from transplants in people without HIV.

Today, more than three years after the transplant, Morales and Benedict are healthy and living their best lives. Within a year of recovery, they were able to travel together to Europe and Disney World—they even recently adopted a new puppy, Grant.

Expert care

Valentina Stosor, MD, is the infectious disease doctor and principal investigator who worked with Morales and Benedict throughout their journey. She has overseen hundreds of organ transplants from HIV-positive donors, living and deceased, at Northwestern Memorial Hospital in Chicago.

Stosor played an integral role in the trials that supported the passage of HOPE and sees the work at Northwestern not only as medical care but as social progress.

"I've been at Northwestern ever since medical school," she says. "I grew up in the infectious disease division, so I spent half my time as an HIV provider and the other half as a researcher. Before HOPE, we had opportunities to participate in trials because it wasn't considered standard of care at all; there was a lot of stigma.

VALENTINA STOSOR, MD

"Transplantation has become a standard part of care, and while we were conducting those trials, there was a surgeon in South Africa whose situation was different. She started performing transplants for people with HIV using kidneys from donors with HIV with generally good outcomes. This was early in 2000 and it inspired us to learn about that here. So a group of transplant advocates worked with people on Capitol Hill to pass this law that Obama signed in 2013 and that was enacted in 2015. We were conducting the studies in both liver and kidney transplantation, engineering completion of both to look at outcomes for people with HIV utilizing deceased donors and living kidney donors with HIV. It's been highly successful. We are showing that it's reducing wait times for people accepting organs from donors with HIV."

Morales and Benedict's experience confirmed what Stosor already understood to be the new standard of care for PLWH.

"People decide to trust you when they come to you for these sorts of procedures," she says. "It's a big responsibility that I don't take lightly. To see it work so well [for Morales] the first time, and to see patients come back after their transplant a couple weeks later, a month later—they visit the office and they're doing really well. Their kidney function is normal, which is really gratifying." >>

The road ahead

The couple were lucky in many ways. Living in Chicago meant they had easy access to Northwestern Memorial, one of only six locations nationwide that has implemented the medical science which makes the HOPE Act such a landmark example of political progress for PLWH. Of the other five locations, two are in New York City. Duke University in Durham, North Carolina; Tulane Medical Center, New Orleans; Johns Hopkins in Baltimore and the University of San Francisco Medical Center also offer liver transplants from living donors but have yet to perform live donor kidney transplantation.

Patients who do not live within commuting distance of one of these locations need to cover the cost of transportation each way for the multiple (as many as a dozen) visits. Prospective patients also need to have the time for that travel. Factor in the cost of food and lodging, and the accessibility to these life-saving procedures becomes a stretch for most people.

> ‘People decide to trust you when they come to you for these sorts of procedures,’ she says. ‘It’s a big responsibility that I don’t take lightly.’

An untold number of HIV-positive patients with ESKD in the U.S. still face systemic barriers to life-saving transplant medicine. Studies published online by the National Institutes of Health in 2019 assert that PLWH have a slightly higher risk of developing chronic kidney disease than people who do not have HIV, but once chronic kidney disease has started, the likelihood of developing ESKD is 2- to 20-fold greater compared to people without HIV. Unsurprisingly, the most vulnerable communities are the ones who are least likely to enjoy the sort of privilege that makes access to HOPE transplants a viable option.

Morales stresses how important it is for anyone with ESKD to understand that transplantation is a safe and viable option. “Having gone through it, it just seems logical in every way. There’s nothing you’re really giving up, especially as far as quality of life by taking this [kidney transplantation] route,” he says.

Morales and Benedict both feel strongly that awareness of the HOPE Act must be expanded, and Morales has connected over social media with other PLWH facing ESKD over the last couple of years. After posting a video about his experience on TikTok, other people with ESKD and HIV found him.

“One guy’s like, *Hey, I have chronic kidney disease. I’m looking for a kidney. I’m [HIV] positive*, and then I reach out to them in a direct message. We’d just message back and forth. Eventually, we called each other so I could provide some form of hope, because he really needed hope more than anything,” he says.

Resources

To become an organ donor, or to get medically evaluated to see if you are eligible, check out these resources.
hopkinsmedicine.org/transplant/programs/kidney/living-donors

How to sign up as an organ donor from your iPhone’s Health app: bit.ly/49JGqzM
Donate Life America: registerme.org
Five Wishes / Voicing My Choices: fivewishes.org

Congressional letter urges HHS to update its HIV organ transplant donor policy

It’s been over a year since an advisory panel made its recommendation

BY **RICK GUASCO**

A letter signed by 25 members of Congress has been sent to Health and Human Services secretary Xavier Becerra, calling on him to update federal policy on organ transplants among people living with HIV.

The HIV Organ Policy Equity (HOPE) Act was signed into law in November 2013. “Within four years of enactment, and annually thereafter,” the letter said, “the Secretary of Health and Human Services is required by this law to ‘review the results of scientific research in conjunction with the Organ Procurement and Transplantation Network [OPTN]…’ to determine whether organ transplants between people living with HIV should remain restricted to clinical research.”

The letter also noted that, “People living with HIV in the South are nearly twice as likely to die while on the organ transplant wait list.”

In November 2022 the HHS Advisory Committee on Blood and Tissue Safety and Availability (ACBSTA) voted to expand access of organ transplants of kidneys and livers among people living with HIV, seven years after research guidelines had been published. Since 2015, a reported 431 HIV-to-HIV organ transplants have been performed. The ACBSTA’s recommendations to revise organ transplant policy for PLWH were sent to assistant health secretary Adm. Rachel L. Levine, MD, in January 2023 and have been waiting for Becerra’s approval since then.

“We encourage you to instruct the Organ Procurement and Transplantation Network to implement a new standard of clinical care to increase the number of kidneys and livers for transplantation, reduce the transplant wait time for people living with HIV, and thus reduce the transplant wait time for everyone else waiting on a life-preserving transplant,” the letter said. “With expanded donor eligibility, advances in HIV treatment and the transplantation science amassed through HOPE Act clinical research to date, we can and should eliminate barriers to HIV-to-HIV transplantation. This new standard of care will shorten transplant waiting lists, reduce wasted organs and eliminate the unacceptable and continued deaths of people who are diagnosed with HIV and end-stage organ disease.”

U.S. Representatives Nikema Williams (Georgia, Dist. 5) and Katie Porter (California, Dist. 47) led 22 other members of Congress, along with the congressional delegate from the District of Columbia—all Democrats—in sending the letter. **READ** the letter at bit.ly/HIV-organ-transplant-policy-letter.

A mosaic of moments

Snapshots from around the world tell the story of 'A Day with HIV'

All in a Day. **8:39 PM: NEW ORLEANS, LOUISIANA.** **Masonia Traylor:** "Eating beignets with my children at Café Du Monde." **10:27 AM: LONDON, ENGLAND; UNITED KINGDOM.** **Matthew Hodson:** "I was diagnosed with HIV 25 years ago. Effective HIV treatment then was new. I never imagined I would live for as long as I have. The drugs which keep me healthy also mean that there is no risk of passing HIV on during sex. **1:50 PM: PATERSON, NEW JERSEY.** **Marissa Gonalez:** "Not quite how I planned to spend the day. It's rainy and gloomy, and that equals a couch, a heating pad, a fuzzy blanket and a good book."

On the first day of autumn in 2023, people across the United States and in 15 other countries around the world snapped a moment of their day, posting the picture to their social media along with the hashtag #adaywithhiv and a caption about what inspired them to take the photo.

A Day with HIV, POSITIVELY AWARE's annual anti-stigma project, portrays 24 hours in the lives of people affected by HIV. Looking through the following eight pages of selected images taken that day, some recurring themes emerge—companionship, activism, family (of all sorts) and the resilient spirit of people living with HIV.

"Loving the skin I'm in," says Sherkila Shaw in one of the first photos taken that September 23.

"Beautiful day to play for my ancestors along with my grandson," says Katie Willingham in Tuscumbia, Alabama. "I want to teach him everything I know and I'm here for it because I take my health seriously."

Ciarra Covin smiles as she holds her two-year-old daughter, who was born on a A Day with HIV 2021.

"Doing my evening farm chores," says Jess, her chicken coop and a couple of chickens in the background. "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."

Chosen family were also included. "Enjoying an HIV retreat with my brother in advocacy, Tony," says Dee Conner about her photo.

The day coincided with a number of HIV-related conferences and events, prompting photos from advocates.

Kalvin Pugh was at Minneapolis-Saint Paul International Airport on his way to the Fast Track Cities conference in Amsterdam. "Feeling very privileged to be traveling the world speaking with and meeting other incredible people thriving with HIV," he says. "As I reflect on this moment, I am grateful that I've learned that nothing is impossible when you learn that that word is made up of *I'm possible*."

In Bogota Colombia, Juan de la Mar asked candidates running for mayor what they would do to reduce discrimination and stigma.

The Reunion Project (TRP), a nonprofit alliance of long-term survivors, held a regional town hall meeting that weekend in Charlotte, North Carolina. TRP executive director Jeff Berry and Chad Hendry were among attendees who posted pictures. "It was an honor to be among so many leaders living with HIV," says Hendry.

The day was not all smiles and sunshine, however. "I'm looking rough," Jeffery Parks says. "Today just happens to fall on my every other Saturday when I take some of my injection medications for other health conditions."

These selfies are portraits of resilience. As Mz Chelle says, "They gave me three years, but I'm still thriving—33 years and counting. There is life after diagnosis."

—RICK GUASCO

THE FOLLOWING EIGHT PAGES feature pictures from A Day with HIV. Some captions have been edited for brevity and clarity. An online gallery is on display at adaywithhiv.com. Follow A Day with HIV on Instagram, @adaywithhiv and on X (formerly Twitter), A_Day_with_HIV.

7:30 AM: DELTONA, FLORIDA > **Sherkila Shaw:** “Loving the skin I’m in.”

8:37 AM: LAKE COEUR D’ALENE, IDAHO >> **Princess Dallas Lyle:** “Standing on the shores of Lake Coeur d’Alene, still searching for my place in this world. The beauty and serenity inspired this picture. 27-year thriver.”

7:32 AM: MINNEAPOLIS, MINNESOTA > **Kalvin Pugh:** “Spending A Day with HIV at the airport. When I was diagnosed in 2016, I never imagined that fateful day would lead to traveling to Amsterdam for Fast Track Cities 2023, yet here I am. Feeling very privileged to be traveling the world speaking with and meeting other incredible people *thriving* with HIV. I am grateful that I’ve learned that nothing is impossible when you learn that that word is made up of *I’m possible*.”

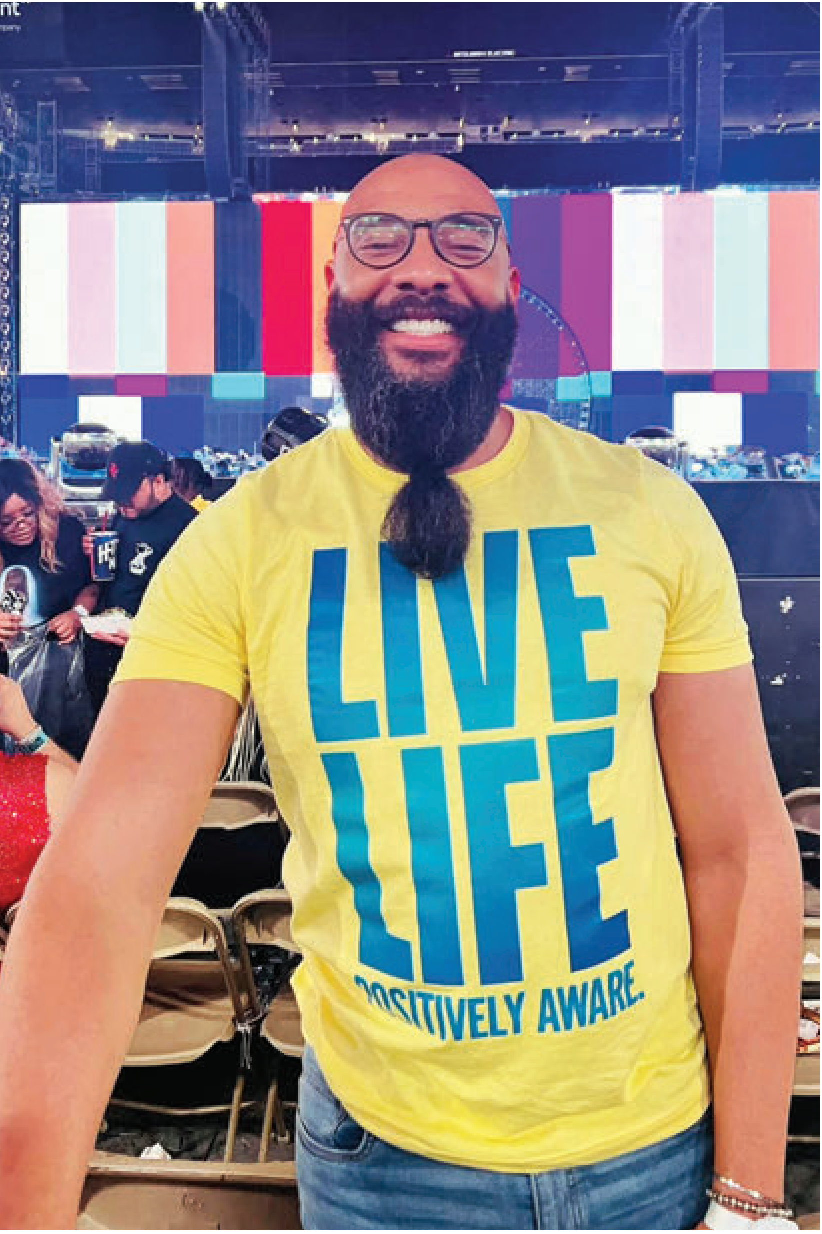
9:03 AM: BOGOTA, COLOMBIA > **Juan de la Mar:** “My speech at a forum for candidates who are running for Bogota’s mayor. I lead the Impulse Committee of Fast Track Cities, a strategy created to accelerate the HIV response with the support of UNAIDS, UNFPA, NGOs and HIV activists. I’m pictured here talking about the Fast Track Cities strategy and questioning candidates about their promises to reduce stigma and discrimination.”

9:15 AM: PHILADELPHIA, PENNSYLVANIA >> **Warren O’Meara Dates:** “As CEO of the 652 Project Foundation, I’m fortunate enough to spend today with others at the ADAP Advocacy Fireside Chat.”

9:16 AM: LIMA, PERÚ >>> **Josué Valera:** “When I made the decision five years ago to cross three countries to build my life elsewhere, I didn’t imagine I would be here at the United Nations headquarters in Lima. I thought my diagnosis would end my life, but today I am an interlocutor of many who live in silence.”

< 10:45 AM:
NEW YORK, NEW YORK
Lillibeth GonzaLez: "When seeing a sex symbol reminds you that you're sexy and resilient. A rose for a rose."

<< 10:47 AM:
MECHANICSVILLE, VIRGINIA
Melissa Blackwell: "Keeping traditions..."



<< 12:00 PM:
HOUSTON, TEXAS
Ken Williams: "She gave me Blue, Megan, Drunk in Love 2.0 and Honey Balenciaga. After three hours of singing along, my voice was gone, my feet were aching and I still wanted more time with her... I love you, Houston."

< 10:46 AM: PHILADELPHIA, PENNSYLVANIA
Andrena Ingram: "Pulled a tarot card that spoke to me: The Star—hope, faith, purpose, renewal, spirituality—all of the things I embody. Cohabitating with this disease for over 35 years, undetectable. We need all three of these attributes (and of course God, Creator and the Universe) to live fully. I embrace my energy and the insights I receive each day. Gratitude is the new attitude. Shout out to my sisters in South Africa with my earrings. We are all Stars."

10:56 AM:
< HOUSTON, TEXAS
Bob Bowers and Nita Costello: "Thankful for each and every day!"

11:17 AM: CHARLOTTE, NORTH CAROLINA >
Jeff Berry (right): “At The Reunion Project in Charlotte, NC, with retired HIV physician assistant Wes Thompson and fearless advocate Janice Shirley.”

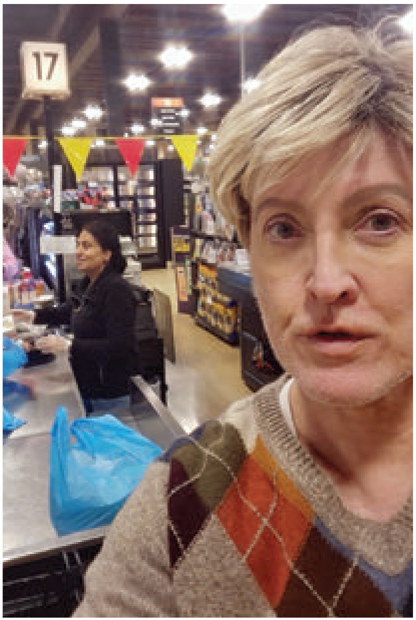
12:40 PM: LONDON, ENGLAND; UNITED KINGDOM >>
Emma Cole: “Enjoying the autumnal sunshine in my 32nd year of living with HIV. Happy to be visible for long-term survivors and HIV-positive women who may not feel able to be part of this day.”

12:50 PM: ST. PAUL, MINNESOTA >>>
Patrick Ingram: “Lunchtime is spent having Dominican food. Usually this is the time I’d take my HIV pill. Now, due to advances in treatment, I’m on an injectable, which decreases my pill burden. Dec. 1, 2023 marks 12 years living and thriving with HIV.”

12:50 PM: PALM SPRINGS, CALIFORNIA >
Chad Sain: “Living with HIV since 2007. Active, healthy and undetectable for 14 years. Honored and proud to celebrate another ‘day with HIV,’ supporting the HARP-PS (HIV + Aging Research Project - Palm Springs) annual conference.”

1:03 PM: TUSCUMBIA, ALABAMA >>
Katie Willingham: “Beautiful day to play for my ancestors along with my grandson. I want to teach him everything I know and I’m here for it because I take my health seriously. I go to my doctor appointments, I take my meds as prescribed and I’m here to teach my grandson his heritage.”

1:42 PM: OVER LEICESTER, ENGLAND; UNITED KINGDOM >
David Rowlands: “A Day with HIV portrays 24 hours in the lives of people like myself who are affected by HIV—that’s all of us everywhere. It combines the power of storytelling with the creativity of photography.”



<<< 1:30 PM: PHILADELPHIA, PENNSYLVANIA

Darnell D. Lewis: “Taking this selfie, I’m reminded of the 17-year-old boy diagnosed with HIV and now 24½ years later, *I’m here*! Free to exist and free to be! Inspired, seen by many, heard by few, I live in the boldness of my creation.”

<< 2:00 PM: BATON ROUGE, LOUISIANA

Dr. Joyce Turner Keller: “This summer marked the milestone of having lived with HIV longer than not. I am grateful for the life I have and the love that surrounds me.”

< 2:15 PM: MONROEVILLE, PENNSYLVANIA

Jeff Olsen: “Just a *very* normal day in the grocery store. Not *exciting*, but *normal*.”

<< 2:43 PM: AMSTERDAM, THE NETHERLANDS

Karl Schmid: “Exploring Amsterdam by bicycle because living with HIV won’t stop me from exploring and enjoying life!”

< 3:39 PM: BAYAMÓN, PUERTO RICO

Israel Samalot Doval: “Viviendo mi vida en voz alta como alguien que prospera con el VIH, espero inspirar a mi comunidad y a cada puertoriqueño a comenzar a hablar sobre el VIH. Al desestigmatizar el VIH, detendremos el VIH juntos.”

“By living my life out loud as someone who thrives with HIV, I hope to inspire my community and every Puerto Rican to start talking about HIV. By destigmatizing HIV, we will stop HIV together.”

<< 2:49 PM: MIAMI, FLORIDA

Mz Chelle: “They gave me three years, but I’m still thriving—33 years and counting. There is life after diagnosis.”

3:00 PM: HOUSTON, TEXAS > **Kalvin and Eunice Marshall:** "Our Day with HIV Adventure. Having a late lunch at What-A-Burger. Celebrating our 39th year of marriage and What-A-Burger's 50th anniversary! Congratulations to us both!"

2:15 PM: SEATTLE, WASHINGTON >> **T.J. Elston (left):** "Spending my birthday today with my husband of four years (our anniversary is also today), together 16 years. He has been my greatest supporter through my journey living with HIV. Wouldn't change a thing."

3:30 PM: ARLINGTON, VIRGINIA > **Jesus Heberto Guillen Solis:** "No better way to enjoy a day than to be with amazing wonderful advocates. I am a 38-year HIV long-term survivor. At the HEALTHeVOICES summit, a groundbreaking leadership conference."

3:45 PM: SACRAMENTO, CALIFORNIA >> **Kimberly:** "Visiting my son and daughter-in-law and playing a spirited game of Wingspan."

4:00 PM: LOS ANGELES, CALIFORNIA >> **Jack Miller:** "Cruising the mean streets of Los Angeles in my friend's classic 1966 Cutlass Supreme, living life to the fullest and with joy in my heart! Long-term survivor 29 years strong!"

<< 4:00 PM: PALM SPRINGS, CALIFORNIA
Jeff Taylor: "Just finished our eighth annual Reunion Project (now called the Positively Aging Project) event for our long-term survivor community here. Veteran activist Peter Staley spoke about his experiences with ACT UP and with Dr. Fauci in the early days of the epidemic and read from his recently released book."

< 4:13 PM: SANDUSKY, OHIO
Dee Conner: "Enjoying an HIV retreat with my brother in advocacy, Tony."

<< 4:07 PM: DUBLIN, IRELAND
Jim Allen: "Picture today whilst facilitating our monthly HIV social and peer support call."

<< 3:56 PM: BRUSSELS, BELGIUM
Arda: "For us activists, advocates and people living with HIV, every day is a day with HIV, but campaigns like A Day with HIV show how far we have come and have touched lives as one big global family. But there is still more work to do, more lives to touch. Keep working together."

< 4:33 PM: CHARLOTTE, NORTH CAROLINA
Chad Hendry: "Just wrapped up The Reunion Project's meeting in Charlotte for survivors of HIV. It was an honor to be among so many leaders living with HIV."

4:00 PM: VANCOUVER, BRITISH COLUMBIA; CANADA >
Deni Daviau (left) and Bradford McIntyre: "Deni, 68, HIV-negative, with husband Bradford, 71, living with HIV 39 years; married 23 years."

4:35 PM: FORT WORTH, TEXAS >>
Jeffery Parks: "It's the autumnal equinox, so you know what day this is. I'm looking rough today. Today, I'm looking rough. But that's the intent of this campaign, to capture an ordinary day in the life of people affected by HIV—both the negative and the positive. It just happens to fall on my every other Saturday when I take some of my injection medications for other health conditions. Polypharmacy creates challenges to how my other health conditions are treated. For me, my HIV is the least complicated health condition I have."

6:34 PM: CATHEDRAL CITY, CALIFORNIA >
Bridgette Picou: "I spent A Day with HIV advocating for people with two of my favorite orgs at the Positively Aging Conference—and three people at the event said they read and enjoy my column in POSITIVELY AWARE. I always wonder if anybody reads my column. Not to forget self-care in the form of big hair and a bold red lip! Life ain't perfect, but it ain't all bad."

6:26 PM: WASHINGTON, D.C. >>
Anthony Olweny: "Feeling incredibly privileged to savor a tranquil evening on the first day of autumn. The world slows down, and I'm reminded to appreciate the simple joys in life."

6:29 PM: PHOENIX, CALIFORNIA >>
Eric Moore: "Waiting for a pepperoni pizza."

<<< 6:35 PM:
DENVER, COLORADO
Jess: "Doing my evening farm chores. 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. I'm grateful today for U=U and how it has the potential to totally put an end to stigma. Won't stop educating and advocating to make sure lifesaving medications are available to all."

<< 7:15 PM: PHILADELPHIA, PENNSYLVANIA
Ciarra Covin (left): "Mothering???"

< 8:20 PM:
WASHINGTON, D.C.
Murray Penner: "I decided to show off my DC Beings U = U Sexual Being shirt while cooking dinner. Thanks to Michael Kharfen and DC Health for the Sexual Being stigma-busting campaign."

<< 10:25 PM:
MANILA, THE PHILIPPINES
Artemus A: "In a country where diagnoses continue to rise, most of us try to live a normal life. It is hard to find work where you will be valued, even as we have a law that is supposed to protect you. Self-stigma continues to grow, even in this age of supposed 'HIV awareness.' On A Day with HIV, I wish that things would improve not later, but as soon as possible."

< 7:40 PM:
LAS VEGAS, NEVADA
Deral: "On my way to see Kelly Clarkson perform!"

<< 10:45 PM:
MIAMI, FLORIDA
Harold and Alecia McIntyre (aka Mr. & Mrs. HIV): "Living our best life. Unapologetically, unconditional and unwavering with HIV. There is love after diagnosis!"

A DAY WITH HIV will return on the first day of autumn in the northern hemisphere—**Sunday, September 22, 2024.**


NMK-STUDIO - ISTOCK

Illuminating provider blind spots in trans health care

A nurse practitioner develops a simple but transformative cultural competency session for care providers

BY **LARRY BUHL**

There's a "cultural competence deficit" among healthcare workers, as well as med school and nursing students, that not only impacts the quality of care received by transgender people, but that keeps them from seeking HIV preventative services, said Steven Cardenas, who teaches at NOVA Southeastern University and Galen College of Nursing, and works as a nurse practitioner at Midland Medical in Oakland Park, Florida. Cardenas has come up with a small but essential solution—an educational session that, while not comprehensive transgender healthcare training, at least helps show healthcare practitioners and students where their trans blind spots are.

"Some healthcare workers know nothing about trans health, more so at the more established clinics with older generations of providers," Cardenas said. "For example, when a patient asks for PrEP, they're more likely to be referred to an infectious disease doctor. Even now, many doctors are still wary of prescribing PrEP." And some are downright clueless about how to care for trans patients, he suggested.

There are data to back up his claims. A 2018 CDC report concluded that transgender patients face persistent and pervasive stigma and discrimination. Some even endure physical and verbal abuse while seeking medical care, and in some cases are denied healthcare services altogether, the report found.

"The biggest challenge for trans patients is fear of rejection by providers," Cardenas said. "This fear prevents trans people from seeking health care."

Such fears can lead to dire consequences for trans people who might benefit from HIV prevention services. There is an estimated HIV prevalence of 9.2% among all transgender people in the United States, and even higher among transgender women. An estimated one in five women who identify as transgender are living with HIV—even higher among African American transgender females in the U.S. Cardenas says that trans patients who mistrust doctors, and the medical establishment in general, are less likely to ask their primary care doctors for PrEP and PEP.

The intervention: one quality improvement project

Inadequate training worsens the challenge in caring for transgender people. Both the U.S. and Canada include only five hours of LGBTQ+ education within their medical and nursing training programs, and at least 18 nursing schools have no LGBTQ+ education. Cardenas set out to raise awareness for providers in primary care settings through what he calls a "quality improvement project," rather than an education module. The goal is to help healthcare professionals understand how stigma and discrimination can influence the willingness of transgender patients to engage in HIV screening.

"Continuing education modules, which are usually credits that healthcare workers need, are usually not engaging," Cardenas said. "Learning in a classroom setting is better," he said. But if not in a classroom, the educational session should be interactive, "with quizzes, to make them want to read."

His clinical question was narrow: can one educational session enhance healthcare professionals' understanding of how stigma and discrimination against transgender people in healthcare settings influence their willingness to offer HIV screening? The answer, he found, was yes.

The interactive educational session took about 30 minutes. Workers at his outpatient clinic, Midland Medical, completed it over their lunch break. There were questions in between every 3 or 4 slides to keep participants engaged, he said, "different from the ones in the survey, but helpful in making sure that everyone was paying attention."

Before and after the education session, participants were asked several questions such as: *True or False: Sexual orientation and gender identity are the same thing. What percentage of transgender people do you think reported negative experiences in a healthcare setting?*

The idea was to see whether a single presentation could not only educate healthcare workers on sexual orientation, trans stigma and the significance of HIV screenings, but also show them where their knowledge fell short. The pre-survey mean score was 43.77% and the post mean score was 74.82%, a greater than 31% mean increase in awareness of trans issues and statistics. "The findings indicate a significant improvement in participants' understanding of trans stigma and discrimination in healthcare settings and how it impacts their willingness to engage in HIV screening," Cardenas said.

What's also noteworthy about the results was how much healthcare workers didn't know about trans patients in what Cardenas described as a clinic that's generally more welcoming to trans folk than most healthcare settings. Midland offers LGBTQ+ STI screening and treatment, as well as HIV care and primary care and is one of the few private care providers for trans people in the Broward County area. Staff members who completed the session included phlebotomists, patient care coordinators, pharmacists, pharmacy technicians, nurse practitioners, medical doctors and members of the linkage team. "All potential participants either provided care to transgender patients or routinely engaged with the transgender community in their daily roles," Cardenas said.

Out of 23 participants in the pre-survey, Cardenas said, most had three to five years in the medical field and most had previously received some LGBTQ+ education in the past. For most participants, that LGBTQ+ training came on the job, Cardenas said.

This project comes amid a backdrop of state laws banning gender-affirming care—one of the most extreme is in Florida—causing demoralization and panic for trans youth and adults, and sometimes the fear of prosecution for their providers.

Cardenas says that he'd like to see the training session incorporated into continuing education for healthcare workers across the country, but he admits that there should be a greater effort to incorporate significant LGBTQ+ education in medical and nursing schools across the country.

"I would rather focus on the newer generation, which is generally more open about trans issues, even if they don't know everything," he said.

FIRST PERSON

Being transgender and living with HIV in today's political environment

BY **KATIE WILLINGHAM**

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Being a woman of transgender identity living with HIV has never been easy. It kills me that so many people believe that being transgender is a choice—like anyone would choose to be abandoned by their family, become a social outcast, and strugge to find employment, housing, health care or even a meaningful relationship. It just sounds insanely stupid to me. People have always attacked the transgender community socially, politically, legally and physically. But in today's political environment, it's getting much worse and becoming increasingly dangerous for me and my community to live our lives authentically.

In recent years since the rise of conservative MAGA Christian nationalism, anti-trans bills have been introduced across the country that seek to block trans people from receiving basic healthcare, education, legal recognition and the right to publicly exist. For each of the last four years, the number of anti-trans bills introduced in state legislatures has broken previous records. In 2023, the total number of bills was more than three times the previous record, according to the trans legislation tracker website translegislation.com. Already in 2024, there are 467 bills targeting the transgender community—and as I write this it's only February.

Many of these bills would allow misgendering, deny students the autonomy of their pronouns and preferred names, require educators to "out" students to their parents, ban basic gender identity education and ban inclusion in K–12 classrooms and even higher education. Many states have adopted bills that ostensibly focus on women's athletics, seeking to codify sweeping definitions of gender and sex. Bills banning gender-affirming care (medical care that is supported by many major medical associations) have surged in recent years. Misinformation about basic facts on gender-affirming care has grown more rampant and has been steadily weaponized in conservative states.

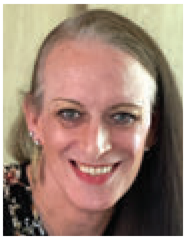
These legislative attacks on my community effectively write transgender people out of existence by state definitions. They impact the ability of transgender people to obtain and update government identification, get an education, use public facilities and much more.

And if that's not enough, Republican members of Congress are proposing cruel funding cuts of $767 million for 2024 to key federal HIV prevention and treatment programs that are already underfunded, as well as extreme cuts to other social safety net programs. These proposed cuts would dramatically reduce or eliminate funding for the Ending the Epidemic Initiative (EHE), launched in 2019 to end the HIV epidemic by 2030, as well as the Ryan White Part F program, which would affect most people living with HIV. It would also slash funding by over half for the Minority HIV/AIDS Initiative—when people of color are disproportionately impacted by the pandemic. All are programs that expand HIV testing, increase access to PrEP (pre-exposure prophylaxis to prevent HIV) and connect people living with HIV to care.

It's clear in my mind that this is a war on the LGBTQ+ community, plain and simple. It seems that conservatives are determined to erase my community by any means available, including denying our right to health care. Culture wars have consumed the Republican Party and evangelicals to the point of madness, consumed with hatred and a war mentality intent on "making liberals cry" while offering nothing of value as an alternative. It's dehumanizing to transgender Americans. It's a distraction from more serious issues facing our country that aren't being addressed. Republicans know that if they can focus their followers' attention and anger on an already marginalized minority group, they can distract their constituents from more important issues that actually directly impact them, such as policies that create economic inequality, erode workers' rights, degrade the environment and make their water, air and food less safe, just to name a few.

I think a lot of this anti-trans legislation is inspired by a cynical brand of identity politics that appeals to people's tribal, us vs. them inclinations, to confuse people as to who is really responsible for the decline in their standard of living. If conservative lawmakers get their way, LGBTQ+ people will have no rights at all. We will never end this pandemic, and many will unnecessarily die.

As a woman of transgender identity living with HIV, I always feel like my life is in danger and under assault, but I've never been this fearful about my safety and my future. The far right wants a Christian nationalist theocracy and will stop at nothing to achieve it. We must remain vigilant in these times; unite across race, gender, and sexual orientation; and fight against unjust legislation, discrimination and hate. And we must continue our commitment to fight for HIV funding until there's a cure. Future generations are depending on us.



KATIE WILLINGHAM, of Tuscumbia, Alabama, is a woman of transgender identity living with HIV. She has worked in HIV advocacy since 2016 with The Positive Women's Network-USA, blogging for organizations such as The Well Project since 2018 and WebMD since 2020. A transgender advocate with Positively Trans, she is also creator of the Facebook group Alabama Transgender Coalition. Katie spends her free time with her many beloved dogs and only grandson and reminds people to fight for social justice while also enjoying the little flowers along the way.

POINTIMAGES - ISTOCK

New amfAR research grants explore how bNAbs could herald an HIV cure

BY **LARRY BUHL**

Four innovative studies investigating broadly neutralizing antibodies (bNAbs) have been awarded research grants totaling nearly $3 million, by amfAR, The Foundation for AIDS Research. These hypermutated antibodies can penetrate components of HIV that are less likely to change genetically, giving bNAbs the potential to target a broad range of HIV strains.

It's believed that these specific types of antibodies, which a small percentage of people living with HIV produce naturally, albeit after many years, could be administered as an infusion to neutralize HIV and make it harmless. That's why researchers have cautious early optimism about the potential for bNAbs to prevent and cure HIV. An HIV cure has been so elusive because of the virus's ability to easily mutate, and because viral reservoirs develop early in the acquisition of HIV. In theory, the body's natural immune system could use bNAbs to create antibodies that prevent HIV from binding to T cells. Using the body's immune system with engineered components is still highly experimental, but over the past decade, there has been rising enthusiasm in the HIV research community about its potential.

"amfAR thinks there is a role for bNAbs as an important part of a cure strategy, but right now there is not enough information about how long they work," amfAR senior scientific consultant Dr. Jeffrey Laurence said.

This round of amfAR grants includes:

Research from the University of California, San Francisco (UCSF), to analyze data from five clinical trials to understand why, in some of the trials, administering a cocktail of bNAbs at the point of stopping antiretroviral therapy (ART) improves control of HIV. Several cure studies have shown that, even though HIV eventually rebounds, using bNAbs at the point of treatment interruption prolongs the period of post-treatment viral control. Rachel Rutishauser, MD, PhD, of UCSF, and a team of investigators from the U.S. and Denmark will explore mechanisms that mediate this control. The team will compare specific immune responses in more than 100 study participants to test the hypothesis that an infusion of bNAbs at the point of treatment interruption leads to boosting the immune response in some people. "This research will explore whether the (immune response) is souped-up T cell immunity or something else," Laurence said.

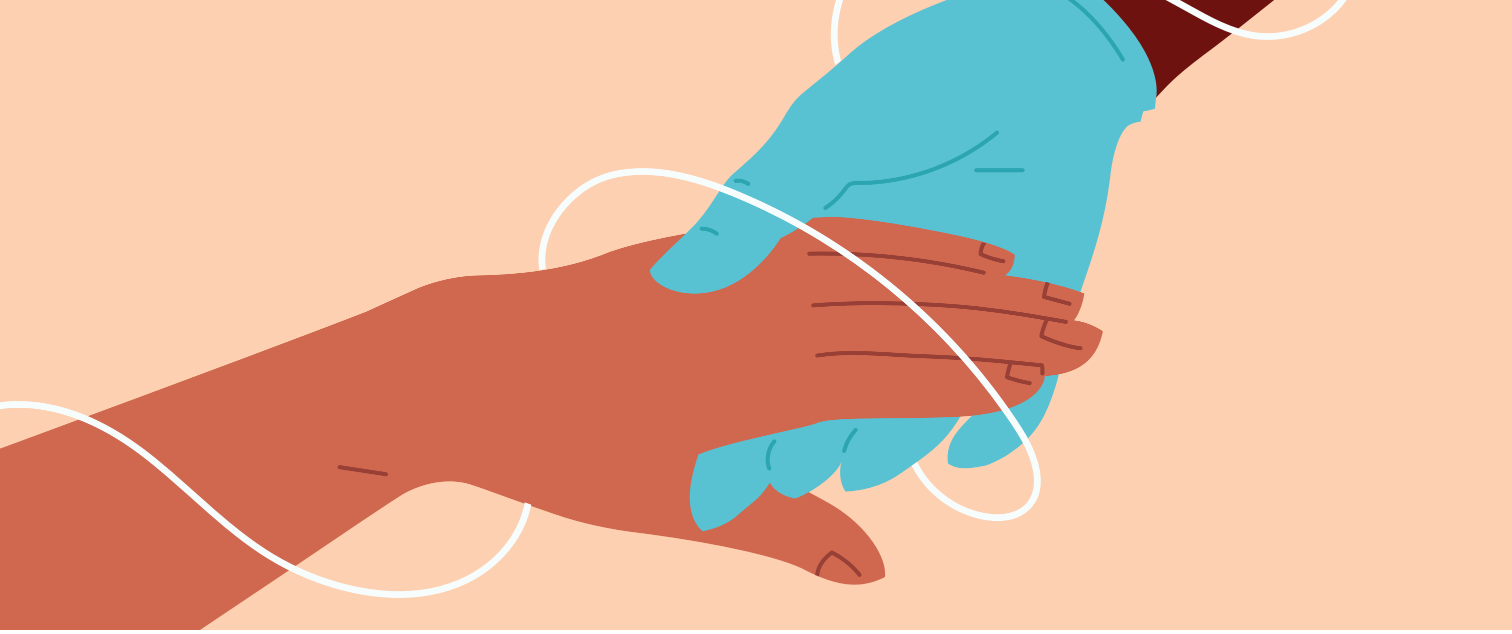
A second amfAR grant will go to James M. Termini, PhD, of the University of Miami, to determine why, in the absence of antiretrovirals in animal models, anti-HIV bNAbs have not been able to eradicate HIV reservoirs. The persistence of viral reservoirs has been a huge, persistent roadblock to developing a cure for HIV.

That viral reservoir is the subject of a third grant, awarded to Mary Ann Checkley-Luttge, PhD, of Case Western Reserve University, who will test two types of genetically-engineered natural killer cells, or iNK cells, to determine whether they reduce the HIV reservoir. Dr. Checkley-Luttge and her team will combine iNK cells with bNAbs in test tube studies to study how potent they may be against HIV reservoirs—if they see a 50% reduction in intact HIV reservoir virus from cells taken from six people living with HIV, they may progress to animal and human studies, according to amfAR.

Finally, a team headed by Xu Yu, MD, of Massachusetts General Hospital, will receive supplemental funding for ongoing research to determine whether some people on antiretroviral therapy have cleared their bodies of HIV without realizing it. The team has followed 66 individuals on ART for at least 15 years. The additional funding will allow researchers to observe what happens when ART is interrupted among the 66 and see if immune selection against HIV reservoirs could lead to them being cured.

In addition to these four, amfAR funded 23 other HIV cure research teams in 2023, according to Laurence. He adds that bNAbs hold promise for a cure, but there are many questions to be answered. "For one, we know that if you treat a monkey with antiretrovirals plus bNAbs, it can go a long time without relapsing, but we don't know how long. Another question is, can you use antibodies that are not broadly acting but equally effective?"

Laurence notes that research into bNAbs could be applied to other common viruses with latent periods, including Epstein-Barr, herpes and SARS CoV-2.



A ‘status neutral’ approach to care

Using a ‘person-first, not disease-first model,’ clinicians encourage and maintain engagement with the people in their care

BY **LARRY BUHL**

At IDWeek 2023 in Boston, one session aimed to give infectious disease doctors tips for incorporating HIV treatment and care into their practices. Beyond getting up to speed on the medications and indications for HIV treatments and pre-exposure prophylaxis (PrEP), presenters said clinicians may need to first adopt a slightly different mindset when caring for patients.

> ‘We ask every patient, *Are you aware of PrEP?* **If the answer is no, then we teach them about PrEP and offer it to them. If the answer is yes, we offer it to them.’**

Dr. Rachel Harold, who is the supervisory medical officer at the District of Columbia Department of Health, started by saying that people living with HIV and people who could benefit from HIV prevention are not two distinct populations. “They’re one group with similar medical and social service needs.” Harold said the term “status neutral” prevention and care, a “person-first, not disease-first model,” is a helpful framework for infectious disease (ID) clinicians who want to encourage and maintain engagement of their clients.

“Despite countless innovative and incredible programs to prevent HIV and to take care of those living with HIV, we’re still not reaching some people or we’re not reaching them in the way they need or we’re not providing the care they need. And PrEP services are very underutilized, only about a quarter of those who would benefit from PrEP are on PrEP.”

One of the main reasons HIV care services are underutilized, she said, is stigma, which keeps people from seeking HIV prevention services. “And many of the barriers to care that those living with HIV face are the same as people without HIV face,” she said. “It may be health insurance, mental health concerns, substance use or housing instability.”

What does status neutral prevention look like? Harold offered an example of HIV testing as “no wrong door.”

“When you enter the system, the first thing would be an HIV test,” she said. “And for people who are HIV-negative, they enter into this continuum of intensive proactive HIV prevention services. That can be safe syringe programs, that can be harm reduction, education and continuous engagement. Those who [get tested often], or [who test] positive, enter into a similarly intensive comprehensive care continuum. And anyone who may be in the prevention pathway, were they to become diagnosed with HIV, they could seamlessly go to the treatment pathway.”

An example of status neutral services is at the DC Health and Wellness Center, which is operated by the District of Columbia. The Center has an on-site lab and phlebotomy services as well as a pharmacy that provides PrEP, PEP and ART directly from the clinic. “And then the wonderful help of disease investigators who can help with partner services and making sure that if we are having a hard time finding someone who needs treatment, they can assist us,” Harold said.

Harold admitted that the center has the benefit of being a categorical STI clinic, and that many general ID practitioners might not be able to offer such a wide variety of on-site sexual health services, but they can refer clients to clinics that do, and they can adopt a status neutral approach to keep clients in the continuum of care.

Other examples of status neutral services at the DC Health and Wellness Center:

- Express clinic services that bypass the need to see a clinician; clients can check off the testing that they want to have done, in and out
- Free at-home STI testing
- A 24-7 hotline for PEP

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FEDRELENA - ISTOCK

Going with the flow

New injectable HIV treatments require clinics to rethink their workflow

BY **LARRY BUHL**

With the good news about the efficacy of long-acting injectable therapy, a question for clinicians is, how does a clinic accommodate every person who may want or need LA-ART? There are challenges for staffing (who will administer the injections, especially at peak times?), and administration (who handles the inevitable denials from payers?). And reminding people to come in for their injections takes resources, too.

A few possible solutions were offered at IDWeek. Christen Kilcrease, PharmD, AAHIVP, a clinical pharmacist at the Johns Hopkins Hospital John G. Bartlett specialty practice, shared how Bartlett, a referral-based clinical service for HIV medication as well as for comorbidity management, has optimized workflow to make way for new injectable HIV treatments.

Bartlett serves 3,000 patients a year and has a wide array of specialists, as well as nurses and social workers who help manage and distribute the workload. The on-site pharmacy has four pharmacists, six pharmacy technicians and two clinic-based pharmacists, which include Kilcrease and another pharmacist. Still, management expected glitches in the rollout of LA-ART, so they prepared. In 2019, they had surveyed providers about possible barriers to serving patients with LA-ART, and an implementation team used those responses to develop a workflow. That workflow went live in August 2021.

The new workflow has two main components: a centralized referral process, and optimized documentation for providers to use when meeting patients; the documentation is integrated into a referral form.

Providers screen patients and educate them on LA-ART, then refer them to the pharmacy team. Pharmacists complete the secondary review, then nurses and pharmacists administer the medication and ensure that appropriate monitoring is taking place between appointments.

The benefits review process is a bit more complicated, Kilcrease said, due to eight Medicaid plans in Maryland having different formularies and different calculations for paying. For benefits, the Johns Hopkins team developed a workaround to explore pharmacy benefits first. If the medication is not covered under pharmacy benefits, the team will explore medical benefits.

"If CAB-LA [long-acting cabotegravir, which is given with a separate long-acting injectable, LA rilpivirine, for HIV treatment or by itself for PrEP] is covered under pharmacy benefits, the pharmacy will administer the medication in the pharmacy," Kilcrease said. "If it is covered under medical benefits, the nurse will administer the medication in the clinic." At the on-site pharmacy, only one pharmacist administers and runs claims.

The workflow isn't perfect, Kilcrease said. Because the pharmacy is not on the same system as the clinic for automated patient reminder notifications, it falls to the pharmacy—specifically, clinical pharmacy technicians—to do follow-ups, manually.

The team also developed a screening tool for each injectable antiretroviral to help providers with decision making when discussing CAB-LA. "[This tool] is the most commonly requested information from both payers as well as our pharmacists and nurses," he said.

Operations are live in two adult clinics, one pediatric clinic and the site pharmacy, and the team is working to get long-acting PrEP at a third adult site. "We also have expansion in efforts for CAB-LA in other sites throughout the health system," Kilcrease said.

According to Johns Hopkins' financial clearance department, in the six months before the new workflow, 22 individuals were started on LA-ART. After starting the new workflow, within three

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The team also developed a screening tool for each injectable antiretroviral to help providers with decision making when discussing CAB-LA.


DRAZEN ZIGIC - ISTOCK

Off to a Rapid stART

How Clark County, Nevada used HIV testing to get more people into treatment and care

BY **LARRY BUHL**

It's estimated that 13% of people in the U.S. who are living with HIV don't know it, which can set them up for serious health consequences. Expanded and accessible HIV testing is a pillar of the Ending the HIV Epidemic (EHE) initiative, and it comes with flexible funding for areas that are significantly impacted by HIV. In 2021, Clark County, Nevada had one of the highest HIV rates in the nation with 153 out of every 100,000 residents living with HIV.

The county, home to Las Vegas, launched an initiative, Rapid stART, to find people who had not been tested, but were living with HIV and had been missed. Rapid stART is the result of a three-year-plus journey to bring healthcare workers, medical centers and community stakeholders together to agree on a standard protocol for rapid testing and rapid hand-off to care, making sure no time is lost getting people onto antiretroviral therapy (ART).

The genesis was the realization by one managing nurse of a major hospital that people with AIDS-defining illnesses were showing up in emergency rooms.

"A patient would be discharged from a hospital and sent back to their primary care doctor who didn't treat HIV, who would then refer the patient to us," said Jan Richardson, who was then a managing nurse at the University Medical Center of Southern Nevada (UMC). "A lot of these people were sick when we saw them and they had probably been [HIV-] positive for a long time."

Many had been treated for health problems, not all related to HIV, but no one had inquired about their sexual health histories or tested them. "If this person had only been tested somewhere else and diagnosed early, we could have prevented a hospitalization, and maybe could have prevented progression to late-stage HIV illness," Richardson said.

In 2019, Richardson, who's now a consultant with the Clark County Social Service Office of HIV, encouraged doctors in UMC's emergency department to provide opt-out testing, where people are tested for HIV unless they decline. They agreed, and within two weeks they had their first person who tested positive for HIV. Two nurse navigators were added to regularly visit the ER to ensure that anyone who tests positive gets into care as soon as they leave. "We wanted to make sure [people] didn't get lost in the system," Richardson said.

BAMUSIIME SYLVIA - ISTOCK

But Richardson knew the county wouldn't find everyone who needed care unless a critical mass of urgent care facilities and emergency departments provided opt-out testing and linkage to care. "My vision was if we could just start making doctors think about HIV and test for it, then we could reduce some of these hospitalizations."

To get all stakeholders on board, a county-wide plan with buy-in from healthcare facilities, and funding, was needed.

Rapid stART learning collaborative

In 2020, a learning collaborative was formed, led by the Clark County Social Service Office of HIV, the Pacific AIDS Education and Training Center, and the University of California-San Francisco (UCSF), along with nine community health organizations. Heather Shoop, assistant manager and grant administrator of the Clark County Social Service Office of HIV, was hired in early 2020, just before the COVID pandemic led to the shutdown of in-person meetings and services. Shoop, who helped organize the collaborative, said leadership group meetings, bi-weekly data performance meetings and the creation of more than two dozen webinars, all done via Zoom, gained agreement on best practices and metrics for Rapid stART.

"We built a coordinated program all online during the pandemic, and we expanded Rapid stART through a coordinated community-wide effort where all of the agencies are in touch with us," Shoop said.

A bill passed in the Nevada legislature, SB 211, which allows primary care and emergency departments to begin opt-out testing for people over the age of 15, was the final piece of the puzzle.

The collaborative agreed on several goals:

- Dramatically expand the number of sites doing Rapid stART testing
- Begin a Rapid stART rideshare program
- Convene a Rapid stART Response team
- Produce a Rapid stART module and manual

The learning collaborative set into motion a process that's producing results. Between 2020 and 2023, Clark County expanded the number of sites doing opt-out HIV testing from 4 to 27, and the number of agencies linking people to care from 2 to 27. A key part of that linkage to care was a navigation system in which a participating clinic immediately sends a staffer to an ER when they get a call about a person testing positive.

While some facilities provide testing but not services, now they are at least aware of where to refer someone. "You'd think agencies would know where to send clients, but in Clark County there were a lot of agencies providing the same services, with no centralized referral system," said Octavio Posada, a consultant who coordinated the learning collaborative.

"We connected agencies that wouldn't know about other services," he added. "If a patient needs a ride, the facilities can send an Uber or Lyft."

The vast majority who get tested turn out not to have HIV, but people who test positive can get into care quickly.

“[Opt-out testing] is rolling out and started with UMC Wellness Center primary and quick cares, and after two years they just hit the 10,000-test mark,” Shoop said. “It is all unfolding as it needs to, and over time we will see more and more clinics, [emergency departments] and primary care centers doing this type of testing.”

> ‘The priority is getting a person into medical care on the day of diagnosis or within a seven-day window afterwards’

Shoop and Richardson emphasized that any county in the U.S. could achieve similar results, and they pointed to a downloadable Rapid stART manual that came out of the collaborative.

HRSA’s Special Projects of National Significance (SPNS), which the county obtained through a joint grant with UCSF, helped fund the Rapid stART learning collaborative.

“The county uses a blend of different funding streams, including Ryan White and EHE funds, but it was EHE that helped the county put the rapid in Rapid stART, specifically by eliminating bureaucratic hurdles,” Shoop said. “The eligibility criteria across Nevada for Ryan White-funded services are multi-pronged: an HIV diagnosis, being a resident of the grant area and having an income less than 400% of the federal poverty level. The more requirements you have, the more time it takes to start people in services, if they’re eligible. With EHE funds the only eligibility requirement is an HIV diagnosis. The priority is getting a person into medical care on the day of diagnosis or within a seven-day window afterwards, and there’s no other barrier around eligibility.”

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DOWNLOAD the Rapid stART manual: bit.ly/rapid-start-manual.

» A ‘status neutral’ approach to care CONTINUED FROM PAGE 40

In the first 18 months of the PEP program, the Center had more than 400 initiations, many who might not have accessed PEP if it had meant long lines in the ER and a big bill. “The program may be an on-ramp to PrEP,” Harold said. “We ask every patient, ‘Are you aware of PrEP?’ If the answer is no, then we teach them about PrEP and offer it to them. If the answer is yes, we offer it to them. It’s a unique opportunity to screen for STIs as well.”

Getting comfortable talking about sex

In the same session, Dr. Jill Blumenthal, associate clinical professor of medicine at University of California, San Diego, shared how general ID practitioners can incorporate inpatient HIV care in their practices. She echoed Dr. Harold, that status neutral care is best. One of the most important ways to incorporate HIV care, including prevention and treatment, is learning to take a patient’s sexual history in a non-judgmental way. To accomplish that, some doctors may have to step outside their comfort zone and ask some very personal questions.

“Staying sex-positive and open-minded is crucial,” she said. “You’re not the judge. You want patients to be able to tell you things about themselves.”

Blumenthal said the CDC’s five P’s of sexual history taking, which many doctors learn in med school—partners, practices, protection, past history of STIs and pregnancy intention—is only a start in learning about a patient’s vulnerabilities, including potential partner violence.

Her advice: No assumptions should be made when you talk with a patient. Validate all sexual practices. Don’t assume people are limited to certain kinds of effects based on their gender. And ask open-ended questions.

“For example,” she said, “*What kinds of sex are you having? Which body parts of yours touch which body parts of another partner?* It’s also important to ask about engaging in sex for money, housing, drugs or other services.”

Remember that PrEP is indicated for adolescents and adults ages 15 to 65 years who are especially vulnerable to HIV, Blumenthal added. A doctor can assess vulnerability by asking non-judgmental questions.

Having a sex partner who had HIV, especially if the partner did not know their viral load and/or had a recent bacterial STI, may be a sign that an HIV test is needed, Blumenthal said. “We can incorporate a lot of people [who are] just not using condoms with sex partners whose HIV status is unknown; that’s going to be a lot of people. And of course, persons who inject drugs, and have a drug injecting partner who has HIV sharing injection equipment.”

She added, “If a patient brings up PrEP, that’s easy: they think they might need it, and that opens up a conversation about the benefits (and possible risks) of PrEP medication and the affordable—sometimes free—ways to get it. It’s also a good time to address PrEP misconceptions. And when a patient asks for PrEP, this sets up a need to perform an HIV test.”

The default, Blumenthal suggested, is testing for HIV rather than not testing. “If they’re in the right age range, or they’re having sex at all, start with an HIV test, and then the conversation can continue.”

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» Going with the flow CONTINUED FROM PAGE 41

weeks, 20 new individuals started on LA-ART. And the wait list has drastically improved, Kilcrease said. “At one point there were over 100 patients on the wait list, and now we’re down to 23.”

Kilcrease shared several lessons in workflow change that other clinics could consider. First, aim for a centralized referral process and hub, and use existing staff to evaluate their scope of practice. “If the scope of practice does not allow them to administer these medications, work with state boards and advocate for those disciplines to practice at the top of their license,” she said.

For better benefits workflow, Kilcrease recommended creating a process for evaluating payer authorizations and reauthorizations, including an appeal template and a pill letter template for providers to help them respond to denials. Because there are always denials, she added.

Finally, clinics could consider using the manufacturer hub for benefits determination for the patient. “If you do go that route, I would recommend creating a tracking system for patient appointments as well as authorization dates,” she said.

Responding to a question about how Hopkins keeps people engaged in care, Kilcrease said that having the advantage of many resources such as dedicated outreach specialists helps. She added that most of the people who expressed interest in CAB-LA do a good job of self-regulating and coming to their appointments.

“We do have the systems in place for automated reminders on the clinic side,” she said. “We are utilizing our clinical pharmacy technicians to help with reminders on the pharmacy side, and we have the automated system on the clinic side. But what I would say is that, mostly, the patients come back because they are treated the way they want to be treated.”

BEING BRIDGETTE

Bridgette Picou

Nursing is not for the weak

Becoming a nurse taught me how to live with HIV

Nursing is not for the weak, and nursing school is the epitome of that. There are two major things I didn't learn in nursing school. The first is how to be a nurse. You don't actually learn to be a nurse until you are a nurse. Nursing school teaches you how to be safe. Basic stuff like how to take a blood pressure, and the body's physiology. In fact, I learned more about what kind of nurse I didn't want to be while in school. Rotations through clinical sites gave me examples of nurses with bad habits I couldn't wait to forget. One of my worst experiences in HIV stigma happened in nursing school from an instructor, and it made me question if a person with HIV could be a nurse. **Yet here I am.**

The second thing I didn't learn was how to lose a patient to death. In thinking back, the only conversation about death was an abstract kind of idea that people die as part of the natural life process. Professionalism and distance make that easier. Or so they said. We didn't talk about what it would feel like to walk into a patient's room and find them and all of their things gone. My instructors never discussed navigating the talks with a patient's family about what active dying looks like. During one of my rotations at an assisted living facility, I walked in to find the patient who had been there the day before had passed away. We had only been there a short time, but this particular patient was cranky and had dementia which made her loud, demanding and at the same time hilariously funny. I had to say, she made an impression. While it was a shock to find she had passed, I remember saying a prayer for her, and noting mentally that we didn't discuss it beyond learning the cause of death. That bothered me, but there were things to learn and people to care for. Professionalism? Disconnection? Maybe a bit of both.

When I began nursing at the AIDS service health clinic I worked at, the idea of death and dying became more than an abstract idea. By that time, I had (mostly) given up the idea that I was going to die of AIDS. I was better educated, taking my meds like my life depended on it (she said tongue in cheek), and applying the *wills* and *wonts* of being a good nurse. It was a journey of navigating not only not dying but relearning how to live.

I was also listening to patients tell me about a time before meds when friends died every day. They spoke of stigma and about attending weekly memorials and funerals and forming a community. I witnessed PTSD and the flawed, but understandable guilt of being alive to talk about life when folks they loved were not. I honestly thought I had faced my personal mortality early on when I was diagnosed with HIV. I realized through their stories, I had only glanced at it in the mirror. Those stories, and the path from diagnosis to nursing in AIDS care, to now aging with HIV gave, and still give, me my own dose of irrational guilt every time I struggle to take my meds or skip doses because I'm burnt out on taking them. Not so long ago, at diagnosis they told people to prepare to die in three months or in a year. Now they say you aren't going to die. The amount of living to be done that flows between those times and words is partially what makes death less abstract and more concrete.

I lost three patients to either comorbidities from, or complications of, an AIDS diagnosis. Three white, gay men I had zero in common with except three letters and some medication. Men whose visits I looked forward to, and whom I daresay felt that way about me. It could be arrogant to say I lost them. Certainly, they had families and lives outside the clinic. Yet, they were mine. I took care of them, knew their spouses and pet's names. I gave them shots, helped them with questions and gave out hugs. We laughed and cried during visits. I was the nurse they asked for when they needed help. What is also true is, sometimes, they nursed the nurse without even knowing it.

In my head, the fact that I don't remain disconnected or "professional" is one of my nursing superpowers. I learned how to be a nurse by practicing nursing. I learned about the reality of losing a patient the same way. Nursing is not for the weak, but neither is life with HIV.

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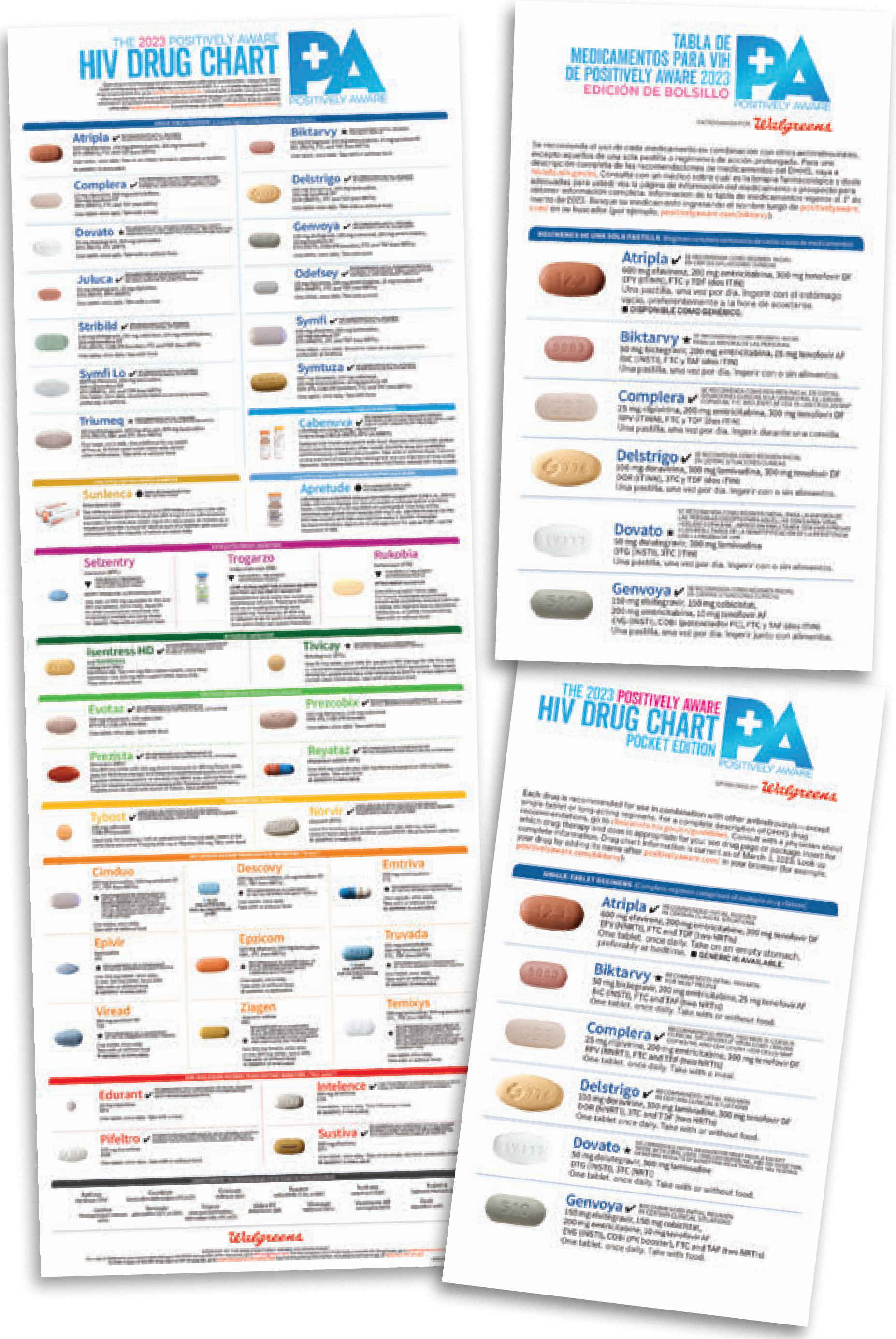

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