POSITIVELY AWARE
SEP+OCT 2025

CONFERENCE UPDATE

IAS 2025: PREP ACCESSIBILITY AND INTEGRATING MENTAL HEALTH

RURAL HIV ADVOCATES ARE FINDING WAYS TO SURVIVE, BUT THEY CAN'T DO IT ALONE

RESEARCHERS BUILD ON COMMUNITY ADVOCACY TO RETHINK MOLECULAR HIV SURVEILLANCE DATA

BEYOND STATUS

BETO SOBERANIS reflects on life as an immigrant living with HIV

MÁS ALLÁ DEL ESTATUS

BETO SOBERANIS reflexiona sobre la vida como inmigrante que vive con VIH

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LIVE LIFE **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.

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In a time of crisis, Carl Baloney, Jr., steps up at AIDS United

INTERVIEW BY **KENYON FARROW**

Coming into a leadership role right now in an HIV organization is no small feat. Onto the field, Carl Baloney, Jr., has stepped up. The New Orleans native, who spent the past decade in the policy department at AIDS United, one of the leading policy advocacy groups, before becoming its vice president, was announced as the new president and CEO of the organization. In his new role, Baloney will help fund local efforts while advocating at the federal level for funding and effective policy. "We need your voices at the federal table here in Washington, D.C., when we can go to reimagine what the HIV care system is going to look like," he says.
positivelyaware.com/new-AIDS-United-CEO

Harold Phillips, NMAC's new CEO: 'I never thought it was going to be easy'

INTERVIEW BY **RICK GUASCO**

His job history reads like a list of leading—now vulnerable—government offices responsible for serving people living with HIV and ending the HIV epidemic. During the U.S. Conference on HIV/AIDS (USCHA), Harold Phillips reached out to POSITIVELY AWARE to talk about the challenges he, NMAC and everyone in the fight against HIV now face as the struggle has become a multifront battle to preserve HIV programs. "There's a lot of advocacy and there's a lot of work we can do, especially around our HIV issues and protecting access to PEP and PrEP," he says.
positivelyaware.com/harold-phillips-at-nmac

Magic Johnson's 1991 TV interview with Arsenio Hall: 'We don't have to be ashamed of it.'

For many people, Earvin "Magic" Johnson might be the most famous person with HIV of all time. In November 1991, the Los Angeles Lakers basketball player announced that he had tested positive for HIV. The news made headlines: If one of the most famous—and beloved—NBA stars could get HIV, who was safe? Ahead of Johnson's scheduled appearance at the U.S. Conference on HIV/AIDS in Washington, D.C., POSITIVELY AWARE reposted the magazine's December 1991 cover story, an edited transcript, adapted with permission, of his appearance on television's "The Arsenio Hall Show."
positivelyaware.com/magic-johnson-1991-interview

Intentional allies: 'A careless ally cannot be my ally'

COMMENTARY BY **BRIDGETTE PICOU**

"I was recently in a space with a person speaking publicly about HIV who is associated with the community but is not living with HIV," writes Picou. "The encounter left me feeling both disappointed and conflicted. Their connection to the HIV community cannot be denied and let me stress: I am in no way detracting from what they experienced. While I appreciate their personal journey and willingness to speak up, I would rather they champion the cause in silence if they perpetuate stigma, no matter how much influence they have. Relatability and reliability matter more than privilege and performance. Allyship cannot and must not be self-defined, it also must not be assigned to those who engage in careless or performative allyship."
positivelyaware.com/intentional-ally

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ROSA MARTÍNEZ COLÓN

PHOTOGRAPHER JOHN GRESS PREPARES TO PHOTOGRAPH BETO SOBERANIS FOR THE COVER IN FRONT OF THE MURAL *DECLARATION OF IMMIGRATION* IN CHICAGO'S PREDOMINANTLY MEXICAN PILSEN NEIGHBORHOOD. THE MURAL IS BY SALVADOR JIMENEZ AND YOLLOCALLI ARTS REACH.

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THE CATEGORY IS

LIFE LESSONS

What's one thing living with HIV has taught you that you'd want someone to know?

We asked our social media followers; here are some of their responses, lightly edited

COMPILED BY **RICK GUASCO**

"Ongoing education is essential; it's very different from what it was 38 years ago."
—**Nathan Franks**

"One thing that living with HIV has taught me is the power of community. Support, understanding and compassion make all the difference. I want others to know that no one should face HIV alone, and that together we are stronger than stigma."
—**Aracelis Quiñones**

"I spent 14 years alone. I wish I hadn't stigmatized myself within a stigmatized world. I have community now, and I feel pounds lighter."
—**Donna Lawson**

"People living with HIV are not as sick as the media and some doctors want us to believe we are."
—**Nestor Rennt Rad**

"I had 'white coat anxiety.' Living with HIV has taught me to ask questions and make doctors explain things about my health until I understand what they are saying. It's taught me to be my own advocate, not just with my health but in every aspect of my life."
—**Rose Mccloud**

"Something I've learned from living with HIV is that I have an activist spirit. My voice and my story matter and make a difference."
—**Donna Mae**

"HIV taught me that taking care of myself has opened the door to a future I didn't think I'd have. HIV didn't end my life but propelled it forward."
—**Adonis Gutierrez**

"Regardless of a *poz*-ative diagnosis, with self-determination, maintaining a consistent therapy schedule, a healthier diet and a moderate exercise routine, one can have a thriving, productive, happy, lifelong existence with HIV."
—**Marvellus S. Prater**

"I'm not alone. There is an amazing family to guide you and be there for you!"
—**Sonya Jean Milliman**

"Because of my journey with HIV and where it has taken me along the way, I've definitely had to consider and reassess priorities."
—**Tim Thompson**

"Life isn't over until it's over! Keep tackling those bucket list items."
—**Nena Walby**

"I and a lot of my friends are a lot stronger than we ever imagined."
—**Hank Trout**

"Although it's not a life sentence, living with HIV complicates life because there is stigma and ignorance. These are best fought with knowledge, acknowledgement of fear—and most importantly—compassion."
—**Rhymer Stewart**

"I learned that I need to plan for my future. When I was diagnosed in the late '80s, I lived like there was no tomorrow because I was ashamed that I had HIV. Today, I plan for my future because I know I have one and am no longer living in shame."
—**Jolene Ford**

"Don't be scared to share your status. It is what makes us human. Being my true self did amazing wonders for my mental health."
—**Erin Shafer Fulton**

"I've learned that HIV or any illness is not who I am—or who we are. It also taught me to love and always remember who I really am."
—**Jim Ferguson**

"To most definitely take care of yourself by going to medical appointments and therapy; making self-care appointments like getting pedicures, manicures and exercise; doing whatever makes you happy. I will attest to that! I love going to the casinos and playing local scratch-off tickets. Just remember that HIV/AIDS is no longer a death sentence. The medications are out there if you need them."
—**Jack Miller**

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EDITOR'S NOTE

Rick Guasco
@rickguasco

Stranger in a strange land

We just want to belong. Whether it's acceptance by our peers, recognition for our work or knowing that we hold a place in society, *belonging* is an affirmation of our lives.

Even though my family never moved from the Chicago suburb where I grew up, through a series of events I attended a different school every year from fifth grade until junior year of high school. It wasn't until then that I finally felt I had *arrived*. It's why I'd often joke that I'm equally uncomfortable wherever I am. I don't need to fit in; I just want to be accepted as who I am.

My dad came to Chicago from Mexico more than 60 years ago, married my mom and started a family. While my mom was born in Texas, half her siblings in a family of seven children were born in Mexico, including my favorite aunt, Mela. Her English was about as good as my Spanish, but we were still able to talk. After she died, I held on to the flashcards she used that helped her pass the U.S. citizenship test in 2005.

Growing up, our mom wanted my sister and me to be fully acculturated so that we would be better accepted. *More American than Americans*, she'd say. Our dad wanted to teach us Spanish, but she thought we would get "confused." They compromised: our dad would talk to my sister and me in Spanish, and we'd answer in English. The irony is that our dad, for whom English was a foreign language, taught my sister and me to read. "If you know Spanish," he'd say, "you already know half the words in the English language." I often remind myself that, for more than two-thirds of his life, he's had to think in one language and speak mostly in another. My dad is why I love languages and word origins.

MY AUNT MELA'S CITIZENSHIP FLASH CARDS

GUASCO: JOHN GRESS • FLASH CARDS: RICK GUASCO

Gilberto Soberanis, 41, has made a place for himself in Chicago. Everyone just knows him as *Beto*. We met in 2016 when POSITIVELY AWARE did an issue focusing on Latinx people living with HIV. Beto shared that he had been undocumented while growing up before becoming a U.S. citizen. With current events unfolding across the country and what's happening here in Chicago, this seemed like the right time to revisit him.

Beto was 10 years old when he and his family left their small Mexican seaside town, where fishing and growing mangoes were the only options, and came to the U.S. in 1995 to look for something more.

"As a child, you don't know you're *undocumented*," he says. "You're just in this foreign land. I don't think I really understood that I was 'undocumented' until I was in high school and understood the consequences of it."

Being gay, acquiring HIV when he was 18, and now in recovery from substance use, Beto has made peace with the different aspects of his life. Still, he feels no less vulnerable because of the immigration raids taking place in Chicago. To see a street vendor, a fixture in Beto's neighborhood, picked up and thrown into an unmarked vehicle leaves him disturbed. Regardless of privilege or status, he worries that he and his community are at risk.

Leave it to Beto to find hope though. "In the Latino culture, you wouldn't talk about your feelings, and I feel that for the first time in a long time, we're actually acknowledging fears," he says. "We're talking about how we're feeling."

You can read our conversation, "Beyond status," starting on page 18. Elsewhere in the issue, contributing writer Tim Murphy reports on how an old HIV drug class might help reduce the risk of Alzheimer's disease (page 10). Researchers found that for people with HIV who were taking nucleoside reverse transcriptase inhibitors (NRTIs, also known as "nukes"), the risk of developing Alzheimer's decreased each year while on the drugs. While promising, experts say the findings are very preliminary.

In his overview of the IAS 2025 conference in Kigali, Rwanda, contributor Larry Buhl focuses on mental health and PrEP. Integrating mental health into HIV programs and services can help improve HIV treatment and prevention efforts. Affordability, price transparency, accessibility and equity are key to successful HIV prevention. As one presenter said, "We must shift from isolated product rollouts to build a comprehensive HIV prevention ecosystem that ensures choice, equity, dignity and sustainable financing for all."

And in her column, Bridgette Picou views life with HIV not as a definition but as a journey of personal change and growth. She writes, "I don't want to define my journey or legacy with HIV because it's still evolving."

Reflecting on what's happening in the news, in his life and in his community, Beto noted that people have become more connected. "We're resilient. Don't hide your feelings," he says. "*No stá solo.*"

You are not alone.

Rick

I don't need to fit in; I just want to be accepted as who I am.

Briefly

ENID VÁZQUEZ @enidvazquezpa

CDC strongly recommends Yeztugo for PrEP

The U.S. Centers for Disease Control and Prevention (CDC) now recommends Yeztugo for HIV prevention as PrEP (pre-exposure prophylaxis).

"On the basis of a high certainty of evidence for its efficacy and safety derived from the agency's analysis, CDC strongly recommends [Yeztugo]...," the agency reported in its September 18 *Morbidity and Mortality Weekly Report* (MMWR).

The long-acting injectable stops HIV with just two doses a year (a pair of injections given every six months). The latest PrEP medication on the market, Yeztugo (generic name lenacapavir, or LEN) was approved by the U.S. Food and Drug Administration (FDA) back in June. It was **100% effective in preventing HIV in cisgender women and 96% effective in a primarily male group** in two randomized control trials (RCTs) over a follow-up of 52 weeks, the CDC recommendation stated.

"CDC has reviewed and graded the evidence on lenacapavir as PrEP from two clinical trials, which demonstrated strong efficacy in preventing HIV infection among both females and males and found no serious safety concerns," the CDC noted.

FDA approval "is a significant step forward in expanding prevention options and reflects decades of research, partnership and commitment to ending the HIV epidemic," the CDC wrote in announcing its clinical recommendation for Yeztugo. "All FDA-approved PrEP options are highly effective in preventing HIV when taken as prescribed. CDC recommends health care providers inform all sexually active adults and adolescents about proven options for PrEP and prescribe PrEP to anyone who requests it."

Another long-acting injectable, Apretude, is given as an injection every two months.

There are also two daily oral PrEP medications, Descovy and Truvada.

The CDC pointed to setbacks in PrEP acceptance, adherence and persistence (continuation) despite being highly effective in preventing transmission of HIV.

"Multiple national assessments have found that approximately one half of oral daily PrEP users discontinue it within 6–12 months of beginning prophylaxis," according to the MMWR report.

Oral PrEP does not have to be taken daily, according to the CDC's own clinical guidance on PrEP. For example, pills can be taken around the time of sex. PrEP can also be used for protection against HIV when injecting street drugs and for pregnancy planning.

The CDC noted that despite the availability of highly effective PrEP, 31,000 people a year in the U.S. acquire HIV, and "LEN has the potential to improve PrEP adherence and thus enhance HIV prevention in the United States."

According to the report:

- "Clinicians should consider PrEP in persons whose behaviors and epidemiologic context place them at risk for HIV acquisition. These populations include but are not limited to those with identified high HIV incidence in the United States (including persons with diagnosed sexually transmitted infections, men who have sex with men, persons whose sexual partners have HIV infection without viral suppression [undetectable viral load], persons who engage in transactional sex, persons who are incarcerated and persons who share needles).
- "Clinicians should educate all eligible persons about current available PrEP options, discuss product choice, provide follow-up and medication adherence support, reassess ongoing risk and align PrEP care goals accordingly. LEN might offer a good option for persons who prefer not to take a daily oral pill."

GO TO cdc.gov/mmwr/volumes/74/wr/mm7435a1.htm?s_cid=OS_mm7435a1_w. For the CDC's "Clinical Guidance for PrEP," GO TO cdc.gov/hivnexus/hcp/prep/index.html. Find the Yeztugo page of PA's annual HIV drug guide at positivelyaware.com/yeztugo.

TOP OF THE NEWS

➤ CDC strongly recommends Yeztugo for PrEP ➤ Pediatric HIV guidelines updated ➤ Is Apretude more tolerable than Yeztugo? ➤ U.S. HIV treatment guidelines add more information on cardiovascular health ➤ National HIV/AIDS and Aging Awareness Day, September 18 ➤ My 30th anniversary at POSITIVELY AWARE

National HIV/AIDS and Aging Awareness Day, September 18

For the National HIV/AIDS and Aging Awareness Day (NHAAD), on September 18, HIV.gov listed several online federal resources related specifically to HIV prevention, care and treatment in aging:

- Administration for Community Living: HIV/AIDS
- HIV.gov: Aging with HIV
- HIV.gov: Supporting Long-Term Survivors of HIV
- HIVinfo.NIH.gov: HIV and Older People
- National Institute on Aging: HIV, AIDS and Older Adults

The theme, **"Protect Our Aging Populations: Meeting New Challenges to Live Longer and Improve Lives!"**, "aims to emphasize the need for prevention, research and data focused on the aging community and increase medical understanding of the impact of HIV on the natural aging process."

In addition, the AIDS Institute and the HIV/AIDS and Aging Awareness websites provide facts about the prevalence of HIV among older adults, including a video addressing HIV stigma among older women.

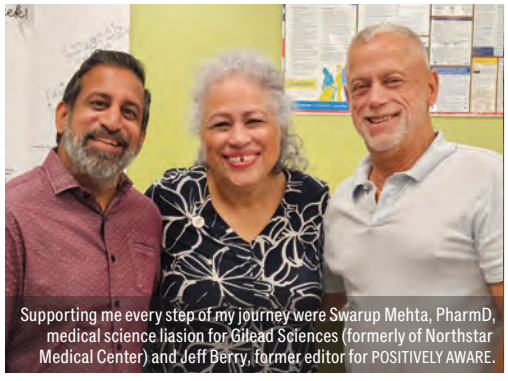
GO TO hiv.gov/events/awareness-days/aging.

My 30th anniversary at POSITIVELY AWARE

In the fall I celebrated my 30th anniversary as associate editor of POSITIVELY AWARE. I always tell my co-workers that **I've been here the longest because I have the best job here.** Although PA has only had three full-time staff members for most of my 30 years, we had another 20 or 30 or more staff members as part of the AIDS service organization that we were part of, Test Positive Aware Network (TPA Network, later TPAN and now Vivent Health + TPAN). I tell people how something I wrote in my first issue helped save someone's life and I discovered it is the most satisfying feeling in the world. It has stayed with me since then. I later learned how important the work of the case managers and peer navigators and social workers is. They save lives too—plus find jobs and apartments and provide mental health care that helps people hold it together, and a million other things. I always mention founder Chris Clason and the 16 men who joined him here in Chicago in 1987 to form TPAN. Now his—*their*—organization has doctors and nurse practitioners prescribing medicine and pharmacists dispensing them. How great is that? We are still in touch with at least one member of that founding group. How great is that? I believe, however, that if there was a cure today, we would still be fighting discrimination tomorrow. There will always be a need for POSITIVELY AWARE. Finally, I always say: "My work is a privilege." It is absolutely a privilege.

To watch a video of my 4-minute talk to colleagues celebrating with me, GO TO youtube.com/watch?v=lljWsMIRJwQ.

2025 Vivent Health+TPAN Chicago staff members


Supporting me every step of my journey were Swarup Mehta, PharmD, medical science liasion for Gilead Sciences (formerly of Northstar Medical Center) and Jeff Berry, former editor for POSITIVELY AWARE.

I thank science and medical providers for my sister Sylvia's life and well-being—along with her indominitable spirit.

U.S. HIV treatment guidelines add more information on cardiovascular health

U.S. guidelines on HIV treatment added more information on cardiovascular health in September. A new chapter contains an introduction along with separate sections on

- Immune Activation and Inflammation Among People with HIV Receiving Antiretroviral Therapy
- Cardiovascular Complications in People with HIV
- Statin Therapy as Primary Prevention of Atherosclerotic Disease in People with HIV
- Weight Gain in People with Treated HIV

"All people with HIV should maintain viral suppression [undetectable viral load, under 20 or 50 according to the test used] with continuous antiretroviral therapy (ART) to reduce the risk of atherosclerotic cardiovascular disease (ASCVD) (AII rating)," the guidelines note.

Other sections of the guidelines received key or minor updates. These included cost considerations of therapy, adverse effects, ART dose recommendations in people with kidney or liver insufficiency and lab testing when starting and monitoring HIV treatment.

Some items of note:

- "Statin therapy is recommended for all people with HIV aged 40–75 years and in additional clinical scenarios for other age groups to reduce the risk of ASCVD and major adverse cardiovascular events."
- "All people with HIV should be counselled about ways to reduce CVD risk through behavioral modifications such as healthy diet, weight control, regular exercise, smoking cessation and limiting alcohol consumption."
- "Optimal management of comorbidities (e.g., hypertension, diabetes, obesity) remains important to further reduce CVD risk among people with HIV."

Although ART reduces the risk of cardiovascular disease, it doesn't do so completely.

The updated guidelines explain that, "Factors related to HIV and its treatment have been shown to be important contributors to excess cardiovascular disease (CVD) risk. Specifically, HIV-related inflammation has been associated with elevated CVD risk. This inflammation is increased in the presence of active viremia [viral load that is not at undetectable levels] and decreases with ART, but still remains elevated when compared to those without HIV (see Introduction). Data from the SMART trial demonstrated that continuous ART not only improves HIV-related outcomes but also significantly reduces non-AIDS events, including CVD, an observation thought to be related to the beneficial effects of ART on inflammation. In the large Veterans Aging Cohort Study (VACS), myocardial infarction (MI [heart attack]) risk was independently associated with detectable or increased HIV RNA [viral load]; compared to people without HIV, MI risk was increased by 39% in those with HIV RNA [less than] 500 copies/mL and by 75% in those with HIV RNA [greater or equal to] 500 copies/mL. In REPRIEVE, even low-level HIV viremia ([an average] 62 copies/mL) was linked to increased rates of major adverse cardiac events (MACE), as viremic individuals had a higher risk than those with viral load below the limit of detection (adjusted hazard ratio 1.4; 95% confidence interval, 1.00–1.97); however, another recent study did not show an association between HIV viremia and CVD. Based on these findings, continuous ART is recommended for all people with HIV to maintain viral suppression and reduce ASCVD risk (AII rating)."

Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV are at clinicalinfo.hiv.gov. The document opens with the section, "What's New in the Guidelines."

Pediatric HIV guidelines updated

U.S. guidelines for treating pediatric HIV were also updated in September.

Treating OIs

In cases where a child has not started HIV treatment and has an opportunistic infection (OI), the guidelines recommend that the OI be treated first. This recommendation refers specifically to three OIs: cryptococcal meningitis, tuberculous meningitis or disseminated Mycobacterium avium complex disease (commonly known as MAC).

Switching to INSTIs is preferred

For children and youth who acquired HIV during pregnancy or around the time of birth and have sustained viral suppression (long-term undetectable viral load), the guidelines recommend optimizing therapy (switching) to medication based on an integrase strand transfer inhibitor (INSTI; for example, the single-tablet regimen Biktarvy or a Tivicay-based regimen).

"INSTI drugs have demonstrated higher efficacy and improved safety profiles compared to non-nucleoside reverse transcriptase inhibitors (NNRTIs) or protease inhibitors (PIs). INSTI-based ART regimens are preferred initial regimens for infants, children and adolescents; thus, optimization to an INSTI-based regimen for eligible children and adolescents should be offered," the guidelines explain.

New pediatric doses: Symtuza, Prezcobix, Edurant Ped and Odefsey

Also for **children with long-term undetectable viral load,** Symtuza—a PI-based single-tablet regimen—has been added as an option for children weighing at least 88 pounds (more than 40

ISTOCK

kg). Also added for children weighing at least 55 pounds (25 kg) was Prezcobix, which contains darunavir, the backbone medication in Symtuza, boosted by cobicistat. Note: An oral suspension is available for darunavir (brand name Prezista).

The new children's dose for Edurant (rilpivirine, an NNRTI) was added. Edurant Ped 2.5 mg tablets for oral suspension was approved by the FDA in August 2025. Edurant Ped is for children 2 years and older weighing at least 31 pounds (14 kg). Dose is based on body weight and is to be taken with a meal. See the guidelines for more instructions. Note: children age 12 and older weighing at least 77 pounds (35 kg) can take the adult dose (one 25 mg Edurant tablet daily) with other HIV medications. Also added was Odefsey, a single-tablet regimen containing rilpivirine, for children weighing at least 55 pounds (25 kg).

Although HIV treatment options are welcome, especially for children, note that INSTI-based regimens are preferred.

Changing failing therapy

New recommendations have been added to the section on **recognizing and treating therapies that are failing.**

Adolescent care

In the section on **special considerations for adolescents,** new references have been added.

"Without ideal HIV care, models project that adolescents with PHIV [perinatal HIV] have life expectancies 10 to 12 years shorter than youth without HIV, highlighting the importance of specialized care that addresses critical barriers to optimal health outcomes in this population," the guidelines state.

TO review *HIV Clinical Guidelines: Pediatric ARV*, **GO TO** clinicalinfo.hiv.gov.

Is Apretude more tolerable than Yeztugo?

A study presented at the European AIDS Conference (EACS 2025) in Paris in October reported greater acceptance of Apretude vs. Yeztugo, the two long-term HIV prevention injectables on the market.

Injection site reactions (ISRs) are the most common side effect for both prevention medications. Apretude (the HIV medication cabotegravir, or CAB, but used for PrEP) is given as one injection every two months and Yeztugo (the HIV medication lenacapavir, or LEN, but used for PrEP) is given as two injections every six months.

The CLARITY study was conducted by ViiV Healthcare, maker of Apretude.

There were 64 HIV-negative adults in the study. Half of the participants were given CAB one day and then LEN 15 days later; the other half received LEN one day and CAB 15 days later.

Following the single dose of each medication:

- 69% found Apretude, "totally or very acceptable" vs. 48% for Yeztugo
- 90% of participants preferred CAB injections over LEN injections

The four most common reasons reported for these differences were:

- Less pain during injection
- Less pain or soreness after injection
- How long the injection nodules or swelling last
- The size of the injection nodules or swelling

Pain was the most commonly reported ISR for both PrEP medications: 80% for CAB and 82% for LEN.

ISRs that were palpable and/or visible were more commonly reported for LEN compared to CAB:

- Induration (87% for LEN vs. 18% for CAB)
- Nodules (74% for LEN vs. 33% for CAB)
- Erythema, or redness (57% for LEN vs. 12% for CAB)
- Swelling (58% for LEN vs. 34% for CAB)

In the real world, if ISRs are found to be more difficult with LEN, people might still prefer to trade off those side effects with a PrEP injectable that's given only twice a year versus one that's given six times a year.

Time will tell. Apretude was approved by the U.S. Food and Drug Administration (FDA) in December 2021 while Yeztugo just received its FDA approval in June 2025. PrEP development continues, as the prevention medications on the market still haven't taken off as CDC and others may wish (see page 6). A biodegradable cabotegravir implant that lasts a year is in the works.

The CLARITY study also reported greater provider acceptance of Apretude vs. Yeztugo.

Six out of seven providers giving the injections (86%) preferred CAB over LEN. The three most common reasons given were:

- Fewer number of reported side effects
- Less severe side effects and
- Less pain reported during injection

READ the study report, "ViiV Healthcare's CLARITY Study Shows Long-Acting Cabotegravir More Acceptable than Lenacapavir Injections After a Single Dose, with 90% Preferring Cabotegravir," at the website of the National AIDS Treatment Advocacy Program (NATAP); **GO TO** natap.org/2025/EACS/EACS_27.htm. **READ MORE** studies from EACS 2025 at natap.org/2025/EACS/EACS.htm.

Could a widely used class of HIV drugs help prevent Alzheimer's disease?

A large database study links NRTIs to lower Alzheimer's risk; while promising, experts say the finding is only preliminary

BY **TIM MURPHY**

It's long been known that certain HIV meds as well as HIV itself may cause cognitive problems or decline in people taking them. But now a study finds that the HIV drug class known as nucleoside reverse transcriptase inhibitors (NRTIs), which make up the backbone of almost every HIV drug regimen, may help *prevent* one form of dementia: Alzheimer's disease.

If confirmed, this is good news: Most people on HIV treatment are already taking NRTIs—for example, the combo of the NRTIs tenofovir and emtricitabine is in almost every single-pill HIV regimen. It's also good news for the millions of people worldwide who develop Alzheimer's, for whom a drug could be developed that extracts the aspect of NRTIs that blocks inflammasomes, a part of the immune system implicated in promoting Alzheimer's.

In the study, published May 8 in the journal *Alzheimer's & Dementia*, researchers from the University of Virginia Health System analyzed data from the insurance databases of the U.S. Veterans Administration and MarketScan (of commercial insurers) containing millions of patients going back several years. The researchers looked for the records of patients over age 50 with no previous Alzheimer's diagnosis who were on at least one NRTI to treat HIV or hepatitis B (which the drugs also treat).

They found 270,000 patients who met that criteria. Then the researchers followed up the patient records over several years from the start date to look for indications of an Alzheimer's diagnosis. Even after correcting for concurrent conditions that might cloud the results, the researchers found that for those on NRTIs, the risk of developing Alzheimer's actually went down more with every year on NRTIs, compared to those in the databases who weren't on them. Importantly, the study found no such beneficial correlation for people on HIV meds in other classes, such as NNRTIs (non-nucleoside reverse transcriptase inhibitors), PIs (protease inhibitors) or integrase inhibitors.

The findings led the researchers to declare in their paper that the reduction in Alzheimer's risk from taking NRTIs was "significant and substantial." They also note that previous studies have had similar findings and have suggested that NRTIs might work against other diseases including diabetes and macular degeneration.

Despite numerous requests, POSITIVELY AWARE was unable to get an interview with the study leader, Jayakrishna Ambati, MD, so PA turned to outside experts for commentary. Said Dr. David Vance, who specializes in HIV, cognition and aging at the University of Alabama: "These results are exciting. After all these years hearing about other HIV drugs like NNRTIs causing cognitive problems, it's nice to see [a study that suggests] there's something positive happening from these meds."

Richard Jefferys, the longtime basic science, vaccines and cure project director at the think tank Treatment Action Group, said that the results were "interesting" but that he hoped the findings would be verified by another research group that might provide better confirmation of Alzheimer's diagnoses than those gleaned from reading codes input into an insurance database—which, in Vance's words, is "what a doctor said this person had."

The study authors seem to agree, writing: "These findings support the concept that inflammasome inhibition could benefit [Alzheimer's disease] and provide a rationale for prospective clinical testing of inflammasome inhibitors such as NRTIs in [Alzheimer's disease]." After being denied an interview, POSITIVELY AWARE emailed the authors, asking if they knew such a study would be happening. A rep answered: "Dr. Ambati and his collaborators agree that further study is warranted. They're planning to test this as part of the clinical trials of an inflammasome-blocking drug, K9, that they have developed."

> ...previous studies have had similar findings and have suggested that NRTIs might work against other diseases including diabetes and macular degeneration.

Jefferys also noted that the study's confidence interval, which is the numerical range in which the study authors believe the "true" answer to their question lies, was close to the line that would render it non-reliable, or "statistically insignificant." And he noted that the protective element of NRTIs could still be at odds with the presumed cognitive damage done by other HIV meds, or HIV itself.

But overall the study is good news for people living with HIV who are on NRTIs—that is, most people with HIV on treatment—in that, they may also be deriving an anti-Alzheimer's benefit from them. Says Vance: "It's exciting that there might be a positive effect from NRTIs besides [working in a complete HIV regimen to help] keep people with HIV alive."

As the study authors themselves note above, more research in the non-HIV population is needed to confirm that the element of NRTIs that appears to block Alzheimer's could be leveraged into its own drug for that purpose. PA

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Deals promise cheaper generic lenacapavir for PrEP to 120 countries by 2027

Low- and middle-income countries will get $40 lenacapavir through partnerships with India-based drugmakers

BY **LARRY BUHL**

Two India-based generic drugmakers—Dr. Reddy's Laboratories and Hetero Labs—have signed separate agreements with Unitaid and the Gates Foundation, respectively, to manufacture a generic version of Gilead's six-month injectable lenacapavir for HIV prevention (PrEP) for about $40 per year, starting in 2027.

More than 100 low- and middle-income countries may have generic versions of twice-yearly injectable lenacapavir (LEN) for HIV prevention (PrEP) by 2027 following two partnerships announced September 24.

India-based generic drugmakers Dr Reddy's Laboratories and Hetero Labs have signed separate agreements with Unitaid and the Gates Foundation, respectively, to manufacture the long-acting PrEP formulation for approximately $40 per year, starting in 2027. This would bring the price long-acting injectable closer to the cost of generic daily oral PrEP.

It's the first concrete announcement of generic pricing since the drug's manufacturer, Gilead Sciences, announced that it had signed royalty-free licensing deals with six companies that make generic drugs last year to produce cheaper, generic versions of long-acting LEN to sell in countries with the highest global HIV disease burden. In addition to Hetero and Dr Reddy's, the other drugmakers include Emcure, Eva Pharma, Ferozsons Laboratories Limited and Mylan.

In the U.S., lenacapavir for PrEP is marketed under the brand name Yeztugo with a widely reported estimated "list price" of $28,218 a year, though it's expected the cost will be much lower once insurers begin adding the drug to their formularies.

Administered as two injections every six months, lenacapavir for PrEP has been shown in a series of clinical trials to reduce the risk of HIV transmission by 100% among young and adolescent cisgender women, and by 97% among cisgender and transgender men who have sex with men.

"Securing a U.S. $40 price for the twice-yearly lenacapavir injection for PrEP is a historic breakthrough that proves the most advanced tools can be made affordable from the very start," said Unitaid's executive director, Philippe Duneton, MD, MPH, in an email statement to POSITIVELY AWARE. "This directly answers the calls from countries and communities to make lenacapavir as affordable as oral PrEP."

Trevor Mundel, president of global health at the Gates Foundation said in a press release: "Scientific advances like lenacapavir can help us end the HIV epidemic—if they are made accessible to people who can benefit from them the most."

In a statement, AVAC (formerly AIDS Vaccine Advocacy Coalition) praised the announcements but also called on all stakeholders to continue coordinated action and investment to create "a viable and sustained market" for long-acting PrEP.

'Ultimately, **lenacapavir [for PrEP] must reach more than five million people per year to have real impact**, build a sustainable market, and drive prices down even further.'
—AVAC

"Ultimately, LEN must reach more than five million people per year to have real impact, build a sustainable market, and drive prices down even further," the statement read. "This means we must act faster and think bigger."

The announcements probably won't not quell criticism against Gilead by patient advocacy groups for not including upper- and middle-income countries, including those in Latin America, in the 2024 generics agreement.

Speaking with POSITIVELY AWARE, Jeremiah Johnson, executive director of PrEP4All, offered tempered enthusiasm for the agreements with Hetero Labs and Dr Reddy's. "I'm happy to see progress that can take place for the 115 countries where this price is going to hopefully improve access, [but] I think we are also mindful of the countries that aren't going to have that price, including here in the U.S., where the list price remains $28,000."

"We would love to see some kind of intervention that allows for generic forms of lenacapavir to be accessible within the U.S. that would immediately and remove barriers that we see in terms of access," he continued. He also said that U.S. government intervention will likely be necessary "to break the patents and get generics here instead of squabbling with a lot of corporate interests."

Dr Reddy's Labs signed its partnership with Unitaid (an agency within the World Health Organization), the Clinton Health Access Initiative and South Africa's Wits RHI. Hetero Labs struck its agreement with the Gates Foundation.

Both the Gates Foundation and Unitaid have assured the two companies that they will cover the cost of any unused doses produced under the agreement. However, neither organization has disclosed the number of doses they're providing volume guarantees for, or the amount of their grants and other investments in either generic manufacturer. The Gates Foundation confirmed that their initial investment will be in effect for five years.

Unitaid noted that the international deals came in record time after lenacapavir for PrEP was first approved in the U.S. and other high-income countries. Without these strategic partnerships, the organization said, making new medications widely available in low- and middle-income countries would take a decade or longer. PA

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Confronting HIV by the numbers

Researchers build on community advocacy to rethink molecular HIV surveillance data

BY **BRIAN MINALGA**

In 2017, the U.S. Centers for Disease Control and Prevention (CDC) began requiring health departments to collect data for molecular HIV surveillance (MHS). According to CDC, the goal of MHS is to improve our understanding of the groups and characteristics associated with recent HIV transmissions, but advocates have raised concerns over privacy and how the personal data, even if anonymized, of people living with HIV (PLWH) are being used.

MHS uses genetic information about HIV routinely collected from PLWH and combines it with other information that health departments already track such as demographics, stage of HIV at the time of diagnosis, and transmission-related factors. The HIV genetic information comes from laboratory tests that doctors order for their patients living with HIV to help determine which HIV medication is best suited for them, based on observed drug-resistance mutations.

The information is then sent to health departments and the CDC, where it is used for public health purposes and, sometimes, research. The CDC says that MHS is a necessary tool to end the epidemic, but many PLWH, scientists and advocates contend that MHS, as it is currently used, raises ethical, legal and social concerns.[1–3] These issues include that PLWH should have a say or at least be informed on the uses of their medical information, and that MHS could increase HIV-related stigma or even criminalization.

Over the years, a variety of partnerships and coalitions have formed to try and resolve tensions with this controversial practice. In this interview, advocate and HIV research professional **Brian Minalga, MSW**, spoke with two researchers, **Sanjay R. Mehta, MD**, and **Susan Little, MD**, who have developed a new approach they think could dramatically reduce the stigma and privacy-related concerns with MHS.

MINALGA Hello, Sanjay and Susan, thank you for joining me.

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Can you start by giving a little more background on MHS and how it's supposed to work?

DR. MEHTA Thank you for inviting us to share our work, Brian. In 2019, the federal government introduced the Ending the HIV Epidemic (EHE) initiative and set a goal of reducing HIV incidence in the U.S. by 90% by 2030. This plan was supported by four pillars: Diagnose, Treat, Prevent and Respond. The "Respond" pillar calls for the use of MHS data to better detect "clusters," or outbreaks of HIV transmission, and deliver resources where they are needed (e.g., testing, linkage to care, PrEP). This process, called **Comprehensive Cluster Detection and Response (CDR)**, relies on comparisons of the similarity of HIV genetic sequences collected from different individuals.

MINALGA What is the value of the HIV genetic sequences in the "respond" pillar of EHE?

DR. LITTLE Every person living with HIV has a unique version of the virus, called a *viral sequence*. When the virus in two people looks very similar, it suggests that HIV has spread recently between them—either directly or through one or more intermediate people. These two people are considered part of a "cluster," as defined by the CDC. By talking to people in these clusters, health workers can find their sex and/or needle-sharing partners, help people who are not in care connect with doctors, offer HIV prevention services, and understand which factors might be contributing to ongoing HIV transmission.

MINALGA How would you describe the concerns that many people have raised about MHS and CDR?

DR. MEHTA As we understand it, the risks associated with Comprehensive CDR fall into two major categories:

Data privacy: Personal data such as demographic information, lab results, and HIV sequence data are collected by health departments as part of standard HIV monitoring. This kind of data use isn't new or unique to CDR; it has been part of public health efforts since early in the HIV epidemic. It is important to note that these data are subject to strict federal privacy protections. However, the concern is that if this information is not stored or shared securely, it could lead to privacy issues. This echoes the concerns we have heard about CDR possibly increasing the risk of HIV stigma, discrimination, and even criminalization.

Data use: There is a possibility that people could be unintentionally identified when public health workers interview individuals in a cluster and their partners. For example, if CDR identifies a new case that is linked to a cluster of PLWH who are using injection drugs, it could unintentionally suggest that the new case is from injection drug use. The use of Comprehensive CDR might result in stigmatizing experiences or other unintended consequences for members of populations in which HIV transmission is occurring.

MINALGA So, you are really focused on concerns about the data—data that are collected from PLWH that inform their own medical care, as well as data that are used in the broader public health "respond" pillar of the EHE plan.

DR. LITTLE Yes, but we are also focused on maximizing the overall benefits of MHS while minimizing the overall potential risks. Take, for example, how comprehensive CDR looks for small groups of PLWH with very similar viruses (more than 99.5% genetic similarity). From a public health perspective, a priority cluster is one that has at least 3–5 people who were diagnosed within the last 3 years. However, only 3–4% of newly diagnosed HIV cases fit into these priority clusters. This means that over 95% of the HIV sequence data collected are not used for any type of action. The result of this is that many people who could benefit from the analysis of MHS data may be left out.

MINALGA It sounds like you're talking about harm reduction, given the reality that CDR is taking place throughout the country, despite the concerns you have described. If there are potential risks to any type of public health action, those risks need to be mitigated to the greatest extent possible, *and* public health action should be optimized to provide the greatest benefit possible, especially for the communities with the greatest likelihood of exposure to these risks.

SUSAN LITTLE, MD

SANJAY R. MEHTA, MD

DR. MEHTA Right. Which is why we have proposed a different method, which we are calling **Regional Intervention Prioritization Strategy—RIPS**. This approach uses the same MHS data as Comprehensive CDR, so we acknowledge that this approach does not address concerns about how MHS data are collected. However, RIPS is different from CDR because it focuses on the density of clustering within populations or geographic regions instead of small clusters of people. This lowers the risk of disclosure for individual-level data while making more comprehensive use of the data (i.e., using the data from all individuals, not just those found to be in priority clusters) to guide public health efforts.

MINALGA What is RIPS?

DR. LITTLE RIPS doesn't require categorizing people into small clusters. Instead, it aggregates individual-level HIV sequences and then analyzes them to assess whether a population or geographic region has a high number of recent HIV transmissions. This is determined by examining the genetic similarity of HIV sequences within the region. By combining these data with other information, such as demographics and clinical data, RIPS can help public health officials figure out where to focus their efforts for maximum impact.

MINALGA RIPS sounds similar to CDR. What are the key components that differentiate RIPS from CDR?

DR. LITTLE The key difference is that RIPS looks at regions

or populations, in other words large groups of people, while CDR focuses on individuals and clusters (small groups of people). Thus, for RIPS reports, only *aggregated* individual-level data are used, while CDR reports begin with individual-level data. By zooming out and focusing on regions or populations, we believe the risks of disclosure and stigma to individuals are significantly decreased. At the same time, we hope these analyses will benefit more people.

DR. MEHTA I can also give you an example. If a neighborhood has a high number of new transmissions that cluster at a high rate, public health agencies and prevention partners can focus their efforts on this geographic area to prevent further spread. They might use tools such as education programs, pre-exposure prophylaxis (PrEP) and harm reduction strategies that are delivered in areas with high levels of clustering. This is different from CDR because if CDR were used in this scenario, public health efforts would typically be directed to specific people who were either members of clusters or their named partners, thus increasing the risk of disclosure and stigma to those people.

MINALGA I'm starting to see how RIPS builds on groundwork laid by advocates, and how it at least *partially* responds to some of their concerns. The influence of advocacy on science and public health too often goes unappreciated, so I really want to emphasize the role of advocacy in your rethinking of MHS, and I appreciate your thoughtfulness to community concerns, which aligns with the principle of the meaningful involvement of people living with HIV. Keeping community in focus, how might RIPS improve upon CDR to support the health of people in the community, especially people living with HIV, while reducing potential risks from this use of their data?

DR. LITTLE Great question. To give another example, if an area has a high number of new HIV diagnoses, but a low rate of clustering, this may suggest that people in this area are being diagnosed late. Even a delay of three years can allow the virus to change enough that genetic links between cases are no longer detectable. We know that early diagnosis and early treatment are essential for reducing the spread of HIV and improving the health of PLWH. When diagnoses are delayed even further—say 5–10 years after transmission—people may also have much lower CD4 counts when they are eventually diagnosed. This suggests that the area might need better access to HIV testing, possibly tailored to specific populations. Because these strategies focus on populations rather than individuals (as in CDR), the risk of disclosure and stigma is much lower.

MINALGA What are some other potential benefits to RIPS?

DR. MEHTA RIPS may help public health officials and community members understand how the HIV epidemic is changing over time. It can show trends in how HIV is spreading and whether prevention interventions are working. For example, if both new HIV diagnoses and clustering rates are increasing in a region, it could suggest that more new transmissions are occurring. However, if over time the number of new diagnoses goes down but clustering remains high, it might mean that people are being tested and diagnosed earlier—before they can pass the virus to others. These patterns can help public health teams understand what is happening in the community and adjust their strategies as needed.

MINALGA You said that you think RIPS could dramatically reduce the concerns related to CDR. Can you explain how?

DR. LITTLE RIPS has the potential to protect privacy better than Comprehensive CDR because it doesn't require interviewing individuals or focusing on small groups. Instead, it looks at neighborhoods or populations, which could lower the risk of stigma or privacy breaches.

MINALGA So, RIPS doesn't address concerns about the lack of informed consent for the public health use of HIV genetic data collected from PLWH for their medical care. It's more focused on reducing potential misuses of the data after they've already been collected. While RIPS may carry less potential for stigma at an individual and small group level, it can still call attention to transmission occurring in specific communities, such as sex workers and gay men. These communities could still face stigma if HIV prevention efforts are not carefully designed and communicated to avoid blaming or singling out any particular group. Overall, RIPS is focused on reducing risks to *individuals* by "zooming out" to the neighborhood or population level when responding to HIV transmission.

DR. LITTLE You are exactly right. Even with RIPS there may still be community-level stigma concerns, but hopefully there will also be important benefits by identifying which interventions may benefit those communities.

DR. MEHTA I want to add that RIPS can also be useful over time by helping track HIV transmission trends in specific regions or populations. Public health workers can see how well their programs and policies are working. Unlike CDR, which depends on fast data collection to manage outbreaks, RIPS isn't as affected by delays in sample collection and sequencing. That's because RIPS looks at all available HIV sequence data over longer periods of time, while CDR focuses on short-term spikes in transmission.

MINALGA So, you're not envisioning RIPS as an approach that would replace CDR, but rather as an approach that could address a different set of challenges in the HIV response. Can you summarize how RIPS adds value for communities—especially people living with HIV—as well as the public health response?

DR. LITTLE RIPS represents a novel way to analyze MHS

'RIPS can help public health officials and community members understand how the HIV epidemic is changing over time. It can show trends in how HIV is spreading and whether prevention interventions are working.'

data. RIPS is expected to lower risks of indirect identification of individuals and small groups when compared to CDR, while providing more valuable and actionable information to communities. It can guide allocation of HIV resources, shifting HIV prevention services to where transmissions are occurring at the greatest rate, and can help evaluate how well these prevention and treatment programs are working. Clustering rates will decline as more people receive effective treatment and prevention. RIPS is still in the research phase, and real-world studies are necessary to determine if it can result in tangible prevention benefits. We expect RIPS will be a helpful addition to support public health efforts. Whether used on its own or alongside Comprehensive CDR, RIPS could be a valuable tool to help public health departments.

MINALGA What's next for RIPS? Are there any opportunities for readers to engage with you further as you continue to develop RIPS?

DR. MEHTA As Dr. Little mentioned, RIPS is still in the research phase. We plan to conduct regional studies using RIPS in real-world settings to see how useful it is for helping public health departments optimize their efforts at HIV prevention. We will start by looking at retrospective data, that is, MHS data that have already been collected. Next, we will run studies to see how using RIPS over time affects prevention outcomes. We expect it may take several years to fully understand how helpful RIPS can be. Throughout this process, we are committed to engaging with stakeholders and community members. This paper is the first step in that engagement. In each study, we will also continue to work with community advisory boards and share our findings, both at research conferences and meetings with advocates. If anyone would like to share their thoughts or feedback on this approach, we can be reached at slittle@health.ucsd.edu and srmehta@health.ucsd.edu.

BRIAN MINALGA, MSW, has worked in the field of HIV for over 15 years in locations ranging from Seattle to Detroit and Namibia to Niger. Brian currently serves as the deputy director of the Office of HIV/AIDS Network Coordination based at the Fred Hutchinson Cancer Center in Seattle, where they facilitate HIV clinical trials operations with a focus on community engagement. The contents of this article are the sole responsibility of the authors and do not necessarily represent the views of any institution.

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Answering concerns about molecular HIV surveillance data

Concern with Cluster Detection and Response (CDR) and Molecular HIV Surveillance (MHS)	Does Regional Intervention Prioritization Strategy (RIPS) address this concern?
HIV genetic data are used for public health and research purposes without the consent of the people living with HIV from whom these data are derived.	RIPS does not address this particular concern because it uses the same data as CDR.
Public health authorities have not adequately informed and engaged communities of people living with HIV about these uses of their data.	RIPS is still in the research phase and this publication is an effort to engage and educate the community during the earliest phases of its evaluation.
Collection and storage of these sensitive data could fall into the wrong hands and be weaponized against individual people living with HIV.	RIPS does not address this concern, as these data are still being collected and stored by public health. However, since only aggregated data are reported, it seems less likely that individual people would be harmed.
The information used in CDR could be shared with law enforcement or otherwise increase the risk of HIV criminalization.	RIPS analyses do not result in identification of direct links, individuals or clusters, so would be less likely to lead to individual harm even if the data was shared with law enforcement.
The individual-level and public health benefits of CDR have not been adequately demonstrated with evidence.	At this time, the individual-level and public health benefits of RIPS have not yet been adequately demonstrated with evidence. However, academic/public health partnerships have been developed to study this question.
CDR may exacerbate distrust in medical and public health systems.	It is expected that RIPS will not lead to significant distrust in medical and public health systems.
CDR could stigmatize individuals and some groups if they are characterized as belonging to "outbreaks" or "clusters."	RIPS will not report any individual level data, and so it would not lead to stigmatization of any individuals or even clusters.

COURTESY OF BRIAN MINALGA

Cut off and left behind: The rural HIV crisis no one's talking about

Rural HIV advocates are finding ways to survive, but they can't do it alone

BY **CECILIA DENNIS**

In 2025, rural America stands at a critical crossroads. The federal budget passed earlier this year slashed funding for the Centers for Disease Control and Prevention (CDC), the Healthcare Services and Resources Administration (HRSA) and Medicaid—programs that are the lifeblood of HIV prevention and treatment. These cuts aren't just line items in a spreadsheet; they are gut punches to communities already holding on by a thread. In small towns and rural counties, where services were sparse even in the best of times, the effects are immediate and deeply felt.

The fiscal 2025 budget delivered some of the most sweeping public health rollbacks in decades. Among the most shocking was the elimination of all domestic HIV work at the Centers for Disease Control and Prevention. Cuts to the Ryan White HIV/AIDS Program and the Ending the HIV Epidemic initiative followed closely behind. Medicaid, a cornerstone of care for low-income individuals, is facing a projected $700 billion in cuts over the next 10 years. In place of the existing infrastructure, a newly proposed agency, the Administration for a Healthy America, promises streamlining and consolidation, but in reality, it dismantles programs targeted at vulnerable populations, including those in rural and communities most affected by HIV.

The impact of these decisions goes far beyond access to medication. They affect housing, employment, mental health and survival itself. The Housing Opportunities for Persons with AIDS (HOPWA) program has taken a direct hit, triggering a cascading crisis. HOPWA is the only federal housing program specifically for people living with HIV. Stable housing is essential for managing health, accessing care and achieving viral suppression. Without it, people fall out of care, viral loads rise and HIV transmission rates increase.

In fiscal year 2023, HOPWA served more than 55,000 households across the country, providing short-term rent support, permanent housing placement and essential services. Nearly half of HOPWA recipients were Black or African American and one in four lived in the rural South. According to the National Low Income Housing Coalition, over 70% of HOPWA-assisted households earned less than 30% of their area's median income. Despite this growing need, the 2025 federal budget includes an $85 million cut to the program.

Service providers report housing waitlists that stretch for months, sometimes years. In Virginia, HOPWA is often the only barrier between people living with HIV and homelessness. Now, programs are turning people away. Individuals are sleeping in cars, crashing with friends or returning to unsafe living environments. When people lack stable housing, medication adherence suffers. A 2021 CDC study showed that people living with HIV who experience housing instability are five times more likely to lack viral suppression than those who are stably housed.

In rural Virginia and across the nation, these cuts are more than theoretical. Clinics are closing their doors. Staff are being laid off. Community advisory boards, spaces where people living with HIV help shape local services, are dissolving due to lack of financial support. Without stipends or transportation, many community leaders can't afford to keep showing up.

The contrast between urban and rural realities grows starker each day. In major cities like Atlanta, New York, San Francisco and Phoenix, people have access to major hospital systems, a wide

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range of clinics and multiple providers offering prevention tools like PrEP and PEP. Urban advisory boards are resourced and included in policy decisions. People with HIV have options and support systems if something goes wrong.

In Southside Virginia, where I live, there isn't even a local HIV clinic. The closest one is over 200 miles round-trip. There's no public transportation and no outreach van. If your car breaks down or you're too ill to drive, you're simply out of options. I consider myself lucky; I own a car, have internet access and know how to navigate the system.

Most rural HIV clinics rely almost entirely on Ryan White funds to remain open. There are very few providers who prescribe PrEP. Stigma remains deeply rooted. Transportation is nearly nonexistent. When funding disappears, there are no substitutes. People fall through the cracks and, too often, those cracks become unbridgeable gaps.

THESE SCENARIOS aren't projections; they are our current reality. Last spring, the Capital Area Health Network in Richmond shut down its HIV program, displacing 500 clients. Nationz Foundation, a cornerstone of HIV care in central Virginia, lost nearly half of its budget. The LGBT Life Center in Norfolk now faces cutting services to over 400 people due to financial constraints.

And this isn't just happening in Virginia. Minnesota is preparing to close 17 community health centers. Wisconsin may lose over $1 million in HIV prevention funding. In St. Louis, the Community Wellness Project is facing a $2 million shortfall. These aren't isolated incidents, they are signs of a nationwide unraveling.

Community advisory boards have long served as vital bridges between policymakers and the people affected by their decisions. Yet in rural areas, these boards are disappearing. Without support, members can't attend meetings, offer feedback or participate in planning. Without that input, decisions are made far from the realities we live every day, by people who don't understand the terrain.

Most rural HIV clinics rely almost entirely on Ryan White funds to remain open. There are very few providers who prescribe PrEP. Stigma remains deeply rooted.

Meanwhile, legal challenges loom. The U.S. Supreme Court is reviewing whether insurers must continue to cover preventive services like PrEP. If the ruling goes against coverage, the results will be devastating, especially for people already struggling with access due to Medicaid restrictions. At the same time, some lawmakers are proposing work requirements for Medicaid. In areas where jobs are scarce, buses don't run and internet access is unreliable, these requirements are more than unrealistic—they're punitive.

Still, we fight back.

Rural advocates are finding ways to survive. Churches are stepping in with food, rides and support. Community is checking in, making sure medications are taken and appointments kept. The rural South may be underfunded and overburdened, but we are not broken.

If you want to help, start by getting informed. Follow groups like AIDS United, the Positive Women's Network-USA and local advocacy organizations in your state. Contact your elected officials and tell them that cuts to Ryan White, HOPWA, Medicaid and rural health programs are unacceptable. Share your story if you feel safe doing so. Personal stories are powerful; they shift perspectives and policies. Support local rural HIV organizations. Donate if you can. Volunteer if you're able. Amplify their work in your networks.

AS SOMEONE who lived through the darkest days of the epidemic, I know how far we have come. But I also know how easily progress can be undone. Rural communities are strong, but we can't do this alone.

We deserve the same access to healthcare, the same dignity in services and the same say in decisions that affect our lives as anyone living in a city. This isn't just about funding. It's about justice.

Let's stop calling these "budget cuts." Let's name them for what they are: moral decisions about who gets to survive and who gets left behind.

If we're serious about ending the HIV epidemic for everyone, then we must fight together. Because when we fight together, we thrive together.

Why your ZIP code matters when living with HIV

Where you live shouldn't determine how well you live with HIV. But for many of us in small towns, rural counties or forgotten corners of the city, our ZIP code tells a story of limited access, long drives to care and too few providers who truly understand our lives.

Still, we're here. And we're thriving anyway. Living with HIV in an underserved ZIP code doesn't mean you're powerless—it means you have to be creative, connected and loud when it matters. Can't find a local provider? Ask about telehealth options or mobile clinics. Know your rights under the Ryan White Program—you may qualify for transportation assistance, case management or even mental health services you didn't know existed.

Advocacy starts with you. Bring up gaps in care at your next doctor's visit. Talk to your local health department. Join (or start!) a support group. Share your story on social media. You'd be surprised how many people are waiting for someone just like you to speak up.

On a community level, push for better broadband access so telehealth becomes a lifeline, not a luxury. Advocate for more funding in your area. And don't be afraid to remind policymakers that HIV lives here too—and so does brilliance, resilience and leadership.

Your ZIP code matters. But so does your voice. So does your joy. So does your power to change the narrative—not just for yourself, but for your community. We're not waiting for someone to save us. We're building the future ourselves—one connection, one conversation, one act of courage at a time.

—CECILIA DENNIS

Beyond status: A conversation with Beto

Reflections of an immigrant living with HIV in challenging times

INTERVIEW BY **RICK GUASCO**
PHOTOGRAPHY BY **JOHN GRESS**

GILBERTO SOBERANIS NUÑEZ, 41, is a Mexican immigrant, a gay man in recovery and living with HIV in Chicago. Everyone simply knows him as *Beto*.

POSITIVELY AWARE first spoke with Beto in 2016. It's only recently that he's been living these aspects of his life all at the same time and finding contentment and serenity in it, something he's holding onto in these times.

Born in a small town of about 5,000, just outside of Acapulco, along Mexico's Pacific coast, he now works for a nonprofit behavioral health services organization, assisting people who are in recovery. Beto spoke about his journey, across cultures and personal distances.

RICK GUASCO: When did you come to the United States?

BETO: In 1995. My sister came first a couple years earlier, then my father, and then my mom, my younger sister and I followed. It was about opportunity. As a 10-year-old, I hated it. I didn't want to leave my friends, my family, everything I knew. But when you're a parent, you want the best for your family. And when you're in a small town, you don't see that much opportunity. You're destined to be what your father and his father and his father's father were. In my hometown, there was just one option—agriculture, growing mangoes—and fishing, because those are our main resources. My parents wanted something more for us.

A large number of people from our hometown came to Chicago. It's much easier to go to a different place if you already have some type of connection than to go to L.A. or Detroit or somewhere else.

We did try to seek proper documentation. We applied for a visa. I remember as a little kid going with my mom to Mexico City to try to get a work visa, and we were denied, as many people were. We had no other options and we wanted to stay together as a family.

When did you start to understand what it meant to be *undocumented*?

As a child, you don't know you're undocumented. You're just in this foreign land. I don't think I really understood that I was "undocumented" until I was in high school and understood the consequences of it. Like, if I state that I am undocumented, I can be deported, my family can be deported. As an immigrant, you want to hide your status; you try to blend in. That lasted for years.

When did being gay come into the picture?

I always knew I was different. Not that I ignored it, but there were bigger things to worry about. In high school, I understood that I was gay, but I didn't feel safe being open about it.

One of my teachers was involved in the 200-mile Ride for AIDS. My high school created "the AIDS Club"—I know (shaking his head), catchy name. But the idea was to raise funds for bike teams or for students to do the ride with him.

It just felt comfortable to be around people that cared—and yeah, who knew that I was gay. People in the club knew that I was gay; we just didn't talk about it. From there, I sought guidance from my high school teacher. He introduced me to a youth drop-in facility that eventually became the Broadway Youth Center. I started attending that every Friday.

I came out to my mom when I was around 17 or 18. Actually, I told her I was bi. It was hard. I mean, she had a life planned for me before I was born. I am the only male in my family; I have three beautiful sisters. My dad is the oldest, and I'm the only male in the house to carry the legacy, so a lot of pressure there. I think they were hurt. My mom was hurt because she cared, but she

Más allá del estatus: Una conversación con Beto

Reflexiones sobre ser inmigrante y vivir con VIH en tiempos difíciles

ENTREVISTA DE **RICK GUASCO**
FOTOGRAFÍA DE **JOHN GRESS**
TRADUCCIÓN POR **ROSA MARTÍNEZ COLÓN**

GILBERTO SOBERANIS NUÑEZ, de 41 años, es un inmigrante mexicano, un hombre gay en recuperación que vive con VIH en Chicago. Para todos, simplemente es *Beto*.

POSITIVELY AWARE habló por primera vez con Beto en 2016, cuando reveló que anteriormente había sido indocumentado y que después obtuvo estatus legal. Solo recientemente ha estado viviendo todos estos aspectos de su vida al mismo tiempo y encontrando en ello contentamiento y serenidad, algo a lo que se aferra en estos momentos.

Nacido en un pequeño pueblo de unas 5,000 personas, justo a las afueras de Acapulco, en la costa del Pacífico mexicano, hoy trabaja para una organización sin fines de lucro de servicios de salud conductual, ayudando a personas en recuperación. Beto habló sobre su recorrido, a través de culturas y distancias personales.

RICK GUASCO: ¿Cuándo llegaste a Estados Unidos?

BETO: En 1995. Mi hermana llegó primero un par de años antes, luego mi papá, y después mi mamá, mi hermana menor y yo. Todo tenía que ver con oportunidades. Como niño de 10 años, lo odié. No quería dejar a mis amigos, a mi familia, todo lo que conocía. Pero cuando eres padre, quieres lo mejor para tu familia. Y cuando estás en un pueblo pequeño, no ves muchas oportunidades. Estás destinado a ser lo que fue tu padre, y el padre de tu padre, y el padre de su padre. En mi pueblo solo había una opción: la agricultura—cultivar mangos—y la pesca, porque esos son nuestros principales recursos. Mis padres querían algo más para nosotros.

Mucha gente de nuestro pueblo llegó a Chicago. Es mucho más fácil ir a otro lugar si ya tienes algún tipo de conexión que ir a Los Ángeles, Detroit u otro sitio.

Sí intentamos buscar documentación adecuada. Solicitamos una visa. Recuerdo que de niño fui con mi mamá a la Ciudad de México para intentar conseguir una visa de trabajo, y nos la negaron, como a muchas personas. No teníamos otras opciones y queríamos permanecer juntos como familia.

¿Cuándo empezaste a entender lo que significaba ser indocumentado?

Cuando eres niño, no sabes que eres indocumentado. Simplemente estás en una tierra extranjera. Creo que no entendí realmente que era "indocumentado" hasta la preparatoria, cuando comprendí las consecuencias. Por ejemplo, si decía que era indocumentado, podían deportarme, podían deportar a mi familia. Como inmigrante, quieres ocultar tu estatus; intentas pasar desapercibido. Eso duró años.

¿Cuándo entró en tu vida el hecho de ser gay?

Siempre supe que era diferente. No es que lo ignorara, pero había cosas más grandes de las que preocuparse. En la preparatoria entendí que era gay, pero no me sentía seguro siendo abierto al respecto.

Uno de mis maestros participaba en el Ride for AIDS de 200 millas. Mi preparatoria creó "el Club del SIDA"—lo sé (niega con la cabeza), nombre llamativo. Pero la idea era recaudar fondos para los equipos ciclistas o para que estudiantes hicieran el recorrido con él.

Simplemente se sentía bien estar rodeado de personas que se preocupaban—y sí, que sabían que yo era gay. La gente del club sabía que yo era gay; simplemente no hablábamos de ello. A partir de ahí, busqué orientación con mi maestro de la preparatoria. Él me presentó a un centro juvenil de atención inmediata que eventualmente se convirtió en el Broadway Youth Center. Empecé a ir todos los viernes.

didn't know how to support me or say, "I accept you for who you are," because you don't talk about it in the Latino culture, right?

You were living in different worlds. Did they collide?

I tried to fit everything into the picture and felt the need to fit in.

Being *gay*, unfortunately, didn't include being Latino or being an immigrant. It just meant being gay men. And gay men are online; that was the only opportunity that I knew. That's what *gay* meant. So I needed to be there because I couldn't be gay in high school. Then I had to do my straight high school life, and I had to do my Mexican, Latino life at home. So there's three different identities I'm trying to do at the same time. They don't really collide; you just keep them separate. I felt that I couldn't be Mexican and gay because there's so much stigma about being a gay man, there's no *machismo*. You're supposed to be manly and be the bread winner for the house and get married and have kids. All that pressure makes you feel stressed, so why combine them when you can just have different lives? It's much easier.

I didn't see anyone gay that looked like me, that I could trust; not to take me under their wing and give me like, guidance, but just say, *Yeah, what you're going through is completely normal*, and it's okay to feel lost and stressed out while trying to figure out life.

HIV entered your life very early.

It happened in June of 2003. I was 18 and had just graduated from high school. I did the OraSure test, because my friend was getting tested, and mine came back positive. I still remember the shock, the pain, the heaviness of like, my life is over, and I cried for (his voice quavers)—for a while, I was sobbing. Because I had already built relationships with some of the people working where I volunteered, I think they felt my pain. I still remember the hug my case manager gave me there. There was this group where if you test positive, they will immediately link you to a case manager and walk you through the process. It felt that someone was there to support you, but I just felt alone and like, *What do I do? Who do I tell?* I have to eventually go home, do I tell my parents? How am I'm gonna show up at home when I'm a full mess? I called one of my sisters, and I told her. It was late at night; we met at the lake, and it was just me and her. Ever since then, she's been my support system.

Did you tell your mom?

Not until many years later. Looking up HIV on Google and AOL, everything on the internet at that time was saying, *You're going to die*. I remember my high school classes, seeing stories about people taking 30 pills [for treatment] and dying.

Everything that I knew about HIV was death, so I thought I was gonna die. I remember reading an article saying people living with HIV only live for 10 years. I felt that I had to keep silent until I figured out what's going on. I met with a doctor but didn't go on medication because I was scared of the side effects. I didn't tell my mom and my dad until years later.

What made you finally tell them?

I just felt more comfortable. In order for you to be living your authentic self, you need to tell people who you are. Because I'd been open about my status for years, but my parents didn't know. Everyone in my family that was on social media knew; it just wasn't spoken about because it wasn't an issue. But my mom took it well. I mean, it was hard. I had to lead with, *there's something that I need to tell you, something that I've wanted to tell you*. My parents were fine, okay. I mean, I was living my worst nightmare because I was trying to protect them from the same pain that I went through. The last thing you want for your loved ones is to suffer the way that you have suffered.

When you and I first talked in 2016, you spoke about having been undocumented.

I felt that I had to do it because back then, I felt that my community was being attacked, and that people had to speak up about their struggles and say, *Hey, there's someone like you who knows what you're feeling*. I had to ask myself, *Is this something that I need to be open about?* But being undocumented is part of my life. I mean, I moved to Chicago when I was 10. I've grown up and lived in this country for most of my life. I know more about Fullerton Avenue than I do about my hometown. It's hard to come out as, I was once undocumented, because there's so much fear. But my community needs to know that we're here, we're part of the community.

How did you attain legal status?

Through DACA (Deferred Action for Childhood Arrivals) first, when [President] Obama announced the program in 2012. [Later] I married my boyfriend; we had started dating in 2010. He proposed to me on the beach. I was finishing a run, so I wasn't at my best, but it was cute and romantic.

Once you marry a U.S. citizen, your spouse can claim you as a dependent and then you can apply for residency and go through the regular process of submitting an application and meeting with someone from Immigration. They interview you to see if it is a legitimate relationship. The residency was approved a year after the process.

What are you doing now? How does your work connect to your life?

I've always been in the HIV field—as a young volunteer, working part-time doing testing, then counseling and case management and moving up the ladder, but always within nonprofit LGBTQ+ services and HIV care. When we met in 2016, I was working with a project that was specifically supporting Mexican men living with HIV, helping them get back into treatment or stay in treatment. It felt like the perfect job for me. I was in the community, meeting with what I call my people, and providing my life experience as an example and that I understand what they're going through. For about seven years now, I work at a large rehabilitation program that provides all levels of substance use services, still within the HIV field. Our goal is to reconnect them back to their HIV care and HIV services. I work under specialty services, helping the client get their life back together, get them healthy, support them with whatever needs they may have. The idea is to take a holistic approach—if you're here to see your counselor, let's have you see a case manager and if you need medication, we can help with that, too.

Have you seen an increased need for services lately?

No. And the reason why is because Latinos are not seeking substance abuse services. Is it because there's no problem? We know that's not the case. But to what extent does a Latino address that they have a substance use problem, or that drugs are an issue or that alcohol has taken over their life? There is a lot of stigma within every community, not just Latinos—African Americans, Asians, white folks—everyone. There's always stigma around addiction. That means that folks have a fear or are not ready yet to seek help or they may not have the resources. It can be complicated. Maybe they're only Spanish speaking, and there are not that many counselors that speak Spanish.

How fluent is your Spanish these days?

My sisters make fun of me. They call me a *Yo no sabo* (a grammatically incorrect Spanish phrase for "I don't know," often used by young Latin folk to describe their limited Spanish fluency). If I'm speaking with a Latino, it will just come out naturally; about five minutes later, it's as

Salí del clóset con mi mamá cuando tenía como 17 o 18 años. Bueno, en realidad le dije que era bi. Fue difícil. Ella tenía una vida planeada para mí incluso antes de que naciera. Soy el único hombre en mi familia; tengo tres hermanas hermosas. Mi papá es el mayor, y yo era el único hombre de la casa para continuar el legado, así que había mucha presión. Creo que se sintieron heridos. Mi mamá se sintió herida porque le importaba, pero no sabía cómo apoyarme o decirme: "Te acepto como eres", porque de eso no se habla en la cultura latina, ¿verdad?

Vivías en mundos diferentes. ¿Llegaron a chocar?

Intenté encajar todo en la misma imagen y sentía la necesidad de encajar.

Ser *gay*, desafortunadamente, no incluía ser latino o ser inmigrante. Simplemente significaba ser hombres gay. Y los hombres gay están en línea; esa era la única oportunidad que conocía. Eso era lo que significaba ser gay. Necesitaba estar ahí porque no podía ser gay en la preparatoria. Luego tenía que vivir mi vida heterosexual en la escuela y mi vida mexicana, latina, en casa. Así que había tres identidades diferentes que intentaba vivir al mismo tiempo. En realidad no chocaban; simplemente las mantenía separadas. Sentía que no podía ser mexicano y gay porque hay mucho estigma alrededor de ser un hombre gay; no hay machismo. Se supone que debes ser masculino, ser el proveedor del hogar, casarte y tener hijos. Toda esa presión te estresa, así que ¿para qué combinarlas si puedes tener vidas separadas? Es mucho más fácil.

No veía a nadie gay que se pareciera a mí, en quien pudiera confiar; no para que me guiara necesariamente, sino simplemente para decir: ***sí, lo que estás viviendo es completamente normal***, y está bien sentirse perdido y estresado mientras intentas entender la vida.

El VIH llegó a tu vida muy temprano.

Ocurrió en junio de 2003. Tenía 18 años y acababa de graduarme de la preparatoria. Me hice la prueba OraSure porque un amigo se estaba haciendo la prueba, y la mía salió positiva. Todavía recuerdo el shock, el dolor, el peso de pensar: mi vida se acabó, y lloré por (se le quiebra la voz)—por un buen rato, sollozaba. Como ya había construido relaciones con algunas de las personas que trabajaban ahí, creo que sintieron mi dolor. Todavía recuerdo el abrazo que me dio mi manejador de casos. Había un grupo donde, si das positivo, de inmediato te vinculan con un manejador de casos y te acompañan en el proceso. Se sentía que alguien estaba ahí para apoyarte, pero yo me sentía solo y pensaba: ***¿qué hago? ¿A quién se lo digo?*** Tengo que regresar a casa eventualmente, ¿le digo a mis padres? ¿Cómo voy a llegar a casa hecho un desastre? Llamé a una de mis hermanas y se lo dije. Era tarde en la noche; nos encontramos en el lago y solo estábamos ella y yo. Desde entonces, ella ha sido parte de mi sistema de apoyo.

¿Se lo dijiste a tu mamá?

No, sino hasta muchos años después. Cuando buscaba información sobre el VIH en Google y AOL, todo en internet en ese momento decía que ***ibas a morir***. Recuerdo mis clases en la preparatoria, ver historias de personas que tomaban 30 pastillas [para el tratamiento] y morían.

Todo lo que yo sabía sobre el VIH era muerte, así que pensé que me iba a morir. Recuerdo haber leído un artículo que decía que las personas que viven con VIH solo viven 10 años. Sentí que tenía que guardar silencio hasta entender qué estaba pasando. Fui al médico, pero no empecé tratamiento porque tenía miedo de los efectos secundarios. No les dije a mi mamá ni a mi papá hasta años después.

¿Qué te hizo finalmente decírselo?

Simplemente me sentía más cómodo. Para vivir de manera auténtica, necesitas decirle a la gente quién eres. Yo había sido abierto sobre mi estatus durante años, pero mis padres no lo sabían. Todos en mi familia que estaban en redes sociales lo sabían; simplemente no se hablaba del tema porque no era un problema. Pero mi mamá lo tomó bien. Fue difícil. Tuve que empezar diciendo: ***hay algo que necesito decirte, algo que he querido decirte***. Mis padres estuvieron bien, estuvieron bien. Yo estaba viviendo mi peor pesadilla porque intentaba protegerlos del mismo dolor que yo había vivido. Lo último que quieres es que tus seres queridos sufran como tú sufriste.

Cuando hablaste por primera vez con POSITIVELY AWARE en 2016, hablaste de haber sido indocumentado.

Sentí que tenía que hacerlo porque en ese momento sentía que mi comunidad estaba siendo atacada, y que la gente tenía que alzar la voz sobre sus luchas y decir: ***oye, hay alguien como tú que sabe lo que estás sintiendo***. Tuve que preguntarme: ***¿es algo de lo que necesito hablar abiertamente?*** Pero haber sido indocumentado es parte de mi vida. Llegué a Chicago cuando tenía 10 años. He crecido y vivido en este país la mayor parte de mi vida. Sé más de la avenida Fullerton que de mi pueblo natal. Es difícil decir: ***yo antes era indocumentado***, porque hay mucho miedo. Pero mi comunidad necesita saber que estamos aquí, que somos parte de la comunidad.

¿Cómo obtuviste estatus legal?

Primero a través de DACA (Deferred Action for Childhood Arrivals), cuando el [presidente] Obama anunció el programa en 2012. [Después] me casé con mi novio; habíamos empezado a salir en 2010. Me propuso matrimonio en la playa. Yo acababa de terminar de correr, así que no estaba en mi mejor momento, pero fue bonito y romántico.

Una vez que te casas con un ciudadano estadounidense, tu cónyuge puede solicitarte como dependiente y entonces puedes aplicar para la residencia y pasar por el proceso regular de presentar la solicitud y reunirte con alguien de inmigración. Te entrevistan para ver si es una relación legítima. La residencia fue aprobada un año después de iniciar el proceso.

¿Qué haces ahora? ¿Cómo se conecta tu trabajo con tu vida?

Siempre he trabajado en el ámbito del VIH—como joven voluntario, trabajando medio tiempo haciendo pruebas, luego consejería y manejo de casos, y subiendo de puesto, pero siempre dentro de servicios LGBTQ+ sin fines de lucro y atención del VIH. Cuando nos conocimos en 2016, trabajaba en un proyecto que apoyaba específicamente a hombres mexicanos que viven con VIH, ayudándolos a regresar al tratamiento o a mantenerse en él. Se sentía como el trabajo perfecto para mí. Estaba en la comunidad, reuniéndome con lo que llamo ***mi gente***, y ofreciendo mi experiencia de vida como ejemplo y mostrando que entiendo por lo que están pasando. Desde hace unos siete años trabajo en un gran programa de rehabilitación que ofrece todos los niveles de servicios para el uso de sustancias, todavía dentro del ámbito del VIH. Nuestro objetivo es reconectarlos con su atención y servicios de VIH. Trabajo en servicios especializados, ayudando a las personas a reconstruir su vida, a recuperar la salud, a recibir apoyo para cualquier necesidad que tengan. La idea es tomar un enfoque integral—si vienes a ver a tu consejero, hagamos que también veas a un manejador de casos y, si necesitas medicamentos, también podemos ayudarte con eso.

¿Has visto un aumento en la necesidad de servicios últimamente?

No. Y la razón es que las personas latinas no están buscando servicios para el uso de sustancias. ¿Es porque no hay un problema? Sabemos que no es así. Pero

natural as drinking water, but it's always difficult to get the conversation started in Spanish.

How important to you is it to speak the language?

Very. It reminds me of who I am. I don't get the opportunity to talk Spanish on a regular basis unless I'm chatting with my sisters. At work, hardly ever. In Mexico, of course, with everyone, but my cousins in Mexico speak English because it's being taught as a regular course, so everyone is bilingual.

What are you feeling about what's been happening the past few months?

It's hard. I had to chat with my therapist about it, and for someone who just started therapy for the first time—it took me long enough to go—it's hard. I live in Rogers Park (a racially and economically diverse neighborhood on Chicago's Far North Side), so seeing my tamal guy (a street vendor who sells tamales) getting dragged into a car, like they were a criminal or terrorist, it broke my heart. I *knew* that person—that person is a staple of Rogers Park. You could see the cruelty. You could see the fear in his face.

I'm grateful that everyone is being vigilant and posting notices online. But coming home [from work], I had to ask myself, *Should I even go outside?* And I have protected status. I'm a legal resident.

But how protected *are* you?

True, they can take anyone, right? They can take *you*, but you're a little white-looking.

I have residency, I'm *protected*. But should I start carrying my green card? To what point should you be vigilant? I remember walking home that day and just looking around, keeping my eyes open. I have never walked like that before. I've never felt that like, even through the times when I didn't have legal status or when we crossed the border. I don't remember any of those feelings. The threat felt real. And that's just an "I" statement—my community, my family, my friends, they're all seeing the same thing. They're all being vigilant. They're all taking precautions, and not because they're at risk, just because they're Latinos. They just feel targeted. They feel that something bad's gonna happen and they're preparing for it.

Do you feel targeted? Do you feel like something bad could happen?

I can't say no. I think everyone is, but I've got privilege. I wear a tie and a shirt with a collar to work. I look a certain way, and that's privilege but still, there's this gut feeling inside of you, like, *Yes, I am at risk; this can happen*. But even if it doesn't happen to me, it happened to someone that I love, and that's just as painful. I'm trying to find the positive out of this, and the positive is that we're talking about it. In the Latino culture, you wouldn't talk about your feelings, and I feel that for the first time in a long time, we're actually acknowledging fears. We're talking about how we're feeling. We're being more connected. I still remember that week, though. I wonder what my therapist thought.

What would you tell someone who is Latine who is going through all this?

No stá solo. [You are not alone.]

There's always someone that you can talk to. We can't fix immigration overnight. But we're resilient. Don't hide your feelings. Have someone that you trust and can speak your truth to. We need to stay diligent, be aware. And know that you are not alone. PA

¿hasta qué punto una persona latina reconoce que tiene un problema de consumo, o que las drogas son un problema, o que el alcohol ha tomado control de su vida? Hay mucho estigma en todas las comunidades, no solo en la latina—afroamericanas, asiáticas, personas blancas, todas. Siempre hay estigma alrededor de la adicción. Eso significa que la gente tiene miedo, no está lista para buscar ayuda o no tiene los recursos. Puede ser complicado. Tal vez solo hablan español y no hay muchos consejeros que hablen español.

¿Qué tan fluido es tu español hoy en día?

Mis hermanas se burlan de mí. Me llaman "yo no sabo" (una frase gramaticalmente incorrecta para "no sé", que a menudo usan jóvenes latinos para describir su español limitado). Si estoy hablando con alguien latino, el español simplemente sale; unos cinco minutos después, es tan natural como beber agua, pero siempre es difícil empezar la conversación en español.

¿Qué tan importante es para ti hablar el idioma?

Muy importante. Me recuerda quién soy. No tengo la oportunidad de hablar español con regularidad a menos que esté hablando con mis hermanas. En el trabajo, casi nunca. En México, claro, con todo el mundo, pero mis primos en México hablan inglés porque se enseña como materia regular, así que todos son bilingües.

¿Cómo te sientes con lo que ha pasado en los últimos meses?

Es difícil. Tuve que hablarlo con mi terapeuta, y para alguien que acaba de empezar terapia por primera vez—me tomó lo suficiente decidirme—es duro. Vivo en Rogers Park (un vecindario racial y económicamente diverso en el extremo norte de Chicago), así que ver a mi vendedor de tamales siendo arrastrado a un auto, como si fuera un criminal o terrorista, me rompió el corazón. Yo ***conocía*** a esa persona—es parte del corazón de Rogers Park. Se podía ver la crueldad. Se podía ver el miedo en su rostro.

Estoy agradecido de que la gente esté vigilante y publique avisos en línea. Pero al regresar a casa [del trabajo], tuve que preguntarme: *¿debería siquiera salir?* Y yo tengo estatus protegido. Soy residente legal.

¿Pero qué tan protegido estás?

Es cierto, pueden llevarse a cualquiera, ¿no? Pueden llevarte a ti, pero te ves un poco más blanco.

Tengo residencia, estoy protegido. Pero ¿debería empezar a cargar mi tarjeta de residencia? ¿Hasta qué punto debes estar alerta? Recuerdo caminar a casa ese día mirando a todos lados, manteniendo los ojos bien abiertos. Nunca había caminado así. Nunca me había sentido así, ni siquiera en los tiempos en que no tenía estatus legal o cuando cruzamos la frontera. No recuerdo haber tenido esos sentimientos. La amenaza se sentía real. Y eso es solo una experiencia personal—mi comunidad, mi familia, mis amigos; todos están viendo lo mismo. Todos están vigilantes. Todos están tomando precauciones, no porque estén en riesgo, sino simplemente porque son latinos. Se sienten señalados. Sienten que algo malo va a pasar y se están preparando para ello.

¿Te sientes señalado? ¿Sientes que algo malo podría pasar?

No puedo decir que no. Creo que todos lo sentimos, pero yo tengo privilegio. Uso corbata y camisa de cuello para ir a trabajar. Me veo de cierta manera, y eso es privilegio, pero aun así hay esa sensación en el estómago de que ***sí, estoy en riesgo; esto puede pasar.*** Pero aunque no me pase a mí, le pasó a alguien que amo, y eso duele igual. Estoy tratando de encontrar algo positivo en todo esto, y lo positivo es que estamos hablando de ello. En la cultura latina no se habla de los sentimientos, y siento que por primera vez en mucho tiempo estamos reconociendo los miedos. Estamos hablando de cómo nos sentimos. Estamos más conectados. Aun así, recuerdo esa semana. Me pregunto qué habrá pensado mi terapeuta.

¿Qué le dirías a alguien latine que está pasando por todo esto?

No stá solo.

Siempre hay alguien con quien puedes hablar. No podemos arreglar la inmigración de la noche a la mañana. Pero somos resilientes. No ocultes tus sentimientos. Ten a alguien en quien confíes y con quien puedas decir tu verdad. Necesitamos mantenernos atentos, informados. Y saber que no estás solo. PA

Addressing mental health to get more people into HIV care

BY **LARRY BUHL**

The intersection of mental health and HIV was the topic of one session at the 13th annual International AIDS Society Conference in Kigali, Rwanda (IAS 2025). Presenters, primarily from the Global South, emphasized research showing that vulnerable populations—including female sex workers, the LGBTQ+ community and young people, as well as women experiencing intimate partner violence—often face both high HIV incidence and significant mental health burdens. These burdens are exacerbated by poverty and unemployment, as well as stigma and discrimination. To make matters worse, mental health distress, including depression, anxiety and suicidal ideation, can reduce a person's likelihood to access HIV prevention tools like PrEP. Presenters at one session emphasized different ways of addressing mental health challenges and explored community-based, inclusive mental health and HIV services to reduce risks and improve health outcomes. They urged health care systems to integrate services to combine mental health screenings, sexual reproductive health, family planning and community involvement. They also called for a shift in community-driven, rights-based approaches that acknowledge the lived realities of vulnerable populations.

Rwanda increases and integrates mental health services

Darius Gishoma, a professor at the University of Rwanda, began his presentation by reporting that **across the globe an estimated half of people with HIV suffer significant psychological distress**.

According to Gishoma, low- and middle-income countries are more likely to let mental health problems go undiagnosed and untreated. "This results in a huge treatment gap, where 85% of people in need of mental health care don't receive it," he said. In Rwanda specifically, there is a high burden of mental health problems, mainly due to consequences of the 1994 genocide against the Tutsi, where one in five experiences mental health concerns, Gishoma added. (The Tutsi are an ethnic group primarily found in Rwanda and neighboring Burundi who were targeted during the 1994 Rwandan genocide.)

This dire situation led Rwanda to build a mental health ecosystem over the last 30 years, including three specialized mental health institutions, as well as teaching hospitals with mental health departments staffed by psychiatrists, psychologists and mental health nurses.

"All 510 health centers now have at least one nurse or psychologist who handles mental health and HIV issues," Gishoma said. Rwanda also introduced mental health tools to assess depression in children living with HIV, leading to a significant drop in mental health distress for children ages 7–14, between the introduction in 2022 and 2025. Essential to addressing mental health, Gishoma said, is the routine screening and basic mental health support provided by non-specialists (nurses) and referral of complex cases to mental health units at district hospitals. Peer counselors can also offer critical support and reduce stigma, while group counseling and peer support groups can also help people with HIV by addressing mental health topics. There is still work to be done: people who inject drugs and people aging with HIV need more tailored intervention, he said.

"In 1994, mental health had one psych hospital with 100 beds. A huge investment was made, and funding for mental health is funded 92% by the government, but there is also an international partner," he added.

Addressing holistic care barriers for women, children and youth

Juliane Etima with the Makere University–Johns Hopkins University Research Collaboration, explored how mental health can be integrated into HIV care, what she summarized as *holistic care*.

Etima identified some of the challenges to holistic care—communication and cultural and educational differences. "These gaps warrant innovative approaches," she said.

Focusing primarily on Uganda, Etima pointed to a recent open label trial which tested mindfulness therapy for adolescents living with HIV. The model uses metaphors, play and conversation to promote psychological flexibility among their abilities. **When young people develop skills of trial-and-error, better self-awareness and developing a relationship with their inner voices, they are more likely to appropriately respond to life challenges.**

Some technology-driven interventions have addressed accessibility in Uganda, helping young people take control of their health, she said. Peer-led initiatives such as the Uganda Network of Young People Living with HIV and AIDS disseminate information, provide support and help change attitudes.

JULIANE ETIMA, MAKERE UNIVERSITY–JOHNS HOPKINS UNIVERSITY RESEARCH COLLABORATION

Community is at the heart of addressing holistic care barriers, she said. Culturally-tailored community-based education should align messages with local customs and traditions and engage community leaders as advocates in HIV prevention and treatment.

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Addressing an audience question about implementation of services, Etima said that Uganda has also been more supportive of mental health services, specifically for adolescents and children, but that it's not only about money. "It's also important to offer care for the caregivers," she said, referring to support staff who also may be living with HIV and suffering trauma. "We have young people supporting other young people, and they should also be offered the same services."

Integrating mental health into primary care

Ndeshiteela Conteh, a PhD candidate at the University of KwaZulu-Natal in South Africa, presented insights on how to integrate mental health into HIV programs, something essential in meeting the UNAIDS 2030 HIV targets of 95-95-95, she said.

"There is no health without mental health, so how do we expect to end AIDS without mental health?" she began. ART (antiretroviral treatment) adherence, viral suppression and retention are stagnating in some areas, threatening the third "95" (of people on HIV treatment reaching viral suppression) of the 2030 targets. Specifically, poor mental health contributes to delayed diagnosis, missed appointments and treatment interruptions and makes many people highly unlikely to seek help at all, she said.

Highlighting her own research, Conteh said **integrating mental health in HIV programs is feasible, but major gaps in funding, policy support and workforce are important barriers**, especially in low- and middle-income countries.

She emphasized that primary care should be frontline HIV care, as well as mental health care. "Mental health screening in primary care only makes sense," she said. Task-sharing, such as enlisting lay counselors or nurses to conduct initial screenings, as other presenters suggested, can break down some barriers to care. In addition, primary health can, and should, foster trust and continuity for people with HIV (PWH).

Conteh offered tested examples of integrating mental health into primary care in resource-limited settings. One is from Zimbabwe's Friendship Bench, where trained healthcare workers offer problem-solving therapy on wooden benches outside public health care facility clinics. South Africa's "integrated chronic disease model" (ICDM) combines care for HIV and STIs at the primary health care level. "It has also demonstrated very positive outcome for people living with HIV, and it can work with very minimal resources."

She also noted the World Health Organization's Mental Health Gap Action Program, which is used to scale up mental health care in low- and middle-income countries by using non-specialist mental health professionals to provide mental health interventions to PLWH. "All of these examples can be scaled up," she said. Concluding, she called on governments to invest in primary health care and mental health services and on donors to fund mental health-HIV integration.

Other mental health studies

One study presented at IAS 2025 explored the mental health and sexual health resources among young (age 14–24) LGBTQ+ people in Peru. This national online survey investigated how clinically significant levels of depression, anxiety and suicidal ideation are impacting access to sexual health resources. Most of the 4,643 respondents were over age 18, 16.1% were transgender or non-binary, nearly half identified as bisexual and nearly one-third as gay or lesbian. Well over half (58%) had clinically significant depression, 54% had anxiety and two-thirds had suicidal ideation at some point. Researchers found that young people with a history of suicidal ideation were 43% less likely to access PrEP. However, mental health issues were not significantly associated with accessing HIV/STI treatment. **Anxiety was associated with a 25% increase in likelihood of condom use, while depression had the opposite effect**—a 25% decrease in the likelihood of accessing condoms.

Integrated therapy for depression and adherence to meds

Another study presented at the conference tested whether the TENDAI psychological intervention was effective for addressing viral non-suppression, depression and ART adherence. In the Shona language spoken in Zimbabwe, where the study is being conducted, Tendai is a gender-neutral name meaning "thankful." TENDAI uses a task-shifting model, where lay **health workers are trained to deliver intervention rooted in problem-solving, psychoeducation and motivational interviewing**, making it, in theory, scalable and cost-effective.

Researchers recruited 280 adult PWH with probable depression and viral non-suppression from clinics across Zimbabwe and randomized them into two arms: the intervention arm received TENDAI, and the control arm received standard of care. The team found that depression was lower for the TENDAI arm at 4 months and remained low, while their self-adherence to HIV meds was significantly higher. Although there was no significant difference in viral suppression between the TENDAI and standard of care arms, TENDAI participants had 70% lower chance of being prescribed second-line ART at 12 months.

"These promising results, including favorable cost-effectiveness, support implementing TENDAI in routine HIV care in low-resource settings," researchers wrote.

Lessons learned for equitable PrEP access

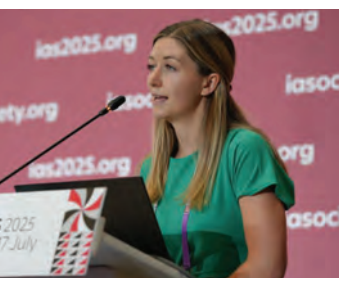
BY **LARRY BUHL**

HIV prevention efforts have seen remarkable breakthroughs over the last few years, among the latest being the U.S. Food and Drug Administration (FDA) approval of long-acting lenacapavir (LEN), the six-month pair of injections marketed as Yeztugo in the states. But having the products is not necessarily good enough if they aren't delivered and available to the people who need them. One symposium at the 13th International AIDS Society Conference on HIV Science (IAS 2025) in Kigali, Rwanda, explored ways of moving medications efficiently to implementation faster and cheaper. **A new funding crisis has hit countries most in need of PrEP services, just as new LEN is about to roll out**, meaning that stakeholders, policy makers and drug manufacturers must do more to ensure equitable access worldwide, presenters said. And they said health policy advocates and even health care systems and clinics have a role as well. Several

presenters shared lessons learned from different aspects of PrEP rollout, from oral to long-acting options.

Affordability and price transparency needed urgently

Anne-Isabelle Cameron, a technical officer at UNITAID, a global effort that works with low- and middle-income countries, told attendees that **affordability, price transparency and restricted access to generic drugs remain challenges to scaling u p PrEP worldwide**. Citing data from PrEPWatch, she estimated the cost of oral PrEP to be $40 per year, the dapivirine vaginal ring at $154 and injectable cabotegravir (CAB-LA) $180 yearly. Cameron decried the fact that long-acting PrEP options are four times as expensive as oral PrEP.



ANNE-ISABELLE CAMERON

"The price for long-acting lenacapavir remains unknown, causing great challenges for countries to plan accordingly," she said. "And this includes the middle-income countries, where about one in every four new infections that occur face the double burden of not having access to the lowest originator price, nor being included in the voluntary licensed territory, and therefore not having access to generics."

These barriers are all the more challenging in the current context of funding interruptions and pullbacks. International assistance accounted for about 80% of prevention programs in low- and middle-income countries, with three more countries—Malawi, Nigeria and Zimbabwe—relying on aid from the U.S. through PEPFAR for more than 70% of their HIV funding as of December 2024. "[Cuts have] led to interrupted services, in particular for key and other vulnerable populations, the exclusion of prevention programs, fragile markets and barriers to economies of scale. UNAIDS figures show that estimated new daily HIV infections have risen from 3,500 per day to 5,800, and that if funding permanently disappears, there could be potentially an additional 6 million infections by 2029 and an additional 4 million AIDS-related deaths."

What's needed, Cameron said, is for drug companies to speed up the pathways to generic medications and equitable access to PrEP. Communities, governments and partner organizations have a role to play as well, she said, in community engagement and demand generation and informing real-time rollout.

UNITAID is seeking investments through a call for proposals for cost effective and high impact rollout of LEN for PrEP.

Cameron also shared some encouraging news: studies have shown that with strategic interventions, long-acting lenacapavir could be an affordable option. One analysis concludes that LEN could be manufactured and delivered for as low as $35 per year at two million treatments annually and as low as $25 per year for five to 10 million people.

Also in the session, Michelle Rudolph of the World Health Organization shared the recently issued WHO guidelines on lenacapavir for PrEP. She reported that as of 2024, 94% of countries worldwide have adopted WHO recommendations on oral PrEP in their national guidelines; only 12 countries adopted policies for CAB and 10 countries have adopted policies for the dapivirine vaginal ring. "Ten countries reported that their national guidelines do not recommend any PrEP products," she said.

For LEN rollout, Rudolph emphasized the importance of provider training. "We are in a place right now where we no longer have boutique key population clinics. We are going to have to look at the existing services and how we can make them more accessible and acceptable to key populations and other people who do not always access those services. [And we need to] train providers to offer this product, and to be comfortable offering clients a choice and to not judge them and encourage them along their prevention journey."

Project PrEP: Service delivery that young people prefer

Saiqa Mullick, MPH, MSc, PhD, a professor with the University of Witwatersrand in Johannesburg, prefaced her presentation by offering a lesson from the rollout of CAB: "**Product innovation has to be matched with delivery innovation.**"

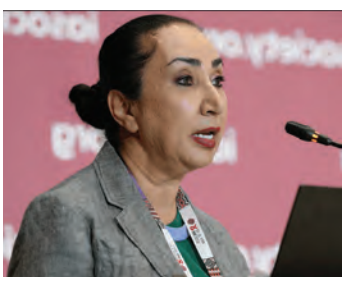
Dr. Mullick shared ongoing research and lessons from Project PrEP, a UNITAID-funded initiative aimed at integrating PrEP into comprehensive sexual and reproductive health services for adolescent girls and young women.

"Project PrEP uses a differentiated service delivery model designed to meet young people where they are," she said. "Services are anchored in fixed health department clinics across three geographic areas. But we go beyond that by extending access through youth-friendly mobile clinics and PrEP pick-up points in community-based organizations and community pharmacies wherever possible." This mix of fixed and flexible delivery helps reduce some of the access barriers, increases convenience and supports young people to engage with HIV prevention in ways that fit their lives, she said.

The first lesson from the interim analysis was that young people prefer long-acting PrEP when it's offered. In a study conducted April–November 2024, students were asked which form of PrEP they preferred—oral PrEP, a vaginal ring or CAB-LA. Overall, 65% of students chose CAB-LA; that included 80% of women over age 24 and 73% of males over age 15.

"It's clear that no single PrEP method fits everyone's needs all the time," Mullick said.

Researchers also learned that long-acting PrEP can increase protection. "People stayed on injectable PrEP longer [than oral PrEP] before stopping." And the restart rate was much higher for CAB than for oral PrEP.


SAIQA MULLICK, MPH, MSC, PHD

Interim analysis from Project PrEP also showed that integration creates efficiency. Among participants who selected a PrEP method at enrollment, the vast majority were also screened for STI symptoms, TB, mental health needs and gender-based violence. Of the 3,000 women who chose a PrEP method, 76% were either already using a contraceptive or received one during that visit; nearly half of the women received their contraception on the same day as their PrEP appointment. "This tells us that same-place delivery of prevention and sexual and reproductive health care is feasible and valued."

Dr. Mullick said that delivery platform readiness is also crucial. Researchers spoke with 34 healthcare providers across three districts in South Africa to understand what's helping or hindering delivery of PrEP. "Providers emphasized the importance of consistent, clear messaging throughout the client journey, supported by tools like pamphlets, models and demonstration products. Just as important was a provider's positive

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attitude, ongoing learning and tailored training for different roles."

But there were real challenges, too: time and space constraints, a perceived increase in workload and missed follow-up visits that disrupted continuity of care. "Some providers and clients also expressed uncertainty or mistrust of newer methods, showing us that both confidence and capacity need to be built as we introduce innovative options like lenacapavir. If we want providers to enable informed choice, we need to invest in them just as much as we invest in products."

Dr. Mullick added that counseling is fundamental, especially when reaching adolescents and young women. "Women respond positively when they're shown different options using visual tools and simple, relatable language, not clinical jargon. They value providers who take time to answer questions honestly and maintain privacy, but when counseling feels rushed, judgmental or confusing, it becomes a barrier."

She said that community awareness and PrEP literacy and engagement are essential. "That means working closely with community-based organizations." Concluding, Dr. Mullick said that product innovation is also important.

"People want convenience, autonomy and digital connection," she said. Researchers found that digital platforms, especially online and social media, were preferred over printed materials for HIV information. For picking up meds, pharmacies, home delivery and vending machines were far more popular than clinics. Most people wanted twice-yearly visits rather than quarterly ones, and they strongly preferred self-testing over provider testing, suggesting "a real desire for privacy and control," Dr. Mullick said.

"Interestingly, pop-up sites were the least preferred for PrEP initiation. People still value trusted, familiar spaces like pharmacies and clinics, and these preferences are a clear guidepost as we think about how to deliver them and other new PrEP options in ways that people will actually use."

South Africa's PrEP journey

South Africa remains the epicenter of the HIV epidemic, with an estimated 400 new cases each day, with transgender individuals, gay and bisexual men and people who engage in sex work making up a disproportionate majority.

Hasina Subedar, a senior technical advisor at South Africa's National Department of Health, told conference participants that **PrEP uptake in the country was notably higher at sites where all options (CAB, oral PrEP and the vaginal ring) were available**. She also reported surprising findings about long-acting cabotegravir: across South Africa, CAB uptake is highest among young women age 20–34; despite earlier concerns, CAB injections were seen as practical in mobile clinics, with no major logistical challenges with transportation or storage.

HASINA SUBEDAR, NATIONAL DEPARTMENT OF HEALTH SOUTH AFRICA

The main challenge in HIV prevention, Subedar said, has been continued use of oral PrEP while rolling out long-acting options.

"Keeping people on oral PrEP has been a challenge, and many users drop off within months. Equity is uneven. Even though we've reached—and we try to reach—all populations, uptake among men and key populations, and service quality, varies across provinces and districts," she said.

Despite having a significant (though improving) burden of HIV, South Africa is well positioned to roll out and scale up long-acting PrEP options, Subedar said. Since 2021, oral PrEP has been financed nationally, which shields the country from PEPFAR cuts. South Africa also has a nurse-initiated antiretroviral drug program, and same-day initiation is now a routine option. "Every single primary healthcare clinic [has] nurses that can initiate data integration; that has been key, especially where PrEP metrics are alongside the ART [antiretroviral therapy] metrics."

She concluded by saying that South Africa's successes show that scale, integration and equity are achievable. "We must shift from isolated product rollouts to build a comprehensive HIV prevention ecosystem that ensures choice, equity, dignity and sustainable financing for all."

Encouraging results from monthly oral PrEP (MK-8527)

Amid the enthusiasm for twice-yearly Yeztugo, health care providers are also pinning their hopes on longer-acting tablets for PrEP, which may be easier to roll out than injectables. Right now, there are no approved oral PrEP medications to be taken less frequently than once daily. But that may change.

MK-8527 is a novel nucleoside reverse transcriptase translocation inhibitor (NRTTI) and works differently from NRTIs by stopping the movement of the reverse transcriptase enzyme and by blocking HIV from copying its RNA to DNA. In 2021 drugmaker Merck's first NRTTI candidate for long-acting treatment and prevention, islatravir, was tabled after some study participants experienced declining CD4 T cell or total lymphocyte counts with higher doses.

MK-8527 study participants were determined to be at low risk for HIV exposure and randomly assigned to receive the drug at 3 mg, 6 mg or 12 mg doses (or a placebo) monthly for up to six months. Presenting safety and PK data from a phase 2 study for MK-8527, Kenneth Mayer, MD, FACP, FIDSA, of Fenway Health and Harvard Medical School, said all dosing levels were well tolerated, with most common adverse events being mild-to-moderate headache, nausea and fatigue. MK-8527 had a similar profile to the placebo group. There were no HIV seroconversions in any group.

The drug had a "rapid onset" of protection, reaching full protective levels within 24 hours, Dr. Mayer said. In the 6 mg and 12 mg dose groups, drug concentrations were sustained above the threshold for protection for a little longer than 28 days, which is helpful if people are late with dosing. He cautioned that drug levels declined after 40 days, making the drug unsuitable for use as an every-other-month option. Importantly, participants did not experience a decline in CD4 cell or total lymphocyte counts. Based on the phase 2 findings, **Merck will move MK-8527 into phase 3 trials**, in partnership with the Gates Foundation and the International Clinical Research Center at the University of Washington.

In another session, Rebeca Plank, MD, MPH, of MSD Research Laboratories, said that once-monthly oral PrEP options could "represent a paradigm shift" by making it easier for people to obtain and to take PrEP. "This would allow more people to start and to continue on PrEP, ultimately helping us reach our collective goal of ending the epidemic," she said.

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Defining a journey

I am practicing sitting with things a bit before tackling them. Projects, tasks, even questions I may be asked. I think it's important in the space and age I am in life. Giving things time to either fall into place or to come to a workable order in my head. Less stress, less rush.

I was speaking to a group of women about HIV and prevention, and they were asking about my advocacy work. Questions like: Is it scary? (Sometimes.) Do my feelings get hurt? (Yup!) Do I worry about disclosure? (Rarely, these days.) How do I think HIV has changed my life? (It has, both infinitely and incrementally.) I answer questions like these all the time. My answers were true, but somewhat habitual. Then one of the women asked how I would define my HIV journey or legacy. I spent some time thinking about it because I didn't want to be flippant or give the same answer that I've heard before. I struggled with the answer, to be honest. Not because I didn't want to answer, or couldn't, but because I don't want to define it. Not in simple terms anyways. Defining something has a sort of finality to it, and I believe that definitions can be oversimplified if you only consider the words and not the emotion and intent beyond them. A definition does not allow room for circumstance. A definition does not allow room for growth. Life with HIV is not definitive; it is change. It is growth. Too often those of us living with HIV get stuck in a place where we allow ourselves to be defined by three or four letters.

A definition does not allow room for growth. Life with HIV is not definitive; it is change. It is growth.

People want to define living with this virus as being sick or dying. For a time that may have been true, but even when the epidemic was raging without treatment that worked and was considered a death sentence, it did not take into consideration the human spirit. The human capacity for discovery. The indefatigable will to not be defined by a social label, a diagnosis or by a disease process.

By definition, HIV is a virus that attacks the immune system and, left unchecked, it can lead to AIDS. But there is so much more beyond that. If you try to describe a life lived with HIV you can apply words like resilient, courageous and survivor, but words don't tell the full individual story. While many of us use the same words to describe our overall experiences with HIV, its impact has shaped and changed each of us in unique ways.

I think at the end of the day, I don't want to define my journey or legacy with HIV because it's still evolving. It's still becoming more as opposed to having reached an end point or pinnacle. It's also critically important we are not reduced to just the HIV/AIDS experiences in our lives. Defining us by one thing reduces our other life triumphs, lessons and contributions to footnotes with a qualifier. I was Sharon's daughter, Dwayne's sister and Shae's friend before HIV. I played sports, served in the military and had a child before I acquired HIV. I became a nurse, someone's grandmother and an advocate after HIV. I did some traveling, wrote a play and started painting after the virus entered my life. Do the "after" things hold more weight because of my diagnosis? I argue not, but it depends on perspective, I guess. Personally, I don't want my obituary or tombstone to say, "all while living with HIV" or "she did blah, blah, blah even though she had HIV." I am who I am because I choose not to let an acronym define me. I choose not to let HIV be the only definitive in my journey or legacy.

Be well. You matter.

BRIDGETTE PICOU, LVN, ACLPN, is a licensed vocational and certified AIDS Care Nurse in Palm Springs, California. She works for The Well Project-HIV and Women as their stakeholder liaison. Bridgette is a director at large for ANAC (the Association of Nurses in AIDS Care) and a sitting member of the board of directors for HIV & Aging Research Project-Palm Springs (HARP-PS). Bridgette's goal is to remind people that there are lives being lived behind a three- or four-letter acronym.

PICOU: CHAD SAIN · ISTOCK