POSITIVELY AWARE
SEP+OCT 2024

NAVIGATING MENOPAUSE WITH HIV

SEX-POSITIVE KINK

PILL FATIGUE IS A REAL THING

CONFERENCE UPDATE

AIDS 2024: MUNICH, GERMANY

PÓQUER TEXAS HOLD' EM

Los defensores luchan para que los tejanos sin seguro tengan acceso a Cabenuva

¿UNA BRECHA VITAL EN PUERTO RICO?

THE PLEASURE ISSUE

IMPORTANT FACTS FOR BIKTARVY®

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

(bik-TAR-vee)

MOST IMPORTANT INFORMATION ABOUT BIKTARVY

BIKTARVY may cause serious side effects, including:

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

ABOUT BIKTARVY

BIKTARVY is a complete, 1-pill, once-a-day prescription medicine used to treat HIV-1 in adults and children who weigh at least 55 pounds. It can either be used in people who have never taken HIV-1 medicines before, or people who are replacing their current HIV-1 medicines and whose healthcare provider determines they meet certain requirements.

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

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

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

BEFORE TAKING BIKTARVY

Tell your healthcare provider if you:

- Have or have had any kidney or liver problems, including hepatitis infection.
- Have any other health problems.
- Are pregnant or plan to become pregnant. Tell your healthcare provider if you become pregnant while taking BIKTARVY.
- Are breastfeeding (nursing) or plan to breastfeed. Talk to your healthcare provider about the risks of breastfeeding during treatment with BIKTARVY.

Tell your healthcare provider about all the medicines you take:

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

POSSIBLE SIDE EFFECTS OF BIKTARVY

BIKTARVY may cause serious side effects, including:

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

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

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

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

HOW TO TAKE BIKTARVY

Take BIKTARVY 1 time each day with or without food.

GET MORE INFORMATION

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

GILEAD

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tenofovir alafenamide 25mg tablets

#1 PRESCRIBED HIV TREATMENT*

*Source: *IQVIA NPA Weekly*, 04/19/2019 through 05/19/2023.

> "I've learned how to live with HIV, and my children and my family are a huge part of that."

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For her today and her tomorrow.

- BIKTARVY is a complete, 1-pill, once-a-day prescription medicine used to treat HIV-1 in certain adults. **BIKTARVY does not cure HIV-1 or AIDS.**
- **Ask your healthcare provider if BIKTARVY is right for you.**

Scan or visit BIKTARVY.com to learn more about recent BIKTARVY updates.

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Please see Important Facts about BIKTARVY, including important warnings, on the previous page and at BIKTARVY.com.

SEP+OCT 2024

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Let's talk about sex: HIV prevention advocate Damon L. Jacobs (left) and long-term survivor and HIV advocate Rodney McCoy photographed on the steps of McCoy's Washington, D.C. home by Jimell Greene.

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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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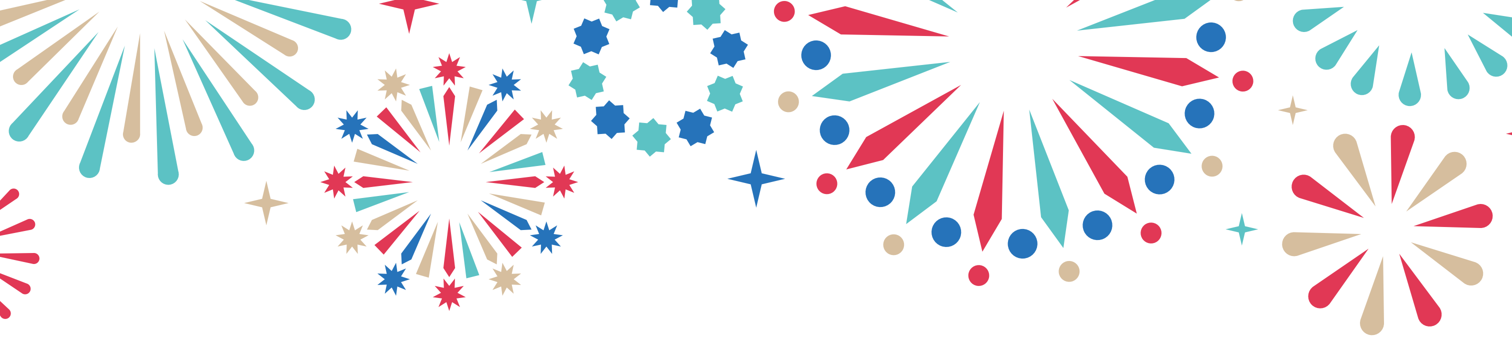

‘People are coming in saying, ***You can’t relate to what I go through.*** Sometimes we do need to bring ourselves into the conversation, to say, *Yes, I have gone through the same thing.* I don’t make it about me, but I bring empathy.’

—RODNEY McCOY, JR., PAGE 31

THIS ISSUE

AIDS 2024 CONFERENCE UPDATE

SECCIÓN DE LENGUA ESPAÑOLA

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Finding connection

I was diagnosed in ’97 at the age of 18. I live in Chicago... OK, 20 minutes north of the city, in Niles. My HIV doctor is at Northwestern Memorial Hospital. I also have lupus and some other chronic illnesses, but I don’t want to brag—just kidding. I’m always looking to read everything and anything about and for the community.

I love your magazine because it makes me feel connected and not so alone. I don’t really know anyone else who is positive, so any connection is very welcome.

—NAME WITHHELD

Getting through it together

I was in a place of worship, when a stranger came up to me and said, “You’re the HIV gal in Facebook?” I responded, yes. She whispered in my ear, “I’m HIV positive.” We sat and chatted for a long while. She was devastated, lost, stigmatized, she had so many feelings. I immediately went into my “HIV mom” mode. I made her feel comfortable and stigma free; her boyfriend was horrible to her and had transmitted the virus to her. I invited her to our organization, gave her my number, told her she’s not alone and to please keep in touch with me. We’ve texted. I will help her get through this! She said, “You’re the only person I know with HIV.” I responded. “No, honey. There are many people living with HIV, but sometimes stigma keeps them in the closet. “Stay strong, let’s keep in touch, go to groups, and outings. I will call you and invite you; let’s get through this together! I wish I can help everyone, especially people who are newly diagnosed. Life goes on. *Do not allow stigma to control your feelings!* Take it by the horns and direct it towards a better healthy lifestyle. Live life!

—LILLIBETH GONZALEZ

Correction

In “Guide to Long-Acting Injectables for HIV” (2024 HIV Drug Guide), it was incorrectly stated that cabotegravir is a capsid inhibitor drug. Cabotegravir is an integrase strand transfer inhibitor (INSTI). POSITIVELY AWARE regrets the error.

SELFIE BY JOURDAN BARNES

It’s finally here. I had the amazing opportunity to shoot the HIV Drug Guide of POSITIVELY AWARE honoring some of Louisiana’s most powerful HIV advocates. I'm honored to be a part of this cover and for my first it means so much to be able to photograph people who have literally inspired me to use my voice no matter what.

—JOURDAN BARNES VIA FACEBOOK

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EDITOR'S NOTE

Rick Guasco
@rickguasco

Sex, pleasure and HIV prevention

“The words *sex* and *pleasure* until recently weren’t applied to HIV prevention,” says HIV prevention advocate and therapist Damon L. Jacobs. “For me, mental health and sexual health are one and the same.”

“*Fun* for me is just a general sense of something that brings me a sense of being alive.” adds long-term survivor and HIV advocate Rodney McCoy, Jr.

In this issue’s cover story, the two advocates and friends have a lively conversation about how pleasure and HIV prevention come together. Sex plays a part in how we see ourselves, express ourselves and identify ourselves.

Talking openly and candidly about sex shouldn’t just happen between the sheets; it should also happen at your doctor’s office or anywhere you receive services. Stigma, guilt and shaming are not effective HIV prevention strategies.

Rod and Damon’s conversation sets the tone for the article that follows it, written by Rod. In “Sex-positive kink,” it’s no one’s place to judge how anyone enjoys sex. Rod recalls going to one clinic after a gonorrhea diagnosis and receiving a moralizing lecture from a counselor. He never went back to that clinic. One bad experience can have ripple effects. “We cannot let our own sexual beliefs and behaviors dictate what we tell our clients,” Rod says.

Our own communities need to be more accepting and less judgmental. We’ve reprinted one of the first commentaries POSITIVELY AWARE published about PrEP shaming, from 2015. Mind you, the language it uses is very much of its time, starting with the headline: “You say ‘whore’ like it’s a bad thing.” Paraphrasing Enid Vázquez, we mislead people into believing they are safe if they don’t have multiple sex partners.

And speaking of talking about sexual health, lead contributing writer Larry Buhl looks at how making patients and care providers more comfortable talking about sex can help in “Closing HIV prevention gaps in Detroit.” The Motor City has the highest incidence of HIV in Michigan amidst huge disparities. For every two white men living with HIV, there are 15 Black men living with the virus.

“Sexual health is a huge part of individuals’ lives, and we want to equip care providers with tools that will eventually make [discussion of sex] a standard practice,” says Elizabeth Lockhart, an assistant scientist at Henry Ford Health’s Center for Health Policy and Health Services Research.

Many of us stress over taking our pills or missing doses. Victoria Noe writes how “Pill fatigue” is a real thing and what to do about it. “What if I forget to take my HIV meds—or even lose them?” is one of Tim Murphy’s biggest nightmares, so he talks with Dr. Antonio Urbina, longtime medical director of Mount Sinai’s HIV clinic in Chelsea, who provides some insight to allay Tim’s fears. Through a series of events, though, Tim writes about “My unexpected treatment failure” and how it happened. It’s a reminder that you have to always advocate for your own health.

Women living with HIV who experience menopause are at increased risk for conditions such as cardiovascular disease, bone loss and frailty. Drs. Sara H. Bares, Sara Looby and Michael T. Yin write about “Navigating menopause with HIV.” They include a clinical trial being planned that will evaluate menopausal hormone therapy in women living with HIV and provide data to inform future treatment guidelines.

Our report on the AIDS 2024 international conference in Munich, Germany, this past July highlights three key announcements. The six-month injectable lenacapavir was found to be an unprecedented 100% effective in protecting cis women from HIV—but questions arise over affordable accessibility. A study found that doxyPrEP reduced the rate of STIs among men who have sex with men by 80%. Plus, there was news of a seventh person to be cured of HIV—the “next Berlin patient”—through a stem cell transplant.

We report on another conference—the National Latinx Conference on HIV, HCV and SUD (substance use disorder)—to examine the state of HIV and care in a region that blurs the line between the U.S. and Mexico. It spans nearly 2,000 miles from the Pacific Ocean to the Gulf of Mexico and reaches 62.5 miles (100 km) on either side of the border. According to a 2016 study, if this region were a U.S. state, it would rank second in deaths from hepatitis, third in deaths related to diabetes and last in access to health care. No wonder that getting people into HIV care is especially challenging.

It takes collaboration and communication between care providers on both sides of the border and community health workers are essential to connecting people to the care they need. Because of the ground it covers, this report also appears in Spanish in this issue. It is followed by Spanish language versions of two articles that appeared in the July+August issue—the reluctance of Texas ADAP to add Cabenuva to its formulary and a change in Puerto Rico’s version of ADAP that could potentially disrupt delivery of HIV medications. It underscores the need to make information as accessible as possible in different languages, particularly the communities in which Spanish is the predominant language, which POSITIVELY AWARE will continue to address in future issues.

Sometimes I think it’s not the virus that gets in the way of our pleasure and living our lives so much as it is the stigma, fear and isolation that can arise because of it.

You are not alone.

Rick

JOHN GRESS · ISTOCK

Briefly

ENID VÁZQUEZ 𝕏 @enidvazquezpa

ISTOCK

WHO declares mpox international emergency outbreak

On August 14, the World Health Organization (WHO) declared that a recent and significant rise in mpox cases in Africa “constitutes a public health emergency of international concern (PHEIC).” Mpox cases have occurred due to different viruses called clades, the agency wrote in a press statement.

WHO reported that director-general Tedros Adhanom Ghebreyesus said there was “transmission of the so-called clade 1b virus in the Democratic Republic of the Congo [DRC] last year which was caused mainly ‘through sexual networks.’ This clade is reportedly deadlier and more easily transmitted from person to person. Clade 1 has been circulating in the DRC for years while clade 2 was responsible for the global outbreak of 2022 which was declared an international public health emergency.”

In a perspective piece published August 28 in the *New England Journal of Medicine* (NEJM), Lawrence O. Gostin, JD; Ashish K. Jha, MD, MPH; and Alexandra Finch, LLM; write, “The previous day, the Africa Centers for Disease Control and Prevention (Africa CDC) declared a Public Health Emergency of Continental Security (PHECS)—the organization’s first-ever declaration of a regional health emergency. This regional declaration and the WHO’s early response—issued without waiting for mpox to affect high-income countries—could offer a historic opportunity to mobilize life-saving resources according to the principles of solidarity and equity.”

The perspective article continues to explain that, “Human-to-human transmission has primarily occurred within households, in health care settings and by means of sexual contact, with the greatest risk seen among men who have sex with men (MSM) and sex workers. Evidence suggests that clade 1b is more likely to be lethal than clade 2b—the clade that drove the global mpox outbreak in 2022, affecting primarily MSM and causing nearly 100,000 cases and 208 deaths in 116 countries. Tragically, most cases and deaths in the current mpox outbreak have occurred in children, indicating that transmission is occurring by routes other than sexual contact.

“The WHO previously declared a PHEIC for the clade 2b mpox global outbreak in 2022. Yet endemic [basically, a condition that has become common in an area] mpox has not garnered the same attention and investment—a disparity that the concurrent regional and global emergency declarations should help to rectify. The rapid international spread of a new mpox subtype is of enormous concern. Though all countries should fortify their preparedness, the priority must be coordinated action and investments focused on response efforts in Africa,” Gostin and colleagues write.

The August 28 issue of NEJM has a separate perspective piece addressing mpox and pregnancy. The article includes a detailed trajectory of mpox spread, above and beyond the needs and means to protect pregnant people and their unborn child.

WHO reported that mpox cases have been spreading throughout many countries in Africa, particularly the DRC, and neighboring Burundi, Kenya, Rwanda and Uganda. The potential for further spread in Africa is worrying, Tedros said. “In addition to other outbreaks of other clades of mpox in other parts of Africa, it’s clear that **a coordinated international response is essential to stop these outbreaks and save lives**,” the director-general added.

There have been more than 14,000 reported cases of the virus this year with 524 deaths, a significant increase in reported cases from last year.

GO TO bit.ly/4ehL4Xr,

GO TO bit.ly/3XndgBF.

Doctors Without Borders/Médecins Sans Frontières (MSF) provided several informational pieces on mpox and its outbreaks, including Q&As and the organization’s efforts to combat mpox, including vaccination. **GO TO** doctorswithoutborders.org.

Doxy-PEP from Ryan White

The HIV/AIDS Bureau from the Health Resources and Services Administration (HRSA HAB) issued a program letter to recipients of the Ryan White HIV/AIDS Program (RWHAP) urging them to provide doxy-PEP, an antibacterial strategy used to prevent STIs following a potential exposure. The recommendation followed establishment of doxy-PEP guidelines from the U.S. Centers for Disease Control and Prevention (CDC) in June. **GO TO** cdc.gov/mmwr/volumes/73/rr/rr7302a1.htm.

“Specifically, **we encourage you to use RWHAP funds to purchase doxycycline for your eligible clients** and for RWHAP Part B AIDS Drug Assistance Programs [ADAPs] to add doxycycline to their formularies to ensure access and coverage,” said HRSA HAB associate administrator Laura Cheever, MD, and colleague Heather Hauck in a note to Ryan White recipients notifying them of the letter.

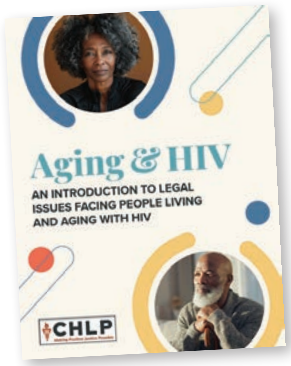
TOP OF THE NEWS

➤ PrEP your booty ➤ PEPFAR: Millions of lives saved ➤ WHO declares mpox international emergency outbreak ➤ Doxy-PEP from Ryan White ➤ Maine reports first infant HIV case in five years ➤ Legal primer for aging with HIV ➤ Children's Investment Fund to promote the HIV prevention vaginal ring ➤ 'Addicts are everywhere, and we look just like you' ➤ New IAS president: Beatriz Grinsztejn ➤ HHS updates OI guidelines on MAC

The July 31 letter also points out that, "Awareness of current mpox vaccination and testing recommendations, especially for the immunocompromised, is vital to prevent future outbreaks. The mpox vaccine is now accessible commercially at locations where other vaccines are offered."

GO TO bit.ly/4dXsft7.

HRSA HAB has an mpox webpage; **GO TO** ryanwhite.hrsa.gov/resources/mpox.



Aging & HIV

AN INTRODUCTION TO LEGAL ISSUES FACING PEOPLE LIVING AND AGING WITH HIV

CHLP

Legal primer for aging with HIV

The Center for HIV Law and Policy (CHLP), a national prison abolitionist and legal policy organization based in New York, in August published the legal guide *Aging and HIV: An Introduction to Legal Issues Facing People Living and Aging with HIV* (PLAHIV).

"The focus of this primer is to help PLAHIV identify and overcome the legal barriers to aging with dignity," CHLP writes.

According to the primer, people living with HIV (PLWH) are affected not just by their HIV status, but by discrimination dominated by ageism, anti-Black racism, homophobia and transphobia. CHLP hopes the guide can help advocates with policy efforts.

"**People living with HIV deserve to age with dignity and to have that ability fully supported and funded by government resources**," the guide states. "They deserve to have their rights protected in both public and private spheres and not face stigma and discrimination. This primer provides as much information as possible about ways that the law supports the ability of PLAHIV to age with dignity while highlighting some of the limitations and flaws of America's aging support systems."

The primer is divided into three categories:

- Federal laws (such as the Americans with Disabilities Act)
- HIV criminalization
- Barriers to, and remedies for, protecting personal decisions for health and medical care

Using clear writing, the primer takes you not just through the law, but through the sociopolitical realities that often affect people living with, or groups most affected by, HIV. For example, PLWH and LGBTQ+ individuals are more likely to experience incarceration than the general population. As one result, they are more likely to have difficulties building a job history or credit.

The 76-page guide covers a lot of territory and contains dozens of links to other publications and articles.

"Just as there are myriad forms of discrimination and administrative roadblocks faced by PLAHIV to aging with dignity with unhampered decision-making capacity, there are accessible tools that they can utilize to best prepare for their future," said Kae Greenberg, CHLP staff attorney and author of the guide.

GO TO hivlawandpolicy.org.

CHLP's definition of aging with HIV includes Dandelions, the group of people born with the virus. "Dandelions" comes from a poem of the same title by poet and performance artist and activist (*artivist*) Mary Bowman, who died in 2019 at the age of 30. Hear her performance of the poem at bit.ly/3BbBS8L.

HPTN 106

REV UP

PrEP your booty

That may not be what researchers say (most of them, anyway) but that's what advocates titled a new study and their recent webinar on the upcoming trial that will test a rectal douche for preventing HIV.

Known as the REV UP trial from the HIV Prevention Trials Network (HPTN), **HPTN 106 will observe the safety and acceptability of a tenofovir-based douche for use by cisgender men and transgender women who have sex with men**.

Different forms of the drug tenofovir are contained in the two current oral HIV prevention medications on the market, Truvada for PrEP and Descovy. "PrEP" stands for *pre-exposure prophylaxis*.

An August 29 webinar features presentations by HPTN 106 researchers Craig Hendrix, MD; and Mark Marzinke, PhD; of Johns Hopkins University. It includes a history of rectal microbicides for HIV prevention and of PrEP in general. PrEPWatch, a data and news tracking initiative from the prevention advocacy organization AVAC, along with co-sponsor HPTN, hosted the program. For a recording and slides, **GO TO** bit.ly/4ebDON6. The page links to several articles on PrEP and microbicides.

AIDS 2024 international conference

Organized by the International AIDS Society (IAS), the 25th International AIDS Conference (AIDS 2024) took place July 22–26 in Munich, Germany. IAS calls the conference "the premier global platform to advance the HIV response."

"As **the world's largest conference on HIV and AIDS, it sits uniquely at the intersection of science, advocacy and human rights, bringing together scientists, policy makers, healthcare professionals, people living with HIV, funders, media and communities**," IAS writes. "Since its start in 1985, the conference has served as an opportunity to strengthen policies and programs that ensure an evidence-based response to HIV and related epidemics."

Following are but a few of the reports coming out of AIDS 2024. **GO TO** iasociety.org.

Maine reports first infant HIV case in five years

The state of Maine issued a health alert in June after an infant tested positive for HIV. "This is a rare event and an opportunity to reinforce HIV testing recommendations to prevent future cases," said the state's Center for Disease Control and Prevention (Maine CDC) in a statement.

According to the report, "The last infant in Maine with HIV infection attributed to perinatal transmission was born in 2019. **Perinatal HIV infections are rare, with 21 cases of HIV attributed to perinatal transmission in the U.S. in 2021, the last year for which data are available**. Perinatal HIV in the U.S. has fallen by more than 95% since the early 1990s. Perinatal HIV [previously referred to as "vertical"] transmission occurs when HIV is passed from a pregnant person to their child during pregnancy, childbirth or breastfeeding/chestfeeding. Having an undetectable viral load in pregnancy, and throughout the duration of breastfeeding/chestfeeding, lowers the risk of perinatal transmission of HIV to less than 1%. Most pregnant people living with HIV can have vaginal deliveries: for people with a high viral load (greater than 1,000 copies/mL) near the time of delivery, a scheduled cesarean delivery can reduce the risk of perinatal HIV transmission."

ISTOCK

Maine health officials recommend that people get tested for HIV at the time of pregnancy. In fact, a test is required by state law for perinatal care. A second test during the third trimester should be given to anyone with "ongoing risk." "Maine CDC recommends testing all people with ongoing risk factors for HIV infection (e.g., shared syringes, needles or other injection drug equipment, exchanged sex for drugs or money or more than one sex partner since their last HIV test) at least *every three months*. This interim recommendation is related to the [recent] HIV cluster occurring in Penobscot County."

A rapid HIV test should be given to anyone without a test result at the time of delivery. An infant born having a potential exposure to HIV should be given HIV therapy immediately, "ideally within 6 hours after delivery."

The Maine report included a list of U.S. CDC recommendations for HIV testing: at least once for everyone between 13–64 years old, but at least once a year for the following groups that may experience a heightened level of potential exposure:

- Men who have sex with men
- People who have had anal or vaginal sex with someone living with HIV
- People who have had more than one sex partner since their last HIV test
- People who have shared syringes, needles or other injection drug equipment
- People who have exchanged sex for drugs or money
- People who have been diagnosed with or treated for another sexually transmitted infection (STI)
- People who have been diagnosed with or treated for hepatitis or tuberculosis (TB)
- People who have had sex with anyone with the above risk factors or anyone whose sexual history they don't know

To find the June 13 notice, **GO TO** bit.ly/4gfscud.

'Addicts are everywhere, and we look just like you'

That's what Lori Lynne Armstrong says about telling her story in *Someday I Will Not Be Ashamed: A Memoir*, released in August.

"Many people have conscious or unconscious ideas of how a junkie looks or talks. I look nothing like that, and **I talk like the love child of a poet and a psychologist**," Armstrong said in a press release for the book. "Addicts are everywhere, and we look just like you. And we who live with mental illness are everywhere, too. Anyone you meet who looks confident on the outside may be battling symptoms or drowning in a swamp of shame."

Armstrong's challenges included an eating disorder, chronic pain, hospitalization for mental illness and an addiction to painkillers. She holds master's degrees in molecular biology and counseling psychology and writes prose and poetry on the subjects of mental health and addiction. Armstrong has also written the poetry compilation *Poppytown: Love Songs from the Opioid Epidemic*.

GO TO lorilynnearmstrong.com, or connect with Armstrong on Facebook (bit.ly/3ZihFIr), X (@LLArmstrong) and Instagram (lorilynnearmstrong).

WHO updates its PEP guidelines

Not enough people receive the medicines that can prevent them from acquiring HIV after a potential sexual exposure

The science is here to prevent HIV with medicine. The science has *been* here to prevent HIV with medicine. And, it continues to get better.

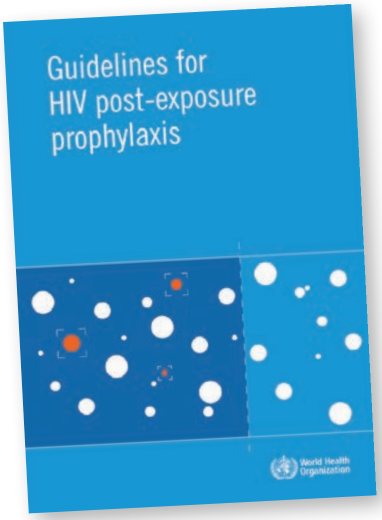
Yet, PEP—medication taken one to three days after a potential exposure to HIV—remains unknown to far too many people.

"Despite advancements in testing and treatment, over one million people became infected with HIV in 2022. This warrants a need for a revitalized focus on proven HIV prevention interventions such as HIV post-exposure prophylaxis (PEP)," the World Health Organization (WHO) reported.

For AIDS 2024, WHO presented its updated PEP guidelines. WHO added two new recommendations that would expand the reach of this prevention strategy:

1. Allow more places, beyond the clinic, that can make PEP available (including mobile clinics, drop-in centers, pharmacies, online delivery and community-based organizations)
2. Allow more individuals (including pharmacists and trained lay and peer health workers) to provide it

“While HIV PEP is an effective HIV prevention intervention that has been recommended by WHO for all potential HIV exposures, access to and uptake of PEP is still sub-optimal, leading to missed opportunities to prevent new HIV transmissions,” the international agency’s guidelines explain. “There has been huge interest and increased programming and uptake of pre-exposure prophylaxis (PrEP) over the past 10 years. In contrast PEP, which also has been recommended for a decade, has received little attention and limited use, even though, with expanded PrEP access, PEP has important additional prevention benefits. Expanding access to PEP after all potential exposures through sexual and injecting drug use is needed.”



According to the updated guidelines, greater access to PEP may help “to mitigate barriers such as stigma and to ensure timely access post exposure.”

The international agency stressed that, “Timely access to PEP is the most crucial factor in PEP effectiveness. PEP is most effective when initiated as soon as possible, ideally within 24 hours and no later than 72 hours after exposure.”

WHO noted that, “While a PEP regimen of two drugs can be effective, three drugs are preferred. It is recommended that people be given a 28-day prescription for PEP.” The guidelines include recommended regimens for adults, adolescents and children.

Outdated policies are restricting access, WHO noted, such as limiting it to cases of sexual assault or to workplace use (primarily needlestick injuries experienced by clinic staff). WHO states that, “Anyone with a known or suspected exposure to HIV should be offered PEP.” Further, PEP knowledge is low among providers, and so is access to the medications that can be used. At the community level, groups or locations with the highest level of HIV transmission also have a low level of awareness about PEP.

And PEP has only a brief time for it to work: people need to get the medicines within three days at the most—preferably within a day. A flowchart of suggested labwork and follow-up steps appears on page 8 of the guidelines. Also, while HIV testing may be desirable, its availability varies from place to place; to be clear: “If HIV tests are unavailable but the person is suspected to have been exposed to HIV, PEP should be started regardless.”

“Therefore, PEP services need to be close at hand when needed,” WHO writes.

A recognized benefit of PEP is linking people with a potentially greater need for prevention to PrEP; a discussion of transitioning PEP users to PrEP appears on page 7. PrEP may be especially beneficial for people who use PEP multiple times.

To read the guidelines, **GO TO** bit.ly/3B1U4lg.

Preferred PEP medications in the U.S.

The following HIV medications are recommended for PEP according to expert opinion. Biktarvy and all the combinations are to be used once a day for at least 28 days, within 1 to 3 days (24 to 72 hours) of a potential exposure to HIV, but the sooner the better. A one-month prescription is probably the easiest way to go to avoid a pharmacy snafu. These regimens are for adults and adolescents ages 13 and older.

There are different recommended regimens for children under the age of 13 and for individuals with kidney problems (defined as creatinine clearance less than or equal to 59 mL/min), found in the PEP guidelines from the U.S. Centers for Disease Control and Prevention (CDC), 2016 update. The newest update is expected soon.

Preferred regimen

A three-drug regimen consisting of one of the following three combinations:

- Biktarvy (single-tablet regimen) or
- raltegravir (Isentress or Isentress HD) *plus* Truvada or Descovy or
- Tivicay (dolutegravir) *plus* Truvada or Descovy

Alternative regimen

A three-drug regimen consisting of 800 mg of darunavir (Prezista) boosted by Norvir (ritonavir, taken as a 100 mg tablet) *plus* Truvada or Descovy

Note: Generic versions of Norvir, Prezista and Truvada are available.

The recommendations are technically referred to as “nPEP” for “non-occupational post-exposure prophylaxis.” **GO TO** bit.ly/4d52equ. **SEE** also the International AIDS Society-USA (IAS-USA) HIV treatment and prevention guidelines, which already list Biktarvy for PEP use. **GO TO** bit.ly/3N2fQZ7.

HHS updates OI guidelines on MAC

The U.S. Department of Health and Human Services (HHS) in August updated its opportunistic infection (OI) guidelines for treating MAC (Mycobacterium avium Complex). The bacterial disease is most commonly associated with tuberculosis (TB). As an opportunistic infection in advanced HIV disease, MAC takes advantage of a weakened immune system that has difficulty fighting back.

The revised *Guidelines for the Prevention and Treatment of Opportunistic Infections in Adults and Adolescents with HIV* from HHS now have:

- “Updated information to prioritize the initiation of effective antiretroviral therapy (ART) and to refrain from primary prophylaxis [prevention] for [MAC] except for people with HIV who are not receiving ART, remain viremic [have a detectable viral load] on ART or have no options for a fully suppressive [achieving undetectable viral load] ART regimen.

- “Added new information indicating that drugs demonstrating substantive in vitro [test tube] activity against MAC might be considered for the treatment of refractory MAC disease (e.g., bedaquiline, tedizolid, linezolid and omadacycline), acknowledging that there is insufficient observational or clinical trial data to support formal recommendations in this setting.

- "Updated information on drug–drug interactions between anti-MAC therapies, particularly rifabutin, and antiretroviral drugs and provided a link to the *Adult and Adolescent Antiretroviral Guidelines* on drug–drug interactions."

GO TO clinicalinfo.hiv.gov.

Children's Investment Fund to promote the HIV prevention vaginal ring

The Children's Investment Fund Foundation (CIFF), in partnership with the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund), announced an initiative to provide up to $2 million over the 2024–2025 period for about 150,000 dapivirine vaginal rings. A form of long-acting HIV PrEP, the ring has shown efficacy in stopping the virus.

CIFF said the DapiRing is manufactured by Sever Pharma Solutions in Sweden for the Population Council. The one-month ring costs approximately $12.80, but a three-month ring in development is expected to cost $16.

"The Global Fund is committed to drive equitable access to quality assured and affordable HIV prevention tools and is working with partners and the industry to shape and create a sustainable market, including injectable lenacapavir," said Hui Yang, who heads Supply Operations at the Global Fund, in a press release.

According to the release, the PrEP ring has received a positive opinion from the European Medicines Agency (EMA) and has received regulatory approval in Botswana, Eswatini, Kenya, Lesotho, Malawi, Namibia, Rwanda, South Africa, Uganda, Zambia and Zimbabwe.

It is hoped that the ring donation will help promote prevention and bridge the gap until a lower-cost three-month ring or an African-manufactured ring becomes available, "which will lead to lower prices over the long-term."

An independent philanthropic organization with offices in Addis Ababa, Beijing, London, Nairobi and New Delhi established in 2002, CIFF "works with a wide range of partners to create a healthy, fair and safe world for children. Areas of work include child health and nutrition, sexual and reproductive health and rights, opportunities for girls and young women, child protection, and catalyzing climate action." **GO TO** bit.ly/47qnSUH.

New IAS president: Beatriz Grinsztejn

The International AIDS Society elected Beatriz Grinsztejn of Brazil as their new president. An infectious disease physician and researcher, Grinsztejn co-founded FIOCRUZ HIV/AIDS Service, the largest care provider in Rio de Janeiro. She has served as director of the HIV/AIDS Clinical Research Unit at the Evandro Chagas National Institute of Infectious Diseases-FIOCRUZ for 25 years and was director of the first established trans health clinic in Rio.

"As a lesbian from Latin America and the director of the first sexual and gender minorities' health clinic in Rio de Janeiro, I witness first-hand every day how we are still failing the most marginalized people," she said. "In Brazil, new HIV acquisitions are rising among young black men who have sex with men, illustrating the structural gender-related violence and racism fueling the epidemic."

Dr. Grinsztejn is a leader in clinical research for the development of new HIV prevention tools, including the HPTN 083 study evaluating long-acting injectable cabotegravir in HIV-negative trans women and men who have sex with men. A pioneering champion of LGBTQ+ rights, she also led efforts to introduce gender-affirming care in Brazil. As a professor of the Infectious Diseases Clinical Research Postgraduate Program at FIOCRUZ, she has mentored more than 25 master's and PhD students.

Kenneth Ngure from Kenya was selected as president-elect. Sharon Lewin from Australia assumed the role of Immediate Past President.

GO TO bit.ly/3MHMZc8.

PEPFAR
U.S. President's Emergency Plan for AIDS Relief

PEPFAR: Millions of lives saved

HIV.gov conducts video reports from most major HIV conferences. Its AIDS 2024 coverage began with a brief overview from John Nkengasong, the ambassador to the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

"Just think of where we were 25 years ago, when HIV meant death," said Nkengasong, calling the program "a game-changing initiative."

"PEPFAR has transformed that, and offered hope to individuals, offered hope to the community, and offered hope to the countries that we supported," Nkengasong continued. "We recognized 25 years ago also that a disease threat anywhere in the world was a disease threat everywhere in the world. And look at where we are today. Over 25 million lives have been saved. About 5.5 million children have been born free of HIV/AIDS. But we need to sustain those gains. We need to make sure that we accelerate our efforts so that by the year 2030 we can bring HIV/AIDS to an end as a public health threat."

Nkengasong said there needs to be continued awareness that HIV is not over, and that prevention is crucial to reaching the goal of ending the epidemic by 2030, particularly with a long-acting injectable drug showing success in clinical trials (lenacapavir). Financial commitment must therefore continue, and complacency must be overcome.

"It's very easy for us to be vulnerable to our own success," said Nkengasong.

To hear ambassador Nkengasong's brief comments, **GO TO** bit.ly/3B4hFly.

The webpage connects to other video reports that include HIV criminalization, research updates and U=U (undetectable equals untransmittable, in which a person living with HIV is unable to transmit the virus to sexual partners after reaching and maintaining undetectable viral load). HIV.gov also posts videos on its Facebook page.

Advocates call for lower cost, greater access to new injectable PrEP drug

What should be the price for lenacapavir?

BY **RICK GUASCO**

When Gilead Sciences announced in June the unprecedented results of a phase 3 HIV prevention clinical trial, it made headlines (**SEE** page XX). Lenacapavir, which is injected once every six months, had a 100% success rate protecting cisgender women from HIV in the PURPOSE 1 study. For the first time in a prevention study, **not a single new HIV diagnosis was reported among the 2,134 women who received lenacapavir**. Now, as more studies are underway, advocates are urging Gilead to make lenacapavir more accessible by cutting its price.

At AIDS 2024, UNAIDS executive director Winnie Byanyima was among the voices calling for lenacapavir to be licensed in low- and middle-income countries through the Medicines Patent Pool, a UN-backed organization that helps development of and access to life-saving medications in those countries.

WINNIE BYANYIMA, UNAIDS. AIDS 2024, THE 25TH INTERNATIONAL AIDS CONFERENCE. MUNICH, GERMANY.

© STEVE FORREST / IAS

Marketed under the brand name Sunlenca, lenacapavir is used in combination with other antiretrovirals as an HIV treatment. It has not been FDA approved for HIV prevention, known as PrEP. Sunlenca's list price is $42,250 a year. In comparison, Gilead also manufactures Descovy, the leading brand name oral PrEP medication, which lists for $26,000 a year. Apretude, the brand name of cabotegravir, sold as another long-acting PrEP drug injected every two or three months and made by rival ViiV Healthcare, lists for $23,000.

‘We have been down this road before… more than a decade after the first approval for PrEP in the United States, we still see significant disparities in getting PrEP to communities of color and cisgender women in the U.S.’

—PREP4ALL

“The list price sets the ceiling from which the complex set of drug distribution players in the U.S. negotiate a lower price,” says PrEP4All in a commentary released on August 26. “Start high and even with discounts, we'll end high. For a drug with such public health significance as PrEP, the high list price also hamstrings the ability of state and local public health departments that perennially struggle with anemic budgets—some of whom qualify for discounts and some of whom do not—to purchase the drug and get it out to uninsured, low-income and vulnerable populations.”

Written by PrEP4All executive director Jeremiah Johnson and consultant Amy Killelea, the commentary appeared in the online journal *Health Affairs*. PrEP4All is an advocacy organization promoting the development of a national PrEP program and wider access to PrEP medications.

“We have been down this road before,” the commentary says. “It was not so long ago that the very same drug manufacturer released similarly jaw dropping clinical trial results first for Truvada and then Descovy, the first two medications approved for the prevention of HIV; it led to widespread speculation of the end of HIV as an epidemic. And yet, more than a decade after the first approval for PrEP in the United States, we still see significant disparities in getting PrEP to communities of color and cisgender women in the U.S.”

The commentary adds, “…there is still always the potential for an alternative future here. We can envision a scenario in which Gilead—perhaps facing significant pressure from the U.S. advocacy community and the U.S. government—commits to working with existing public health programs and, eventually, a national PrEP program to set a public health price point for lenacapavir to ensure a simple, transparent and intuitive pathway for uninsured populations. This would be a new, bold approach—not a repeat of past charitable and donation programs that fail to provide an integrated approach to PrEP delivery. Instead, it would be a true, significantly lower price point that empowers public programs and health departments to come up with simple and comprehensive financing and delivery mechanisms that are highly accessible for end users. Only then will we stop repeating the same pattern in which the bang of a big scientific breakthrough is followed by the whimper of inaccessibility.”

Several other PURPOSE clinical trials are underway or are being planned that will look at how well lenacapavir works in specific groups of people including men who have sex with men, trans men and people who inject drugs. Results of at least one of these PURPOSE studies are expected by early next year, if not sooner, before the drug is submitted for FDA approval.

To read the complete commentary on *Health Affairs*, **GO TO** bit.ly/3z8mEkx.

With reporting from Enid Vázquez

Closing HIV prevention gaps in Detroit

BY **LARRY BUHL**

Inequalities around HIV transmission and prevention fall along racial lines for a variety of reasons. Detroit, where more than three-quarters of the population is Black, has the highest prevalence of HIV in Michigan, according to the state's Department of Health and Human Services. For every two white men living with HIV, there are 15 Black men living with the virus, according to the department. That's partly due to the lack of access to PrEP, which when used as prescribed is highly effective in preventing HIV acquisition.

Numbers from the Centers for Disease Control and Prevention (CDC) show that, nationally, among PrEP users, 69% are White, 13% are Hispanic or Latinx, 4.5% are Asian American, but only 11% are Black. The disparities may seem overwhelming, but researchers at one of the region's largest health systems, Henry Ford Health, hope a new computer-based PrEP training module for primary care providers will go a long way toward closing those gaps. Still in development, the module would teach doctors how to prescribe PrEP and simulate interactions with patients who could most benefit from it. And it's hoped that it would get doctors talking about a patients' sexual history as part of routine care, something that both doctors and many African American patients, experts say, are typically squeamish about bringing up.

Talking about sex

One goal of the physician intervention is to encourage primary care doctors to interact with patients like one family medicine doctor at Ford Health, Bianca Pittiglio, MD, already does, by opening up a sexual health discussion as part of routine care. "I will start with simple questions," Pittiglio said. "'Are you sexually active?' And generally, if they say that they have more than one partner, I'll ask if they ever heard of PrEP."

If they don't know about PrEP, and almost half of her patients know little or nothing about it when she brings it up, Dr. Pittiglio provides a handout and discusses the importance of the medication. If they choose to start PrEP, Pittligio will initiate testing that day (a negative HIV test result is necessary to start PrEP). This discussion is done even if the patient has come for an annual physical. But Pittiglio admits her approach is not typical. "With some of my colleagues, when a patient comes in and asks for PrEP, they have no idea how to start it, what to do and what the follow-up is," she said. Pittiglio admits that many doctors didn't learn about PrEP in med school or in residency, even if they're relatively new doctors, unless they already had an interest in HIV prevention.

Another roadblock to PrEP access is departmental silo-ing. Even if a primary care doctor and the patient are comfortable talking about sex, and if the patient shows a need or desire for PrEP, there will be a hand off to an infectious disease doctor, throwing up one more barrier to getting the medication. "These aren't really necessary referrals, and if physicians had information on how to prescribe it and what the follow-up looks like, I think that that would help physicians feel more comfortable with prescribing as well," Pittiglio said.

> 'With some of my colleagues, when a patient comes in and asks for PrEP, they have no idea how to start it.'

Helping patients feel comfortable with their care provider is key. An issue in Detroit, and in Black communities, is often medical mistrust, according to Brianna Kline, a nurse practitioner at Detroit Public Health STD Clinic. Kline said that historical instances of medical mistreatment in communities of color have played a major role

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in why medical mistrust exists today, and that mistrust can prevent Black patients from opening up, or from coming to a healthcare facility at all.

"As an African American woman, I'm very transparent with my patients and telling them directly, that their communities, communities of color, or men who have sex with men, are highly affected, but HIV is a possibility no matter who they are," Kline said. "[By saying that] they won't feel like I'm labeling them, or making them think PrEP services are only for 'certain types' of people. Every day I feel like we are combating the issues related to stigma and medical mistrust in various ways."

Kline underscored another issue facing some of the clinic's patients: a lack of access to primary care doctors. "We might be helping them out by connecting them to a primary care doctor because they may have other things going on with their blood pressure that we checked while they were there, or not having seen a primary care doctor for an annual physical. Sometimes we create a pathway to get patients to other aspects of their care."

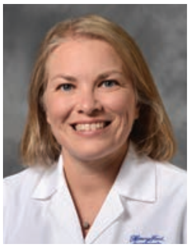
In other cases patients have a primary care doctor, but that doctor won't discuss sexual health. "Some patients say they feel uncomfortable talking to their primary care provider about sexual health needs, or feel they are being judged if they need services related to HIV testing or prevention," Kline said.

Some patients may not feel comfortable going to a sexual health clinic, either. Pittiglio worries those patients, especially if they could benefit from PrEP, will fall by the wayside.

Removing some barriers to PrEP

At Henry Ford, about 10% of all people who are eligible have been prescribed PrEP. That's unacceptable, said Elizabeth Lockhart, assistant scientist at Henry Ford's Center for Health Policy and Health Services Research. Lockhart is researching the best ways to boost the percentage of PrEP users. The module she's developing won't necessarily remove the barriers of medical mistrust or lack of physician access, but she said it should go far in spreading awareness of PrEP among doctors and patients.

"For physicians, that will involve some training on who's eligible for PrEP, how to prescribe PrEP, the tests that go with it, the types of medications that are currently available and what follow-up is needed." Lockhart said. In another part of the training, primary care doctors view scripted interactions between patients and providers to provide a model for talking to patients about sex in general, with the goal of taking PrEP out of the infectious diseases department and make prescribing it routine for a wider range of physicians.



'One of the unique aspects of being at Henry Ford Health is that we are in the city of Detroit but also serve a large patient population that may be either vulnerable to or living with HIV'

An educational video will be "Detroit-specific," she said. "There are some TV commercials about PrEP, but what we're hearing thus far is that people don't necessarily identify with those commercials. And specifically in the case of Detroit we've heard from some people that having different skin tones is important; having specific language and identities where people can identify with the city is important."

The project also includes an interactive HIV risk assessment tool for patients, which Lockhart hopes will spur them to bring up the topic with their doctors. And to help them become more proactive about prevention, another goal is to give patients the option for a home HIV test.

"The idea is that we'll be sending this [test] to patients who have an appointment with primary care prior to their appointment," she said. "That way they can either request the HIV test ahead of time or decide if they want to talk with their provider about an HIV test during their appointment, and then be connected with results and resources at that point."

As for helping doctors to become more PrEP-savvy, Lockhart said the project is in the information-gathering stage, with an internal survey to see what tips would be most useful for providers to help patients open up about sex and take a sexual health history.

"We want to provide them concrete examples of standardized language, and how to talk with patients about sex," she said. "The hope is that we give providers the tools that they will be able to use to work into their clinical workflow. We're not trying to overburden them with additional things that they need to do. But sexual health is a huge part of individuals' lives, and we want to equip care providers with tools that will eventually make [discussion of sex] a standard practice."

Sexual history should also be part of a patient's record, especially if they might be at risk for HIV, Lockhart said. "Being in a healthcare system, we have access to knowing if somebody has been diagnosed with an STI in the last six months. We can see the last time somebody was tested for HIV, for example. So we're going to be basing these kind of PrEP alerts off of STI status, and other indicators, based off of the CDC protocol guidelines."

Lockhart said the next area of research will be how to identify people who may need PrEP in other settings, like urgent care, and get them connected to primary care for follow-up. "One of the unique aspects of being at Henry Ford Health is that we are in the city of Detroit but also serve a large patient population that may be either vulnerable to or living with HIV," she said. "I hope once we figure out which combination of different factors works best, that it could be made applicable in other large healthcare systems and other cities."

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LARRY BUHL is a multimedia journalist based in Los Angeles. He has covered HIV/AIDS and other infectious diseases for more than two decades. In addition to POSITIVELY AWARE, he is a regular contributor to TheBody.com, Everyday Health and capitalandmain.com. His work has appeared in USA Today, Salon, Undark, KQED, The New York Times and others.

Detroit, where more than three-quarters of the population is Black, has the highest prevalence of HIV in Michigan

Pill fatigue

BY **VICTORIA NOE**

Wanda Brendle-Moss has been living with HIV since 2002. In late 2007, in the depths of a serious depression, she stopped taking her meds—*Why bother?* she thought. The boyfriend she was living with didn't notice until she was seriously ill. "All I wound up with was shingles and AIDS," she said. She hasn't gone off her meds since then, because now she believes "the truly most important relationship is the one with myself, with my physical and mental health and well-being."

'THE TRULY MOST IMPORTANT RELATIONSHIP IS THE ONE WITH MYSELF, WITH MY PHYSICAL AND MENTAL HEALTH AND WELL-BEING.'
—WANDA BRENDLE-MOSS

Pill fatigue is real, and the reasons for it can be complex. HIV drugs are generally less toxic today than they were 35 years ago, but we're still learning about the long-term effects of taking these medications. Any drug can be difficult to tolerate, especially when taking other medications. In the U.S., more than half the people living with HIV are over 50 years old, their aging exacerbated by the virus and the medications to control it. Housing insecurity is a factor for people with unstable or unsafe living situations. Substance use can lead someone into believing that they're "fine" and don't need their HIV meds. And though there are programs to help cover the cost, the inability to afford those drugs can tip the balance.

It can be overwhelming, whether you've been living with HIV/AIDS for decades or are newly diagnosed.

Shekinah Rose has lived with HIV/AIDS since 1985. She's taken many different types of antiretroviral medications over the years and has been on Cabenuva since 2022. The toxic side effects of the first drugs she was prescribed made staying adherent unsustainable, leading her in 2001 to take a "structured treatment interruption," she said.

"Risk-to-benefit ratio always comes to mind. I believed that if I was so unwell and my labs reflected that, it didn't make sense to stay on something that could affect my well-being, so I stopped," Rose said "Eventually I restarted, my CD4 count went up and my viral load decreased. I was living with AIDS since 2007. I lived with chronic pain from polyneuropathies bilaterally [a diffuse peripheral nerve disorder that usually occurs symmetrically, on both sides of the body] from the hips down. I had received a clinical marker from spinal tap for multiple sclerosis (MS). It matched up with all the clinical symptoms I was experiencing, so I made the decision to go into hospice, no longer able to live with my complex medical conditions of living with HIV/AIDS, plus potential MS, along with mental health challenges."

'I WENT BACK ON MY ARVS [ANTIRETROVIRALS]. I GOT BETTER PHYSICALLY WHILE IN HOSPICE AND MADE A DECISION TO RESTART THEM.'
—SHEKINAH ROSE

What changed her mind was that the science had changed, showing that structured drug interruption was not helpful and potentially harmful. "So I went back on my ARVs [antiretrovirals]. I got better physically while in hospice and made a decision to restart them," she said.

Masonia Traylor has gone off her HIV meds multiple times since being diagnosed in 2011. Why?

"Transition to a new provider during lapse in coverage, depression, fear," she said. "The longest time period was two years. I wanted to see how my body would respond. I had no insurance. I was only prescribed meds because I was pregnant. Maybe I was a slow progressor."

'I CREATE A ROUTINE AND CHECK IN WITH FRIENDS LIVING WITH HIV FOR ACCOUNTABILITY.'
—MASONIA TRAYLOR

When her viral load was no longer undetectable, and her T cell count dropped to 445, the same level as when she was first diagnosed, she went back on, and her T cell counts increased to the 800s. How does she now avoid going off meds again?

"I create a routine and check in with friends living with HIV for accountability," she said. "One friend, Lynette Trawick, has a campaign called Medication Motivation. It helps because we take our meds together. I also have others that check in periodically. I find others in the community who will share extra pills, grab samples, skipped doses to have extra just in case... I guess I am very resourceful."

For anyone considering going off their meds, Traylor said, "Do not play with being on and off. Choose what works best for you and talk to someone before you decide to go off."

A 2021 report, *Real-World Adherence to Antiretroviral Therapy Among HIV-1 Patients Across the United States* (by lead author Grace McComsey and colleagues), surveyed 206,474 people with HIV in the U.S., averaging 47.9 years old age. Sponsored by Janssen Scientific Affairs, LLC, it found that the average adherence to antiretroviral therapy was approximately 74%. It also reported 14.8% of participants lived with depression, and another 11.3% with anxiety. A previous study, conducted 2015–2017, found an average adherence rate of 72%.

PHOTOS COURTESY OF BRENDLE-MOSS, ROSE AND TRAYLOR

How do you strike that delicate balance between requiring adherence to a treatment regimen and respecting an individual's right to make their own decisions? More importantly, how do we ensure that everyone with HIV has the best chance to be a long-term survivor?

The sense of community forged by necessity in the fires of the early days of HIV/AIDS is needed more than ever. The COVID pandemic shutdown made loneliness and isolation part of the national conversation for a while, but these challenges persist in the HIV/AIDS community. There's still work to be done. And though it may seem daunting, there's a lot one person can do. Rose has very specific suggestions.

"Spend time with that person," she says. "Use active listening to understand what they may be experiencing. Support the person where they're at. As a long-term survivor, I know how hard it is. I had to learn and develop new ways of thinking and to change my mindset...Allow for a person to be heard. Being and feeling heard can create the first step to changing someone's mindset. Check in with the person to see how they're doing. Offer suggestions. Empower others to be the drivers of their own self-care and become proactive in their health again. It's all a process and can take time."

Long-term survivor and New York HIV advocate Sean McKenna has a clear idea of what people living with HIV/AIDS need most:

"I'll say it over and over again—*support*. Social support."

Those suggestions sound suspiciously like "be a good friend." That's not surprising. What better way to combat isolation and depression than creating and maintaining strong friendships and social connections?

'I'LL SAY IT OVER AND OVER AGAIN—SUPPORT. SOCIAL SUPPORTI'LL SAY IT OVER AND OVER AGAIN—SUPPORT. SOCIAL SUPPORT.'
—SEAN MCKENNA

Reach out to those who have gone silent; reach out more than once. Meet for coffee, or just hang out together. Be someone your friend can trust when they feel emotionally and physically exhausted. Learn to recognize the signs of struggle, even in individuals who give Oscar-worthy performances every day to convince the world that they're "fine." These suggestions may sound trivial, or not grand enough to make a difference, but making friendship a priority in your life benefits all of us.

One friendship at a time. That's how to create the kind of community people living with HIV/AIDS need and deserve. And in an era of treatment as prevention and "undetectable equals untransmittable" (U=U), it is a strategy that can help bring an end to HIV.

READ the report, *Real-World Adherence to Antiretroviral Therapy Among HIV-1 Patients Across the United States* at bit.ly/2021-adherence-report.

VICTORIA NOE is an award-winning author, speaker and activist. Her writing career began by fulfilling a promise made to a dying friend: the *Friend Grief* series. In 2019, her long-time HIV/AIDS activism led her to write *F*g Hags, Divas and Moms: The Legacy of Straight Women in the AIDS Community*, honoring women at the height of the AIDS epidemic. Her latest book, *What Our Friends Left Behind: Grief and Laughter in a Pandemic*, shares challenges of people who grieved the loss of a friend during COVID. **MORE** at victorianoe.com.

PHOTO BY MICHAEL INGULLI · ISTOCK

What if I forget to take my HIV meds—or even lose them?

Don't panic! Some things to know

BY **TIM MURPHY**

I probably speak for other folks living with HIV when I say that I have a chronic recurring nightmare in which I somehow "forget" to take my HIV meds, fail to take them with me on a trip or suffer some natural disaster like a flood or hurricane in which I lose them. What would I do? If I could not get back on meds immediately, would I develop debilitating resistance? Once reunited with my meds, could I just jump back on them or would I need a doctor's visit, testing, etc.? And if I could not get back on meds quickly, would I progress swiftly to AIDS, illness and death?

I decided to take these questions to my former HIV doctor, **Antonio Urbina, MD**, longtime medical director of Mt. Sinai's HIV clinic in NYC's Chelsea neighborhood, where he counts many long-term survivors among his clinic's roughly 5,000 patients. He's navigated patients through every variation of these scenarios, so here's what he had to say.

Let's start with an open question: Should you worry if, for whatever reason, you don't take your HIV meds for an indefinite period of time?

URBINA: For the most part, you're going to be okay. With most of the current HIV regimens, many of which are single-pill, if you're undetectable, you're not going to have viral breakthrough and develop resistance from not being on them for a few days and you can just restart when you're reunited with your meds without having to see your doctor or have a resistance test. Although you would want to have a viral load test within about a month of restarting just to make sure you're still undetectable.

But basically your virus wouldn't become detectable until you'd been off meds for one to two weeks, jumping higher [if you had stopped] two to four weeks, and then showing really significant rebound within eight to 12 weeks. And of course one usually doesn't show symptoms of viral progression and AIDS for months or even years without meds, depending on one's treatment history.

So, no real worry then about a temporary interruption?

The only worry is if, for some reason, you go off one or some of your HIV meds and not others (see sidebar). This scenario could pertain to long-term survivors who've developed resistance and are on more than one pill, or maybe a combination of pills and an injectable med like Sunlenca (lenacapavir). What would happen here is that you would be on a suboptimal regimen and you could develop resistance to the med(s) you are still on...

...and even the ones you are off? That seems to be what happened to me.

The longer you stayed on that suboptimal regimen, the more you would court even deeper resistance that would really complicate finding a working regimen going forward. So it's very important, if you take more than one pill or med, to either make sure you take them all or none at all. In other words, if you don't have access to Pill #1, *do not* take Pills #2 and #3 until #1 is back in the mix.

Most of us know about U=U, that if you're undetectable then you can't transmit the virus to sexual partners. But what if you become detectable?

Research shows that you are highly unlikely to transmit HIV sexually with your viral load anywhere below 1,000. Having said that, you can't know what your viral load is off meds day to day unless you're tested—so until I'd been back on meds for a few weeks, I would probably refrain from condomless sex with an HIV-negative sex partner unless they were on PrEP [the HIV prevention regimen].

What if you *do* develop resistance to a med that is in virtually every HIV regimen, such as tenofovir, which is what happened to me? Are you screwed?

It's true that developing resistance to tenofovir would be a concern because it is found in so many regimens and because other drugs in its class (NRTIs, or "nukes"), like abacavir and AZT, are not as desirable because of side effects. However, these days, you could put together a regimen with no NRTIs whatsoever, such as a regimen of a boosted protease inhibitor like Prezcobix (darunavir + cobicistat) and an integrase inhibitor like Tivicay (dolutegravir). Other new meds that have helped many drug-resistant folks get to undetectable include Sunlenca (lenacapavir), Rukobia (fostemsavir) and Selzentry (maraviroc).

And in the very worst-case scenario of not being able to put together a regimen that gets you to undetectable, because you've amassed so much resistance, then research has shown that staying on a regimen that suppresses your HIV partially is better than being on no regimen at all, because, over time, drug-resistant HIV tends to become less virulent.

The other thing I should add is that, if you do develop resistance and need to switch meds, you need a provider who is really proficient in interpreting resistance tests to help you figure out a new regimen. Especially if your provider is new to or not very familiar with HIV medicine, don't hesitate to seek a second opinion, or to ask your provider if they can consult with a more experienced colleague before prescribing your switch.

What about another worst-case scenario of losing your meds in a natural disaster or some unforeseen circumstances?

In the U.S. in 2024, it's very unlikely that you are not going to be able to get new meds in a reasonable amount of time even after a natural disaster. A provider's call to your insurer could probably sort that out, and additionally, one of the reasons we have the AIDS Drug Assistance Program (ADAP) within the Ryan White CARE Act is so that no person living with HIV ever goes without HIV meds—even if, say, you had to move states because of a natural disaster, such as people who fled New Orleans for Houston after Hurricane Katrina.

But again, even if for some reason you were not able to go back on HIV meds for a very long time, it would nonetheless be a very long time—months or even years—before you would develop AIDS and get sick. It's far from ideal to be off HIV meds, because active HIV can create damage in the body in all sorts of ways, but it's highly unlikely that you're going to get sick and die anytime soon if you go off your meds.

What's the final takeaway?

You should do everything possible to stay on your meds because you're healthier with your HIV fully suppressed, but if for whatever reason you are off meds for a few days or even a few weeks, you can probably restart with very little harm done.

My unexpected treatment failure

BY TIM MURPHY

Having been undetectable on HIV meds since shortly after my diagnosis in 2001, I never thought I'd be anything else. As a longtime HIV reporter, I've written countless stories about people developing resistance and becoming detectable, for reasons spanning from flubbing the taking of their own meds to simply having amassed so much prior resistance that no new med addition could seem to suppress them. *That would never happen to me*, I told myself. I even gamed the system for several years: working with my doctor, I managed to downscale my longtime regimen—Viramune plus Truvada—to every other day and still stay undetectable, allowing me build a stockpile of those meds in case of some future catastrophe. I did this by still getting subscriptions that provided 30-day supplies, then only needing half. I amassed years' worth of med surplus!

But all that changed last year when I was hospitalized for a stomach complication and found myself understandably groggy and not fully with it after three surgeries in about three weeks. In that time, I had to come off *all* my meds for about a week—and when I went back on them, unbeknownst to me for about three days, the hospital care team put me back on Truvada *without* the Viramune. When I found out, I was horrified. I knew all too well that being on an incomplete HIV regimen could lead to resistance.

Some quick studying confirmed what I already knew, which is that tenofovir is in almost every HIV regimen

Soon I was back on the full regimen, but a few weeks later, in a realization of my worst fears, I learned that not only was I detectable, with my viral load around 600, but that I'd developed resistance to both Viramune (the common NNRTI mutation M184V) *and* tenofovir (the common NRTI mutation K65R). Some quick studying confirmed what I already knew, which is that tenofovir is in almost *every* HIV regimen, including almost every one-pill regimen. What was I going to do?

Thankfully, I had the assistance of not only my current provider, an excellent nurse practitioner at the NYC clinic APICHA, but of my former doctor, Antonio Urbina, MD (**SEE** page 15). Independent of each other, they both recommended what I suspected from my own reading: the combination of the protease inhibitor Prezcobix (darunavir boosted by cobicistat) and the integrase inhibitor Tivicay (dolutegravir). That regimen, free of both NNRTIs and NRTIs, would give me a clean slate. And it was only two pills a night—no different from my old regimen, even if I had to take it nightly and could no longer stockpile a surplus.

It worked! In a few weeks, I was undetectable again, which was a great feeling. After more than 20 years undetectable, it had been highly unnerving to have extra HIV circulating in my body again, even at low levels. But the incident reminded me that undetectability is not a given—something beyond our control can happen that strips us of that status, even temporarily. Mostly, I was grateful that, in 2024, I had options to help me get back to undetectable. Twenty years ago or more, many people were not so lucky.

Navigating menopause with HIV

The challenges and some hope

BY **SARA H. BARES, MD; SARA LOOBY PHD, ANP-BC, FAAN** AND **MICHAEL T. YIN, MD, MS**

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Menopause is a natural process that occurs when a woman's ovaries stop producing eggs as the production of the female hormones (estrogen and progesterone) decline. Menopause can also occur if a woman's ovaries are removed or injured.

Natural menopause is comprised of different stages. Perimenopause (also known as the menopausal transition) typically begins when a woman is in her mid-40s. During perimenopause, menstrual periods become irregular and eventually begin to taper off. A woman is considered to have reached menopause once menstrual periods have stopped for a full 12 months.

On average, American women reach menopause around the age of 51, but menopause can occur earlier or later, and some research suggests that women living with HIV experience menopause at an earlier age than women without HIV. This is particularly important given women represent a significant portion of people living with HIV.

Overlapping symptoms

Menopausal transition is a challenging phase for most women, but for women living with HIV, it can be particularly difficult. Vasomotor symptoms (VMS), also known as hot flashes or flushes and night sweats, are the most common symptom of menopause. VMS typically begin during perimenopause and have been shown to be more severe and frequent among women living with HIV. Further, VMS sometimes evoke memories of the symptoms associated with HIV that women living with the virus may have experienced when they were first diagnosed. VMS can lead to heightened anxiety and stress and compound the psychological burden that can accompany the menopausal transition. Other common symptoms of menopause include depression and mood changes, sleep disturbance, cognitive changes, weight gain and vaginal dryness.

The need for specialized care

Women living with HIV are at increased risk for conditions such as cardiovascular disease, osteoporosis (bone loss) and frailty due to HIV. Of concern, estrogen loss that occurs during menopause heightens the risk for the development of these conditions. This necessitates a tailored approach to healthcare that accounts for the unique challenges faced by women living with HIV. Education on menopause, regular preventative health screenings and a proactive approach to managing these risks and conditions are essential.

Current treatment options

Menopausal hormone therapy (estrogen with or without progesterone) is considered the *most effective* therapy for hot flashes and prevention of menopausal bone loss, but the safety and efficacy has not specifically been studied in women living with HIV. Non-hormonal alternatives such as selective serotonin reuptake inhibitors (often prescribed as anti-depressants) and a novel neurokinin 3 receptor antagonist (fezolinetant) are also approved by the U.S. Food and Drug Administration (FDA) for the treatment of menopausal hot flashes. These options are available by prescription only, and women should discuss them with their care providers to determine which therapy might be best for them.

A call for research and awareness

Despite the growing awareness of the challenges faced by menopausal women living with HIV, more research is needed. One area that requires urgent attention is the safety and efficacy of hormone therapy for menopausal women living with HIV. Current guidelines for the use of menopausal hormone therapy are based on data from women without HIV and may not be applicable to women living with HIV. To address this gap, the Advancing Clinical Therapeutics Globally (ACTG) study group has planned a study, Menopausal Hormone Therapy for Women Living with HIV (A5424 HoT). The study aims to evaluate the safety and efficacy of menopausal hormone therapy in women living with HIV and will provide much-needed data to inform future treatment guidelines. It is funded by the National Institute of Aging, along with the Division of AIDS and the authors of this article are principal investigators. Recruitment and enrollment for the HoT study will open in 2025.

Conclusion

Menopause in women living with HIV is a complex and multifaceted reproductive health phase that requires a comprehensive and interdisciplinary approach. By increasing awareness, tailoring healthcare strategies and expanding research efforts, women living with HIV can receive better support during this challenging midlife phase. PA

GO TO actgnetwork.org to check on enrollment openings and progress of the HoT study.

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Borderline

Immigration and HIV care along the U.S.-Mexico border looms large at the largest national Latinx HIV conference in the U.S.

BY **LARRY BUHL**

The 2024 **National Latinx Conference on HIV, HCV and SUD** (which addresses hepatitis C and substance use disorder, in addition to HIV), held last May in El Paso, brought together clinicians and advocates from across the country to share best practices for a population that's key to ending the HIV epidemic: Latinx people, within and outside of the U.S. Issues of the border, including immigration and health care coordination, were prominent at the conference, which was organized by the south central AIDS Education and Training Center (AETC).

One of many unintended consequences of red state governors sending migrants to blue cities is the impact on healthcare providers.

Educating clinicians along the border

The border region, known as a Health Professional Shortage Area (HPSA), has overstretched resources for clients, many of whom have great need, whether they acknowledge it or not. Across nearly 2,000 miles from the Pacific Ocean to the Gulf of Mexico, the border region includes four U.S. states—California, Arizona, New Mexico and Texas—44 U.S. counties, six Mexican states and 80 municipalities in Mexico. Defined as the area within 62.5 miles (100 km) of either side of the boundary, it is home to approximately 13 million individuals and to 26 U.S. federally recognized Native American tribes.

If the U.S.-Mexico border region were a U.S. state, said a 2016 analysis, it would rank first in the number of uninsured school children, second in death rates from hepatitis, third in deaths related to diabetes, last in access to health care and lowest in per capita income. With that baseline, getting people into HIV care is especially challenging.

One presentation at the conference began with a very plausible scenario about a female migrant:

[She] *is 28 years old and living with HIV but does not know it. She crossed the border last year from Honduras and made her way to a family in a U.S. city. Through a health fair she was given a wellness checkup that included a pregnancy test and an HIV test. The HIV test came back positive. What can you or your agency do for her?*

It was a rhetorical question, but raises significant questions for clinicians. The U.S.-Mexico Border AETC Steering Team (UMBAST) is a collaboration of AETCs intended to enhance HIV care across the border, encompassing Texas, Arizona, New Mexico and California and supported by the HIV/AIDS Bureau of the U.S. Health Resources and Services Administration (HRSA) and the Minority AIDS Initiative.

The presenter offering the scenario, Peter Coronado, the UMBAST border training coordinator for Texas, spoke with POSITIVELY AWARE after the conference to share his thoughts about the challenges of serving border communities. He started by explaining that a primary mission of UMBAST is to create tools for healthcare providers who want to educate their patients on the available services in their home countries.

"For example, [if] I'm somebody who's from Mexico, and I'm going back to Mexico to live there and I'm a person with HIV, but I've been getting my services in the U.S., what medications are available in Mexico in terms of antiretroviral therapy? What organizations, what kind of health insurance do I need?" UMBAST also advises clinicians on the rights of people living in the U.S. who may not be documented. "Are they eligible for ADAP or patient assistance programs? We want them to be aware of what a person without documentation can access in the U.S. for HIV care and treatment and prevention," Coronado said.

People who don't know their HIV status present an even bigger challenge for clinicians, because testing might come, as in the hypothetical case presented, by chance, and they may not want or be ready to seek care. "I don't like to call [them] hard to reach populations, because we can reach them," Coronado said.

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"But we know that Latino communities often access health care when they need it, when their leg is broken, and their primary care providers tend to be emergency rooms," he said. "So we have to kind of be a little bit more creative in reaching them."

Coronado noted one group of professionals best equipped to do outreach: community health workers. "Community health workers are gatekeepers that already have the trust of their communities. We're not only training people who are already living in that community, we're giving them the tools on how to be able to get them involved in HIV, either testing or treatment."

Cultivating and relying on community health workers is especially helpful in making undocumented people feel safe. "We ask, *How does your organization build trust within the Latino community, especially for people who are undocumented? How do you present yourselves to them? Who is presenting themselves to them? Do they look like them? Do they speak like them?*"

Coronado emphasized that UMBAST has training modules for all these needs, including specific modules on how to prescribe antiretroviral therapy, PrEP or hepatitis C treatments.

There's another hurdle that keeps many migrants and undocumented people from seeking care, especially preventative care. Recalling a walk with a colleague near the conference hotel in El Paso, Coronado and a colleague encountered two young men, asylum seekers from Venezuela, and began chatting them up about their health concerns.

"But we didn't say anything about HIV," he said. "They both mentioned oral care and that they were taking a lot of Tylenol for tooth pain. We told them they could access services with community health centers, and their response was, 'No, no, no, we didn't come to this country to take away from it. We came to this country to give to it.' We reminded them that if they don't access the services the money would be taken away, because it's not being spent. They didn't understand the health care system. I could only imagine that when it comes to preventive services like PrEP, they might feel like if they access it, that might take it away from the country."

Both sides now: Cross-border collaboration to serve PLWH

Immigration was the focus of another presentation, this one about a more hands-on approach to getting people in the border region linked to care. Mayra Mollo, STD/HIV Disease Intervention Specialist (DIS) coordinator from the Arizona Department of Health Services (ADHS) and colleagues shared how their team intervenes to help binational clients access resources on both sides of the border.

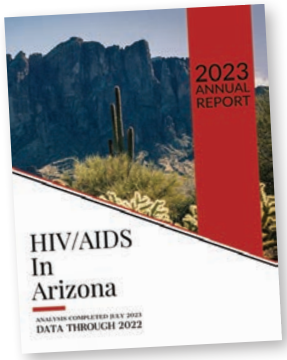
After the conference Mollo spoke with POSITIVELY AWARE and shared some of the complexities and intersecting factors that make binational people increasingly vulnerable to HIV, including immigration status, stigma, lack of access to culturally competent care and history of the U.S. government denying entry to people with HIV. These issues and more make binational clients vulnerable to falling out of care or could make them forgo care altogether.

According to the ADHS' HIV Surveillance 2023 Report, nearly half of reported new incidences of HIV/AIDS in the state last year (405 out of 975) were Hispanic, and it's not known how many were binational compared to permanent Arizona residents. The ADHS Disease Intervention Specialist team Mollo leads was formed in 2020 to coordinate cases where binational clients have tested positive for HIV or syphilis. "[HIV positive tests] might be from prenatal services, or because they went to an outreach event or an emergency department, or maybe even they went to donate plasma," she said. "Every client is different."

Following up starts with making sure an individual knows their test results. "Then we try to figure out who else may have been involved," she said. "Who are their partners, who else is at risk, to connect the dots and minimize the spread of the infection." Case managers answer questions and offer referrals and resources. The resource connection can be tricky because it depends on which side of the border a client resides at a given time. In the U.S., HIV coverage is provided by private health insurance, Medicare/Medicaid and Ryan White services. In Mexico, it's a mix of private insurance, the military and three social services organizations.

Not surprisingly, clients need linkage to care for more than HIV. Mollo recalled a case where a mother with HIV gave birth in a rural community in Arizona, was diagnosed with HIV after delivery, before moving back to Mexico. Knowing the mother needed ongoing care for herself and her baby, the DIS team found resources on the Mexico side of the border. Her husband, who lived in Mexico, couldn't cross the border. "We knew he needed [HIV] care, so we figured out ways to be able to get him tested and into PrEP care," she said. From that experience DIS created a directory of resources for maternal and congenital HIV/STI cases.

Client follow-ups are done through email, WhatsApp phones and international phones given to clients. The point, Mollo said, is to make it easy for the client. Over time, and through collaboration and communication between health care providers on both sides of the border, the process is becoming easier for the DIS team as well.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To meet the demand, Arguello and colleagues determined that collaboration between agencies was crucial.

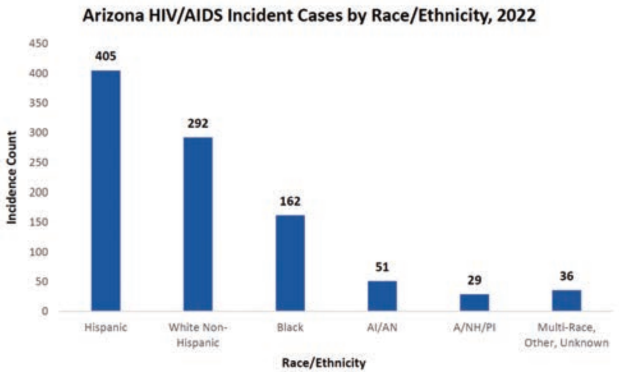

CHART COURTESY OF THE ADHS' HIV SURVEILLANCE 2023 REPORT

Mollo emphasized that migration in border regions can be an ongoing process rather than a one-time event. Short of a binational HIV prevention approach, which would require resources and policies agreed on by both countries, it's up to health care workers and advocates on both sides of the border, like the ADHS team, to improve outreach.

How the migrant crisis affects HIV care in Chicago

One of many unintended consequences of red state governors sending migrants to blue cities is the impact on healthcare providers. In Chicago, which has seen tens of thousands of displaced people arriving from Central and South America in recent years, clinicians have been scrambling to provide services and struggling to understand their unique needs.

It's a given that migrants will need health care, and some will have HIV, even if they don't know it. Few are likely to have health insurance or even the necessary documents to get covered, all factors creating a growing conundrum for providers. Building resources to care for migrants was the topic of a presentation by Luricella Arguello, lead medical benefits specialist for AIDS Foundation of Chicago (AFC). Arguello spoke to POSITIVELY AWARE after the conference and explained that migrants showing up in a city where they know nobody presented extra challenges for care workers.

"What might be a normal conversation to someone who has lived in the U.S. for a while, around insurance, deductibles, copays, are something that [new migrants] have had zero familiarity with," Arguello said. Getting people into the office to qualify for coverage can be an issue as well. "Even though with Ryan White there are services to help like transporting people through Uber, they can only utilize those services once they're enrolled in the program."

AFC is not a clinic; it's an intermediary for many HIV services between the state and agencies that provide clinical services, which means the burden falls on Arguello and other AFC colleagues to help healthcare partners manage the maze of rules for benefits for migrants. She gave an example of a migrant without a state ID, which typically requires a call or a trip to a consulate office. However, the Venezuelan consulate in Chicago has been closed for years. Barring a consulate visit, a case manager must find state programs that let clients self-attest to their identity and present whatever documents they have for their asylum case. "We were just trying to find any way to be creative to get people through these processes," Arguello said.

And it isn't just a few new clients, she explained. The number of applications for medical benefits for victims of trafficking and torture and other crimes has exploded the past two years in Illinois. "Not even the HIV-positive folks, but individuals in general, [Illinois] went from getting maybe a couple hundred applications for that program to getting 1,000 minimum per day." She noted that some migrants who show up at a clinic with a health issue may or may not let the provider know they have HIV and need medication. That's when AFC gets a call.

To meet the demand, Arguello and colleagues determined that collaboration between agencies was crucial. They started a task force to decide what internal and external resources were available and make sure everyone caring for migrants, especially at local Ryan White clinics, was aware of this. They came up with a list of best practices for making a cumbersome process as streamlined as possible.

Arguello said resource sharing among healthcare administrators is essential. "Try to come together to share both your struggle as well as the resources that you have found, because there's going to be a variety of your partners in the community that are having the same struggles and the same questions. Some of them already figured out a way around some of the issues you're facing."

Mollo emphasized that some softer skills come in handy, too, including the ability to approach clients with cultural humility. Because the danger of not helping these individuals, Arguello emphasized, is that they will fall out of care. "If they have no housing, no food, health care isn't necessarily going to be at the forefront of their thinking, at least until they're faced with a serious problem."

LARRY BUHL is a multimedia journalist based in Los Angeles. He has covered HIV/AIDS and other infectious diseases for more than two decades. In addition to POSITIVELY AWARE, he is a regular contributor to TheBody.com, *Everyday Health* and capitalandmain.com. His work has appeared in *USA Today*, *Salon*, Undark, KQED, *The New York Times* and others.

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Important Facts About CABENUVA (KAB-en-ew-vah)

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

ABOUT CABENUVA

CABENUVA is a complete prescription regimen used to treat HIV-1 infection in people 12 years and older who weigh at least 77 lbs (35 kg), to replace their current HIV-1 medicines when their healthcare provider determines that they meet certain requirements.
HIV-1 is the virus that causes Acquired Immune Deficiency Syndrome (AIDS). CABENUVA contains 2 different medicines:

- cabotegravir
- rilpivirine

It is not known if CABENUVA is safe and effective in children younger than 12 years of age or weighing less than 77 lbs (35 kg).

DO NOT RECEIVE CABENUVA IF YOU

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

BEFORE RECEIVING CABENUVA

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

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

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

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*Your every-other-month regimen begins after 2 once-monthly starter doses. It's important to receive CABENUVA as scheduled and attend all treatment appointments.

Important Facts About CABENUVA (cont'd)

BEFORE RECEIVING CABENUVA (cont'd)

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

- are breastfeeding or plan to breastfeed. CABENUVA may pass into your breast milk. Talk to your healthcare provider about risks to your baby from breastfeeding during or after treatment with CABENUVA.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines interact with CABENUVA. Keep a list of your medicines and show it to your healthcare provider and pharmacist when you get a new medicine. You can ask your healthcare provider or pharmacist for a list of medicines that interact with CABENUVA. **Do not start taking a new medicine without telling your healthcare provider.** Your healthcare provider can tell you if it is safe to take CABENUVA with other medicines.

POSSIBLE SIDE EFFECTS OF CABENUVA

CABENUVA may cause serious side effects, including:

- **Allergic reactions.** Call your healthcare provider right away if you develop a rash with CABENUVA. **Stop receiving CABENUVA and get medical help right away if you develop a rash with any of the following signs or symptoms:**
  - fever
  - generally ill feeling
  - tiredness
  - muscle or joint aches
  - trouble breathing
  - blisters or sores in mouth
  - blisters
  - redness or swelling of the eyes
  - swelling of the mouth, face, lips, or tongue
- **Post-injection reactions** have happened within minutes in some people after receiving their rilpivirine injection. Most symptoms resolved within minutes after the injection. Symptoms may include:
  - trouble breathing
  - narrowing of airways
  - stomach cramps
  - sweating
  - numbness of your mouth
  - pain (e.g., back and chest)
  - feeling anxious
  - feeling warm
  - rash
  - feeling light-headed or feeling like you are going to pass out (faint)
  - blood pressure changes

POSSIBLE SIDE EFFECTS OF CABENUVA (cont'd)

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

- **Liver problems.** Liver problems have happened in people with or without history of liver problems or other risk factors. Your healthcare provider may do blood tests to check your liver function. People with a history of liver problems or people who have certain liver function test changes may have an increased risk of developing new or worsening changes in certain liver tests during treatment with CABENUVA. **Call your healthcare provider right away if you develop any of the following signs or symptoms of liver problems:**
  - your skin or the white part of your eyes turns yellow (jaundice)
  - dark or "tea-colored" urine
  - light-colored stools (bowel movements)
  - nausea or vomiting
  - loss of appetite
  - pain, aching, or tenderness on the right side of your stomach area
  - itching
- **Depression or mood changes. Call your healthcare provider or get emergency medical help right away if you develop any of the following symptoms:**
  - feeling sad or hopeless
  - feeling anxious or restless
  - have thoughts of hurting yourself (suicide) or have tried to hurt yourself

The most common side effects of CABENUVA include:

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

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

GET MORE INFORMATION

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

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ViiV Healthcare

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NOTA DEL EDITOR

Rick Guasco
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SEXO, PLACER, Y PREVENCIÓN DEL VIH

“Hasta hace poco, las palabras *sexo* y *placer* no se aplicaban a la prevención del VIH”, dice el terapeuta y defensor de la prevención del VIH Damon L. Jacobs. “Para mí, la salud mental y la salud sexual son lo mismo.”

“Para mí, la *diversión* es sólo una sensación general de algo que me da la sensación de estar vivo,” agrega Rodney McCoy, Jr., sobreviviente a largo plazo y defensor del VIH.

En el artículo de portada de esta edición, los dos defensores y amigos mantienen una animada conversación sobre cómo se unen el placer y la prevención del VIH. El sexo influye en cómo nos vemos, nos expresamos y nos identificamos.

Hablar abierta y sinceramente sobre sexo no debería ocurrir simplemente entre las sábanas; también debe ocurrir en el consultorio de tu médico o en cualquier lugar donde recibas servicios. El estigma, la culpa y la vergüenza no son estrategias eficaces de prevención del VIH.

La conversación de Rod y Damon marca el tono del artículo que le sigue, escrito por Rod. En “*Kink* sexo-positivas,” a nadie le corresponde juzgar cómo alguien disfruta del sexo. Rod recuerda haber ido a una clínica después de que le diagnosticaron gonorrea y haber recibido un sermón moralizador de un consejero. El nunca volvió a esa clínica. Una mala experiencia puede tener efectos en cadena. “No podemos permitir que nuestras propias creencias y comportamientos sexuales dicten lo que le decimos a nuestros clientes,” dice Rod.

Nuestras propias comunidades deben ser más tolerantes y menos críticas. Hemos reimpreso uno de los primeros comentarios publicados por POSITIVELY AWARE en 2015, acerca del avergonzamiento sobre el PrEP: “Dices ‘puta’ como si fuera algo malo.” Parafraseando a Enid Vázquez, engañamos a las personas haciéndoles creer que están seguras si no tienen múltiples parejas sexuales.

Y hablando de salud sexual, el escritor contribuyente principal Larry Buhl analiza cómo puede ayudar el hacer que los pacientes y los proveedores de atención se sientan más cómodos hablando sobre sexo en “Cerrando las brechas en la prevención del VIH en Detroit.” El Motor City tiene la mayor incidencia de VIH en Michigan en medio de enormes disparidades. Por cada dos hombres blancos que viven con el VIH, hay 15 hombres negros que viven con el virus.

“La salud sexual es una parte muy importante de la vida de las personas y queremos equipar a los proveedores de atención con herramientas que eventualmente hagan que [la discusión sobre sexo] sea una práctica estándar,” dice Elizabeth Lockhart, científica asistente del Centro para Políticas de Salud e Investigación de Servicios de Salud de Henry Ford Health.

Muchos de nosotros nos estresamos por tomar nuestras pastillas o por omitir dosis. Victoria Noe escribe cómo la “Fatiga de las Pastillas” es algo real y qué hacer al respecto. “¿Qué pasa si me olvido de tomar mis medicamentos contra el VIH o incluso los pierdo?” es una de las mayores pesadillas de Tim Murphy, por lo que habla con el Dr. Antonio Urbina, director médico de la clínica de VIH de Mount Sinai en Chelsea, quien le brinda algunas ideas para disipar los temores de Tim. Sin embargo, a través de una serie de eventos, Tim escribe sobre “Mi inesperado fracaso del tratamiento” y cómo sucedió. Es un recordatorio de que siempre debes defender tu propia salud.

Las mujeres que viven con VIH y experimentan la menopausia tienen un mayor riesgo de padecer condiciones tales como enfermedades cardiovasculares, pérdida ósea y fragilidad. Los Doctores Sara H. Bares, Sara Looby y Michael T. Yin escriben sobre “Navegando por la menopausia con VIH.” Incluyen un ensayo clínico en planificación que evaluará la terapia hormonal menopáusica en mujeres que viven con VIH y proporcionará datos para informar futuras pautas de tratamiento.

Nuestro informe sobre la conferencia internacional AIDS 2024 celebrada en Munich, Alemania, en julio pasado destaca tres anuncios clave. Se descubrió que el lenacapavir inyectable de seis meses tiene una efectividad sin precedentes del 100% para proteger a las mujeres cis del VIH—pero surgen dudas sobre su accesibilidad asequible. Un estudio encontró que doxy-PrEP redujo la tasa de ITS entre hombres que tienen sexo con hombres en un 80%. Además, hubo noticias sobre una séptima persona que será curada del VIH—el “próximo paciente de Berlín”—mediante un trasplante de células madre.

Informamos sobre otra conferencia—la Conferencia Nacional Latinx sobre VIH, VHC y TUS (trastorno por uso de sustancias)—para examinar el estado del VIH y la atención en una región que desdibuja la línea entre los Estados Unidos y México. Se extiende por casi 2,000 millas desde el Océano Pacífico hasta el Golfo de México y alcanza 62.5 millas (100 km) a cada lado de la frontera. Según un estudio de 2016, si esta región fuera un estado de EE. UU., ocuparía el segundo lugar en muertes por hepatitis, el tercero en muertes relacionadas con la diabetes y el último en acceso a atención médica. No es de extrañar que conseguir que las personas reciban atención para el VIH sea especialmente desafiante.

Se necesita colaboración y comunicación entre los proveedores de cuidado en ambos lados de la frontera y los trabajadores de salud comunitarios, que son esenciales para conectar a las personas con la atención que necesitan. Debido al tema que cubre, este informe también aparece en español en esta edición. Le siguen las versiones en español de dos artículos que aparecieron en la edición de julio y agosto—la renuencia de ADAP en Texas a agregar Cabenuva a su formulario y un cambio en la versión de ADAP de Puerto Rico que podría potencialmente interrumpir la entrega de medicamentos contra el VIH. Esto enfatiza la necesidad de hacer que la información sea lo más accesible posible en diferentes idiomas, particularmente en las comunidades en las que el español es el idioma predominante, algo que POSITIVELY AWARE continuará abordando en futuras ediciones.

A veces pienso que no es el virus lo que se interpone en el camino de nuestro placer y nuestra vida, sino el estigma, el miedo y el aislamiento que pueden surgir a causa del mismo.

No estás solo.

Rick

JOHN GRESS · ISTOCK

Póquer Texas hold’ em

En Texas, los defensores luchan para que los tejanos sin seguro tengan acceso a Cabenuva

POR **LARRY BUHL**

Aprobado en enero de 2021, Cabenuva fue el primer inyectable de acción prolongada para el tratamiento del VIH. Pero en Texas, las personas que viven con VIH (PLWH) sin seguro médico todavía tienen que pagar de su bolsillo o conformarse con tratamientos orales. Esto se debe a que el Programa de Medicamentos para el VIH de Texas (THMP), el Programa de Asistencia para Medicamentos contra el SIDA (ADAP) del estado, todavía no lo ha agregado a su formulario, y los defensores del VIH están protestando.

Texas es uno de los siete estados que no incluyen Cabenuva en sus formularios ADAP.

Otros pagadores de Texas cubren Cabenuva, incluidas aseguradoras privadas, así como Medicare y Medicaid. Sin cobertura, las inyecciones de cabotegravir más rilpivirina cuestan más de $6,000 por tratamiento, de bolsillo. THMP, el pagador de último recurso para las PLWH, atiende a aproximadamente una sexta parte de las personas con VIH en Texas, según su informe anual.

THMP cubre dos tratamientos inyectables de acción prolongada contra el VIH, Sunlenca (lenacapavir) y Trogarzo, pero están indicados para personas que viven con el VIH con mucha experiencia en tratamientos y que han tenido dificultades para encontrar un régimen de funcionamiento optimizado, incluidas aquellas con resistencia a múltiples medicamentos.

Dora Martínez, médica del Valley AIDS Council en el sur de Texas y directora de relaciones gubernamentales de ViiV, tiene alrededor de 60 pacientes en lista de espera para Cabenuva. Martínez, quien recomendó agregar Cabenuva al formulario de Texas cuando formó parte del Consejo Asesor de THMP, dijo que Texas es el único estado que no tiene vías para que las PLWH sin seguro obtengan el medicamento. “Muchas personas no pueden obtener Medicaid y realmente no existe ningún otro programa aquí”, dijo. “Algunos de los otros estados que no tienen [Cabenuva] en su formulario de ADAP esencialmente pagarán las primas para que alguien quede asegurado”.

El ingreso máximo actual para que un solo tejano sea elegible para Medicaid es poco menos de $30,000. Cuarenta estados más el Distrito de Columbia han ampliado Medicaid en virtud de la Ley de Atención Médica Asequible, proporcionando otra vía de cobertura para los estadounidenses de bajos ingresos. Texas no ha ampliado Medicaid, lo que dificulta aún más que las personas obtengan cobertura.

Alrededor de 4,9 millones, o el 17% de los tejanos, no tienen seguro médico, según datos del censo de 2022. El número de personas con VIH en el estado, en 2019, era de cerca de 100.000, siendo la mayoría los tejanos negros e hispanos/latinos.

“En pocas palabras, si eres un tejano con VIH y tienes seguro, potencialmente tiene acceso a Cabenuva y si no tiene seguro médico, no lo tiene”, dijo Martínez. “Puede acudir a un programa de asistencia al paciente donde, de otro modo, sus ingresos calificarían, pero como [ADAP] se considera un seguro, no califica”.

Supuestos “especiosos”

Según Michael Elizabeth, director de políticas de salud pública de la organización de defensa del VIH Equality Federation, THMP ha dado “razones engañosas” para no proporcionar Cabenuva. La suposición es que las personas que cambien de un medicamento oral menos costoso podrían potencialmente arruinar el presupuesto. Pero al analizar las cifras, Elizabeth dijo que eso supone que todos los tejanos que toman medicamentos orales cambiarían a Cabenuva. “ADAP dice que la cantidad de personas que cambian sumaría $6.4 millones al año para Texas, pero eso supone que 100% de los pacientes con supresión viral que toman regímenes orales de una sola pastilla cambiarían a Cabenuva, pero no vemos esas cifras [de cambio] en otros estados. No estamos viendo un éxodo de personas que toman Biktarvy, por ejemplo, que cambien inmediatamente a Cabenuva”.

Martínez estuvo de acuerdo en que los supuestos de THMP son erróneos. “Hemos visto en los ADAP de otros estados que tal vez entre el 2 y 5% han cambiado a Cabenuva”.

“No se puede desarrollar resistencia a ninguno de los componentes [de Cabenuva] y habrá personas que hayan desarrollado resistencia en su historial de tratamiento previo”, dijo. “Y hay que ser alguien que realmente quiera recibir inyecciones. No a todo el mundo le gustan las agujas”.

Datos recientes del ensayo de fase 3 LATITUDE, presentados en la CROI en marzo, indican que los inyectables de acción prolongada pueden ser mejores que las píldoras diarias para las personas que tienen dificultades para cumplir con el tratamiento. La

TEXAS HOLD ’EM: MICROVONE-ISTOCK ADAPTED BY RICK GUASCO

Red Transgénero de Texas (TENT), en una carta al Departamento de Servicios de Salud del Estado de Texas (DSHS), la organización que supervisa THMP, enfatizó que los tejanos transgénero se beneficiarían de Cabenuva.

"Debido a la prevalencia de la inestabilidad de la vivienda, la discriminación laboral y otros determinantes sociales de la salud, muchos tejanos transgénero fluctúan entre Medicaid y THMP en función de los ingresos y otros factores de elegibilidad", escribió TENT. "El acceso abierto y completo a todos los medicamentos aprobados por la FDA contra el VIH no debería dificultarse, especialmente para los más afectados por esta epidemia".

Martínez agregó que una posible oleada de PLWH que se cambien a Cabenuva no debería afectar el presupuesto del estado. "El costo es similar [al de los medicamentos orales], dentro del rango, y hubo una negociación de buena fe entre ViiV y ADAP para que Cabenuva fuera neutral en cuanto a costos".

En un correo electrónico, Douglas Loveday, un portavoz del DSHS, dijo que la estimación del departamento se basaba en la suposición de que solo el 80 por ciento de los clientes de THMP, no el 100, cambiarían a Cabenuva (el porcentaje estimado de clientes de THMP con supresión viral y elegibles para cambiar).

"La incorporación de Cabenuva también requerirá un aumento de las visitas al consultorio y de solo inyecciones para los clientes", escribió Loveday. "El costo de una inyección varía de $25 como parte de una visita de enfermería a $75 como parte de una visita a un proveedor médico. El costo promedio de las visitas de inyección varía de $75 a $125 por cliente por año. Esto resultará en un aumento proyectado de $857,175 a $1,428,625 por año".

El costo proyectado de las visitas al consultorio más la medicación aumentaría el costo para THMP hasta $6.4 millones por año, escribió Loveday. "DSHS está experimentando un aumento en la inscripción a THMP que, si continúa, superará los fondos del programa. DSHS está completando un análisis adicional para ver cómo resolver mejor este déficit proyectado del programa".

La legislatura de Texas podría presionar a la agencia para que agregue Cabenuva al formulario, pero los legisladores se reúnen sólo cada dos años y la próxima sesión comienza en enero. Elizabeth agrega que es dudoso esperar que la legislatura aborde el tema, a pesar de algunos defensores en la cámara.

Aun así, cualquier esfuerzo legislativo para incluir Cabenuva en el formulario de THMP enfrentará fuertes vientos en contra, dijo Elizabeth. "Cualquier cosa que tienda a apoyar remotamente a las comunidades marginadas tiene una dura lucha por delante", dijo. "La legislatura es uno de los impulsores detrás de todos los proyectos de ley anti-LGBTQ que estamos viendo en todo el país... y generalmente ha estado en contra de cualquier cosa que pueda verse como un apoyo a estas comunidades".

Martínez dijo que el hecho de no proporcionar Cabenuva a los tejanos sin seguro podría tener consecuencias para poner fin a la epidemia del VIH, y señaló que cinco jurisdicciones (los condados de Bexar, Dallas, Harris, Tarrant y Travis) están en la iniciativa Ending the Epidemic (EHE) de EE. UU.

Se estima que la tasa general de supresión viral del VIH en Texas es del 63%, muy por debajo del objetivo del estado del 75% para 2025.

"Están apareciendo más datos que indican que los inyectables de acción prolongada son potencialmente un medio para que las personas alcancen la indetectabilidad", dijo Martínez. "Estamos muy lejos de poner fin a la epidemia del VIH y de cumplir esos objetivos, los objetivos 90-90-90, y especialmente no vamos a lograrlo con esta disparidad flagrante. Tenemos que pensar en quiénes son las personas que tienden a tener más desafíos, y las personas sin seguro ya tienden a tener más desafíos".

¿Una brecha VITAL en Puerto Rico?

Un cambio reciente en la cobertura de medicamentos contra el VIH en Puerto Rico ha preocupado a los defensores de cómo afectará a las 7.000 personas en la isla que viven con el VIH.

Puerto Rico, a diferencia de Texas, cuenta con atención médica financiada por el gobierno para las personas que la necesitan. Pero un cambio reciente en este plan tiene a los defensores del VIH preocupados de que las personas que viven con el VIH (PLWH) vean brechas en la cobertura de todos los medicamentos contra el VIH.

Al igual que Texas y otros estados, Puerto Rico brinda cobertura ADAP para PLWH que no están aseguradas a través de un plan de salud gubernamental llamado VITAL. Pero a partir del 1 de julio, las personas que dependían de VITAL para obtener medicamentos fueron cambiadas a un Programa de Reembolso de Medicamentos de Medicaid, lo que afecta a unos 7.000 puertorriqueños en la isla que viven con VIH, y posiblemente no para mejor, dicen los defensores.

Según el MDRP, las farmacias y clínicas que suministran medicamentos tendrán que pagar por adelantado el costo de los medicamentos y luego serán reembolsados por el gobierno. Pero algunas de las farmacias y clínicas no tienen el flujo de efectivo para pagar los medicamentos de todos sus pacientes, según Pedro Julio Serrano, gerente de desarrollo y políticas públicas de Waves Ahead, una organización de servicios LGBTQ+ con sede en San Juan. "Esto significa que es posible que las farmacias y clínicas no puedan comprar medicamentos por adelantado", dijo.

Para evitar obstáculos involuntarios a la obtención de medicamentos, Waves Ahead y otros defensores se reunieron con Mellado López, el Secretario de Salud de Puerto Rico, y pidieron que los medicamentos contra el VIH fueran excluidos del MBRP y que en su lugar estuvieran disponibles a través de ADAP, pero no tuvieron éxito.

"El gobierno dice que esto permite que más farmacias puedan proporcionar los medicamentos, pero en realidad, algunas personas no pueden ir a las farmacias u otros lugares para obtener sus medicamentos porque sólo pueden pagar un viaje, para ir a a la clínica para obtener sus medicamentos y sus análisis", dijo Serrano. "Esto pone en peligro a las personas que cumplen con sus medicamentos".

El gobierno proporcionó un parche temporal para garantizar que los farmacéuticos y las clínicas tengan una asignación suficiente de medicamentos hasta diciembre. "Pero no sabemos qué pasará después de enero", dijo. "Por eso me preocupo".

A la incertidumbre se suman las elecciones de noviembre. Serrano teme que una ola de nuevos candidatos de derecha "que fomentan un clima de odio que incita a la violencia contra las personas LGBTQ+" puedan llegar al poder.

"Algunos candidatos están compitiendo por los votos del sector de derecha que propone cosas que son peligrosas para [las personas con VIH]. Por eso nos preocupa que algunos de los éxitos que hemos tenido en términos de adhesión en Puerto Rico, y servicios y proyectos, puedan estar en peligro si se eligen más candidatos de la derecha".

Hasta ahora no ha habido interrupciones en la obtención de medicamentos contra el VIH en la isla, dijo Serrano.

—**LARRY BUHL**

En la frontera

La inmigración ocupa un lugar preponderante en la conferencia Nacional Latinx sobre el VIH

POR **LARRY BUHL**

La Conferencia Nacional Latinx sobre el VIH del 2024, celebrada en El Paso en mayo, reunió a clínicos y defensores en el ámbito del VIH de todo el país para compartir las mejores prácticas para una población que es clave para poner fin a la epidemia del VIH: los Latinx, dentro y fuera de los EE. UU. Los problemas de la frontera, incluyendo la inmigración y la coordinación del cuidado de la salud, fueron prominentes en la conferencia, que fue organizada por el Centro de Educación y Capacitación sobre el SIDA (AETC) del centro sur.

> Una de las muchas consecuencias no deseadas de que los gobernadores de los estados rojos envíen migrantes a ciudades azules es el impacto en los proveedores de cuidado de salud.

Educando a los clínicos a lo largo de la frontera

La región fronteriza, conocida como Área de Escasez de Profesionales de la Salud (HPSA, por sus siglas en inglés), ha estirado los recursos para los clientes, muchos de los cuales tienen una gran necesidad, ya sea que lo reconozcan o no. Según un análisis de 2016, si la región fronteriza entre EE. UU. y México fuera un estado de EE. UU., ocuparía el primer lugar en la cantidad de niños en edad escolar sin seguro, el segundo en las tasas de mortalidad por hepatitis, el tercero en muertes relacionadas a la diabetes, el último en el acceso al cuidado de la salud, y el más bajo en ingresos per cápita. Con esa base de referencia, lograr que las personas reciban atención para el VIH es especialmente desafiante.

Una presentación comenzó con un escenario muy convincente:

María tiene 28 años y vive con VIH, pero no lo sabe. El año pasado cruzó la frontera desde Honduras, y se dirigió a una familia en una ciudad de los EE. UU. A través de una feria de salud, le hicieron un chequeo de bienestar que incluyó una prueba de embarazo y una prueba del VIH. La prueba del VIH resultó positiva. ¿Qué puede hacer usted o su agencia por María?

Fue una pregunta retórica, pero plantea preguntas importantes para los clínicos. El Equipo Directivo de AETC de la Frontera EE. UU.-México (UMBAST, por sus siglas en inglés) es una colaboración de AETC destinada a mejorar la atención al VIH a través de la frontera, que abarca a Texas, Arizona, Nuevo México y California, y cuenta con el apoyo de la Oficina del VIH/SIDA de la Administración de Recursos y Servicios de Salud de los EE. UU. (HRSA, por sus siglas en inglés) y la Iniciativa de las Minorías contra el SIDA (MAI, por sus siglas en inglés).

Peter Coronado, el coordinador de capacitación fronteriza de UMBAST para Texas, y quien presentó la situación de María, habló con POSITIVELY AWARE después de la conferencia para compartir sus pensamientos sobre los desafíos de servir a las comunidades fronterizas. Comenzó explicando que una misión principal de UMBAST es crear herramientas para los proveedores de cuidado de salud que desean educar a sus pacientes sobre los servicios disponibles en sus países de origen.

"Por ejemplo, [si] yo soy alguien que es de México, y voy a regresar a México para vivir allí, y soy una persona con VIH, pero he estado recibiendo mis servicios en los EE. UU., ¿qué medicamentos están disponibles en México en términos de terapia antirretroviral? ¿Qué organizaciones, qué tipo de seguro de salud necesito?"

UMBAST también asesora a los clínicos sobre los derechos de las personas viviendo los EE. UU. quienes pueden no estar documentadas. "¿Son elegibles para ADAP o programas de asistencia al paciente? Queremos que estén conscientes sobre lo que una persona sin documentación puede acceder en los EE. UU. para la atención, el tratamiento y la prevención del VIH," dijo Coronado.

Las personas que no conocen su estado serológico sobre el VIH representan un desafío aún mayor para los clínicos, porque las pruebas pueden llegar, como en el caso hipotético de María, por casualidad, y es posible que

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no quieran o no estén preparados para buscar cuidado. “No me gusta llamar[las] poblaciones difíciles de alcanzar, porque *podemos* llegar a ellas,” dijo Coronado.

“Pero sabemos que las comunidades Latinas a menudo acceden la atención médica cuando la necesitan, cuando tienen una pierna rota, y sus proveedores de atención primaria tienden a ser las salas de emergencia,” dijo. “Por lo tanto, tenemos que ser un poco más creativos para llegar a ellos.”

Coronado señaló a un grupo de profesionales mejor equipados para llegar a ellos: los trabajadores de salud comunitarios. “Los trabajadores de salud comunitarios son controladores de acceso que ya tienen la confianza de sus comunidades. No solamente estamos capacitando a las personas que ya viven en esa comunidad, les estamos dando las herramientas sobre cómo poder involucrarlos en el VIH, ya sea con pruebas o tratamiento.”

Cultivando y dependiendo en los trabajadores de salud comunitarios es especialmente útil para hacer que las personas indocumentadas se sientan seguras. “Nos preguntamos, *¿cómo desarrolla su organización la confianza dentro de la comunidad Latina, especialmente para las personas que son indocumentadas? ¿Cómo se presentan ustedes ante ellos? ¿Quién se está presentando ante ellos? ¿Se parecen a ellos? ¿Hablan como ellos?*”

Coronado enfatizó que UMBAST tiene módulos de capacitación para todas estas necesidades, incluyendo módulos específicos sobre cómo recetar terapia antirretroviral, PrEP o tratamientos para la hepatitis C.

Hay otro obstáculo que impide que muchos migrantes y personas indocumentadas busquen atención, especialmente cuidado preventivo. Recordando una caminata con un colega cerca del hotel de la conferencia en El Paso, Coronado y un colega se encontraron con dos hombres jóvenes, solicitantes de asilo de Venezuela, y comenzaron a charlar con ellos sobre sus preocupaciones de salud.

“Pero no dijimos nada sobre el VIH,” dijo. “Ambos mencionaron el cuidado bucal y que estaban tomando mucho Tylenol para el dolor de muelas. Les dijimos que podían acceder a los servicios de los centros de salud comunitarios y su respuesta fue: ‘No, no, no, no vinimos a este país para quitarle nada. Vinimos a este país para darle algo.” Les recordamos que, si no acceden a los servicios, el dinero será detraído porque no se está gastando. Ellos no entendían el sistema de cuidado de salud. Yo solo me puedo imaginar que cuando se trata de servicios preventivos como PrEP, podrían sentir que, si acceden a ellos, eso podría despojar al país.”

Ahora ambos lados: Colaboración Transfronteriza para servir a personas que viven con VIH

La inmigración fue el foco de otra presentación, esta vez sobre un enfoque más práctico para enlazar a las personas en la región fronteriza con la atención. Mayra Mollo, coordinadora Especialista en Intervención de Enfermedades de ETS/VIH (DIS, por sus siglas en inglés) del Departamento de Servicios de Salud de Arizona (ADHS) y sus colegas compartieron cómo su equipo interviene para ayudar a los clientes binacionales a acceder a recursos en ambos lados de la frontera.

Mollo habló con POSITIVELY AWARE después de la conferencia y compartió algunas de las complejidades y los factores interrelacionados que hacen que las personas binacionales sean cada vez más vulnerables al VIH, incluyendo el estatus migratorio, el estigma, la falta de acceso a un cuidado culturalmente competente y el historial del gobierno de los EE. UU. de negar la entrada a personas con VIH. Estos y otros asuntos hacen que los clientes binacionales sean vulnerables a abandonar el cuidado, o podrían hacer que renuncien al cuidado por completo.

Según el Informe de Vigilancia del VIH 2023 del ADHS, casi la mitad de las nuevas incidencias de VIH/SIDA reportadas el año pasado (405 de 975) eran Hispanas, y no se sabe cuántas eran binacionales en comparación a los residentes permanentes de Arizona. El equipo de Especialistas en Intervención de Enfermedades del ADHS que dirige Mollo se formó en el 2020 para coordinar los casos en los que los clientes binacionales dieron positivo en la prueba del VIH o la sífilis. “[Las pruebas positivas del VIH] podrían haber sido de servicios prenatales, o porque fueron a un evento de alcance o a un departamento de emergencias, o tal vez incluso fueron a donar plasma,” dijo. “Cada cliente es diferente.”

El seguimiento comienza con asegurarse de que la persona conozca los resultados de su prueba. “Luego tratamos de averiguar quién más pudo haber estado involucrado,” dijo. “Quiénes son sus parejas, quién más está a riesgo, para conectar los puntos y minimizar la propagación de la infección.” Los administradores de casos contestan preguntas y ofrecen referidos y recursos. La conexión a recursos puede ser complicada porque depende de qué lado de la frontera resida un cliente en un momento dado. En los EE. UU., la cobertura del VIH la proporciona el seguro médico privado, Medicare/Medicaid y los servicios Ryan White. En México, es una combinación de seguro privado, el ejército y tres organizaciones de servicios sociales.

No es sorprendente que los clientes necesiten un enlace para recibir atención más allá del VIH. Mollo recordó un caso en el que una madre con VIH dio a luz en una comunidad rural de Arizona, fue diagnosticada con HIV después del parto, antes de regresarse a México. Sabiendo que la madre necesitaba atención continua para ella y su bebé, el equipo de DIS encontró recursos en el lado mexicano de la frontera. Su esposo, que vivía en México, no pudo cruzar la frontera. “Sabíamos que él necesitaba atención [para el VIH], así que buscamos formas de poder hacerle la prueba y que recibiera atención de PrEP,” dijo. A partir de esa experiencia, DIS creó un directorio de recursos para casos de VIH/ITS maternos y congénitos.

El seguimiento a los clientes se realiza a través de correo electrónico, teléfonos de WhatsApp y teléfonos internacionales que se les dan a los clientes. El objetivo, dijo Mollo, es facilitarle las cosas al cliente. Con el tiempo, y a través de la colaboración y la comunicación entre los proveedores de cuidado de salud de ambos lados de la frontera, el proceso también se está volviendo más fácil para el equipo de DIS.

Mollo enfatizó que la migración en las regiones

> Para satisfacer la demanda, Arguello y sus colegas determinaron que la colaboración entre agencias era crucial.

fronterizas puede ser un proceso continuo en lugar de un evento único. A falta de un enfoque binacional de prevención del VIH, que requeriría recursos y políticas acordadas por ambos países, depende de los trabajadores de la salud y los defensores de ambos lados de la frontera, como el equipo de ADHS, mejorar el alcance.

Cómo la crisis migratoria afecta a la atención del VIH en Chicago

Una de las muchas consecuencias no deseadas de que los gobernadores de los estados rojos envíen migrantes a ciudades azules es el impacto en los proveedores de cuidado de salud. En Chicago, que ha visto llegar a decenas de miles de personas desplazadas de Centro y Sur América en los últimos años, los clínicos se han estado esforzando para brindar servicios y luchando para comprender sus necesidades particulares.

Es un hecho que los migrantes necesitarán cuidado de salud, y algunos tendrán VIH, incluso si no lo saben. Es probable que pocos tengan seguro de salud, e incluso los documentos necesarios para obtener cobertura, todos estos factores creando un creciente enigma para los proveedores. La creación de recursos para atender a los migrantes fue el tema de una presentación de Luricella Arguello, especialista principal en beneficios médicos de la Fundación de SIDA de Chicago (AFC). Arguello habló con POSITIVELY AWARE después de la conferencia y explicó que el hecho de que los migrantes se presenten en una ciudad donde no conocen a nadie presenta desafíos adicionales para los trabajadores que prestan cuidado.

"Lo que podría ser una conversación normal para alguien que ha vivido en los EE. UU. durante un tiempo, sobre seguros, deducibles, co-pagos, son algunas cosas con las que [los nuevos migrantes] no están familiarizados," dijo Arguello. Conseguir que las personas acudan a la oficina para calificar para la cobertura también puede ser un problema. "Aunque con Ryan White hay servicios para ayudar, como transportar personas a través de Uber, solo pueden utilizar esos servicios una vez que están inscritos en el programa."

AFC no es una clínica; es un intermediario para muchos servicios de VIH entre el estado y las agencias que brindan servicios clínicos, lo que significa que la carga recae sobre Arguello y otros colegas de AFC para ayudar a los colaboradores de cuidado de salud a manejar el laberinto de reglas para los beneficios para los migrantes. Ella dio un ejemplo de un migrante sin una identificación estatal, que generalmente requiere una llamada o un viaje a una oficina consular. Sin embargo, el consulado venezolano en Chicago ha estado cerrado durante años. Salvo una visita al consulado, un administrador de casos debe encontrar programas estatales que permitan a los clientes auto certificar su identidad y presentar todos los documentos que tengan para su caso de asilo. "Simplemente estábamos tratando de encontrar cualquier manera de ser creativos para ayudar a las personas a superar estos procesos," dijo Arguello.

Y no se trata solo de unos pocos clientes nuevos, explicó. La cantidad de solicitudes de beneficios médicos para víctimas de trata, tortura y otros delitos se ha disparado en los últimos dos años en Illinois. "Ni siquiera las personas VIH positivas, sino las personas en general, [Illinois] pasó de recibir quizás un ciento de solicitudes para ese programa a recibir un mínimo de 1,000 por día." Señaló que algunos migrantes que se presentan en una clínica con un problema de salud pueden o no informar al proveedor que tienen VIH y necesitan medicamentos. Es entonces cuando AFC recibe una llamada.

Para satisfacer la demanda, Arguello y sus colegas determinaron que la colaboración entre agencias era crucial. Crearon un equipo de trabajo para decidir qué recursos internos y externos estaban disponibles, y asegurarse de que todos los que atendían a los migrantes, especialmente en las clínicas locales Ryan White, estuvieran al tanto de esto. Elaboraron una lista de prácticas recomendadas para agilizar al máximo un proceso engorroso.

Arguello dijo que es esencial compartir recursos entre los administradores de cuidado de salud. "Intenten reunirse para compartir tanto sus luchas como los recursos que han encontrado, porque va a haber una variedad de sus colaboradores en la comunidad que tendrán las mismas luchas, y las mismas preguntas. Algunos de ellos ya han descubierto una manera de resolver algunos de los problemas que ustedes enfrentan."

Mollo enfatizó que algunas habilidades blandas también son útiles, incluyendo la capacidad de abordar a los clientes con humildad cultural. Porque el peligro de no ayudar a estas personas, enfatizó Arguello, es que se van a quedar sin cuidado. "Si no tienen vivienda ni comida, el cuidado de salud no necesariamente estará en el primer plano de sus pensamientos, al menos hasta que se enfrenten a un problema grave." PA

ISTOCK

Injectable lenacapavir 100% effective at preventing HIV in cis women

But advocates ask: Who will be able to access it?

BY **LARRY BUHL**

Excitement generated by stellar results from the PURPOSE 1 trial evaluating the effectiveness of lenacapavir (LEN) in preventing HIV among cisgender women was tempered by a demand for lower prices and equitable access for this PrEP medication. Injectable LEN, which offers an alternative to a daily pill, was deemed 100% effective in preventing HIV, according to newly released data from a double-blind, randomized trial of cisgender women in South Africa and Uganda.

Sponsored by Gilead Sciences, the study showed that its lenacapavir injection once every six months provided total protection against HIV. The results were so impressive that the drug maker halted the study early, in June, and allowed all participants to receive injections.

Starting in August 2021, 5,300 women were separated into two study arms: 2,134 participants received an injection while the rest took a daily pill, either F/TAF (Descovy) or F/TDF (Truvada) for PrEP. Of the women taking F/TAF, 39 acquired HIV during the study period, a rate of 2%. Of participants taking F/TDF, 16 (1.69%) acquired HIV. No one who received lenacapivir injections acquired HIV. LEN was considered safe and well tolerated. Injection site reactions, including nodules, pain or swelling, were observed after 68 percent of all injections, but most were minimal and decreased with subsequent doses, according to presenter Linda Gail-Bekker, chief operating officer of the Desmond Tutu HIV Foundation in South Africa.

The PURPOSE 1 data published last month in the *New England Journal of Medicine* showed that the difference in the study arms was likely a result of adherence rather than an issue of effectiveness of the oral medications. This has been an issue for years with studies of oral PrEP. Researchers measured the amount of medicine in the blood of some participants and estimated that they had taken fewer than 2 tablets per week, far less than the recommended dosage. However, 92% of those in the lenecapavir arm received timely injections. That tracks with a growing body of research suggesting that oral PrEP, while highly effective in preventing HIV, is often not taken as prescribed for a variety of reasons.

breakthroughs in medicine “are only meaningful when the **people who need those medicines can access them.**”

SHARON LEWIN, IAS PRESIDENT AND INTERNATIONAL CHAIR, DURING THE OPENING THE SESSION.

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“Twice-yearly LEN offers an efficacious, safe and discreet choice to improve PrEP use among cisgender women and reduce the global burden of HIV,” Gail-Bekker concluded.

Lenacapavir was approved by the FDA in the United States for multi-drug resistant HIV treatment in 2022, but it’s not yet approved in the U.S., or anywhere else, for PrEP. PURPOSE 1 is the first clinical trial of the drug for preventing HIV and is part of efforts to increase HIV prevention across the Global South.

A PURPOSE 2 trial is currently measuring the effectiveness of lenacapavir among cisgender men, transgender men, transgender women and non-binary people who have sex with male partners across Argentina, Brazil, Mexico, Peru, South Africa, Thailand and the U.S.

The PURPOSE 1 demographics are significant: sub-Saharan Africans comprise an estimated two-thirds of people living with HIV worldwide. According to UNAIDS, approximately 4,000 teen girls and young women in Africa acquire HIV every week. In theory, lenacapavir would be a game changer for these populations in low- and middle-income countries if it were available and affordable, advocates say.

Advocacy groups demand affordable access

Advocacy groups, while sharing enthusiasm about lenacapavir as a PrEP option, say its potential to stop HIV can only be realized through rapid access and low cost. In a letter to Gilead, the People’s Medicine’s Alliance, with

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the support of more than 300 signatories, urgently demanded that the drug maker license lenacapavir for cheap generic production via the Medicines Patent Pool. In the closing session of AIDS 2024, IAS outgoing president Sharon Lewin alluded to the need for affordable PrEP worldwide, saying breakthroughs in medicine "are only meaningful when the people who need those medicines can access them."

Pricing analysis presented at AIDS 2024 estimated that LEN could be priced at one thousand times less than Gilead's price of $42,250 per year. The analysis said that would be equivalent to $100 USD per person per year at first, and later at $35–40 through mass production of generics under a voluntary licensing ramp up.

Gilead has not committed to any numbers, but in a statement said the company will deliver lenacapavir "swiftly, sustainably and in sufficient volumes, if approved, to high-incidence, resource-limited countries." Gilead's access strategy includes developing a voluntary licensing program that would enable generic versions to be produced before the original patent expires.

Many access advocates are not assured by the lack of specificity in Gilead's statement. At AIDS 2024 a coalition that included Médecins Sans Frontières (MSF; known in the U.S. as Doctors without Borders), called on the company to quickly make lenacapavir accessible and affordable worldwide.

In 2022 the World Health Organization called on countries to consider the first long-acting drug for PrEP, cabotegravir (CAB-LA), manufactured by ViiV. But CAB-LA is still inaccessible in many low- and middle-income countries, and cost is a main barrier. It is estimated that 1.3 million people worldwide acquire HIV every year, or one every 24 seconds, with a quarter occurring in countries Gilead routinely excludes from licensing deals, including Russia, Brazil, the Philippines, Ukraine and Thailand. According to MSF's Access Campaign, HIV organizations in India, Argentina and Vietnam, including the Thai Network of People Living with HIV, Fundación Grupo Efecto Positivo and the Vietnam Network of People Living with HIV, have filed oppositions against Gilead's lenacapavir patent applications.

LARRY BUHL is a multimedia journalist based in Los Angeles. He has covered HIV/AIDS and other infectious diseases for more than two decades. In addition to POSITIVELY AWARE, he is a regular contributor to TheBody.com, Everyday Health and capitalandmain.com. His work has appeared in USA Today, Salon, Undark, KQED, The New York Times and others.

DoxyPrEP significantly reduces STIs

BY **LARRY BUHL**

Results from two small studies showed that doxycycline pre-exposure prophylaxis (doxyPrEP) can effectively prevent sexually transmitted infections (STIs) when taken before sex.

The antibiotic doxycycline has been around for nearly six decades and is commonly used to treat a number of bacterial infections, but its use for prevention is relatively new. There is a large and growing body of evidence showing that doxycycline, taken within 72 hours after sex—a strategy known as doxyPEP—can prevent bacterial STIs, and even lower the rates of STIs community-wide. In June, the Centers for Disease Control and Prevention issued guidelines for doxyPEP to reduce bacterial STIs among gay and bisexual men and transgender women.

Two studies presented at AIDS 2024 suggest that doxyPrEP could provide similar benefit.

DoxyPrEP led to an 80% reduction in STIs among men who have sex with men

Troy Grennan, MD, MSc, a clinical associate professor at the University of British Columbia, shared findings of a randomized controlled trial that studied the efficacy, tolerability and use patterns of doxyPrEP. The trial included 52 men who have sex with men, all living with HIV and having a history of syphilis, in Toronto and Vancouver, Canada. The men were randomized to receive either a daily dose (100 mg) of doxycycline or a placebo. Adherence was measured through blood tests to measure the amount of doxycycline used, and researchers concluded nearly 80 percent took the medication throughout the trial period.

The outcomes were significant and in line with studies showing the efficacy of doxyPEP (post-exposure prophylaxis). Among the 41 (78.8%) participants who finished the 48-week study, there was a 79% reduction in syphilis, a 92% reduction in chlamydia and a 68% reduction in gonorrhea in the doxycycline arm compared to the placebo arm. The trial controlled for any differences in drug adherence or sexual behaviors. Three participants developed resistance to doxycycline, but Brennan said that because the number of people who developed resistance was small, it was hard to draw any definitive conclusions.

> **"People often prefer to take a pill daily [for STI prevention] because they're already taking pills for other reasons…"**

The researchers also looked at tolerability and side effects, and found no difference between the doxyPrEP and placebo arms, Grennan said at a press conference held before AIDS 2024. "People often prefer to take a pill daily [for STI prevention] because they're already taking pills for other reasons," he said.

The findings support further evaluation of doxyPrEP compared to doxyPEP in an ongoing larger trial, he said, and to that end, he added that his team started recruiting people for a larger, nationwide doxyPrEP trial and plan to have more than 500 participants by the summer of 2025.

Right now, doxyPrEP isn't the standard of care for people who are most vulnerable to bacterial STIs, but Grennan thinks it should be. "**I think it's reasonable in many situations to prescribe [doxycycline] if it's indicated, as long as you're having a reasonable conversation with your patients about the pros and the cons and the unknowns**," he said.

"I think we need to move this research towards... other key populations like cisgender women and youth who are always ignored in STI and HIV research. And we need to do some work on implementation of these interventions in an equitable way."

It should be noted that the CDC's guidelines for doxyPEP were limited to men who have sex with men and to trans women because a recent clinical trial of doxyPEP among cisgender women in Kenya did not demonstrate any benefit.

Syphilis vanished for female sex workers on doxyPrEP

A second study presented at AIDS 2024 showed a significant benefit for ciswomen who took doxyPrEP. Researchers looked at the feasibility, tolerance and efficacy of doxycycline for STI prevention for female sex workers (FSW) in Tokyo, Japan. In this retrospective cohort study, started in October, 2022, 40 FSWs with a median age of 29 years were selected from a larger group of 96 who sought care at a private STI clinic. Researchers were looking for the difference doxyPrEP made in the rates of Chlamydia trachomatis, Neisseria gonorrhoeae, and syphilis. All women were offered a choice of doxyPrEP (100 mg daily) or doxyPEP. Six of 96 chose to take only post-sex (PEP) doses, and were excluded from the study, as were 50 women who did not take STI tests either before or after starting doxycycline.

Though there was no placebo group, researchers studied the efficacy of doxyPrEP by comparing incidence rates (per 100 person-years) before and during doxyPrEP use. They also examined abnormalities and antimicrobial treatment in the vaginal microbiome through microscopic examination of vaginal smears every 1–3 months. The team used surveys to measure adverse events and user satisfaction.

Almost all participants adhered strictly to doxyPrEP and none reported severe adverse events related to doxycycline, according to presenter Seitaro Abe of the National Center for Global Health and Medicine in Japan. Notably, most of the women—95%—used condoms, both before and during the study. In surveys, **nearly three-quarters of participants said they had less anxiety about acquiring STIs while on doxyPrEP**.

There was a notable reduction in STIs. Before doxyPrEP, the overall STI incidence rate was 232.3 per 100 person-years among the 40 participants. After initiating doxyPrEP, the overall rate of all STIs declined to 79.2 per 100 person-years. The most stunning finding was that syphilis incidence vanished: an 8% annual incidence rate prior to taking doxycycline turned to zero infections.

The findings translated to an average efficacy across all three STIs of 67%. In terms of STI incidence, the rate for all three STIs fell from 108 to 18 new cases. For chlamydia, the rate fell from 74 to 13 cases; gonorrhea fell from 26 to five cases. Syphilis dropped from eight new cases to zero. Abe said the reduction in chlamydia was "marginally significant," but the reduction in the incidence of gonorrhea was not statistically significant.

There was also a reduction in bacterial vaginosis, from 36 to 23 cases, as well as candidiasis, from 18 to 12 cases.

In follow-up interviews, nearly one out of four reported occasional nausea and vomiting, but no serious doxycycline-related adverse events. And even when they experienced nausea, among the 22 women who completed surveys, 73% never missed a dose, even on days they didn't have sex, according to Abe.

Abe concluded saying the findings "support the introduction of DoxyPrEP in populations that are highly vulnerable to STIs."

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WELCOME TO THE PREVENTION CHOICE AGENDA.

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What the next Berlin patient means for HIV cure

BY **LARRY BUHL**

A case study of the seventh and latest person to be apparently cured of HIV was presented at the International AIDS Conference in Munich in July, raising hope, and more questions, about genetic determinants and functional cures for people living with HIV. A key to this functional cure is genetics: the so-called next Berlin patient and his stem cell donor both have a single copy of a rare genetic mutation that prevents HIV from entering cells, according to a case study.

A rare mutation also aided in the functional HIV cure for the first Berlin patient, Timothy Ray Brown, who was diagnosed with HIV in 1995 while living in Berlin. Brown received two stem cell transplants harvested from a donor with a rare homozygous C-C chemokine receptor 5 (CCR5)-delta 32 mutation. Although the transplants were meant to treat only Brown's leukemia—and they did—they also eradicated HIV infection, and he remained in HIV remission until his death in 2020.

Since then, six other people achieved HIV remission, all after stem cell transplantation, including a person dubbed “the Geneva patient,” with results presented at the 12th International AIDS Society Conference on HIV Science in Brisbane, Australia, last year.

In an oral abstract presentation Christian Gaebler, MD, of Charité University of Medicine in Berlin explained the apparent success of an anonymous man called the next Berlin patient, a 60-year-old German man who tested positive for HIV in 2009 and was diagnosed with acute myeloid leukemia (AML) in 2015. The man stopped antiretroviral therapy in 2018, approximately three years after receiving a stem cell transplant as treatment for AML. The clinical team at the Charité-Universitätsmedizin hospital in Berlin reported that this patient remains virally suppressed almost six years later.

After nearly six years, the second Berlin patient's plasma viral load remains suppressed, and he has no detectable HIV DNA in peripheral blood cells, Gaebler said. In addition, researchers could not induce virus production from his CD4 cells in the lab. No HIV-specific T cell responses were detected, and his HIV antibodies have been decreasing, which Gaebler said suggests there is no remaining virus to trigger an immune response.

SS04: CO-CHAIRS' CHOICE SESSION
CHRISTIAN GAEBLER, MD, OF CHARITÉ UNIVERSITY OF MEDICINE IN BERLIN

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“We see waning HIV-specific antibody and T cell responses and we really think that effective reservoir reductions, durable HIV remission and potential cure can be achieved with functional viral co-receptors,” he said. “And we believe that allergenic immunity really fundamentally contributes to HIV eradication.”

The speed at which the new immune system replaced the old one might play a part in the quick depletion of the HIV reservoirs, Gaebler said, in a press conference just prior to AIDS 2024. “In the second Berlin patient, that was done... in less than 30 days. But the donor's immune system might also have special characteristics, such as highly active natural killer cells, which ensure that even minor HIV activity is detected and eliminated.”

Gaebler defined an HIV cure as enabling a person living with HIV to safely stop therapy and live a long and healthy life. “And this includes strategies for achieving HIV remission through reservoir modulation or immunological control, but also the eradication of the HIV reservoir.”

Gaebler and other experts have emphasized that stem cell transplantation cannot be used as a standard treatment for HIV because the procedure is too risky for people who don't have life-threatening malignancies.

The mutation

Genetics likely played an important role in depleting the next Berlin patient's HIV reservoir after the stem cell transplant. Four of the previous six patients who received stem cells from donors with homozygous CCR5-delta 32 mutations experienced sustained viral suppression after interrupting ART. The second Berlin patient had a single copy of the CCR5-delta 32 mutation, known as heterozygous. While CCR5-delta 32 heterozygous people can acquire HIV, the mutation causes the disease to progress more slowly. Less than 20% of Northern Europeans have a single copy of the mutation, and about 1% have two copies, meaning it was inherited from both parents, Gaebler said.

The common denominator in four of the seven people cured with stem cell transplants is the CCR5-delta 32 mutation, whether heterozygous or homozygous, Gaebler said. “What I think is happening is this combination of effects between allogenic stem cell transplantation and donor immunity, in addition to, in the case of homozygous CCR5 mutation, an additional safety layer... contributes to these successful cases of long-term HIV remission. We're shifting a little towards the allogenic immunity part that is leading to the depletion of the HIV reservoirs and thinking that CCR5 is an additional safety layer that gives us protection with a resistant immune system.”

Sharon Lewin, MD, PhD, the outgoing IAS president and the director of the Peter Doherty Institute of Infection and Immunity at the University of Melbourne, agreed that viral remission might not be only due to the CCR5-delta 32, either heterozygous or homozygous. In a press conference, Lewin said that multiple factors, differing from patient to patient, may play a role in remission. Lewin added that the seven patients who’ve experienced long-term HIV remission from stem cell transplants can be a positive sign for HIV cure research because they suggest it’s not necessary to eliminate every piece of CCR5 for gene therapy to work. “[With] every case, you learn more about what is possible and what could be mimicked in an intervention,” she said.

> **A key to this functional cure is genetics: the so-called next Berlin patient and his stem cell donor both have a single copy of a rare genetic mutation that prevents HIV from entering cells**

A study of people with HIV who received allogeneic stem cell transplants recently showed that factors beyond CCR5-delta 32 mutations, such as the immunity of the donor cells, may affect the HIV reservoir after transplantation.

Gaebler noted that it’s possible that the second Berlin patient could relapse in the future, but added that the length of time he had been in remission means viral rebound is unlikely.

LARRY BUHL is a multimedia journalist based in Los Angeles. He has covered HIV/AIDS and other infectious diseases for more than two decades. In addition to POSITIVELY AWARE, he is a regular contributor to TheBody.com, *Everyday Health* and capitalandmain.com. His work has appeared in *USA Today*, *Salon*, Undark, KQED, *The New York Times* and others.

MEETING IN MUNICH: (1) SHARON LEWIN, BEATRIZ GRINSZTEJN (2) AT THE CONFERENCE (3) JUMOKE PATRICK (4) BIRGIT PONIATOWSKI, IAS EXECUTIVE DIRECTOR (5) WINNIE BYANYIMA, UNAIDS (6) VOLUNTEERS’ GROUP PHOTO (7) DELEGATES AT THE RECEPTION (8) PERFORMERS OF THE BAVARIAN TRADITIONAL FOLK DANCE CLOSING THE OPENING SESSION

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Sex talk: Mixing pleasure with prevention

Sexual health activists Damon Jacobs and Rodney McCoy talk about making the conversation more fun

BY **ROD MCCOY** AND **DAMON L JACOBS** • PHOTOGRAPHY BY **JIMELL GREEN**

Avoid death and destruction! STI prevention can be so grim. But it doesn't have to be. Talking about STIs doesn't need to fill people with dread. Bringing prevention information out of the dark ages is part of the Sex Talk *interview with sexual health activists* **Damon L. Jacobs** *and* **Rodney McCoy, Jr.** *They illustrate the need to allow the idea of fun and pleasure into the conversation.*

DAMON JACOBS: We've been asked to interview each other on the topic of pleasure and fun in sexual health. I got stuck on *fun*, not because I don't like it, but let's be honest. The words *sex* and *pleasure* until recently weren't applied to HIV prevention.

RODNEY MCCOY, JR.: I have been working or volunteering in this field, on one level or another, since 1991. And I don't think the topic of fun has been integrated into that until relatively recently—I'd say the last 10 years. *Fun* for me is just a general sense of something that brings me a sense of being alive.

So that can be sexual pleasure. Or it can be playing board games. It can be exercise. It can be whatever gives somebody a sense of feeling alive in their body. Something you just do because you enjoy doing it.

I started in HIV prevention when I was 18, at Oberlin College. The sexual information center had a need for educators in the dorms. And there was this thing called HIV. Well, at the time, it was GRID [gay-related immunodeficiency]. People were trying to figure out what exactly it was. And I think because of the seriousness of AIDS, because people were dying, and people who look like me, and then returning to New York, where there was ACT UP—there was all this anger and rage because you had governments at the federal and at the local level that not only did not know what to do, but were not invested in doing anything. We're willing to let people die and families be torn apart because of their own sense of morality. Let's call it what it was. So the idea of fun really did not enter into our head, certainly not mine. It was all very serious business.

I would say that in the past maybe four years now, we're talking about sex and pleasure as important, integral parts of HIV prevention. I looked up *fun* for this talk and found *something that brings joy, something that brings pleasure, something that brings delight.* And I've been thinking, *how is that necessary for HIV prevention?*

When a person comes for services, they may be dealing with a whole lot of life stuff. It could be stigma, it could be racism, homophobia, sexism, misogyny, assault, homelessness—all those things. If the care encounter, the testing, the diagnosis, the treatment really doesn't take care of the person, if it reinforces feeling bad, how can I support you in feeling good?

I often think that because of the work you do as a therapist, that it would be easier for you to help your clients start thinking about the sex that they want to have.

DAMON: Yeah, it's this idea that fun is important. Fun is a relevant, meaningful part of life. It's not ancillary to all the services that you were talking about. Meanwhile, we've got other stuff to attend to here, because we have boxes to check and we have grant writers and we have testing to do and pills for you to take, and we leave out the fun. Organizations are like, *Well, that's secondary*. For me, mental health and sexual health are one and the same. They're highly correlated. And when we help people find the mechanisms by which they can effectively seek out that fun, to say *yes* to their *yes* and *no* to their *no* and *maybe* to their *maybe*, then we get to participate in the process of someone experiencing extended amounts of fun, extended amounts of pleasure and consequently, extended amounts of good mental health.

ROD: POSITIVELY AWARE asked us to also integrate kink into this. *Kink* is anything that gives pleasure, that causes sexual and erotic arousal, to the point of orgasm or not, that is outside of the missionary sex position. I think that there is a stigma around kink, and one of the things I like doing with my kink workshops, whether it's the Beyond the Red Ribbon training or a play workshop specific for the kink and leather communities, is break down that stigma. *For those of you who are uncomfortable around kink, let's have an honest, grown folk conversation. Are we all grown folks in the room?* And people are quick to say, *Yeah, we're grown*. Okay, so let's go there. If we have sex, do you like getting your ass spanked, or do you like slapping some ass while you're having sex? Do you like having your hair pulled? Do you like having your nipples teased? Do you like dirty talk? Do you like someone holding you down where you can't move, or restraining a part of your body, if not your full body, while you're having sex? And you can see the eyes light up. You can see the lightness and the understanding going across people's faces. I'll say, *Congratulations. You just crossed into the realm of kink*. I tell my colleagues, why wouldn't you want to bring that light to the testing room?

Looking back in the almost 40 years I've been in this, HIV prevention has been so serious, so doom and gloom, because there was a lot around HIV we didn't understand. So our default when we don't understand something is to be afraid of it.

> ***Fun*** for me is just a general sense of something that brings me a sense of being alive.

When we understand it, that helps us relax. It empowers us to take control, to take ownership. I prefer the word *ownership*: to take ownership of our sexuality, of our sexual health. When I demystify kink, when I demystify sex and talking about it, we see that it doesn't have to be accompanied by giggles. It becomes something that yes, as grown folks, this is what we can and need to be okay with talking about. Okay, so how can we keep you being sexually active and reduce your worry around HIV or gonorrhea or chlamydia or whatever you're in this space for. People are more willing to have those conversations.

I did a presentation at a high school in Virginia, and one brilliant young man brought up stigma, and he asked, *Do you think people see HIV as a scary monster, so that they don't want to talk about it or make jokes about it, so it seems less scary?* And that made me stop and think. That's what stigma is. This young man, at 15, understood stigma, that that's how it works. That people have these defenses against it because it's so scary.

That's why for me, in talking about kink and about sex, we really empower people. We don't scare them away from prevention, but we help move them toward it. To say, *I can take control. I can take ownership of my own body, of my own sexual desires, of my own health*.

DAMON: When you walk into an HIV testing site and you're sitting there, that tester can have a lot of power. Emotionally, that person has the power to shame and condemn.

I want you to tell more about your story, not just your thoughts.

ROD: I know what led you to your PrEP work, and why you are so passionate for PrEP, and I would like for you to share that first.

DAMON: I have always wanted to be a therapist. I've always wanted to be a healer. And I was coming of age at a time when HIV and AIDS in the Bay Area of California was ravaging the community. My training academically was clinical, meaning you kind of sit in your office. Patients come in and they tell you about their past, and then you try to help them feel better. But that wasn't reflecting the reality of the times that we were living in. It wasn't about the past. It was the immediate here and now, grief and trauma that was happening that was devastating our community, physically and spiritually and emotionally. For me, it meant that if I was going to be serious as a healer in the '90s, it's not about just sitting on your ass in a clinic all day. It means being active, doing something, anything, to fight HIV and AIDS. So I was getting involved in volunteering in HIV prevention and talking about condoms and harm reduction. When I learned about PrEP in 2010, it was a time when my primary relationship was coming to an end, and I was turning 40 and really thinking about HIV as an inevitability for me, meaning that we weren't going to see a vaccine or a cure anytime in the near future. I'm like, *How much of my life has to be consumed by fear of HIV? I'm so sick of this. I'm so tired of all of my sexual fun being dominated by the fear of what might happen, I might as well get it over with. I'm probably not going to die of HIV at this point [if I acquire it]*. So my mind was registering that HIV was a *when*, not an *if*.

Then I learned about PrEP, and this new science, and this new study called iPrEX, showing that if you take Truvada—at the time, they were saying every day—that you would have 99% protection from HIV. And I thought, *Oh, so I could take a pill and then have the kind of sex I want to have, and I don't have to worry about condoms, and I don't have to get HIV.* And suddenly it was like, Yeah, this is for me. So I started using PrEP July 19, 2011.

And then, because I wasn't feeling empowered to talk about that openly, but I talked to a person who talked to a person who talked to a person, eventually that led to an opportunity to go on Huffington Post Live to talk about this with Alicia Melendez, who is now on MSNBC. And I thought, *Okay, God doesn't make mistakes. If I'm being given an opportunity to do this in such a public way, that means that I'm meant to have it. It also means I've got to ditch this whole traditional model of 'professional self here, slutty self there.' It's time to integrate that, because if I don't, if I don't talk openly and honestly about PrEP and the celebration of sex, I'm going to be shortchanging this opportunity to help other people learn about it.*

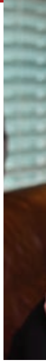
I felt like my impact in the HIV prevention community took on a different level, making space for other people to be able to be transparent and think about PrEP and sex as something that is jubilant, that we celebrate, not cower away from in shame. We really start to take back the power and the energy and the fun around that, and how different it feels when we do that together.

ROD: I'm feeling a lot right now, because I think there is a parallel intersection in our stories. The pivotal time for me was when I was first diagnosed, and I remember feeling a lot of shame about having HIV.

DAMON: Can we talk about that?

ROD: Yeah, so I was diagnosed January 29, 2002. At that point, I had been in HIV prevention for 16 years. I was in a relationship with someone. We were monogamous. I had been tested a few months prior. He said that he had been tested, so we made the decision to not use condoms. So when I did find out I was HIV-positive, there was a lot of shock. There was a lot of anger. There was also a lot of shame. A good part of that shame was, here I am in HIV prevention, telling other people what to do.

I went to my bishop at the time, Bishop Zachary Glenn Jones—I'm going to give him his props—and saying this is what happened. Among the things he said was, *If you decide to stay in this field, what do we need to do to make sure the messages of prevention click?* And sitting with that, the first thing that kept coming to me was, *Tell the truth*. Yes, sometimes I used condoms, even as I told other people to use condoms all the time. And if someone had the nerve, the audacity, to even suggest that they didn't like condoms, I was like, *No, you've got to use them every single time*. I was so hip to toeing the party line, saying the message that was expected of me, I did not allow space for anyone else, including myself, to tell the truth. I didn't always like using condoms my own self, especially when I was topping. And when I was dating monogamously, I was like, *Okay, I don't need to use condoms*, or just, *I trust you*.



DAMON: Why weren't you honest?

ROD: Because I worked in an industry that was not. That's why PrEP was such a game changer, because it finally felt safe and necessary to tell the truth. And dare to finally say, *I don't like using condoms; here's an alternative*. By the time PrEP came out in 2012, to be honest with you, as happy as I was, I also resented it because I already had HIV. It was not an option given to me. I was already 10 years into HIV living with me.

That's why, for me, doxy-PEP is another game changer. [**SEE** "Briefly."] It means a lot to me because I'm going back to the resentment I felt around PrEP. So I do get emotional sometimes when I think about it, that I could now be part of the conversation around something other than condoms that would protect me as someone who is HIV-positive. Doxy-PEP is one of the few things in this industry that is truly status neutral [a healthcare standard referring to care for people both living with HIV or HIV-negative]. By the way, I don't believe in *status neutral*. I do believe in *status inclusive*.

Also, doxy-PEP takes away probably one of the biggest barriers from providers who are against PrEP. *Well, PrEP doesn't protect against STIs*. Well, bitch, now here's something that does, that you can use in conjunction with PrEP.

You know this, that [care providers are] still resistant to doxy-PEP, and it really is a sexual pleasure resistance. Because when people say to me, *Oh, well, we don't know how much doxy-PEP is going to hurt people who take it in this way*, I'm like, *Don't play me for a fool*. We use doxycycline to treat syphilis. We use doxycycline to treat acne. We use doxycycline in larger doses for longer periods of time to treat other conditions with not a bat of an eye. But the moment we talk about using doxycycline to treat and prevent STIs so that people can enjoy sex the way that they want to, and reduce their worry around STIs, particularly bacterial infections, now there's an issue? Don't blow smoke up my ass and tell me that's the problem. No, this is still about sex negativity, particularly homo sex negativity, because that's the context in which we talk about doxycycline.

I love talking to women, trans folks and straight men about doxy-PEP. People are like, What? *Oh, I'm interested. Can I learn some more?* PrEP is only for people who are HIV-negative and treatment as prevention [also known as U = U] is for people like myself who are HIV-positive and who by staying on our medications can be undetectable and therefore not pass on HIV and can still enjoy the sex that we like. Anyone can use doxy-PEP.

I'm so excited for it, even as I see some of the trends that we saw 12 years ago in terms of the rhetoric against PrEP. We didn't learn our lesson, but that's why you've got old heads like me and like you to say, *Oh, didn't we have similar conversations about PrEP 12 years ago, and whatever happened to the mass drug resistance that we were so concerned about around PrEP? The superbug? Gurl, where's the superbug? What happened?*

DAMON: Growing up in the 70s, not even understanding what sex was about, I would see the hairy chests of guys on TV and knew I wanted to do something with them. I didn't know what, but I also knew I couldn't—that I shouldn't. There was something wrong with that, something bad. Then I was about 10 years old when the AIDS crisis started being reported. So I was coming of age and starting to understand my desires for men in a time when I knew that if you were to do something about that, you could die. Everything in my mind has been embedded to associate sex with fear, to associate pleasure with fear. The thing that began to shift that for me was PrEP.

However, just because I started using PrEP didn't mean the fear went away. There was still the fear of, *What if?* Because it was a habit. What about gonorrhea? What about syphilis? What about all these things that everyone was telling me I should be afraid of? And then when doxy-PEP came around, it was like I can be *proactive, responsible* and *empowered* about my pleasure and protection in this way. And what a liberating experience this continues to unfold for me in my 50s, to say I don't have to associate sex and pleasure with something traumatic or devastating or deadly.

ROD: There are cultural things that we need to keep in mind. As African Americans, we have a different history where our sexuality was actually abused and used against us. Rape, forced labor, separation of families, a basement where wives were raped in front of their husbands, just to name a few. That has had an impact on how we as African Americans talk about sex, definitely in terms of how we talk about kink.

So by virtue of the fact that we're male or gay, or by the color of our skin, we may not be the one to talk to. We as an industry have to be okay with that, to say different people may have different needs and may have different languages and different experiences. I'm not always so quick to talk with women, for example, about sex and sexuality, or at least I'm careful.

There is a truth that if you keep doing the same thing over and over again, but expecting different results, it is insanity. As an industry, we have been talking about risk and death and disease as motivators for people to make behavior change. *Honey, it doesn't work.* Talking about sex and pleasure is our opportunity to stop being insane and to do something different.

This is too much of an issue for us to hide behind cultural fears of *we can't talk about that.* We can talk about that, and we need to.

DAMON: CDC data tell us that more than 50% of new HIV diagnoses are coming from nine states in the South. Do you think that this message of pleasure and fun and kink and celebration—does that translate to the communities that are most impacted by HIV today?

ROD: Yes. The South has traditionally been a more conservative part of the country. That doesn't mean that people don't want to talk about sex. It doesn't mean that people don't want to talk about fun. It doesn't mean that people don't want HIV prevention. Now, there may be a generation of folks who still feel it's wrong, bad or not necessary. But I think that's changing. So once upon a time, it would have been *Oh, hell no.* I think right now it's, *Oh, hell yeah.* The numbers don't lie.

DAMON L. JACOBS is a family therapist and founder of the PrEPFacts Facebook page. He is the author of Absolutely Should-Less: The Secret to Living the Stress-Free Life You Deserve.

RODNEY (ROD) MCCOY, JR. is a research assistant at Us Helping Us in Washington, D.C. He created a sex positivity training for public health professionals called Beyond the Red Ribbon in collaboration with Louis Shackelford of the HIV Vaccine Trials Network.

ISTOCK

Sex-positive kink

BY **RODNEY McCOY, JR.**

Many years ago I received a notice from the state Department of Health to come in for a follow-up STI counseling session. I was not happy about receiving a gonorrhea diagnosis and didn't want to do this part of the STI treatment process. But when I saw that my counselor was a colleague, a kind Christian woman with whom I had quite a few pleasant interactions, I thought maybe the session wouldn't be so bad.

I was so wrong.

When I admitted to having multiple sexual partners, she gave me a stern lecture about how I needed to find a man to settle down with and just be monogamous, and that was the best way for me not to catch diseases. When I tried to voice my objections and concerns, she talked over me by repeating what she had said. After a while I just muttered "okay" to whatever she said, not paying attention. As I left her office, she smiled softly and said "I love you."

As a result of my experience, I never returned to that clinic. **Nor did I encourage people to go. Our negative provider experiences have ripple effects.**

It's because of experiences like the one I described above, as well as experiences as a provider where I was judgmental with clients, that I began to explore and embrace sex positivity and pleasure-based strategies in my work.

What do I mean by "sex positivity?" I use this definition courtesy of the International Society of Sexual Medicine: It involves having positive attitudes about sex and feeling comfortable with one's own sexual identity and with the sexual behaviors of others. I also like the definition of pleasure-based strategies, provided by the Pleasure Project: "A pleasure-based approach is one that celebrates sex, sexuality and the joy and well-being that can be derived from these... It focuses on sensory, mental, physical and sensual pleasure to enable individuals to understand, consent to and gain control over their own bodies and multi-faceted desires."

In an industry that centers around a virus that is transmitted primarily via sexual activity, one would think that talking about sex and pleasure in an affirming way would be a "given" for HIV prevention. It is not. For far too long, talking about HIV prevention and sexual health in general has been mired in fear of disease and death.

One thing I have learned about sex positivity is there is no room for proselytizing in relationships, including the consumer/provider relationships. What do I mean by that? Most of us associate "proselytizing" with religious persuasion. We may understand that the provider space is not the space to push our religious beliefs onto consumers who come to us for service. Yet **we cannot let our own sexual beliefs and behaviors dictate what we tell our clients.** For example, as someone who is non-monogamous, my colleague did me no favors by directing me to "marry, or at least settle down."

I wasn't ready for that at the time. By the same token, I have to honor the consumers who tell me that they are monogamous, and further explore ways to reduce their concerns about STIs and still enjoy the sex they want. (I prefer the word *consumer* because ironically, I think *client-centered* still suggests a power dynamic that says we as the provider have the power, access and means, and you still rely on us. *Consumer* recognizes that the person who comes to our space for services is actually operating in agency, in self-determination. It's not desperation, it's *agency*, particularly if they have insurance that pays for them. There are plenty of places they can go to.)

'A pleasure-based approach is one that celebrates sex, sexuality and the joy and well-being that can be derived from these...'

This speaks to the public health principle of "client-centered care." Focusing on the needs and desires of the people who come to us for services results in a safe space for HIV prevention and care. Why is this important? Many of us in HIV prevention may be familiar with the "HIV care continuum," also known as the *Gardner Scale*. This measure of the effectiveness of HIV prevention and care efforts is represented by five bars, signifying diagnosis, linkage to care, treatment, retention and virus undetectability. I want to acknowledge my friend and colleague Louis Shackelford, who introduced me to the concept of the "Bar before the Bars." It's an expansion of the care continuum that acknowledges that consumers (and providers) bring a host of experiences to an encounter that may act as barriers to accessing services.

I cannot mention how many times consumers come to the provider space with their stuff (anxiety, shame and fear) if they need to get tested for STIs, particularly HIV.

As a provider, I don't need to add to that. **As a provider, I need to teach and reinforce that pleasure is an integral part of sexual health, even when accessing sexual health services. This is where "fun" comes in. Knowing that consumers may be feeling bad about needing to come to the clinic, I do my best to make the experience as "light" as possible.** When a client feels embarrassed about having multiple partners, I congratulate them on being "sexually successful" (borrowing a phrase from a colleague). When consumers get concerned that they are "ticking off" so many boxes in their sexual history, I share that I am also sexually active (without going into details), so there is no judgment from me about their behaviors. People are coming in saying, *You can't relate to what I go through*. Sometimes we do need to bring ourselves into the conversation, to say, *Yes, I have gone through the same thing*. I don't make it about me, but I bring empathy. Even when there's embarrassment over a gag reflex with the throat swab, I gently remind them (with a smile) that this is not "the same thing," so such a reflex is fine. I have found that after the laughter and smiles, clients are not only more open to discussing prevention methods to reduce their STI concerns but are also more open to discussing treatment options if they get a result they don't expect.

I hope my experiences show that, as providers, we can communicate with our communities about sex and sexual health without shame, judgment or awkwardness. And contrary to how many of us have been trained, we can bring our full selves to the provider space and still offer consumer-centered services.

RODNEY (ROD) MCCOY, JR. is a research assistant at Us Helping Us in Washington, D.C.

You say **‘whore’** like it’s a bad thing

How stigma fuels the HIV epidemic

BY **ENID VÁZQUEZ**

COLLAGE: DAVID DURÁN

***The following opinion piece** first appeared in the POSITIVELY AWARE Summer 2015 special issue on PrEP. The fabulous David Evans, super-smart and always kind, served as guest editor. A great writer and editor, he worked at the time with Project Inform, a national HIV treatment information service based in San Francisco that has, unfortunately, closed. I will always remember how David gently led me to cut back on the issue of sexual assault. The statement that remains here serves its purpose of awareness. David was concerned about adding stigma to men living with HIV. He was correct, of course. One other note: we no longer use the word “risk” around HIV acquisition. Rather than blaming people and making things worse, we choose to acknowledge the disproportionate effects of a world still filled with discrimination and resulting discrepancies that disproportionately harms our health. We also no longer use “infected” (yuk) or “HIV-positive” (opting for “living with HIV” instead). One last thing: the pediatric HIV doctor who shared the insightful story was the incomparable Donna Futterman, MD.* —EV

Years ago, when a doctor in the Bronx was told that he should test his 18-year-old pregnant patient for HIV, he asked, “Why? What do you think she’s been doing?”

With that story, the effects of stigma became clear to me. If a doctor doesn’t understand how HIV is transmitted, what chance does the public have? He seemed to think that you had to be a prostitute to get HIV, a position of ignorance and misinformation. Because that’s what stigma does, it drives misinformation. *You have to be a prostitute to get HIV. You have to be gay. You have to sleep around.*

The most vulnerable communities affected by HIV were dehumanized with stigmatizing words that helped delay research and treatment.

Faggot.
Junkie.
Whore.

Today, stigma remains as alive and well as ever while the epidemic evolves, except that now it’s a pill for HIV prevention that has moralistic panties up in a bunch.

That’s right: A pill to prevent the scariest STI in history is being condemned, along with the people who dare to take it, thereby making a bid for greater sexual freedom. (How dare they!)

You would think that people taking a pill shown to reduce the risk of HIV by 92% or more would be hailed as responsible heroes in the fight against the epidemic. Instead, the Sex Police have labeled them “whores.” After all, Truvada PrEP, just like the birth control pill before it, gives you greater freedom to be a slut. (Never mind that you can be a slut without taking any prevention pills or methods at all. You would just be a slut at higher risk of every STI.)

It is sadly bizarre that we've stigmatized having HIV for so long and now we're stigmatizing a prevention method that helps people stay HIV-negative.

What's even more bizarre is that the stigma towards gay and bisexual men is coming primarily from the last group of people I would have expected to be anti-PrEP: gay men, many of them themselves HIV-positive.

It was an HIV-positive gay male writer who coined the phrase "Truvada whore" to condemn HIV-negative men taking the daily pill to prevent infection. Although he took it back later, the damage was done.

Outreach workers on the West Side of Chicago heard "Truvada whore" over and over as they promoted a PrEP study to young black gay men, who have the highest rate of HIV in this country. It's heartbreaking. The neighborhoods where they promoted the study have the highest infection rate in in the city and desperately need as many prevention methods as possible.

Later, on Chicago's North Side, a nurse who had heard about PrEP told his gay doctor that he wasn't at risk, but would think about it. He returned three months later and found he had HIV. We mislead people into feeling safe if they don't "whore" around. As with pregnancy, it's hard to believe you can get it after just one time. Or maybe three times. Or one partner—or three.

And even if someone was sleeping around, wouldn't that be all the more reason to suggest that they consider using Truvada PrEP to avoid HIV infection if they're at risk?

Kudos to Adam Zeboski for taking back the term and creating the Truvada Whore educational campaign (with fabulous T-shirts).

Although pretty much any sexually active person is at risk for HIV if they don't protect themselves, it's been shown that those at particularly high risk often don't recognize it. For example, research has found that many gay men who reported not being at risk for HIV were actually already infected.

At any rate, it would be a disservice to lead people to believe that they are safe when that is not exactly how the epidemic works—marriage, monogamy, fewer partners, and so forth are not vaccinations against HIV. On the surface, all of these would seem to reduce risk. Instead, each can lull a person to falsely assume that their partner actually knows their HIV status or is being faithful. In communities where HIV is highly concentrated, particularly the gay and African American communities, these forms of risk reduction are simply too impotent to overcome the odds that a partner is HIV-positive and doesn't know their status.

All in all, the words "high risk" or "at risk" for HIV are misleading, and even stigmatizing in themselves. Anyone honest enough to recognize a need for PrEP is truly courageous.

We're also told to "just use condoms," which ignores some ugly secrets, such as the fact that sexual assault among many, especially gay men, remains an unrecognized danger, sometimes resulting in seroconversion.

Here's the irony: PrEP puts power back into the hands of the most vulnerable individuals, notably because unlike condoms it doesn't require getting your partner to slip on some latex. There are many people at risk who could benefit from Truvada PrEP who are already particularly vulnerable to shame for who they are: trans men and women, people who have multiple partners or partners outside a primary relationship and people who love someone who has HIV.

COVER OF THE SUMMER 2015 SPECIAL ISSUE ON PREP

SUMMER 2015 COVER: NOËL GORDON PHOTOGRAPHED BY JOHN JACK GALLAGHER

Yet, this self-empowerment may bring stigma upon them.

PrEP taker and advocate Damon Jacobs recalls the backlash against distributing free condoms in gay bars in the 1980s and '90s, because many people thought it would only encourage more gay sex, which they considered immoral. For decades, condoms were actually illegal in 30 states. The cure for syphilis in the 1930s was also condemned because many believed that curing people of an "immoral" disease would only make them more immoral, he said.

It is sadly bizarre that we've stigmatized having HIV for so long and now we're stigmatizing a prevention method that helps people stay HIV negative.

A small report on the approval of the birth control pill in the *New York Times* on May 9, 1960 quoted an FDA spokesman as saying, "We had no choice as to the morality that might be involved.'' The statement seems astounding now, but was clearly the norm then.

There's a catchphrase going around that says "community is immunity." It comes from research showing that people who thrive are those who have the closest relationships, including friendships and the tribes they've built around them. With others who have your back and want the best for you, you—and your health—will do better.

It's a disgrace that at this point in the epidemic we have to fight for our right to medication and to protect ourselves from HIV. It's a shame that some of the biggest moralizers in this battle to end the epidemic have come from the group most at risk for HIV themselves, the gay men who have been shamed for their sexuality perhaps more than any other group at risk, even legally prosecuted with sodomy laws. The group, ironically, that has always led the battle to end the epidemic.

Sex shaming is such a shame. PA

IN MOMENTS OF CHANGE, WHAT KEEPS YOU GROUNDED?

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always reminding me I'm not alone.

PIFELTRO is a once-daily, one pill HIV-1 treatment option that is part of a complete ARV regimen in adults.

Model living with HIV

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PIFELTRO is a prescription HIV medicine used with other antiretroviral medicines to treat human immunodeficiency virus-1 (HIV-1) infection in adults who have not received HIV-1 medicines in the past, or to replace their current HIV-1 medicines for people whose healthcare provider determines that they meet certain requirements.

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

IMPORTANT SAFETY INFORMATION

Do not take PIFELTRO if you are currently taking any of the following medicines:

- carbamazepine
- oxcarbazepine
- phenobarbital
- phenytoin
- enzalutamide
- rifampin
- rifapentine
- mitotane
- St. John's wort

Ask your healthcare provider or pharmacist if you are not sure if your medicine is one that is listed above. If you have taken any of the medicines in the past 4 weeks, talk to your healthcare provider or pharmacist before starting PIFELTRO.

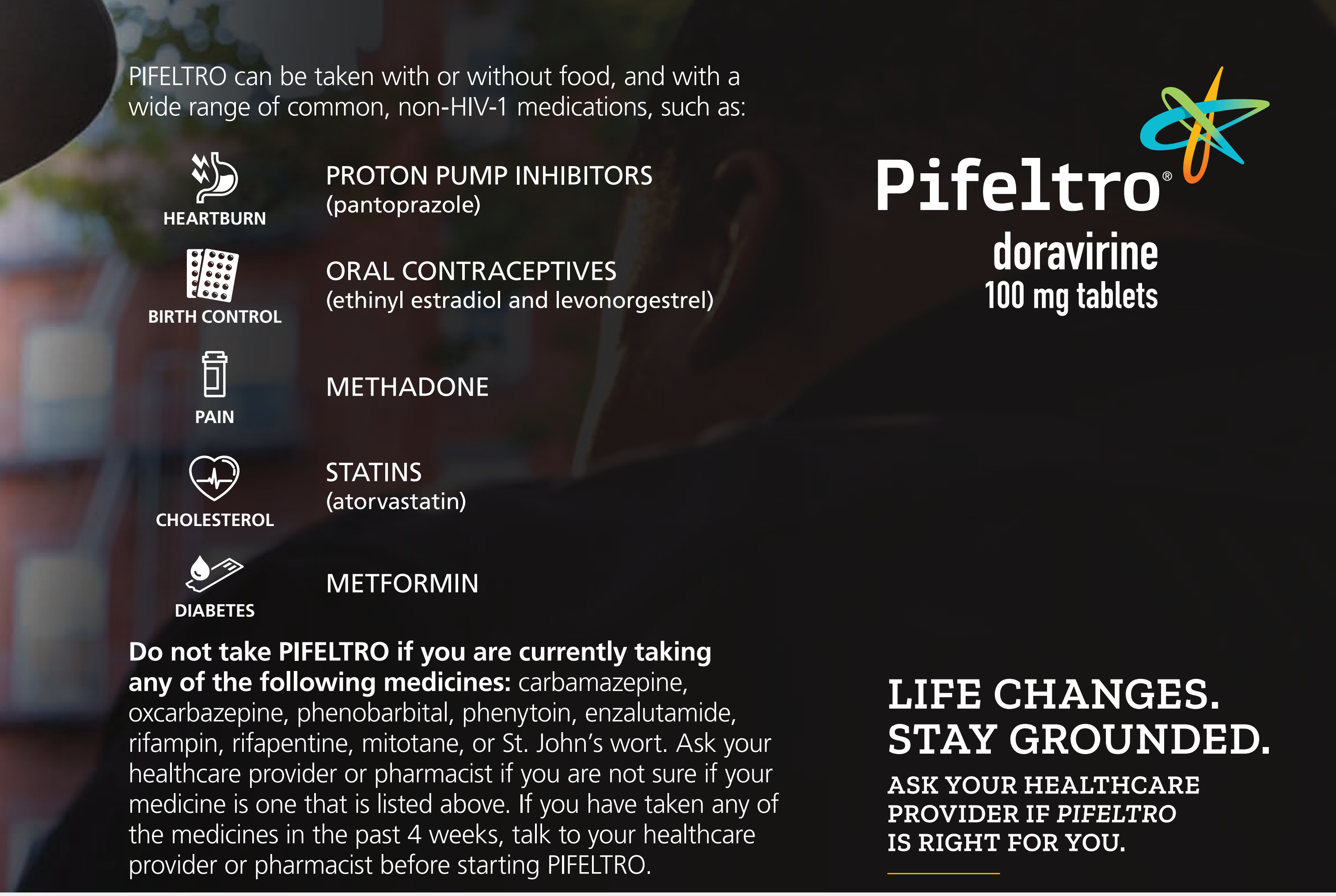
Changes in your immune system (Immune Reconstitution Syndrome) can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your healthcare provider right away if you start having new symptoms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

The most common side effects of PIFELTRO include: nausea, dizziness, headache, tiredness, diarrhea, stomach (abdominal) pain, and abnormal dreams.

These are not all the possible side effects of PIFELTRO. For more information, ask your healthcare provider or pharmacist.

Before starting PIFELTRO, tell your healthcare provider about all your medical conditions, including if you are pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed. It is not known if PIFELTRO can harm your unborn baby. Do not breastfeed if you take PIFELTRO. Women with HIV should not breastfeed because their babies could be infected with HIV through their breast milk.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal



PIFELTRO can be taken with or without food, and with a wide range of common, non-HIV-1 medications, such as:

HEARTBURN	PROTON PUMP INHIBITORS (pantoprazole)
BIRTH CONTROL	ORAL CONTRACEPTIVES (ethinyl estradiol and levonorgestrel)
PAIN	METHADONE
CHOLESTEROL	STATINS (atorvastatin)
DIABETES	METFORMIN

Do not take PIFELTRO if you are currently taking any of the following medicines: carbamazepine, oxcarbazepine, phenobarbital, phenytoin, enzalutamide, rifampin, rifapentine, mitotane, or St. John's wort. Ask your healthcare provider or pharmacist if you are not sure if your medicine is one that is listed above. If you have taken any of the medicines in the past 4 weeks, talk to your healthcare provider or pharmacist before starting PIFELTRO.

Pifeltro®
doravirine
100 mg tablets

LIFE CHANGES. STAY GROUNDED.

ASK YOUR HEALTHCARE PROVIDER IF *PIFELTRO* IS RIGHT FOR YOU.

IMPORTANT SAFETY INFORMATION *(CONTINUED)*

supplements. **Some medicines interact with PIFELTRO.** Keep a list of your medicines to show your healthcare provider and pharmacist. Tell your healthcare provider if you have taken rifabutin in the past 4 weeks. **Do not start taking a new medicine without telling your healthcare provider**. Your healthcare provider can tell you if it is safe to take PIFELTRO with those other medicines.

Take PIFELTRO every day exactly as your healthcare provider tells you to take it. Take PIFELTRO 1 time each day, at about the same time every day.

Tell your healthcare provider if you have taken rifabutin in the past 4 weeks.

If you take the medicine rifabutin during treatment with PIFELTRO, take PIFELTRO 2 times each day, about 12 hours apart, as prescribed by your healthcare provider. You may not have enough doravirine in your blood if you take rifabutin during treatment with PIFELTRO.

Do not change your dose or stop taking PIFELTRO without talking to your healthcare provider. Stay under a healthcare provider's care when taking PIFELTRO.

Take PIFELTRO on a regular dosing schedule as instructed by your healthcare provider. Do not miss doses.

If you miss a dose of PIFELTRO, take it as soon as you remember. If it is almost time for your next dose, skip the missed dose and take the next dose at your regular time. Do not take 2 doses of PIFELTRO at the same time.

Get your PIFELTRO refilled from your healthcare provider or pharmacy before you run out.

When your PIFELTRO supply starts to run low, get more from your healthcare provider or pharmacy. This is very important because the amount of virus in your blood may increase if the medicine is stopped for even a short time. The virus may develop resistance to PIFELTRO and become harder to treat.

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

Please read the adjacent Patient Information for PIFELTRO® (doravirine) and discuss it with your healthcare provider.

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

MERCK

Patient Information
PIFELTRO® (pih-FEL-tro)
(doravirine) tablets

What is PIFELTRO?

PIFELTRO is a prescription medicine that is used together with other HIV-1 medicines to treat Human Immunodeficiency Virus-1 (HIV-1) infection in adults and children who weigh at least 77 pounds (35 kg):

- who have not received HIV-1 medicines in the past, or
- to replace their current HIV-1 medicines for people whose healthcare provider determines that they meet certain requirements.

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

It is not known if PIFELTRO is safe and effective in children who weigh less than 77 pounds (35 kg).

Who should not take PIFELTRO?

Do not take PIFELTRO if you take any of the following medicines:

- carbamazepine
- oxcarbazepine
- phenobarbital
- phenytoin
- enzalutamide
- rifampin
- rifapentine
- mitotane
- St. John's wort

Ask your healthcare provider or pharmacist if you are not sure if your medicine is one that is listed above. If you have taken any of the medicines in the past 4 weeks, talk to your healthcare provider or pharmacist before starting treatment with PIFELTRO.

What should I tell my healthcare provider before treatment with PIFELTRO?

Before treatment with PIFELTRO, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if PIFELTRO can harm your unborn baby. Tell your healthcare provider if you become pregnant during treatment with PIFELTRO.
  Pregnancy Registry: There is a pregnancy registry for people who take PIFELTRO during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk to your healthcare provider about how you can take part in this registry.
- are breastfeeding or plan to breastfeed. Do not breastfeed if you take PIFELTRO.
  - You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.
  - It is not known if PIFELTRO can pass into your breast milk.
  - Talk with your healthcare provider about the best way to feed your baby.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

- **Some medicines interact with PIFELTRO. Keep a list of your medicines to show your healthcare provider and pharmacist.**
- Tell your healthcare provider if you have taken rifabutin in the past 4 weeks.
- You can ask your healthcare provider or pharmacist for a list of medicines that interact with PIFELTRO.
- **Do not start taking a new medicine without telling your healthcare provider.** Your healthcare provider can tell you if it is safe to take PIFELTRO with other medicines.

How do I take PIFELTRO?

- Take PIFELTRO every day exactly as your healthcare provider tells you to take it.
- Take PIFELTRO **1** time each day, at about the same time every day.
- If you take the medicine rifabutin during treatment with PIFELTRO, take PIFELTRO **2** times each day, about 12 hours apart, as prescribed by your healthcare provider. You may not have enough doravirine in your blood if you take rifabutin during treatment with PIFELTRO.
- Take PIFELTRO with or without food.
- Do not change your dose or stop taking PIFELTRO without talking to your healthcare provider. Stay under a healthcare provider's care when taking PIFELTRO.
- It is important that you do not miss or skip doses of PIFELTRO.
- If you miss a dose of PIFELTRO, take it as soon as you remember. If it is almost time for your next dose, skip the missed dose and take the next dose at your regular time. Do not take 2 doses of PIFELTRO at the same time.
- If you have any questions, call your healthcare provider or pharmacist.
- When your PIFELTRO supply starts to run low, get more from your healthcare provider or pharmacy. This is very important because the amount of virus in your blood may increase if the medicine is stopped for even a short time. The virus may develop resistance to PIFELTRO and become harder to treat.

What are the possible side effects of PIFELTRO?

PIFELTRO can cause serious side effects, including:

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

The most common side effects of PIFELTRO include:

- nausea
- dizziness
- headache
- tiredness
- diarrhea
- stomach (abdominal) pain
- abnormal dreams

These are not all the possible side effects of PIFELTRO.

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

How should I store PIFELTRO?

- Store PIFELTRO tablets at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep PIFELTRO in the original bottle.
- Do not take the tablets out of the bottle to store in another container, such as a pill box.
- Keep the bottle tightly closed to protect PIFELTRO from moisture.
- The PIFELTRO bottle contains a desiccant to help keep your medicine dry (protect it from moisture). Keep the desiccant in the bottle. **Do not eat the desiccant.**

Keep PIFELTRO and all medicines out of the reach of children.

General information about the safe and effective use of PIFELTRO.

Medicines are sometimes prescribed for purposes other than those listed in the Patient Information leaflet. Do not use PIFELTRO for a condition for which it was not prescribed. Do not give PIFELTRO to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about PIFELTRO that is written for healthcare professionals.

What are the ingredients in PIFELTRO?

Active ingredient: doravirine.

Inactive ingredients: colloidal silicon dioxide, croscarmellose sodium, hypromellose acetate succinate, lactose monohydrate, magnesium stearate, and microcrystalline cellulose. The tablet film coating contains hypromellose, lactose monohydrate, titanium dioxide and triacetin. The coated tablets are polished with carnauba wax.

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MERCK

BEING BRIDGETTE

Bridgette Picou

See me seeing you

Two separate things happened recently that got my mind going and my feelings, well, *feeling*. A friend told me a friend of hers was interested in meeting me, as in to date me. In general, I'm wary of friend-of-friend dating. The potential for being messy is real. What threw me for a loop this time was that she asked if I wanted her to disclose my HIV status to ease the pressure of that off me. A lot of things happened emotionally to me at the same time, like within 45 to 60 seconds.

I'll be honest about all of them, even the ones that are a little negative, because they are all valid emotions. One, I was grateful for her asking my permission before telling my story. Even though I am open with my status it's still my story to tell. Considered and rejected simultaneously was the thought that she was asking because she wanted to make sure I actually told him. I rejected that thought because that's internal trauma and stigma thinking, not the healed version of me. She's a dope human being and genuinely wanted to help. The onus to share status and initiate the conversation is always on the person living with HIV and the attitude and judgement that some people have about that is frustrating. There are women I know who have had their status blasted on social media or in their friend circles and that is an unquantifiable harm and disrespect.

The other thought I considered (and rejected) was letting her tell him. Disclosure really is a pain in the neck. But, again, my status, my story. In the end, I let her introduce us. I haven't yet decided if he needs to know my story, because frankly, not everyone does. That fact that I and others living with HIV don't feel an immediate need to disclose our status makes folks not living with HIV feel a way—outraged or shocked—because they think it's the biggest, most important factor in our lives, and because they still operate from thinking that it's a terrible death sentence. Personally, I want to have an idea of a person's temperament, attitude and thought process before I feel rushed to share something so intimate. Besides, they may not even make it to date two, so why rush?

The other thing that happened was I watched the stage version of "The Normal Heart." It's a compelling, heartfelt look at AIDS, activism, love and loss. Of normalcy vs. the abnormal. It's a stark look at the beginning of the epidemic, and an even harsher look at apathy and social stigma. This isn't about the play, although I strongly suggest folks in the younger "generation" of living with HIV see it—but seeing it so soon on the heels of my girlfriend's question about my disclosure and my subsequent feelings meant that certain things stood out for me, and I had to really sit with them.

I've talked a lot about normalizing HIV. I've written about it and spoken about it. In my advocacy, normalizing what's seen as abnormal is a way to change the narrative and help us end stigma and consequently, the shame and fear of being tested, which can in turn help us end the epidemic. Ned Weeks' character in the play strongly believed gay men needed to out themselves to be *seen*. Not only make people see them as they were, dying from AIDS, but see them as whole humans beyond acts of sex or as "sinners" (or as in his brother's eyes as "sick"). I disagree with outing people, just like I disagree with people telling others' stories, be it disclosure or identity.

I did understand and agree with the idea of seeing people as whole. When we target things like status or individual identity, we allow for a disregard of a person's humanity, which makes it easy to ignore suffering.

> When we target things like status or individual identity, we allow for a disregard of a person's humanity, which makes it easy to ignore suffering.

I see these two things happening to me so closely as a reminder to be grateful for love and respect and how far we have come, and as a reminder of how far we yet have to go. Feeling seen feels a little like feeling love.

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

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Thank you to John Zenc for our artwork and Judith Shaw for our theme.