



POSITIVELY AWARE

JAN+FEB 2025

'I WANT MY NAME BACK'

Lashanda Salinas and Kerry Thomas share their experiences of being incarcerated under state HIV criminalization laws—and talk about how they're working to change them

AN HIV WARRIOR IS CALLED HOME

Remembering Bryan C. Jones

A LEGAL GUIDE FOR PEOPLE AGING WITH HIV

What federal protections exist for people living and aging with HIV? Excerpts from the Center for HIV Law and Policy's legal primer

CAN LONELINESS IMPACT FRAILTY IN OLDER PEOPLE WITH HIV?

POSITIVELY AWARE EN ESPAÑOL

LA SOLEDAD PUEDE AFECTAR LA FRAGILIDAD DE LAS PERSONAS MAYORES CON VIH, PERO ¿CUANTO?

ALICIA DIGGS

found something she loved doing. How it motivated her to start exercising.



TAKING THAT FIRST STEP

If you don't exercise much, this story is for you

TAKE OUR 2025 READER SURVEY

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

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- ▶ 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.





BIKTARVY®

bictegravir 50mg/emtricitabine 200mg/
tenofovir alafenamide 25mg tablets

**#1 PRESCRIBED
HIV TREATMENT***

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

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KEEP BEING YOU 

Because HIV doesn't change who you are.

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.

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Please see Important Facts about BIKTARVY, including important warnings, on the previous page and at [BIKTARVY.com](https://www.biktarvy.com).

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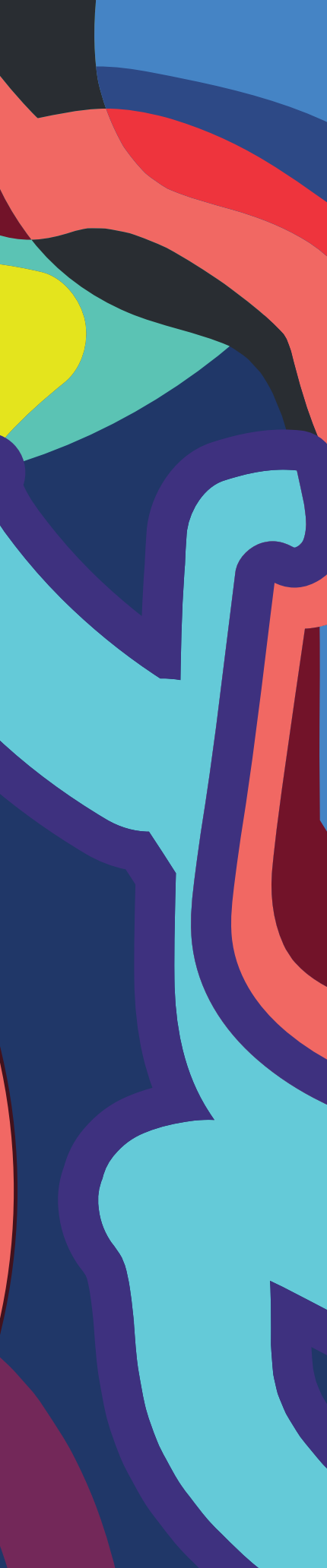
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TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals living with HIV gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission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



Fun with pictures

Getting to know Alicia Diggs through her silly side

BY RICK GUASCO • PHOTOGRAPHY BY MILES DARDEN

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The cover photo shoot for this issue was not the first time HIV advocate Alicia Diggs and photographer Miles Darden met. Years earlier they had met at a community business networking event in the Raleigh-Durham area of North Carolina.

“In the area that we live in, a lot of entrepreneurs and community people come together for different events,” Diggs said during a Zoom conversation with Darden and

POSITIVELY AWARE. “You never know who you’re going to see there.”

“The first time we met, I said, I’ve gotta do a shoot with her, she’s special,” Darden said.

“I like to document people’s lives and capture the essence of who they are.”

“I love the camera,” Diggs says. “I was telling Miles during the shoot that I was trying to do serious faces, but I’m so silly, everything is funny to me. When I’m doing photos, I have to think, *Alicia, make a serious face*. But I have so much fun with it.

“As a kid, I didn’t like photos for so many traumatic reasons,” she adds, “but once I found myself and the beauty in myself and really accepted myself and fell in love with myself, absolutely I love the camera. The camera allows me to tell a story with my expression, with whatever I wear, if I’m using a prop, whatever I’m doing. But it’s also fun because people who don’t know you, they can kind of get to know you through a photo.”

“I feel connected with her,” Darden said, “because I live with someone who has an immune deficiency condition, I’m always sensitive to that—watching people, how they live their lives, how they interact and how they feel about themselves in any situation, especially when some types of illnesses or diagnoses have a stigma attached to them. All I can think of her is joy, celebration, living her life. I’m proud of her; I’m excited that I get to be a part of that. I feel honored.”

As the conversation neared its end, Diggs said, “The art of photography, the art of sharing myself with other people—and to see the light shine through my life. I’m hoping people will see that in these pictures feel it for themselves.”

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EDITOR'S NOTE

Rick Guasco
@rickguasco

Let the fun begin

Getting started is the hardest part. Knowing you should do something that's good for you is not the same as being motivated to do it. This is often true about good health, and especially so when it comes to exercising. Alicia Diggs, a 52-year-old long-term survivor of HIV in North Carolina, knew she had to exercise, given her family history of diabetes and heart disease. She started making some small but simple and effective lifestyle changes—she stopped drinking soda and began taking walks in the park. She even joined a gym. But what really got Alicia going was that she had found a local Double Dutch Club of mostly Black women who jumped rope, played with hula hoops and danced.

Alicia had discovered something fun.

"It's like a support system. A sisterhood," she tells Tim Murphy in the cover story, "Taking that first step" (page 14). A health and exercise enthusiast and long-term survivor of HIV, Tim advocated for the story, intending it for people who put off or lack the motivation to exercise. He's a big believer in how small changes can lead to big changes and that consistency is the key to success. All you need is motivation—finding something you love to do and have fun doing.

We underestimate the importance of fun. Many people define themselves by their work, but I think that what we do for fun says a lot about who we really are and who we wish to be in those unguarded moments. It's a respite, a break, a getaway. It allows us to feel joy. We might even experience connection.

That's why fun can also be an antidote.

A study published last October in the *Journal of Acquired Immune Deficiency Syndrome (JAIDS)* found that being single and lonely had a greater connection to frailty in older people with HIV than a person's lowest recorded CD4 count or even multiple co-existing conditions. It raises the question, "How much can loneliness impact frailty in older people with HIV?" (which is the title of Larry Buhl's article on page 18).

Larry interviews the study's author, Alice Zhabokritsky, MD, MSc, a professor at the University of Toronto's Department of Medicine. "Our study shows that companionship, whether through intimate relationships or social networks, is incredibly important for the health of older adults living with HIV," she says. Dr. Zhabokritsky believes it might be a feedback loop—social isolation could contribute to frailty and frailty could exacerbate social isolation. Other co-existing conditions might also factor into the loop.

The article is accompanied by a sidebar on tools for combatting social isolation. The report starts on page 18, immediately followed by a Spanish-language version on page 21 as part of our continuing effort to engage readers for whom Spanish may be their primary language.

Elsewhere in the issue, how to mitigate weight gain associated with integrase inhibitors (INSTIs), a common HIV drug class, was a topic at last fall's IDWeek 2024 medical conference in Los Angeles (page 24).

Switch meds? Take one of the popular weight loss drugs? The answer isn't so clear cut.

A former boyfriend accused Lashanda Salinas of exposing him to HIV in 2006 in Tennessee. She was arrested, took a plea deal of three years' probation—and discovered she had to register as a sex offender. Lashanda couldn't prove that she had told him she had HIV and that she was undetectable at the time. In Idaho, Kerry Thomas served 15 years of a 30-year sentence for criminal exposure of HIV. Like many state laws that criminalize HIV, Idaho's law took no account of Kerry's undetectable status. So it's no wonder Lashanda and Kerry say, "I want my name back," in a conversation the two HIV de-criminalization advocates have as they share experiences (page 26).

Just a few days after this past Christmas, longtime HIV activist Bryan C. Jones fought his final battle with cancer, dying peacefully at home in Cleveland accompanied by his partner Derek Barnett, his family and his beloved chihuahua Diva Pearl. Derek shares some personal recollections of his life with Bryan (page 12). A personal note of appreciation to Derek for revealing a vulnerable side to an HIV warrior who is deeply missed.

Rounding out the issue, in her column, Being Bridgette, Bridgette Picou looks ahead to an uncertain year ahead with a measure of hope (page 34). But instead of waiting for something to happen, she says, "hope is something you can work toward."

Kerry says something similar in conversation with Lashanda. "You gotta be an active participant in your own survival," he says. You make your own survival. You make your own hope. And I hope you make your own fun. Together.

You are not alone.

P.S. Please take our 2025 Reader Survey on page 35. Learning more about you helps PA to better understand where you're coming from and how we can serve you better. You can also take the survey online: positivelyaware.com/2025survey. Your answers are completely anonymous. Thank you!

What we do for fun says a lot about who we are and who we wish to be in those unguarded moments.



Briefly

ENID VÁZQUEZ @enidvazpa

Sharing doxy-PEP at sex parties

Wouldn't it be nice to get free STI prevention pills at a sex party? It depends. While using doxycycline for the prevention of STIs has shown success (SEE doxy-PEP guidelines from the CDC), it doesn't mean that prescription medications can be used willy-nilly. Community education is needed and maybe changes to the healthcare system.

So warns a letter to *The Lancet* medical journal, in its December 2024 infectious disease issue (published online November 8).

note that doxy cannot be taken with:

- isotretinoin (commonly used to treat acne)
- systemic vitamin A derivatives, such as retinoids, which if taken together may cause intracranial hypertension and may even lead to permanent vision loss, and

UCLA Center for LGBTQ+ Advocacy, Research & Health, they discuss the issue of gay men who are closeted from their primary care providers.

"Many individuals feel compelled to turn to alternatives outside the formal health-care system due to fears of judgement or inadequate access to culturally competent care. This concern highlights a need for HCPs [health care providers] and primary care settings



Authors Matthew J. Mimiaga and Nina T. Harawa talked with community members who distributed or received free doxy-PEP pills at sex parties.

"Although the desire to share medications such as DoxyPEP at sex parties might stem from a place of care for the community, it raises potentially important health risks that cannot be overlooked," they write.

Although generally safe, doxycycline has drug-drug interactions that many individuals may not be aware of. For example, the authors

- acitretin, a different type of retinoid

Some commonly used over-the-counter medications and supplements can also interact with doxycycline. These include:

- antacids
- iron supplements, and
- bismuth (for example, Pepto-Bismol)

As they tell the stories of people who come to the

to create safer, more inclusive environments where sexual and gender minorities can feel comfortable seeking guidance on sexual health and be informed about medications that can prevent HIV and other STIs," write Mimiaga and Harawa. They are both with the Department of Epidemiology, UCLA Fielding School of Public Health at the University of California Los Angeles (UCLA).

To read the letter, which includes footnotes, GO TO bit.ly/41xEf0N.



New podcast for Black women and girls

The Empower program (SEE November+December 2024 *Briefly*) has launched the *Girlfriends Podcast*, a new series "dedicated to addressing the unique health challenges faced by Black women and girls, particularly in the context of HIV prevention."

Topics include sexual health, mental well-being, access to healthcare, and "strategies for HIV prevention tailored to the needs of Black women and girls. Through insightful discussions, expert interviews, and personal stories, this podcast aims to **empower Black women and girls to take control of their health, make informed decisions, and advocate for their well-being.** Together, we can break down barriers, reduce stigma, and promote a healthier future for Black women everywhere."

Topics of the first episodes include intergenerational trauma and health disparities, shattering stigma and cultivating cultural understanding for mental wellness, and boundaries and healing to nurture healthy relationships.

Meanwhile, new episodes from the *Wellness Chronicles* reported on in November+December include *Safe & Sound: Your Guide to Healthy Intimacy.*

GO TO healthhiv.org.

TOP OF THE NEWS

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U.S. HIV guidelines updated

List of meds to start simplified, plus other changes

Some of the older HIV meds have finally hit the dust and are no longer options for first-line treatment, according to updated U.S. HIV guidelines. **The drugs dropped were, for the most part, recommended only for certain situations** that may exist for some people who are taking HIV medications for the first time.

The expert panel that puts together the guidelines explains that, "The regimens recommended by the Panel as initial ART [antiretroviral therapy] for people with HIV include those that have demonstrated clinical efficacy [good effect on health], have a high barrier to resistance [are not easily evaded by the virus], are well tolerated, and can be given as once-daily therapy."

Dolutegravir, one of the newer drugs, remains on the list of *what to start for most people with HIV* under the brand names Dovato (a two-drug single-tablet regimen) and Tivicay (by itself, taken with Descovy or Truvada). The longtime single-tablet regimen (STR) Trimeq, however, was moved down to the start-in-certain-clinical-scenarios list "due to the need for HLA-B*5701 testing before initiating therapy, the potential increase in the risk of cardiovascular events, and the availability of other options for initial therapy." The testing and potential cardio effects are not due to dolutegravir, but to one of the other medications contained in Trimeq, abacavir.

Oral rilpivirine remains play in certain scenarios under the brand name Edurant and as part of the single-tablet regimen Odefsey, but the STR Complera has been booted off the list. Complera contains the older medication tenofovir DF, while Odefsey contains the newer tenofovir

alafenamide. Rilpivirine in the form of a long-acting injectable is available under the brand name Cabenuva (given with the long-acting injectable cabotegravir). Cabenuva does not yet have an approval from the U.S. Food and Drug Administration (FDA) for use as first-time HIV therapy. That approval is expected sometime this year.

Other drugs that are *adios* for the what-to-start category in certain clinical situations are:

- Sustiva (a single medication) and the STRs Atripla, Symfi, and Symfi Lo (all four contain efavirenz)
- The STRs Genvoya and Stribild (containing elvitegravir as the backbone medication)
- Isentress and Isentress HD (each containing a single medication, raltegravir)
- Evotaz and boosted Reyataz (each containing atazanavir)

Other updates

- New section on transplants in HIV
- New information in the sections on:
 1. Virologic Failure
 2. Optimizing Antiretroviral Therapy in the Setting of Viral Suppression
 3. HIV and the Older Person
 4. Substance Use Disorders and HIV
 5. Transgender People With HIV
 6. Hepatitis B Virus/HIV Coinfection
 7. Tuberculosis/HIV Coinfection
 8. Adherence to the Continuum of Care
 9. Drug-Drug Interactions

SEE footnotes and ratings from the table below in *Guidelines for the Use*

of Antiretroviral Agents in Adults and Adolescents With HIV, updated September 12, 2024; GO TO [clinicalinfo.hiv.gov](#).

Recommended starting regimens for most people with HIV without a history of using Apretude (CAB-LA) for PrEP:

(Previously recommended but now deleted drugs are struckthrough):

- Biktarvy (A1)
- Tivicay + Descovy or Truvada* (A1)
- Dovato* (A1)
- Trimeq (downgraded to "certain clinical situations")

Recommended starting regimen for people with a history of using Apretude (CAB-LA) for PrEP (no changes in this category):

- Symtuza (A3)
- Prezcobix + Descovy or Truvada* (A3)
- Boosted Prezista + Descovy or Truvada* (A3)

Recommended starting regimens in certain clinical situations

(Previously recommended but now deleted drugs are struckthrough):

- Trimeq (A1)
- Symtuza (B1)
- Prezcobix* + Descovy or Truvada* (A1) or Epzicom (B2)
- Delstrigo (B1)
- Pifeltro + Descovy (B3)
- Odefsey (B2)
- Complera
- Stribild
- Genvoya
- Isentress + Descovy or Truvada
- Isentress HD + Descovy or Truvada
- Evotaz + Descovy or Truvada
- Boosted Reyataz + Descovy or Truvada
- Atripla
- Symfi
- Symfi Lo
- Sustiva + Descovy

U.S. HIV OI guidelines updated

Most recent updates to the **U.S. HIV guidelines on opportunistic infections (OIs) in adults and adolescents living with HIV were released in November**. These referred to vaccinations and included updated recommendations for COVID-19, flu, hepatitis B, and respiratory syncytial virus (RSV) vaccines.

Other updates from 2024 included information on:

- anal cancer screening and treatment (in the human papillomavirus, or HPV, section)
- coccidioidomycosis (including pregnancy, lung infections, and meningitis)
- cryptococcosis (including pregnancy)
- histoplasmosis (including severe disease and blood level monitoring)
- bacterial enteric infections (including drug resistance as well as pregnancy)
- candidiasis (yeast infection or thrush; updates include the newer medications ibrexafungp and oteseconazole)

- pneumocystis pneumonia (PCP, including pregnancy and simplification of prevention, which is used in advanced HIV disease)
- toxoplasmosis (including pregnancy)
- Mycobacterium avium complex (MAC)
- leishmaniasis

SEE *What's New in the Guidelines* at bit.ly/49wg1Gt. GO TO clinicalinfo.hiv.gov.

U.S. HIV OI guidelines for children updated

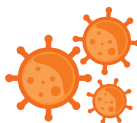
U.S. HIV **guidelines for preventing and treating opportunistic infections (OIs) in children living with HIV, and children who were exposed to the virus (usually in utero) but did not acquire it**, were updated in November. [HIV.gov](https://www.hiv.gov) presented the following summary of the changes.



Bacterial infections

- Added vaccine recommendations for the use of pneumococcal vaccines PCV15, PCV20 and PPSV23 in children with HIV.

- Updated the literature [research findings] for bacterial infections, including epidemiology, infection risk and vaccine recommendations.
- Updated recommendations for the diagnostics and management of bacterial infections with considerations made for newer technology (including molecular testing), antimicrobial stewardship, and changes in relevant treatment guidelines.



Hepatitis C virus infection

- Recommended hepatitis C virus (HCV) RNA testing for infants between 2 to 6 months with perinatal [around the time of birth] HCV exposure.
- Added information and recommendations supporting the use of pangenotypic direct-acting antivirals (DAAs) [for treating HCV] in children aged 3 years and older.
- Noted treatment for HCV during pregnancy can be considered with shared decision-making

[discussion between parents and medical providers]. [SEE the Hepatitis Drug Guide for more on treatment in pregnancy, JUL+Aug 2024.]

Last summer, on July 3, the pediatric OI guidelines also updated information regarding COVID-19:

- Published a new section describing the approach to the prevention and management of COVID-19 in children with and exposed to HIV.
- Added recommendations for the use of pre-exposure prophylaxis [OI PrEP] to fight off infections, including COVID-19 vaccination in all children and the monoclonal antibody pemivart in certain populations.
- Added recommendations for the treatment of COVID-19 with ritonavir-boosted nirmatrelvir, remdesivir, and/or corticosteroids, depending on the age of the child, clinical presentation, and risk factors for progression.

To read the *Guidelines for the Prevention and Treatment of Opportunistic Infections in Children with and Exposed to HIV*, GO TO clinicalinfo.hiv.gov.

Misinformation online fueled by outrage

Misinformation—that is, information that is wrong or an out-and-out lie—is more likely to be shared online when it makes people feel outraged. That’s according to a study published in the November 28, 2024 issue of *Science*.

“Misinformation remains a major threat to U.S. democratic integrity, national security, and public health. However, social media platforms struggle to curtail the spread of the harmful but engaging content. Across platforms, McLoughlin et al. examined the role of emotions, specifically moral outrage (a mixture of disgust and anger), in the diffusion of misinformation,” explains Ekeoma Uzogara in an editor’s summary of the study and its findings. “Compared with trustworthy news sources, posts from misinformation sources evoked more angry reactions and outrage than happy or sad sentiments. **Users were motivated to reshare content that evoked outrage and shared it without reading it first to discern accuracy.** Interventions that solely emphasize sharing accurately may fail to curb misinformation because users may share outrageous, inaccurate content to signal their moral positions or loyalty to political groups.”

GO TO science.org/doi/10.1126/science.adl2829.



Conservative media's effect on vaccination

“COVID-19 underscored that public health crises are social-behavioral problems as much as biomedical problems. Rapid vaccine development and delivery provided an opportunity to minimize the pandemic’s damage. But vaccine hesitancy hindered vaccine uptake in the United States and elsewhere. Vaccine hesitancy cost hundreds of thousands of

lives during the COVID-19 pandemic, not to mention vast social and economic costs,” reported an international study led by Marrison D. Grant of the University of Colorado at Boulder.

The study found that following conservative media was associated with greater rejection of vaccination.

According to the study abstract (summary),

“Findings show that, **regardless of personal ideology, individuals who consumed less conservative media and had a more ideologically diverse media diet were more likely to be fully vaccinated and boosted.**

Additionally, consuming more conservative media was negatively associated with trust in science, but this relationship was weaker among

those with a more ideologically diverse media diet.”

The authors noted that, “Vaccine hesitancy was identified as a top ten global threat in 2021 and remains a significant public health challenge.”

The study was published in the November 22, 2024 issue of *Nature*. It is available via open access (for free); GO TO [nature.com/articles/s41598-024-77408-4](https://www.nature.com/articles/s41598-024-77408-4).



Improving the taste of children's HIV medicine

A spoonful of sugar may help the medicine go down, as the song says, but some researchers are finding a different way to deal with it.

In particular, researchers from the University of Strathclyde in Scotland and the University of Western Cape in South Africa teamed up to take aim at children's HIV medicine.

“The standard conventional method [for improving the taste of medicine] involves adding sweeteners and flavoring agents for pediatric medicines, but this is often ineffective at masking strong bitterness and an unpleasant aftertaste can persist due to the short duration of the sweetener taste,” the University of Strathclyde reported in a press release. “Instead, by **using co-crystallization—where two or more different molecules are combined to create a new crystalline structure—the unpleasant taste can be reduced.**”

According to the release, around 100,000 infants and children under the age of 14 were living with HIV in sub-Saharan Africa as of 2023, per UNAIDS.

The research team began testing the use of co-crystallization with nevirapine (NVP), an HIV medication rarely used in the U.S. but commonly used in other parts of the globe.

“After creating five different co-crystal materials of NVP, they used an electrical tasting system to assess the results. The findings showed that co-crystallization could significantly reduce the bitterness of the drug, making it much easier to take,” the University of Strathclyde reported.

The research was published in the *Royal Society of Chemistry Pharmaceuticals Journal*. GO TO [bit.ly/3OSFBMd](https://doi.org/10.1039/D3PY00000A).

To read the December 5, 2024 press statement, GO TO bit.ly/41VVk4J.

World AIDS Day 2024

“World AIDS Day serves as an important reminder that we must remain steadfast in our commitment to prevent new HIV infections and provide essential services to all people living with HIV globally,” reported the U.S.-based [HIV.gov](https://www.hiv.gov).

“Collective Action: Sustain and Accelerate HIV Progress” was the theme for World AIDS Day 2024, commemorated on December 1.

“Together with our partners, the National Institutes of Health (NIH) commemorates World AIDS Day and affirms our commitment to bolstering the extraordinary gains achieved in HIV science and to persevering until we end HIV-related illness and stigma,” wrote Jeanne Marrazzo, MD, MPH, director of the National Institute of Allergy and Infectious Diseases (NIAID), and Geri Donenberg, PhD,



associate director for AIDS Research and director of the Office of AIDS Research (OAR) at NIH.

Considering the partnership theme of the day, they thanked U.S. partners

around the globe “who model and demand the scientific excellence required to propel groundbreaking HIV science. Above all, we thank the clinical trial participants who allow their individual health experiences to become evidence that improved the lives of others.”

The comprehensive NIH statement covers disturbing trends in HIV acquisition around the world and some of the latest scientific findings around HIV, including behavioral studies, prevention, drug development, a vaccine, and a cure.

“Looking to the future, we can envision ending HIV as a health threat. There is more evidence than ever before that a vaccine and cure are possible,” Marrazzo and Donenberg note in their conclusion.

“Yet, **it is essential that HIV research dovetail with expanded access and acceptability for people who historically have benefited less from HIV research advances and remain overrepresented in the pandemic.** Furthermore, we must address HIV-related coinfections and conditions that disproportionately affect people with HIV, especially as they age, including tuberculosis, sexually transmitted infections, viral hepatitis, and mpox.”

GO TO bit.ly/49R7UVb.



Using PrEP to help end HIV around the world

“In Zimbabwe, the fact that PrEP was initially promoted for men who have sex with men and commercial sex workers created a sense of stigma around its use, leaving some people at risk of HIV reluctant to take PrEP, out of fear of being associated with groups that are criminalized or experience social and political discrimination,” writes Katherine E. Bliss in a policy brief for the prominent think tank Center for Strategic and International Studies (CSIS), based in Washington, D.C. “Interviews with potential PrEP users in Kisumu County in Kenya revealed that some adolescent girls at risk of HIV were hesitant to take the products out of concern that their parents would instead believe they were taking antiretrovirals to treat the virus.”

Stigma is one challenge discussed in *Closing the Prevention Gap: Expanding Access to Pre-Exposure Prophylaxis (PrEP) Options*

to *Sustain the Global HIV Response*.

“How and where PrEP is dispensed impacts initiation and retention as well. The fact that PrEP services are primarily available through HIV clinics in many contexts reinforces potential users’ concerns over being erroneously perceived as living with HIV,” continues Bliss, who is a senior fellow and director of immunizations and health system resilience with the Global Health Policy Center of CSIS. “At the same time, health worker concerns that prescribing PrEP will lead to high-risk sexual behavior and a rise of sexually transmitted infections have led them to limit recommending PrEP for some clients. As an alternative, disseminating PrEP through youth-friendly spaces, including DREAMS programs [a partnership to reduce HIV rates in adolescent girls and young women], as well as pharmacies, primary health care settings, or even family

planning programs may create space for adolescent girls and young women, in particular, to feel comfortable seeking guidance regarding PrEP and access to the products.”

Ending the epidemic by 2030—the goal of UNAIDS and health organizations around the globe—needs (in part) to increase access to biomedical prevention methods like HIV PrEP, according to the report.

“The recent development of highly effective, long-acting PrEP methods makes this a pivotal moment for global HIV prevention efforts. ... Success will depend on ensuring a comprehensive set of PrEP options are produced, financed, and delivered in a way that makes them available, affordable, and acceptable to populations most vulnerable to HIV,” Bliss writes.

To hear a 5-minute recording on the report by Bliss and to read the brief itself, [GO TO \[csis.org/analysis/closing-prevention-gap\]\(https://www.csis.org/analysis/closing-prevention-gap\)](https://www.csis.org/analysis/closing-prevention-gap).

Access to HIV and hep C medications

Nailing down information on how to access or pay for medical care can be difficult.

The National ADAP Working Group (NAWG) helps people follow the financial resources near them, including veterans programs, Medicaid, and the Patient Assistance Programs (PAPs) available through pharmaceutical companies. “ADAP” stands for AIDS Drug Assistance Program, of which there is one in every state and in U.S. territories.

NAWG’s *HIV/HCV Co-Infection Watch* – October 2024 updates and maps out coverage of viral hepatitis medications. The states on the U.S. map are highlighted in different colors depending on the coverage of their government. The *Watch* also provides a round-up of other access news, such as insurance coverage for long-acting HIV prevention medications under the Affordable Care Act.

Other updates from NAWG include a two-and-a-half minute video on prescription drug affordability boards (PDABs) and their threat to HIV service delivery, titled *PDABs Price Control Wolves in Sheep’s Clothing*, and online reports that include studies on transgender violence and the impact of anti-LGBTQ+ legislation on HIV prevention; the intergenerational impact of aging with HIV; and how HIV prevention pills are free, but insurers are still charging the people who take them. Sign up for updates online.

[GO TO \[tiicann.org\]\(https://www.tiicann.org\)](https://www.tiicann.org).

NAWG is a program of the Community Access National Network (CANN), which was formerly the Ryan White CARE Act Title II Community AIDS National Network.



A 'time capsule' of service and sacrifice

Voices of Champions honors HIV care providers over the years

BY DEE CONNER AND LARRY BUHL

A new award recognizes longtime care providers, social workers and others in the HIV care field. Organized by the Ribbon Organizing Center HIV/Aging Positively (known as ROC4Aging+), Voices of Champions spotlights providers who have worked 15 years or more to elevate the health outcomes of people with HIV (PWH), particularly within marginalized communities. The awards are part of drug maker Gilead Science's HIV Age Positively initiative.

"There's so much history, and we don't have a legacy that's been written with the voices of those across multiple generations of HIV," said Linda H Scruggs, co-executive director of the Ribbon, A Center of Excellence, a capacity building nonprofit that oversees the initiative. She said the award is both a celebration and a "time capsule" of champions who have sought to improve the lives of PWH across the decades while facing their own personal challenges.

"HIV has gone from the very horrid place that many of us remember in the early '80s, and that sad place where we were struggling before the onset of antiretroviral drugs, today's medications," Scruggs said. Scruggs herself was diagnosed with HIV in 1990. "There are a number of providers that have been... champions, fighting this battle with us, [while] dealing with their own stigma."

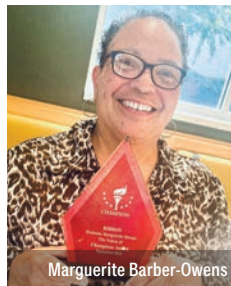
Scruggs added that many care providers who chose to work in HIV often faced personal and professional stigma, often to the detriment of their careers. The Voices of Champions awards acknowledge their sacrifice.

A look at the award recipients:

Marguerite Barber-Owens, MD, was driven to become one of the first HIV specialists in Alabama because of a near encounter she had. "My very dear friend who was in medical school with me passed away from HIV a short time after we vacationed in the Caribbean," she says.

She tells POSITIVELY AWARE that she wants people with HIV to be treated with dignity and respect by the health care system, something the system doesn't always do. She also feels that the community needs to be more open to HIV testing and education, and has taken that up as her personal cause.

"Early in my career, I felt inadequate because so many people had so many problems that had not been tested or treated," she says.



Marguerite Barber-Owens

Still in private practice in Montgomery although semi-retired now, she does clinical work one or two days a week. The rest of her professional time is focused

on getting local providers to test for HIV. "It is sometimes challenging that medical providers will listen to scientific data, expert recommendations and even agree with each other, but that may not translate into action," she says. "But it is a challenge that I am excited about."

Barber-Owens reminds up-and coming health practitioners that HIV is not over; there's still a great need for service, and that the rewards are meaningful. "This is

'I may never be famous to the world, but I know that I have made a difference in the lives of many, and many have made a difference in my life.'

Marguerite Barber-Owens, MD

some of the most rewarding work I have done in my 41 years of being a provider," she says. "It is also one of the most ever-changing, with new data coming out all the time, so it does require constant updating of knowledge. I may never be famous to the world, but I know that I have made a difference in the lives of many, and many have made a difference in my life."

Ratonia C. Runnels, PhD, MSW, also had a personal connection to HIV early in life. She was diagnosed with HIV in 1994 as a 20-year-old student at the University

of Texas at Austin. "At that time, the only personal experience I had with HIV/AIDS was my friend Terry, a gay man that we grew up with who belonged to my church and had AIDS," she says. "I didn't like it when people wouldn't hug him or touch him. He deserved love, too. He died during my freshman year in college."

Not long afterward, new, effective HIV medications became available.

"I began the then-new HAART therapies immediately and quickly began experiencing side effects, including lipo-dystrophy [a change in how the body produces, uses and stores fat]. I had no one to discuss these startling changes with. The following semester I took a social work elective where I was introduced to volunteer opportunities in the HIV community, as well as a support group for women living with HIV. I was 21 years old. The volunteer work set me on my career trajectory, and the support group changed my life. Since then, I have worked continuously to provide services and support to men and women living with HIV."

An associate professor and director of field education at Texas Woman's University, Runnels is concerned with raising HIV awareness, especially among the most affected populations. "Most people do not seek out information about HIV prevention and/or treatment until it impacts them, or someone close to them," she says. "Our community events are often filled with individuals who already work in the field on some level, so much of it seems like preaching to the choir."

Keeping up with new developments and maintaining an open mind are essential to education and outreach, she says. "Stay current on HIV-related news

and research. We have to stay relevant and innovative to keep communities engaged. Stay open to new ways of doing things. Our motivation may start us in one direction, but things can

change and change the course of our path. Also, it is important to establish good boundaries, and practice self-care daily. Recognize your value and



Ratonia C. Runnels

importance in your corner of the world. It may not seem like you are making much difference, but your presence impacts others in ways you may never know.”

And don't forget self-care.

“Sometimes the line can get blurry when you are both a practitioner and patient, professional and client,” she says.

Dorcas Baker, RN, BSN, ACRN, CDP, MA, started as a research nurse in 1992. She answered a newspaper ad from the Johns Hopkins AIDS Clinical Trials Group (ACTG) looking for a full-time registered nurse with research experience.



Dorcas Baker

“I was hired on the spot without research experience,” she says. “Little did I know that this position would impact me for the next 32 years.” For the next year, Baker visited prisons

in Maryland, following people with HIV who were incarcerated on receiving antiretroviral treatment.

In 2004, she co-founded Older Women Embracing Life (OWEL), a support group of women aging with or impacted by HIV that also advocates and engages in public policy. OWEL's prevention initiatives include its annual Testing for Turkeys Faith-Based Community HIV Testing Initiative, offering a frozen Thanksgiving turkey as an incentive for health screenings that include HIV, hepatitis C, blood pressure, podiatry and oral exam. “Our work for Testing for Turkeys has been published twice in the *Journal of the Association of Nurses in AIDS Care* [ANAC],” she says.

The following year Baker became site director for the MidAtlantic AIDS Education and Training Center (AETC) for Hopkins, where she serves within the School of Nursing, Center for Infectious Disease and Nursing Innovations. She started Hopkins' annual AETC-sponsored Graying of HIV Symposium, now in its 19th year. “As regional coordinator, we are working to expand the capacity of HIV providers to integrate geriatric/aging assessments into their practice to improve the care for people over 50,” she says.

Baker hopes that her legacy will be, “that I helped to make a difference in some way, to improve the care and quality of life for someone.”

She said, “In the early days I asked, *Are we prepared to care for an aging population?* This is still the same question today, as we advocate to integrate HIV and aging and promote models of care to improve quality of life.” **PA**

An HIV warrior is called home

Remembering Bryan C. Jones

BY RICK GUASCO • PHOTOGRAPHY BY SEAN BLACK



Many who knew him called Bryan C. Jones a “warrior.” A long-term survivor of HIV and a vocal advocate, he also overcame several bouts of cancer. On Saturday afternoon, December 29, Jones finished his last fight, this time with colon cancer. He passed peacefully at the home in Cleveland he shared with his partner Derek Barnett, accompanied by his family, Barnett and his beloved chihuahua Diva Pearl at his side.

Barnett and Jones were together for six years; the last year or so, Barnett had become Jones' primary caregiver. With his partner, Jones shared a side of himself that few others saw. In a

conversation with POSITIVELY AWARE, Barnett offered some glimpses of the man many saw as an outspoken advocate.

“He was always trying to do the right

thing for the community and for people who he knew individually if they're having a crisis," Barnett said. "Not that he had any means himself, but that's just the kind of person he was. But he was also the kind of person who wasn't afraid of bending some noses and stepping on toes if it meant that the community would get what it needed. He would say all the time, *If I have to be uncomfortable in the room, then everybody in the whole damn room can be uncomfortable. But I'm going to say what needs to be said.* That was the essence of his brand of advocacy.

Jones was diagnosed with HIV in 1984, which would set him on a lifelong path of advocacy. Much of his work centered on equity and accessibility for the Black community and disadvantaged peoples, efforts to update laws criminalizing HIV, aging and U=U (Undetectable Equals Untransmittable), the message that people with HIV who have an undetectable viral load do not transmit HIV through sex. He was a founding member of the Ohio Health Modernization Movement, an HIV decriminalization organization; a founding member of the U=U campaign and one of the Prevention Access Campaign's first U=U ambassadors. As a same-gender-loving man and Orthodox Muslim, he was on the board of RAHMA, a national organization for Muslims living with HIV.

"Bryan, I found out later, had a Facebook crush on me for a while before I even met him," Barnett said. "We had become Facebook friends. This was during a time when I was pretty depressed. It hadn't been too long that I had moved back to Cleveland to be the caretaker for my mom. After having been away for 10 years, the people who would have been my social network were all spread out across the country, and I felt really alone. I know that it's harder to make friends the older you get, so I made a conscious effort. One day, it was Election Day 2018, Bryan had posted a video on Facebook, and he was ranting that he has to walk all the way back home because he went to the poll to vote and they wouldn't accept his passport as a valid ID. I thought it was funny. I posted a comment saying, *It doesn't make sense they wouldn't accept a passport as proof that you are a citizen, but you know, it is kind of bougie that you'd take your passport to the poll, you know? LOL.* From there, we struck up a conversation, agreed to meet, hang out, and the rest is history.

"In the last year the cancer had been progressing such that the pain was intensifying, and it was a lot more frequent. He was in almost constant pain. But when we were out in public or with friends or family, he didn't really let on. He did a lot to suppress what was

actually going on with him. He was the same Bryan that people were used to—laughing and joking and flirting—but the minute we were together alone was when he could let go. I'll never forget the nights when he was wailing in pain. I would rub his leg, rub his arm, rub his back all night long—six, seven, eight hours straight. I didn't get to experience the Bryan that everybody else did because this was the space where he could let it all go. I started to miss him before he was gone.

"People are complicated, and Bryan was no different," Barnett said. "He was always very passionate, but he was also insecure. He was concerned that, *People might think that I'm the angry Black guy. People might think that I'm very aggressive.* He was very, very sensitive, despite his outward appearance sometimes. But he very much believed in telling it like it was. Having validation from the community was important to him. I'm so glad that he got to receive his roses while he was still alive."

Asked how he is doing, Barnett paused. "It's a bittersweet time," he said. "I don't have a large family. I lost my mother a couple of years ago. Now that Bryan is gone, it's a little lonely, but I'm glad that he is at rest. I'm an introvert; I'm not a people person. It's one of the reasons I was drawn to Bryan, because we complemented each other that way. He lit a fire under me and I calmed him down. I wasn't necessarily ready for a relationship when we met. He later told me, *I never thought I would be with someone like you. You were a gift from God for me.* I can't imagine a higher compliment."

"He is truly going to be missed by so many lives that he has changed," said his longtime friend and fellow HIV advocate Dee Conner. "His loss is one that saddens me because I lost a brother. He was more than a friend."

Conner and Jones wrote for the May+June 2023 issue of POSITIVELY AWARE as Jones shared that he was undergoing chemotherapy and radiation treatment for his fifth bout with cancer, this time throat cancer. In "Taking care of our own," Conner wrote about coming to the side of her longtime friend, whom she had nicknamed "Jethro," and he had called her "Ella." Jones wrote a firsthand account, reflecting on surviving cancer while living with HIV, titled, "I'm still standing."

"Bryan is a warrior inside and out, and a lot of times I wish people understood him the way that I do," Conner wrote in her cover story.

In his reflection, Jones wrote, "...one thing I know about myself and the people whom I've grown accustomed to and have welcomed into my life, we are all

resilient people. We come with our own set of strengths and weaknesses."

"I tell people that when I'm living my worst life, I'm living my best life because I learn so many things while in that valley trying to claw my way up and out. I've learned so many things that have helped me in these dark moments. I've thought about what advice I would give somebody in this situation. It's always a message of hope, so I take my own advice and I push on, move out and climb up to the next plateau, ready to take on the next fight."

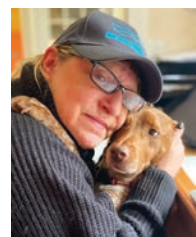
A memorial is being planned for April in Atlanta; details to be announced. Community advocates close to Jones have organized a fundraiser to support the event. Contributions will be managed by PositivelyU, a community-based organization for people with HIV in central Florida founded by Janet Kitchen. **PA**

As 2024 was drawing to a close, the HIV community was stunned by the passing of other HIV advocates, among them, A. Cornelius Baker and Cindy Stine.



For nearly 40 years, **Cornelius Baker's** work in various roles in government, advocacy organizations and global health included promoting HIV testing, securing federal

funding for research and pushing for a vaccine. A champion for access and equity, he led by example and was a hero and mentor to many. Baker, 63, died November 8 at his home in Washington, D.C. At the time of his passing, he was serving as special advisor to the Office of AIDS Research and PEPFAR liaison at the National Institutes of Health and as board chair for Us Helping Us People Into Living.



On December 14, **Cindy Stine**, who had been The Sero Project's development director and a strong advocate for HIV decriminalization, passed. "Cindy was more than just

a friend, coworker, and advocate," said Sero co-executive director Tami Haught, "she was a beacon of strength, compassion, and unwavering dedication. To everyone who had the privilege of knowing her, Cindy embodied kindness, resilience, and an unshakable commitment to justice and equity for all, particularly for those who have been marginalized and overlooked by society."

Taking that first step



If you don't exercise much—or at all—this story is for you.

It can be hard to get motivated. But you have no idea the benefits that await you—often within only days of becoming a little more active

BY TIM MURPHY

If anyone knows how exercise over the course of a lifetime can be a bumpy ride of hills and valleys, it's Alicia Diggs, 52, of North Carolina. Diagnosed with HIV in 2001, she recalls, "There was a time when I did not work out at all and I weighed almost 300 pounds." Based in part on her family history, she knew that she was at severe risk for diabetes, heart disease and countless other ailments—and that she had to make a change.

So, first she stopped drinking soda. Then she

started walking a lot in the park. Then she joined

a gym and started taking different dance classes. And—not surprisingly—she lost weight and felt a whole lot better.

But then about a decade ago, in her words, "life situations happened"—her brother died, she hurt her knee and her father got sick—"and I started eating my emotions and stopped doing anything." That brought her into the COVID pandemic, during

which—once again feeling deeply compelled to get back in shape—she found something that not only motivated her to get back in shape, it was also among the most fun she'd ever had: She joined her local chapter of the 40+ Double Dutch Club, a nationwide network of mostly Black women who get together not only to jump rope as they did in their girlhood but also to stretch, hula

DIGGS: MILES DARDEN

hoop, dance to the classics of yesteryear—and, perhaps most crucially, just be there for each other. “It’s like a support system,” says Diggs. “A sisterhood.”

“I cried joyful tears” the first time she saw them in online videos, says Diggs—women in their 70s and even 80s jumping rope. Once she joined, other women in the group got wind via social media that she was living with HIV and involved in HIV activism—and completely supported her.

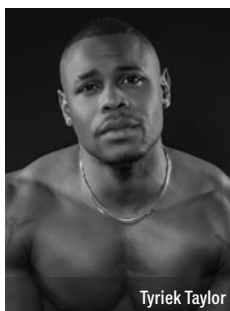
“They said, ‘Alicia, oh my gosh, you’re amazing!’” she says. “I’d been worried that they’d be uneducated about HIV and not want me to touch the rope, but nobody acted differently at all. It was like telling them I had diabetes or high blood pressure or anything else.”

The dangers of sitting and the gifts of moving

Diggs hit the ideal when it comes to exercise: Not only did she find something that made her move and was good for her health and longevity, she found something she absolutely loved—with people she loved. That’s crucial, say experts, because the most important thing about exercise isn’t how hard or long you go for in any one session but sticking with it *over time*, weaving it into the permanent fabric of your life.

“If you and your friends are going for a run or walk every weekend before brunch, then those are relationships you want to build on and maintain,” says Austin, Texas-based fitness trainer Tyriek Taylor, 35, who says that his workout routine helped him get through his 2019 HIV diagnosis.

There are repercussions to being sedentary and eating highly processed foods high in sugar, salt and white flour—leading to putting on weight. A mountain of research going back decades has shown how sitting all day on the job and couch-potato’ing in your off hours sets you up for a world of woes, especially as we age—everything from the bad-health trifecta of



Tyriek Taylor

diabetes, high blood pressure and heart disease to a higher risk of numerous cancers to pain of all sorts, inflexibility, muscle and bone decay, lack of stamina when doing even the simplest tasks (like climbing a flight of stairs), depression, and accelerated cognitive decline.

A slightly smaller mountain of research suggests that all these things might happen harder and faster in folks with HIV, due to the virus’ tendency to accelerate aging, even when it’s well-controlled by meds. All the more reason why exercise is so crucial.

The benefits

But let’s stop focusing on the negative outcomes of *not* moving and look instead at the bounty of desirable outcomes when you *do* move. Research has shown that once you do, even before you start losing weight, you can lower your blood sugar in as soon as one hour, not to mention increase your energy, strength, stamina, and mood.

If you increase, intensify, or consistently stick with exercise—to the point that you’re doing something strenuous enough to raise your heart rate for at least 30 minutes most days of the week—and especially if you add some form of strength training to the mix, like squats and even chair push-ups—then the benefits really start to rack up. Not only will you lose weight and feel better, you’ll improve your blood sugar control, lower your blood pressure, develop stronger bones and muscles, reduce your risk of diabetes complications, and improve your mood, sleep quality, long-term mental cognition—and, likely, ultimately your longevity.

These rules apply to everyone, but they have special resonance for folks with HIV. A 2010 review of several studies found that people with HIV who did aerobic exercise, or a combination of aerobic and strength-training exercise, for at least 20 minutes at least three times a week for at least five weeks enjoyed “significant improvements” in the areas of heart and lung function, body composition (muscle to fat ratio), and mood (decreased depression).

And that’s just one piece of a large body of research finding similar results, including

that regular exercise improved adherence to meds for folks with HIV, in part because exercise lifts a person’s mood (when you’re depressed, you’re less likely to take your meds).

About the *only* thing that exercise has been found *not* to improve in folks with HIV is their viral load. The only thing that can get a person with HIV to long-term undetectable status is sufficiently suppressive HIV medication.

This one’s for all the sitters out there

There are plenty of folks with HIV for whom moderate or intense exercise—such as biking, running, and/or some kind of cardio and strength training program at a gym—is a central part of our lives. This writer, in fact, is one of them: I’ve been a runner and gym goer since well before I was diagnosed with HIV in 2001; it’s so central to my wellness and happiness that sometimes I have to motivate myself *not* to work out and, instead, go for a relaxed walk or go see a friend.

For this story, POSITIVELY AWARE put out a query over several Facebook groups for folks with HIV asking about exercise habits—and plenty of people (mostly gay men as well as a few women) wrote back to describe intense routines they stick to religiously.

IN FLORIDA, Lepena Reid,

68, and diagnosed with HIV in the mid-1980s, said that her routine consisted of walking 30–60 minutes in her neighborhood or at the mall every day—plus strength training (which most people said they did on machines at a gym) a few days a week at the YWCA.



Lepena Reid

IN BRAZIL, L.F. (who withheld his full name), 58, and diagnosed with HIV in 2015, said that he joined a \$30-a-month gym where he goes three to five times a week to do strength training. He goes early in the morning before putting in a full day taking care of his elderly father. Since he took up the gym again seriously several months ago, he says, “I’ve noticed I’m leaner, my legs are stronger, and I have some arms and chest now.”

But this story is more geared toward folks with HIV who barely get out of the chair or off the couch, who perhaps haven't exercised in years or never have. And that focus starts with an acknowledgement that going from sedentary to active isn't necessarily easy and eludes many people for a variety of reasons, from being stuck in a depressive rut to being too busy with work and/or caring for others to feeling set back from chronic pain or other ailments.

"I watched my mom do everything for us and nothing for herself," says Taylor, "and I've seen a lot of moms like that, especially Black moms, bust their ass to raise their kids and die while doing it." But the thing is, he says, "if you want to stay strong and live long enough to see your grandkids grow up, you have to take

moments away from the people you care for to exercise."

Taking the first step

What should the first step be? It doesn't matter, say experts, as long as you take one—literally. If you have the time and money to access a trainer or some kind of gym or outdoor fitness group, like a walking group, that's great. (Start by calling or googling to see if your local HIV services group or other nonprofit, charity, or community center has offerings.)

It doesn't even have to be structured. One of the easiest things to improve a lot of baseline health markers is simply to walk more, says Omar Kent, an independent trainer in New York City who has often worked with people with HIV. "You need three to five hours a week of activity that has nothing

to do with the gym to maintain a certain quality of life," he says. "So do things like get off the subway or train a few stops early and walk the rest of the way home."

You could also take the stairs instead of the elevator or escalator on a regular basis, or even just walk a few flights of stairs every day for the sole purpose of exercise. If you sit most of the day—whether at a desk or on the couch—you could benefit simply by setting your phone or watch to go off every hour to get up and walk around for 10 minutes.

"I have a client who started working with me when he was 60 who couldn't do much," says Kent. "He was busy and we found a schedule where he could meet me at the gym two days a week. We worked on a lot of things over a period of time. And then he started

telling me that he felt better just walking down the street. One day, he ran across the street just before the light changed and then realized that he wouldn't have been able to do that a year before."

'That's really what people care about—to participate in life without feeling like they're limited.'

—OMAR KENT

Kent recalls another client who, because of her physical condition, was unable to raise her arms above her head; after some training, she was able to lift her luggage into an overhead compartment on a plane. "That's really what people care about," he says, "to participate in life without feeling like they're limited."

In this feature, you'll find tips to get

Need motivation? Follow these tips

Start with a teeny-tiny step. Almost literally. If you sit or lie down most of the day but are physically able to walk, even if you need a walker, then resolve that you are going to get up and walk around your house, or outside, for 10 minutes once a day for a week. (Text a friend about it so they can hold you accountable.) Then up it to twice a day for a week. Then to fifteen minutes three times a day for a week. And so on and so on.

Add joy to your movement. Would it be easier to get up and walk around, or to put in an hour at the gym, if you were listening to your all-time favorite music? If you were immersed in a podcast or a really good audiobook? If your walk had a happy destination like grabbing a coffee or watching dogs in a dog park? If you lost yourself in a cooking show on a TV screen in front of your treadmill? Then go for it! Anything that makes exercise the backdrop to something fun rather than a slog will help you sustain your routine. Machines have a place to plug in your headphones.

Don't do it alone! There are so many ways you can tie exercise to connection, socializing, and fun. Call your local HIV services organization or poke around online (google your city or region plus terms like "free walking group," "free exercise group," or "free fitness options") until you find a really cool group of people to be active with, like Alicia Diggs

did with her Double Dutch "sisters." Ask a neighbor or friend if they'll take a daily or several-times-weekly walk with you or hit the gym with you. Or call or FaceTime a friend while you're out walking. You can always do a YouTube class at home alone. (Google "Positive Fitness: An online fitness class for people living with HIV" for one option.)

Build fitness into your life. Especially if you're busy, you don't necessarily have to carve out special time to exercise, although many people swear that such dedicated time is crucial to their mental health. Walk to your errands instead of taking a car (if they're within what is walking distance for you). Dance in the kitchen while making dinner. Walk while taking work calls. Or you could resolve to take the stairs anytime you'd ordinarily take the elevator or escalator. (The health benefits of stair-climbing can't be overstated.)

Keep a movement journal. In addition to wearing an exercise-tracking device like a FitBit or setting your phone to track your movement, keeping a diary of your daily movement or exercise, as well as how it changes your body and mood, is a great way to stay motivated. It'll make you more generally mindful of how much you are—or aren't—moving, and what you're getting from it. And it's a great place to sketch out new fitness goals for yourself from week to week.

moving—or to take your exercise game from one level to the next. And read some of the capsule stories from folks with HIV. Then—take that first step! (Or that second or third step.) You may dread the thought of it, and you may feel discomfort at first as you push yourself out of your comfort zone. (It's advisable to consult with your primary health provider before taking a new fitness step.)

As for Diggs, her joy at being part of the Double Dutch community was cut short in June when she was in a car accident, which caused some muscle damage (fortunately, she didn't break anything). "I'm not able to jump right now," she says—she misses her Double Dutch friends, three of whom dropped everything and drove long distances to be with her after the accident—"so I've been doing hula in the house a little bit. I also just joined Gold's Gym, which has a trainer I talked to who is going to work with me. I have to be careful with some machines, but I can do stuff like the elliptical machine and free weights."

Various events may have paused her exercise at certain points in her life, but she always returned to it—at the level and pace she could manage at that time. Why? "I'm completely afraid of being diagnosed with diabetes and heart disease—my family has a history of obesity," she says. But her main reason is rooted not in fear but in a zest for living: "It gives me a better quality of life," she says. "I have grandchildren—and I want to be around for them as long as I can." **PA**

A simple start

FEDERAL GUIDELINES for adults recommend at least 150 minutes of moderate-intensity physical activity a week. You might split that into 22 minutes a day or 30 minutes a day for 5 days. You can use any combination that fits your schedule. The Centers for Disease Control and Prevention offers suggestions and additional information: [cdc.gov/healthy-weight-growth-physical-activity/getting-started.html](https://www.cdc.gov/healthy-weight-growth-physical-activity/getting-started.html)



Folks with HIV speak up about exercise

On social media, POSITIVELY AWARE asked several folks with HIV to share their exercise choices—and, in some cases, to challenge themselves to upping the stakes for a week and then reporting back. Here are some of their responses.

Vivian, North Carolina, diagnosed in 1999

"I do a combo of walking and dancing for 20–25 minutes a day."

Teo Drake, Massachusetts, 61, diagnosed in 1995

"I've always been an athlete. Prior to gender transition, I found moments of ease in my body through strength training and sports in general. For the past 22 years, I've regularly trained in, and now I teach, mixed martial arts. In the spring and fall, I paddle board on a lake and ride my bike a few times a week. Last spring, I started a physical therapy/personal training program to figure out how I can create a strong foundation as I age. Now I'm in the gym four times a week for 30–45 minutes. Exercise is a big part of my self-care and trauma symptom regulation."

Sandra Harrigan Thompson, Philadelphia area, 70, diagnosed in 1989

"I exercise for one hour at Planet Fitness four or five days a week. Yesterday, I did the stationary bike for five miles in under 30 minutes. Then, some rowing and weightlifting. Since April I've had sciatica, but with cortisone shots I've been able to keep going to the gym, with two days a week of physical therapy. If I'm working out and it hurts, I stop and find something else to do that doesn't cause pain."

Bruce Ward, New York City, 66, diagnosed in 1986

"I still go to the gym, but less frequently than I used to. I had a great trainer but stopped going to him because he was very expensive. But he motivated me because I've had chronic fatigue for 36 years, which is my [biggest] detriment [to] my health. Working with the trainer, I lost about 18 pounds two years ago but have since gained about half of it back. Now, I generally do about an hour on the elliptical machine twice a week. I added some upper body machines in but I'm currently not using them because I'm going to physical therapy twice weekly for tendonitis in my right shoulder. The bottom line for me is consistency in working out. As a 66-year-old single gay man, my mind says, "What's the use?" But then I remind myself that it's not just about how I look. It's dealing with my diabetes and heart and overall well-being."

David Mayfield Phillips, Virginia, 59, diagnosed in 1998

"I've engaged in some regular exercise regimen since I began managing my HIV in 1998. I'm eagerly awaiting my return to the YMCA once my income picks up, and in the meantime I walk five to eight miles most days and do yoga three times a week." *Phillips was challenged by PA to add some non-gym strength training, such as squats and push-ups, to his routine. Nine days later he reported back:* "Yes, I added bicep and forearm curls using large laundry detergent bottles filled with water, along with inverted push-ups [when you keep your hands on the floor but slightly elevate your feet on the sofa or other raised surface]. That exercise after healing has helped me to prevent sudden blood pressure drops and to continue rehab on my shoulder, which I injured in January."

Barbara Kingsley, South Africa, 54, diagnosed in 2000

"I lift heavy weights five days a week minimum and on weekends I do cardio and hiking. I work with a trainer I'm lucky to have gotten a great deal from. It gives me so many health benefits—flexibility, strength, cardio fitness. I'm stronger and fitter than most people my age but also I don't have the aches or pains of people much younger than me. My lung capacity and oxygen level is that of somebody in their early 40s and my general fitness is of someone in their mid-30s."



How much can loneliness impact frailty in older people with HIV?

BY LARRY BUHL

A study published in October in the *Journal of Acquired Immune Deficiency Syndrome (JAIDS)* had an unexpected finding: that being single and lonely—and, in contrast to other studies, not nadir CD4 count or multi-morbidity—correlated with frailty in older people with HIV (PWH).

The cross-sectional analysis included 439 participants over age 65 (with a median age of 69) from the Correlates of Healthy Aging in Geriatric HIV (CHANGE HIV) study. Frailty criteria included unintentional weight loss, self-reported

exhaustion, weakness, slow walking speed, and low physical activity, and participants experiencing three or more criteria are considered frail. Researchers found that just over 16% of participants met at least three criteria, while 62% met one or

two criteria (and were considered prefrail) and 21% met no frailty criteria and were considered robust. After researchers adjusted for nadir CD4 count, age, gender, time since HIV diagnosis, and comorbidities, being single had an adjusted risk ratio of 2.09, or more than double.

In an email to POSITIVELY AWARE, the study's author, Alice Zhabokritsky, MD, MSc, a professor at the University of Toronto Department of Medicine, said that her team differentiated being single from experiencing loneliness. "We



found that the majority of study participants were not in a relationship (65%) but they reported various degrees of loneliness,” Zhabokritsky wrote. “Our study shows that companionship, whether through intimate relationships or social networks, is incredibly important for the health of older adults living with HIV.”

Acknowledging that many studies show that people with HIV (PWH) are more likely to experience frailty earlier than people without HIV (PWOH), due in part, though maybe not entirely, to chronic inflammation, stressors of older treatments (such as protease inhibitors) and even newer antiretroviral therapy (ART), Zhabokritsky suggested that findings from the CHANGE HIV study may suggest a bidirectional feedback loop of HIV-frailty-isolation. That is, social isolation could contribute to frailty, and frailty further exacerbates social isolation. Other comorbidities could also be part of that negative loop.

“Although it is difficult to know whether social isolation is a cause or a consequence of frailty (potentially contributing to both), our findings show that social connections can be protective as people age with HIV,” Zhabokritsky wrote. “Similar to other studies, we observed a higher prevalence of frailty in our cohort than in comparable cohorts of older adults in the general population although we did not observe a correlation between the nadir CD4 count (the lowest point of the immune system before treatment is started) and frailty in our cohort.”

At least one advocate urged against concluding that loneliness is more significant to the onset of frailty in older PWH than CD4 nadir, or immune dysregulation, in general.

“This study was cross-sectional, not prospective or retrospective,” said Jules Levin, director of the National AIDS Treatment Advocacy Program (NATAP). “I am convinced immunosuppression and a predisposition to low CD4 nadir, which predicts immune senescence [aging], does increase risk for frailty and cognitive impairment, and often these go together with older PWH,” Levin said.

Findings presented at the 2023 International Workshop on HIV and Aging showed that cognitive frailty affects PWH more than a decade earlier than PWOH. Other research concluded that prevalence of a frailty-related phenotype (FRP) that

approximates a clinical definition of frailty, correlates with a lower CD4 count, independent of ART use.

“For life, you have a dysregulated immune system [with HIV] which leads to immune senescence,” Levin said, “which leads to ongoing lifetime viral low-level replication, which leads to immune activation, which causes inflammation and all that is associated with a higher risk of comorbidities. There’s [a higher risk of] heart disease, there’s diabetes, there’s peripheral artery disease, eyesight and hearing disability that aging people

Social isolation could contribute to frailty, and frailty further exacerbates social isolation.

experience... Social isolation is associated with [comorbidities], in addition to all the other factors that cause social isolation, like social determinants of health. It’s multifactorial, but immune dysregulation is the link.

“Once you get to advanced frailty, there’s no coming back,” Levin added. “The only hope is that maybe you can catch it in prefrailty, and slow it down, undertake an exercise program, intervene with a high-quality diet, and prevent comorbidities.”

And, head off frailty by identifying and addressing social isolation and loneliness, the CHANGE HIV study suggests.

Zhabokritsky doesn’t dispute that HIV itself is key to the onset of frailty. She and researchers wrote that persistent immune dysregulation seems to play an important role in the development of frailty in people living with HIV in addition to multimorbidity, lifestyle factors, and social determinants of health.

“I think our study highlights just how important loneliness and social isolation are for the well-being [of] older adults living with HIV and points towards potential opportunities to attenuate risk of frailty,” Zhabokritsky wrote in an email. “For researchers, this may open new avenues for interventions to prevent development of frailty. Health providers are encouraged to inquire about loneliness and social isolation when seeing older adults living with HIV and linking those in their care to local communities and organizations.”

Resources for whole-person approach to aging with HIV

Screening for frailty—ideally for pre-frailty—can help prevent the worst health outcomes for many older PWH, whether they’re socially isolated or not, said Sean Cahill, director of Health Policy Research at the Fenway Institute, an LGBTQ+ health organization in Boston. Cahill pointed out that screening for frailty is among the American Academy of HIV Medicine’s recommendations for treating older patients with HIV. However, screenings—including for cardiovascular disease, chronic obstructive pulmonary disease (COPD), smoking, kidney disease, hypertension, diabetes, and osteoporosis—are standard of care, there are no data as to whether clinicians are adhering to them, or whether doctors are conducting pre-frailty screenings for PWH in their 50s, or 40s.

“Now we understand that some frailty and pre-frailty happens sometimes decades earlier [for PWH], and we see earlier onset of certain health conditions with people living with HIV,” Cahill said. “So I would say even if you’re in your 40s, and you want to get screened for something, ask your provider.”

Whether insurance will cover screenings at an earlier age is another open question, Cahill added.

Levin said that PWH will likely have to advocate for early screenings if doctors don’t provide them. “Despite several guidelines recommending screening for all people over 50, there’s no screening for frailty, bone mineral density and cognitive function. And unless you do frailty screening, doctors and clinics can’t discuss interventions with patients. Very few doctors do eyesight and hearing disability, and there is a direct link for eyesight and hearing disability with social isolation.”

“Interventions aimed at reducing loneliness should be assessed in people living with HIV to determine whether this could prevent or reverse frailty and ultimately improve functional status and quality of life,” Zhabokritsky and colleagues wrote. “In the interim, loneliness and not being in a relationship should be recognized by clinicians as potential indicators of frailty risk.” **PA**

Tools for combatting social isolation

BY LARRY BUHL

Even if the association between loneliness, social isolation and frailty (and comorbidities) for older PWH is complex and not fully understood, there's evidence, for people with or without HIV, that loneliness is detrimental to physical health, and is estimated to do as much harm to the body as smoking a pack of cigarettes a day.

"We're a species that developed to be dependent on other people," Sean Cahill, of Fenway Institute, said.

Cahill noted that unlike being single, the state of loneliness is subjective. "Loneliness is related to your expectations and if you're lonely, your social support networks and friendship networks and/or family networks are not satisfactory," he said. "You may have one really great friend who's dependable, who provides a lot of satisfaction in that person's life. Somebody else could have 50 friends and be lonely because the relationships are not satisfactory."

Commit to Connect (bit.ly/3OZSYtY) helps link people living with isolation to programs and resources that build the social connections they need to thrive, said Andrea Callow, a program analyst at the Office of Policy and Analysis at the Administration for Community Living (ACL), which is part of the U.S. Department of Health and Human Services (HHS). The program includes a social engagement innovations hub with best practices and evidence-based interventions from across the U.S. In addition, there are consumer and professional resources and a nationwide Network of

Champions, self-identified leaders at the national, state, and local level committed to ending social isolation and loneliness.

For facilities interested in expanding their practice to address isolation and other determinants of health for older PWH, there is the Self-Management Resource Center. ACL also compiled examples of collaborations around the country, including a Texas senior center that provides group therapy for people aging with HIV.

Katie Clark, who leads the HHS

Commit to Connect Initiative, shared several interventions that can improve social connection and, ultimately, reduce chronic illness and promote longer, healthier lives.

"That could be group therapy or cognitive behavioral therapy, mindfulness-based practice, community-based exercise or physical activity, or health education courses," Clark said. "This could include leisure activities or exercise that is conducted by programs and community settings, like tai chi or Silver Sneakers [an exercise program for seniors, with some gym memberships free to Medicare members over 65]. Health education courses might be particularly relevant for older adults or

people aging with HIV because a lot of these programs are designed for specific groups in mind, many of them also focus on managing chronic disease and frailty."

She also noted that technology and phone-based programs can be useful for older adults or people aging in community settings, like those that connect older adults to volunteers. "This could also include tablet distribution, smartphone distribution, specialized apps with virtual senior centers or programming and even voice-activated virtual assistants or kind of social robots, which are more and more common on the market."

Chronic disease self-management programs, Clark said, can have a secondary benefit of increasing social engagement. "[These programs] help assess and manage their chronic disease through support groups, where you're connecting people with shared experiences in a peer-to-peer format for social support, which we know is a huge protective factor, although they were not designed [for the purpose of] social connection."

Is there a role of doctors in referring patients to these interventions? Yes, Clark said, noting that doctors caring for patients with HIV are starting to conduct more screening assessments on social determinants of health, including asking about nutrition, housing, transportation, and, increasingly, social connectedness. "More and more we're seeing [clinicians] ask, 'do you feel like you have someone you can rely on for social support?'"

But she noted an ethical challenge with screening and referral. Specifically, providers may be naturally reluctant to screen for anything if they can't address the needs identified in the screening.

"There are a lot of workforce challenges and burden on providers," Clark said. "And the levels of evidence for programs and interventions are not super rigorous, especially for ones in community settings. If you screen, you want to be able to refer patients to programs that are meaningful to them."

"Ideally [a provider] would be plugged into the community, to have more options for person-centered counseling... where you're able to spend a lot of time with that patient and identify things that they're interested in and connect them to a program or service that supports them. It's tough, because there are a lot of factors that are contributing to someone's social disconnectedness."

Optimal person-centered care would mean clinicians coordinating with local agencies on aging and other resource centers in a "no wrong door" approach, she said. **PA**



Cahill also noted that many older PWH have additional stressors, including stigma around HIV, early loss of a partner, lack of children or grandchildren (for many), as well as ageism in the LGBTQ+ community, all of which can contribute to social isolation and/or loneliness.

Even if doctors don't measure or intervene in their patients' social isolation, there are many things older PWH, whether single or coupled, can do to boost their social support networks, Cahill said. These include, if they're available, a local LGBTQ+ center, LGBTQ+-affirming elder services, meal programs, bereavement groups, and online support services.



La soledad puede afectar la fragilidad de las personas mayores con VIH, pero ¿cuánto?

POR LARRY BUHL • TRADUCCIÓN POR ROSA E. MARTÍNEZ COLÓN

Un estudio publicado en octubre en el *Journal of Acquired Immune Deficiency Syndrome (JAIDS)* obtuvo un hallazgo inesperado: que estar soltero y solitario—y, a diferencia de otros estudios, no tener un recuento de CD4 bajo o multimorbilidad—se correlaciona con la fragilidad en las personas mayores con VIH.

El análisis transversal incluyó a 439 participantes mayores de 65 años (con una mediana de edad de 69 años) del estudio Correlates of Healthy Aging in Geriatric HIV (CHANGE HIV). Los criterios de fragilidad incluían pérdida de peso involuntaria, agotamiento autoinformado, debilidad, velocidad al caminar lenta y poca actividad física, y los participantes que experimentaran tres o más criterios eran considerados frágiles. Los investigadores encontraron que poco más del 16% de

los participantes reunían al menos tres criterios, mientras que el 62% reunían uno o dos criterios (y se consideraban prefrágiles) y el 21% no reunía ningún criterio de fragilidad y se consideraban robustos. Después de que los investigadores ajustaron el recuento mínimo de CD4, la edad, el sexo, el tiempo transcurrido desde el diagnóstico del VIH y las comorbilidades, estar soltero tenía un índice de riesgo ajustado de 2.09, o más del doble.

En un correo electrónico a POSITIVELY AWARE, la autora del estudio, Alice Zhabokritsky, MD, MSc y profesora del Departamento de Medicina de la Universidad de Toronto, dijo que su equipo diferenciaba estar soltero de experimentar soledad. “Descubrimos que la mayoría de los participantes del estudio no estaban en una relación (65%), pero reportaron diversos grados de soledad”, escribió Zhabokritsky. “Nuestro estudio muestra que el compañerismo, ya sea a través de relaciones íntimas o redes sociales, es increíblemente importante para la salud de los adultos mayores que viven con VIH”.

Reconociendo que muchos estudios muestran que las personas con VIH (PWH, por sus siglas en inglés) tienen más probabilidades

de experimentar fragilidad antes que las personas sin VIH (PWOH, por sus siglas en inglés), debido en parte, aunque tal vez no en su totalidad, a la inflamación crónica, factores estresantes de tratamientos más antiguos (como los inhibidores de la proteasa), e incluso una terapia antirretroviral (TAR) más nueva. Zhabokritsky sugirió que los hallazgos del estudio CHANGE HIV pueden sugerir un circuito de retroalimentación bidireccional del VIH-fragilidad-aislamiento. Es decir, el aislamiento social podría contribuir a la fragilidad, y la fragilidad exagera aún más el aislamiento social. Otras comorbilidades también podrían ser parte de ese círculo negativo.

“Aunque es difícil saber si el aislamiento social es una causa o una consecuencia de la fragilidad (que potencialmente contribuye a ambas), nuestros hallazgos muestran que las conexiones sociales pueden ser protectoras a medida que las personas con VIH envejecen”, escribió Zhabokritsky. “Al igual que en otros

El aislamiento social podría contribuir a la fragilidad, y la fragilidad exagera aún más el aislamiento social.

estudios, observamos una mayor prevalencia de fragilidad en nuestra cohorte que en cohortes comparables de adultos mayores en la población general, aunque no observamos una correlación entre el recuento nadir de CD4 (el punto más bajo del sistema inmunológico antes de comenzar el tratamiento) y la fragilidad en nuestra cohorte”.

Al menos un defensor instó a no concluir que la soledad es más importante para la aparición de la fragilidad en las personas mayores que viven con VIH que el nadir de CD4, o la desregulación inmune, en general.

“Este estudio fue transversal, no prospectivo ni retrospectivo”, dijo Jules Levin, director del Programa Nacional de Defensa del Tratamiento del SIDA (NATAP, por sus siglas en inglés). “Estoy convencido de que la inmunosupresión y la predisposición a un nadir bajo de CD4, que predice la senescencia [envejecimiento] inmune, aumentan el riesgo de fragilidad y deterioro cognitivo, y a menudo estos van de la mano con las personas con VIH de mayor edad”, dijo Levin.

Los hallazgos presentados en el Taller Internacional sobre VIH y Envejecimiento 2023 mostraron que la fragilidad cognitiva afecta a las personas con VIH más de una década antes que a las personas sin VIH. Otra investigación concluyó que la prevalencia de un fenotipo relacionado con la fragilidad (FRP, por sus siglas en inglés) que

se aproxima a una definición clínica de fragilidad se correlaciona con un recuento más bajo de CD4, independientemente del uso de TAR.

“Durante toda la vida, tienes un sistema inmunológico desregulado [con VIH] que conduce a la senescencia inmune”, dijo Levin, “lo que conduce a una replicación viral de bajo nivel continua durante toda la vida, lo que conduce a la activación inmune, lo cual causa inflamación y todo lo que está asociado con un mayor riesgo de comorbilidades. Hay [un mayor riesgo de] enfermedades cardíacas, diabetes, enfermedad arterial periférica, discapacidades visuales y auditivas que experimentan las personas que envejecen... El aislamiento social está asociado con [comorbilidades], además de todos los otros factores que causan el aislamiento social, como los determinantes sociales de la salud. Es multifactorial, pero el vínculo es la desregulación inmune.

“Una vez que se llega a una fragilidad avanzada, no hay vuelta atrás”, añadió Levin. “La única esperanza es que tal vez puedas detectarlo en la prefragilidad y frenarlo, emprender un programa de ejercicios, intervenir con una dieta de alta calidad y prevenir comorbilidades”.

Y evitar la fragilidad identificando y abordando el aislamiento social y la soledad, sugiere el estudio CHANGE HIV.

Zhabokritsky no discute que el VIH en sí mismo es clave para la aparición de la fragilidad. Ella y los investigadores escribieron que la desregulación inmune persistente parece desempeñar un papel importante en el desarrollo de la fragilidad en las personas que viven con VIH, además de la multimorbilidad, los factores del estilo de vida y los determinantes sociales de la salud.

“Creo que nuestro estudio destaca cuán importantes son la soledad y el aislamiento social para el bienestar [de] los adultos mayores que viven con VIH y señala oportunidades potenciales para atenuar el riesgo de fragilidad”, escribió Zhabokritsky en un correo electrónico. “Para los investigadores, esto puede abrir nuevas vías de intervención para prevenir el desarrollo de la fragilidad. Se alienta a los proveedores de salud a preguntar sobre la soledad y el aislamiento social cuando ven a adultos mayores que viven con VIH y a vincular a quienes están bajo su cuidado con las comunidades y organizaciones locales”.

Recursos para un enfoque integral del envejecimiento con VIH


La detección de fragilidad (idealmente pre-fragilidad) puede ayudar a prevenir

los peores resultados de salud para muchas personas mayores que viven con VIH, ya sea que estén socialmente aisladas o no, dijo Sean Cahill, director de Investigación de Políticas de Salud en el Instituto Fenway, una organización de salud LGBTQ+ en Boston. Cahill señaló que la detección de fragilidad se encuentra entre las recomendaciones de la Academia Estadounidense de Medicina del VIH para el tratamiento de pacientes mayores con VIH. Sin embargo, los exámenes de detección—incluidos los de enfermedades cardiovasculares, enfermedad pulmonar obstructiva crónica (COPD, por sus siglas en inglés), fumar, enfermedades renales, hipertensión, diabetes y osteoporosis—son estándar de atención, no hay datos sobre si los médicos los cumplen o si los médicos están realizando exámenes previos a la fragilidad para las personas con VIH entre los 50 y 40 años.

“Ahora entendemos que algunas situaciones de fragilidad y pre-fragilidad ocurren a veces décadas antes [en las personas con VIH], y vemos una aparición más temprana de ciertas condiciones de salud en las personas que viven con VIH”, dijo Cahill. “Por lo tanto, yo diría que incluso si tienes 40 años y quieres hacerte una prueba de detección de algo, pregúntale a tu proveedor”.

Otra cuestión no resuelta es si el seguro cubrirá las pruebas de detección a una edad más temprana, añadió Cahill.

Levin dijo que las personas con VIH probablemente tendrán que abogar por exámenes de detección tempranos si los médicos no los realizan. “A pesar de que varias directrices recomiendan realizar pruebas de detección a todas las personas mayores de 50 años, no existen pruebas de detección de fragilidad, densidad mineral ósea y función cognitiva. Y a menos que se realicen pruebas de detección de fragilidad, los médicos y las clínicas no pueden discutir las intervenciones con los pacientes. Muy pocos médicos se ocupan de las discapacidades visuales y auditivas, y existe un vínculo directo entre las discapacidades visuales y auditivas y el aislamiento social”.

“Las intervenciones dirigidas a reducir la soledad deben evaluarse en personas que viven con VIH para determinar si esto podría prevenir o revertir la fragilidad y, en última instancia, mejorar el estado funcional y la calidad de vida”, escribieron Zhabokritsky y sus colegas. “Mientras tanto, los médicos deben reconocer la soledad y la falta de una relación como indicadores potenciales de riesgo de fragilidad”. 

Herramientas para combatir el aislamiento social

POR LARRY BUHL • TRADUCCIÓN POR ROSA E. MARTÍNEZ COLÓN

Aún si la asociación entre la soledad, el aislamiento social y la fragilidad (y las comorbilidades) de las personas mayores con VIH es compleja y no se comprende del todo, hay evidencia, para las personas con o sin VIH, de que la soledad es perjudicial para la salud física y se estima que causa tanto daño al organismo como fumar un paquete de cigarrillos al día.

“Somos una especie que se desarrolló para depender de otras personas”, dijo Sean Cahill, del Instituto Fenway.

Cahill señaló que, a diferencia de la soltería, el estado de soledad es subjetivo. “La soledad está relacionada con tus expectativas y si te sientes solo, tus redes sociales de apoyo y tus redes de amistad y/o familiares no son satisfactorias”, dijo. “Es posible que tengas un gran amigo que sea confiable y que brinde mucha satisfacción en la vida de esa persona. Alguien más podría tener 50 amigos y sentirse solo porque las relaciones no son satisfactorias”.

Cahill también señaló que muchas personas mayores con VIH tienen factores estresantes adicionales, incluyendo el estigma en torno al VIH, la pérdida temprana de una pareja, la falta de hijos o nietos (para muchos), así como la discriminación por edad en la comunidad LGBTQ+, todo lo cual puede contribuir al aislamiento social y/o soledad.

Incluso si los médicos no miden ni intervienen en el aislamiento social de sus pacientes, hay muchas cosas que las personas mayores con VIH, ya sean solteras o en pareja, pueden hacer para impulsar sus redes de apoyo social, dijo Cahill. Estos incluyen, si están disponibles, un centro LGBTQ+ local, servicios para personas mayores que afirman a la comunidad LGBTQ+, programas de comidas, grupos de duelo y servicios de apoyo en línea.

Commit to Connect (bit.ly/3OZSYtY) ayuda a vincular a las personas que viven aisladas con programas y recursos que construyen las conexiones sociales que necesitan para prosperar, dijo Andrea Callow, analista de programas de la Oficina de Políticas y Análisis de la Administración para la Vida Comunitaria, que forma parte del Departamento de Salud y Servicios Humanos de EE. UU. (HHS, por sus siglas en inglés). El programa incluye un Centro de Innovación de compromiso social con mejores prácticas e intervenciones basadas en evidencia de a través de los Estados Unidos. Además, hay recursos para consumidores y profesionales y una Red

de Campeones a nivel nacional, líderes autoidentificados a nivel nacional, estatal y local comprometidos a poner fin al aislamiento social y la soledad.

Para los centros interesados en ampliar su práctica para abordar el aislamiento y otros determinantes de la salud de las personas mayores con VIH, existe el Centro de Recursos de Autogestión. ACL también recopiló ejemplos de colaboraciones en todo el país, incluyendo un centro para personas mayores en Texas que brinda terapia grupal para personas que envejecen con VIH.

La soledad es perjudicial para la salud física y se estima que causa tanto daño al organismo como fumar un paquete de cigarrillos al día.

Katie Clark, quien dirige la Iniciativa Compromiso para Conectar del HHS, compartió varias intervenciones que pueden mejorar la conexión social y, en última instancia, reducir las enfermedades crónicas y promover vidas más largas y saludables.

“Eso podría ser terapia de grupo o terapia cognitivo-conductual, práctica basada en la atención plena, ejercicio o actividad física en la comunidad, o cursos de educación de la salud”, dijo Clark. “Esto podría incluir actividades de ocio o ejercicios dirigidos por programas y entornos comunitarios, como tai chi o Silver Sneakers [un programa de ejercicios para personas mayores, con algunas membresías a gimnasios gratuitas para los miembros de Medicare mayores de 65 años]. Los cursos de educación de la salud podrían ser particularmente relevantes para los adultos mayores o las personas que envejecen con VIH porque muchos de estos programas están diseñados para grupos específicos y muchos de ellos también se centran en el manejo de enfermedades crónicas y la fragilidad”.

También señaló que la tecnología y los programas telefónicos pueden ser

útiles para los adultos mayores o las personas que envejecen en entornos comunitarios, como aquellos que conectan a los adultos mayores con los voluntarios. “Esto también podría incluir la distribución de tabletas, la distribución de teléfonos inteligentes, aplicaciones especializadas con centros virtuales para personas mayores o programación e incluso asistentes virtuales activados por voz o tipos de robots sociales, que son cada vez más comunes en el mercado”.


Los programas de autocontrol de enfermedades crónicas, dijo Clark, pueden tener el beneficio secundario de aumentar el compromiso social. “[Estos programas] ayudan a evaluar y controlar sus enfermedades crónicas a través de grupos de apoyo, donde se conecta a personas con experiencias compartidas en un formato de pares para apoyo social, lo cual sabemos que es un enorme factor de protección, aunque no fueron diseñados [con el propósito de] conexión social”.

¿Existe un papel de los médicos a la hora de referir pacientes a estas intervenciones? Sí, dijo Clark, señalando que los médicos que atienden a pacientes con VIH están comenzando a realizar más evaluaciones de detección de los determinantes sociales de la salud, incluyendo preguntas sobre nutrición, vivienda, transporte y, cada vez más, conectividad social. “Cada vez vemos más [médicos] preguntar: ‘¿Siente que tiene a alguien en quien puede confiar para su apoyo social?’”

Pero notó un desafío ético con la detección y los referidos. Específicamente, los proveedores pueden naturalmente mostrarse reacios a realizar pruebas de detección si no pueden atender las necesidades identificadas en la prueba.

“Hay muchos desafíos para la fuerza laboral y cargas para los proveedores”, dijo Clark. “Y los niveles de evidencia para los programas e intervenciones no son muy rigurosos, especialmente para los que se realizan en entornos comunitarios. Si conduces una evaluación, querrás poder referir a los pacientes a programas que sean significativos para ellos.”

“Lo ideal sería que [un proveedor] estuviera conectado a la comunidad, para tener más opciones de consejería centrada en la persona... donde puedas pasar mucho tiempo con ese paciente e identificar las cosas que le interesan y conectarlos a un programa o servicio que los apoye. Es difícil, porque hay muchos factores que contribuyen a la desconexión social de una persona”.

Una atención óptima centrada en la persona significaría que los médicos coordinaran con las agencias locales del envejecimiento y otros centros de recursos en un enfoque de “ninguna puerta equivocada”, dijo. 

What's the best strategy to deal with INSTI weight gain?

BY LARRY BUHL

Studies have reported that one in six patients gain significant weight—at least 10% of their body weight—within two years after starting HIV treatment. This weight gain is more common in women, Black people, and people who had poorer health when starting treatment, but the reasons for weight gain are still unclear. Weight gain is strongly correlated with integrase inhibitors (INSTIs) and tenofovir alafenamide (TAF), particularly second-generation integrase inhibitors dolutegravir and bictegravir. Weight gain is a concern because it can increase the risk of diabetes, cardiovascular disease, and other comorbidities.

Mitigating weight gain was the topic of a lively discussion at IDWeek 2024 in Los Angeles in October, with two experts, Christine Erlandson, professor of medicine at the University of Colorado in Denver, and Cecile Lahiri, an associate professor at Emory University in Atlanta, each defending different strategies.

The case for switching medications

Lahiri started by listing the characteristics of a fictional (but typical) patient who has experienced weight gain: A 55-year-old cisgender Black woman who was on Atripla (efavirenz/tenofovir disoproxil fumarate/emtricitabine) for about a decade, then was switched to Odefsey (rilpivirine/tenofovir alafenamide/emtricitabine). She did well for five years, until two years ago, when her treatment was “modernized” to Biktarvy

She's pre-diabetic, has hypertension, and a body mass index (BMI) of 34 (considered obese). She's a non-smoker, has good renal functions and is on a statin drug to lower cholesterol.

“If this were your patient, what would you do?” Lahiri asked, providing six possible options:

- Continue the current regimen of BIC/TAF/FTC, and give some lifestyle modification counseling
- Switch back to RPV/TAF/FTC
- Start a new regimen of DOR/3TC/TDF
- Switch to long-acting CAB/RPV
- Switch to DRV/c/TAF/FTC
- Add a GLP-1 receptor agonist (the diabetes drugs also used for weight loss)
- Add a different agent

off of an INSTI might stabilize weight gain,” she said.

But it's not all about integrase inhibitors, Lahiri said, pointing to a study looking at over 6,000 people in a Swiss cohort that was switched from TAF, in which the most pronounced weight change was in participants who were switched from TAF to TDF. “Whether [weight change] resulted from going off TAF or going on TDF, we don't know, but switching from TAF to TDF may prove beneficial for weight loss.”

Lahiri said that some data will be coming from another clinical trial, ACTG A5391, aka the Do It study, a randomized clinical trial to look at doravirine for people who are obese and on integrase inhibitors and TAF. The Do It study has completed enrollment, and the primary endpoint, weight loss at 48 weeks, will be analyzed soon.

The case for not switching medications

Erlandson followed up by arguing that switching regimens can lead to toxicity. “Any time we're talking to our patients about weight, we need to also weigh the consequences of therapies that might decrease their bone density, might contribute to renal insufficiency,

(bictegravir/tenofovir alafenamide/emtricitabine) and since then has gained about seven kilograms, or about 15 pounds; she is not happy with the added weight.

Making a case for changing the antiretroviral treatment (ART) regimen to reduce weight gain, Lahiri pointed to a 2022 study of women and Black and Hispanic people who discontinued INSTIs. “In a real-life scenario, we see that switching

and as we know, efavirenz can cause cognitive impairments, even psychiatric effects and many other toxicities,” she said. Erlandson added that the regimens that Lahiri mentioned were primarily stabilizing weight, but didn't lead to weight loss.

Making the case for lifestyle

'GLP-1 receptors can have numerous benefits, but almost 20% of people probably won't have much of a weight change with GLPs, so they're not a magic pill for everyone.'

recommendations and modifications, Erlandson pointed to studies showing that people with HIV (PWH) have experienced weight loss with nutritional counseling and supervised exercise.

"These lifestyle interventions can also have benefits well beyond weight reduction, in maintenance or things that we might see just with switching someone over to tenofovir or other therapies that might stabilize their weight," Erlandson said. "We can see decreases in mortality, improvements in neurocognitive function, improvements in physical function, reduced inflammation and the risk for

glucagon-like (GLP)-1 receptor agonists, can be more effective for weight loss than changing an ART regimen. Recently the SLIM Liver Study showed that semaglutide not only reduced the severity of common liver disease in PWH, but participants also lost a significant amount of weight.

Erlandson also noted that metformin, which is approved for pre-diabetes, not weight loss, could nevertheless be a cost-effective option for losing weight, at least for PWH who are able to access it.

"Metformin is a very cheap medication, with potential benefits. As we think about our patients that are getting older,

Consensus

Lahiri and Erlandson concluded by agreeing on several points. First, there are no current data supporting weight loss by changing ART, although switching regimens can stabilize weight in some people. "We both agree that everyone should have intensive counseling on nutrition and exercise with ongoing support, even in people that are receiving GLPs," Lahiri said.

"GLPs are not going to change the entire face of weight loss without some lifestyle changes, in part because of the reversible effects as soon as someone stops these therapies," she added. "GLP-1 receptors can have numerous benefits, but almost 20% of people probably won't have much of a weight

change with GLPs, so they're not a magic pill for everyone."

Both Lahiri and Erlandson agreed that food and housing insecurity can limit options for weight change in some populations, and

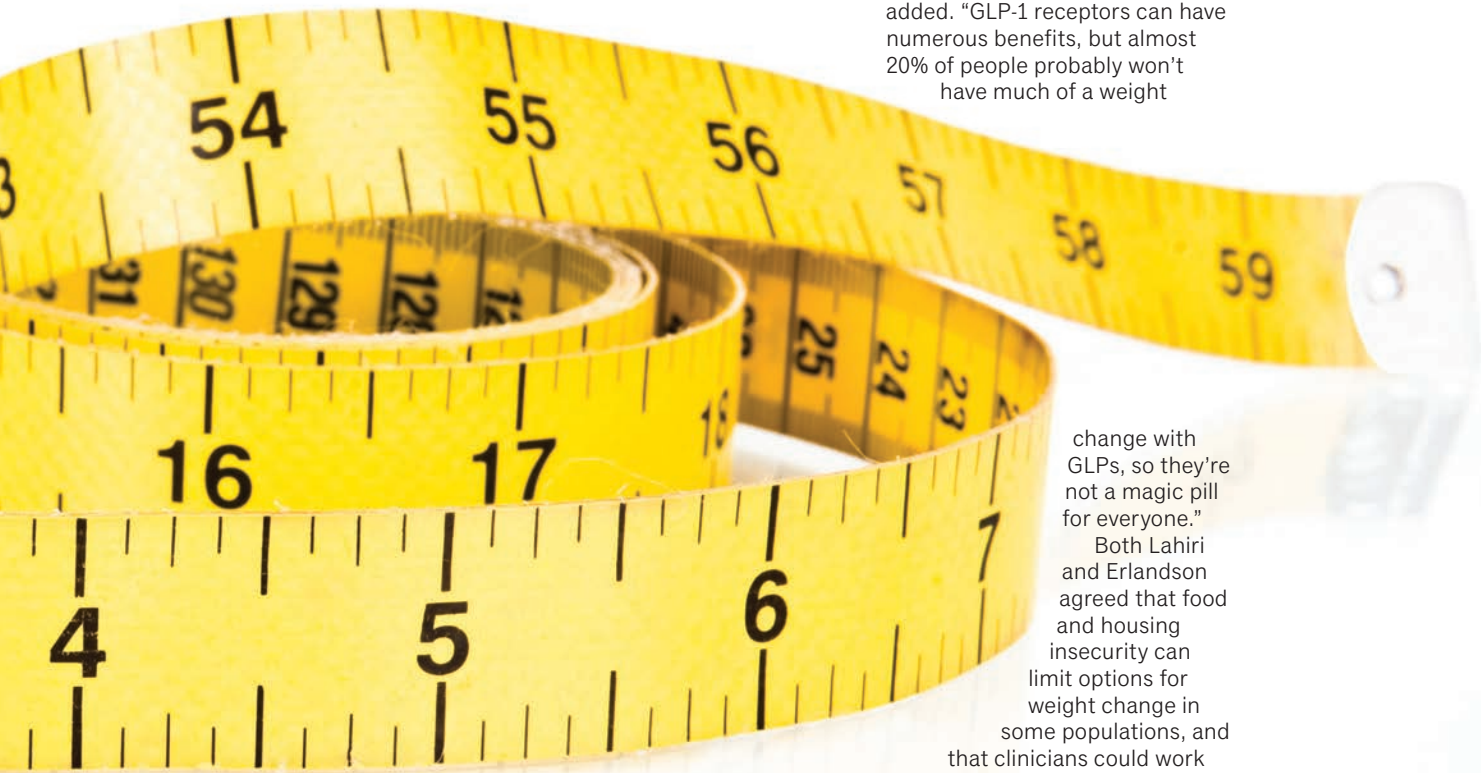
that clinicians could work with patients to find preferable healthy food options that can also fit within budgets.

Erlandson concluded by saying clinicians should develop a unique treatment plan for each patient, using the combination of options that's right for each individual. **PA**

diabetes and ultimately decrease the use of additional medications, which is often a major concern in our patients as they're getting older with HIV."

Acknowledging that some people won't respond enough to a lifestyle intervention, Lahiri said weight loss meds, including

there's interest in looking at metformin as an anti-aging drug. It can improve cognitive function, decrease cancer risk, and have expanded lifespan. You hear of various people that are taking this on a daily basis to improve their longevity. And it has relatively few drug interactions with HIV medications."



'I WANT MY NAME BACK'

Lashanda Salinas and **Kerry Thomas** share their experiences of being incarcerated under state HIV criminalization laws—and talk about how they're working to change them

In 2006, a former boyfriend accused Lashanda Salinas of never having disclosed her HIV status while they had been dating. Unable to prove she had told him (and that she had an undetectable viral load, meaning she was unable to transmit HIV during sex), Salinas accepted a plea deal and was convicted under Tennessee's criminal exposure to HIV law. She was sentenced to three years' probation—and then learned she was required to register as a sex offender. In May 2023, Tennessee Governor Bill Lee signed a bill amending the state's law, allowing people charged with criminal exposure of HIV to be removed from the registry. Less than two months later, Salinas's name was taken off the list. She's started to open up about her experience, talking with audiences across the country, from small groups of individuals living with HIV to state and federal elected officials. She is an active member of the Tennessee HIV Modernization Coalition, a Health Not Prisons advocate, member of The Elizabeth Taylor AIDS Foundation Council of Justice Leaders and is a graduate of Justice Institute 3.0, a program of The Sero Project, a national advocacy and HIV decriminalization organization for people with HIV.

Kerry Thomas has been living with HIV for 36 years, having served 15 years of a 30-year prison sentence at the Idaho State Penitentiary. Although he was undetectable and had used a condom, he was convicted of not telling the woman he had had sex with of his HIV status. Like many state laws that criminalize HIV, Idaho's law took no account of Thomas's undetectable status and that no transmission of the virus had occurred. Now 60, Thomas is the community decriminalization strategist for The Sero Project. He also contributes to several organizations, including the Center for HIV Law and Policy's Aging Advisory Council, the U.S. People Living with HIV Caucus, the Idaho Coalition for HIV Health and Safety and the Vera Institute of Justice's Designed for Dignity project.

The two advocates talked about their experiences and insights in a Zoom conversation for POSITIVELY AWARE in November. The 80-minute exchange has been excerpted and edited for brevity and clarity. —RICK GUASCO

KERRY THOMAS: Let's start with a little bit of your story, wherever you want to start.

LASHANDA SALINAS: Back in 2006 I was dating a gentleman. We met online. Before we met [in person] I told him, *I'm HIV-positive—are you okay with that?* He said he was okay with it, and we proceeded to date. But the relationship wasn't what I thought it would be, so we decided to break up. About a week or two after we broke up, two police officers walked into my job and asked to speak to me. The first thing that ran through my head was, *What did I do?* I had just moved to Nashville a month or so earlier. They tell me, *Your boyfriend has filed charges against you stating that you did not tell him you were HIV-positive.* I said I had told him. And they're like, *Well, do you have proof?* I said that I didn't. I didn't think I ever needed proof. That night, they arrested me. I was under a \$100,000 bond. There was no way I was going to ask my family to come up with 10% [to be released from custody]. I wasn't about to do that. So, I stayed in there about two days shy of two months. My public defender came back with a plea deal, three years' probation. I didn't want to take the plea because I knew I was innocent, but in order to get out and spend time with my family, because my father had just passed, I took the plea. I thought, I can get out, spend time with my family and not have to worry about anything. When I got out, my probation officer calls me while I'm at work and tells me that I have to register as a sex offender. I'm like, *You got the wrong person.* She said because I was charged with criminal exposure of HIV, that this was part of the sentence. I was on the sex offender registry for about 17 years, when Governor Lee amended the criminal exposure law to remove the sex offender registration. I was the first person with HIV to come off the registry. And from there, my life has taken off.

KERRY: You mentioned that you didn't want to ask your family for bond money. Why? Was it financial?

LASHANDA: It was financial. I knew that my family wasn't able to come up with \$10,000. I didn't want to put that on my mom, because she was at the hospital every day to see my father. It was just something I didn't want to ask them for.

KERRY: Stigma is such a big part of HIV criminalization—someone being able to just make an accusation. What were your thoughts and feelings when the police came to your job?

LASHANDA: When they said that my boyfriend had pressed charges because I didn't tell him I was HIV positive, my heart sank to my feet.

KERRY: I'm assuming you had never been arrested before?

LASHANDA: Well, I have, but nothing like this. When you get arrested for a little thing, you pretty much know what the outcome will be. I knew this was a big thing. I thought I would have a bond of maybe \$100 and then get out of there. But when I went before the judge and she said \$100,000, I was like, *Are you serious?*

KERRY: If you look at cases across the country, that's

one of the things that we notice, extremely high bonds that are placed again and again. The narrative from the public becomes, *Holy cow, why would they give someone such a high bond? She must've done something serious.* Instantly, it's no longer about medical facts. It's about stigma and criminalizing the person, dehumanizing them. Because you're a person living with HIV, they paint it as if you're an imminent threat to society. *If we let you out on a low bond, you're going to try to spread this to everybody.*

LASHANDA: Exactly, and that's what they did with me. I was trying to get a bond reduction. The prosecutor said, *You've got family in such and such cities; you're a flight risk.* Because he said *flight risk*, the judge agreed and there was no bond reduction.

KERRY: One thing I want folks to know because it's not talked about much, and if it's something that you're not comfortable speaking to, I understand. Can you describe what it was like when they put the [handcuffs] on you? Especially from a woman's standpoint.

LASHANDA: Luckily, I had a woman police officer there. When she told me to turn around and put my hands behind my back, and I did that, you could hear a pin drop, it was so quiet. And then you hear the cuffs clink. At that time, I was like, *You are about to go to jail for something you really don't know nothing about.* And I'll never forget the booking process.

KERRY: What was that like?

LASHANDA: Oh, my Lord. It made me feel dirty because you've got these males patting you down, touching you where you don't feel comfortable for them touching you, and then they ask you all these questions, like, *Have you been arrested before? If you have been arrested, what was it for? When did you get arrested?*

KERRY: Do you think that they knew that you were a person living with HIV?

LASHANDA: I don't think they knew because they didn't treat me any different. But the thing was, after the booking, they put you in what they call a holding cell. That holding cell, to me, was like I was in a dog kennel.

KERRY: Were you in there by yourself?

LASHANDA: No. This is where they put everybody. It's an open space that's a fenced in pen. I just felt like a dog. After the bond hearing, I was placed in what they call a *pod* with all these other women. How they heard about my charge before you get there, I will never know.



'I said I had told him. And they're like, Well, do you have proof? I said that I didn't. I didn't think I ever needed proof.'

LASHANDA SALINAS

I went to sleep, woke up the next morning for breakfast, and the lady that was in the room with me said, *Oh, you have HIV. I'm like, How do you know I have HIV? What are you talking about?* She said, *Well, your charges are criminal exposure of HIV. And I'm like, Oh, God, she knows I'm HIV-positive. How is she going to treat me? Is she going to treat me like the judge did?* I told her, *Yes, I am HIV-positive. I am undetectable.* She said she doesn't know what "undetectable" meant. *But you can't give it to me, can you?* she asked. I was like, *Just by sleeping in the room with you, on my own in this bed? How am I supposed to give it to you?* She said, *Well, I heard you can get it by touching something that an HIV-positive person has touched.* At that point, I just sat her down and explained it to her. *Ma'am, by you touching my toothbrush or touching my towel or whatever, you're not going to get HIV. It doesn't work that way.* The sad part was that the lady was 50-something years old; I was in my late 20s at the time and was having to explain this to her.

In there, you're always thinking, *What's the next step? What do I need to do to get myself out of the situation?* You hear about the public defenders having a bad rep, they don't help you with your case or they don't care. But I have to applaud my public defender. After my bond hearing, her next step was to have somebody from Vanderbilt [University], from their infectious disease department, come and basically state, *She's undetectable, there is no way she can pass HIV on to anybody.* But then the plea came—three years' probation. I didn't want to take it, but I did.



I'm gonna live my life the best I can, on my terms. Part of my willingness to have a conversation like this is to reclaim that. I want my name back.

KERRY THOMAS

LASHANDA: A year and a half in a women's prison and a year and a half on probation. I was thinking of taking the plea, but then I was like, *No, I'm innocent. I'm not taking that plea.* And then I had to request a furlough—that's what I thought I was going to court for that day, but there was the plea with three years' probation. I'm sitting there debating, *Okay, do you want to take this plea or do you take the furlough, go to the funeral and come back.*

KERRY: Whose funeral was it?

LASHANDA: It was for my father. [Salinas' father died in the hospital while she was in custody.] I was thinking, *Lashanda, what do you want to do? You know you're*

innocent, but people are making it out that you're guilty, that you did not tell [your boyfriend]. If I take this plea, are people going to think that I'm guilty? I made the decision to take the three years' probation just to get out and be with my family because that seemed like the only way I could get out.

KERRY: Do you bake? Have you ever made bread?

LASHANDA: No, I've never made bread.

KERRY: You get the dough, you spin it around, put it on the table and you start kneading it. You soften it up a bit. That's what they do at the prosecutor's office. I call it *knead 'em and plead 'em.* They put you in difficult conditions. They're kneading you, then they hit you with a plea deal. That's knead 'em and plead 'em. That's why I'll push back on anyone who says only guilty people take a plea. No, not when you're in that oven.

It's amazing to me how our stories are so similar. This is my 14th month since returning to the community after serving 15 years under Idaho's criminalization statute. They didn't play around. I had a \$1 million bond. Basically, you're saying, *This dude ain't getting out.* And then you compound that with the ignorance surrounding HIV. *If he's got a \$1 million bond, he must be a real threat to society.*

I remember going for sentencing the day after I accepted the plea. I was sentenced to 30 years of incarceration. Similar to your circumstances, one of the reasons I took the plea was because at the time, both my parents were elderly. Because of the bond, the media attention on my case was through the roof. As naïve as I was, I thought the best thing to do to cut off the media attention was to accept the plea, go to the judge and for the judge to make an honest decision. Not one time in the sentencing hearing did anything about HIV come up. It was about villainizing the individual. Not one time in the sentencing does the fact that you're undetectable come up.

LASHANDA: It becomes about you and your character, exactly.

KERRY: We need to talk about the scientific facts, the medical facts, about HIV.

I think it's important that folks understand that both of us are doing amazing things now. Maybe you can share a little bit of some of the projects you've worked on after incarceration.

LASHANDA: Where do I start?

KERRY: How about start with *why?* Why did you choose to get involved in HIV decriminalization advocacy?

LASHANDA: I chose to get involved after I realized that so many people were being criminalized. There's advances in medication for HIV, and I realized that the laws didn't match today's science. I knew there were people out there who wanted to speak, but were afraid.

KERRY: Afraid of what?

LASHANDA: Afraid of being stigmatized, of being told, *you're dirty.* At first, I was scared to speak out because

I was like, *Now everybody in the world is going to know I'm HIV-positive.* So I had a conversation with myself, had a conversation with my family to ask how they felt about it. Everybody said they were okay. I put on the whole armor of God to do this. I will take the beatings and the backlash on behalf of people who feel they cannot speak for themselves.

KERRY: I think we're similar that way. And what I had to realize is that part of my *recovery*, for lack of a better term, has been I do it because no one should ever have to go through the experience of HIV criminalization. I've been very blessed that almost from the moment of my arrest to this day, that I've had a lot of support. I'm thankful for that.

The question for me is, *What do I want my son to think of me?* When I was arrested, my son was 14 years old. He had just turned 14. I made a conscious choice to do my time with dignity. How I'm gonna do my time is how I define myself as an adult, as a man. I'm not talking about machismo stuff, but I'm gonna live my life the best I can, on my terms. Part of the willingness to have a conversation like this is to reclaim that. I want my name back, I want some respect on my name.

LASHANDA: Exactly. I want that back.

KERRY: That's my motivation. That is decriminalization to me.

I was very fortunate to have an opportunity to work with The Sero Project upon my release. I worked with them for 12 years while I was incarcerated. I did 15 [years], 12 of those years was being a part of The Sero Project, on their board and in other capacities. That has been my focus, my outreach into the community. I love that you said that you're motivated to advocate for the many people who don't have the capacity.

LASHANDA: When I was in jail, I had no resources whatsoever. There was no support besides my family, but I needed somebody else there. I didn't have anybody to tell me what criminal exposure to HIV was, no one to give me advice as to what I should do. When I felt like I needed to cry, I had nobody.

KERRY: And there was nobody there to tell you that it was going to be okay.

LASHANDA: Exactly. Nobody, not even me. I didn't say that to myself because of the simple fact I didn't know if it was gonna be okay.

KERRY: I'm often asked, *How did you do 15 [years]?* You know what? I can't do 15 years, but I can do today. And God willing, I can do tomorrow. That literally became my mantra, *I can do today.* Sometimes I had to break it down—I *can do this. I can do this hour.* Sometimes it was, *I can do this minute.*

LASHANDA: Exactly.

KERRY: Early on, I said, *There's no such thing as a bad day.* I never had 24 hours of that. I might've had an hour here, an hour there. I've had multiple bad moments in the course of a day, over the course of a lifetime, but God, I'm blessed. There's something to be thankful for every day, if not every moment, and that speaks to gratitude.

One thing that The Sero Project does is that we have our HINAC [HIV Is Not A Crime] 6 training academy [to be held May 31–June 3 at North Carolina State University in Raleigh]. It's more than just an academy. It's about coming together in a sense of community. The training is teaching us how to love each other and work together.

LASHANDA: I think of it as, I'm going somewhere to visit with my family, to come together with one goal. We're going to see how we can take this a step further.

KERRY: I always say HIV is not a crime, but choosing to be ignorant of it is. What is it that motivates you to swing your feet out of bed?

LASHANDA: It all boils down to somebody needs me. So I've got to swing my feet out of this bed and get started. If everybody else can do it, I can do it as well.

KERRY: Yes, you can. You can reach out to organizations like Sero, reach out to your local clinic, to your state's legislature. You can reach out and get training. You can stand up.

LASHANDA: I think I want to do one-on-one advocacy training. I don't know what that looks like yet...

KERRY: Why not?

LASHANDA: Because when I started, there was no blueprint. I was just throwing it out there. And it just so happened that Sero caught me.

KERRY: If you want to do one-on-one advocacy training, we can plan for that. I choose the term *mentorship*. I'll even take it further and call it *peer support*. Because that's what it takes, having one-on-one life conversations with folks. That's what moves the needle.

LASHANDA: This is one of the ways to get started in advocacy. Reach out to an organization. It all starts with reaching out.

KERRY: It's empowering. Just like with our HIV care, we have to become an active participant in our own survival. Surviving criminalization is the same thing. You gotta be an active participant in your own survival. **PA**

FOR MORE INFORMATION about the HIV Is Not A Crime 6 summit, GO TO seroproject.com/hinac.



'There's advances in medication for HIV, and I realized that the laws didn't match today's science.'

LASHANDA SALINAS



A LEGAL GUIDE for people aging with HIV

EXCERPTED AND CONDENSED FROM THE CENTER FOR HIV LAW AND POLICY

EDITOR'S NOTE: The following is condensed from Section 1 of *Aging & HIV: An Introduction to Legal Issues Facing People Living and Aging with HIV*, from the Center for HIV Law and Policy (CHLP), a national abolitionist legal and policy organization.

"This country's social services and healthcare infrastructure are not prepared to address the needs of the rapidly expanding population of people living and aging with HIV. This primer is focused on not just identifying the legal barriers to aging with dignity and self-determination but identifying avenues for self-advocacy and recommending priority areas for policy work. These excerpts highlight some of the federal antidiscrimination protections that are in place to protect people living and aging with HIV and explain how to access those services and remedies."

—Kae Greenberg, CHLP STAFF ATTORNEY AND PUBLICATION AUTHOR

The focus of the legal primer *Aging & HIV: An Introduction to Legal Issues Facing People Living and Aging with HIV* is to help people living and aging with HIV identify and overcome legal barriers to aging with dignity. It should serve as a tool to explain existing support systems and as a guide for advocates to identify where policies could be changed or created to provide increased support. ... The primer is geared toward long-term survivors of HIV (people who have been living with HIV for a decade or longer) who are now reaching or are over the age of 50 and are preparing to age with HIV, but also contains information applicable for Dandelions, or lifetime survivors.

There are three main sections of the primer:

1. Federal laws such as the Americans with Disabilities Act that protect people with HIV from discrimination and the agencies that can assist with remedying complaints.
2. The criminalization of people living with HIV and the collateral consequences of criminal legal system involvement and criminal records on them.
3. The barriers to and remedies for protecting the power of people living with HIV to make decisions about their health and medical care.

Excerpts from Section 1: Federal Anti-Discrimination Laws and Remedies

[C]haracteristics [such as]—age, living with HIV, race, sex, etc.—are special categories known as “protected classes” that are subject to one or more federal laws that protect people from discrimination. ... Discrimination does not necessarily require negative or unfair treatment; it can be, instead, “different treatment for similarly situated parties, especially when no legitimate reason appears to exist.” ... [I]f one can show that they are a member of a “protected class,” they can use these federal statutes for protection or redress and potentially pursue compensation for damages suffered.

Not every federal law protects every identity category from discrimination ... some laws, such as the Fair Housing Act, provide protection only within a specific area. There are also typically exceptions regarding when and to what extent these protections are applicable. ...

Not every component of a person's identity that causes differential or negative treatment is

protected under anti-discrimination law. And not all manifestations of bias, even in one of these categories, may be covered by anti-discrimination law. For example, in most cases it is perfectly acceptable to deny someone a job or housing based on their having a criminal record regardless of what kind of record it is. Demonstrating an explicit bias against people with a criminal record (as long as it is not being used as a proxy for discrimination against people based on race [a blanket ban]) is permitted under various federal anti-discrimination laws.

Regardless of whether a form of discrimination or bias is covered by anti-discrimination laws, many people living and aging with HIV face discrimination because of different aspects of their identities and lives, and those experiences have an impact on their ability to access services as they age. Nearly half of LGBTQ+ residents in long-term care facilities have been mistreated in ways ranging from verbal harassment to expulsion based on their real or perceived sexual orientation and/or gender identity. ... As a result [of potentially a lifetime of battling stigma], they are more likely to have lower incomes and when faced with discrimination, lack the resources to pursue remedies. ...

It is important to note that anti-discrimination laws are almost entirely unresponsive to the ways in which people living and aging with HIV may be targeted due to their intersectional identities. The laws can only address the harms caused by differential treatment based on each characteristic separately. In 1989, law professor Kimberlé Crenshaw coined the term “intersectionality” to describe Black women's multilayered experiences of institutional oppression (manifested in part as discrimination). Since then, the term has become a framework for understanding how a person's identities (race, gender, sexuality, etc.) compound the totality of harm that individuals and communities experience every day. ...

What federal protections exist for people living and aging with HIV?

The federal laws outlined here are not all of the federal laws that protect people living and aging with HIV from discrimination, but they represent some of the important ones.

The Americans with Disabilities Act (ADA)

The protections of the ADA preempt, or take precedence over, any state law that is in conflict with them, as written, or as applied. Since the ADA's passage in 1990, and through its subsequent updates and amendments, Congress has directed the courts to take an expansive and inclusive view of disability,

Not every federal law protects every identity category from discrimination ... some laws, such as the Fair Housing Act, provide protection only within a specific area.

...many people living and aging with HIV face discrimination because of different aspects of their identities and lives, and those experiences have an impact on their ability to access services as they age.

defined as any “physical or mental impairment that substantially limits one or more major life activities” or with a history or perception of such impairment. HIV is a covered disability protected by the ADA, regardless of a person’s viral load or of the impact that living with HIV currently has on their ability to navigate their day-to-day life. ...

The ADA consists of five sections. ... The titles that are most applicable to the issues that people living and aging with HIV may face are Titles I–III.

The Americans with Disabilities Act Title I: Employment

Title I of the ADA ... prohibits discrimination against individuals who can “perform the essential functions of the job, either with or without reasonable accommodation” unless they pose a significant risk to the health or safety of themselves or others that cannot be eliminated by reasonable accommodations. This risk assessment “must be based on medical or other objective evidence,” and even a good faith belief in the existence of such risk does not allow employers to discriminate in the absence of such evidence. ... “[t] may not be based on generalizations or stereotypes about the effects of a particular disability.” Recent case law involving employers who made employment decisions based on the purported risk posed by employing a person living with HIV shows that courts are unlikely to accept an argument that a person living with HIV poses a risk to others if employed.

[Under Title I, a covered individual can request a reasonable accommodation.] Reasonable accommodation can be a physical change to one’s workspace, a change in hours, a change in responsibilities, or even the ability to take time off under the Family Medical Act Leave without a fixed return date. But just because it is determined that an employee or a prospective employee can perform a job activity with the use of a reasonable accommodation does not automatically entitle the individual to one. ...

The Americans with Disabilities Act Title II: Public Entities

Title II of the ADA prohibits government entities from engaging in discriminatory practices either directly, by explicitly excluding or denying someone’s access to programs, or indirectly, by failing to prevent or ameliorate such discrimination. Examples of covered programs and activities include attending public schools, accessing public recreation facilities and receiving healthcare and social services. ... If a government agency or program claims that the discrimination (differential treatment) is justified in the case of a person living with HIV, there is then an inquiry into whether the person is “otherwise qualified” to access the service. ... Essentially, the ADA instructs officials to do an assessment to determine if someone with a communicable disease is actually a direct threat and if such a threat could be ameliorated through reasonable modifications to policies, practices, or procedures.

The Americans with Disabilities Act Title III: Public Accommodations

Public accommodations such as nursing homes are expressly covered in the Title III regulation as

social service center establishments. Other residential facilities, such as congregate care facilities, retirement communities, and independent living centers, are also covered by Title III if they provide significant social services such that they can be considered social service center establishments. ... If a facility meets the criteria of a social services center, the facility must ensure that people living with disabilities are treated equally and that they have equal opportunity to benefit from safe, inclusive communities.

The Older Americans Act

The Older Americans Act (OAA) was first passed in 1965. ... Over the decades since its initial passing it has been reauthorized and updated many times in an effort to improve its services and supports to allow people to live at home as they age. ... [In the 2023 Rule people living and aging with HIV were] mentioned as [a group] that [has] the “greatest social need.” Services funded through Title III of the OAA are supposed to prioritize aiding aging people, and their caregivers, identified as having the greatest social need. This “[a]ffects all levels of Older Americans Act policy, funding, planning, and service delivery.” This provision should translate into the needs of LGBTQ+ people and people living and aging with HIV being explicitly incorporated into State Plans on Aging, or blueprints for state services, expanding resources for and support to people living and aging with HIV.

The Age Discrimination in Employment Act of 1967

The Age Discrimination in Employment Act (ADEA) makes it unlawful for employers to discriminate against any individual employee over the age of 40. ... “[T]he ADEA requires employers to consider individual ability, rather than assumptions about age, in making an employment decision.”

The Civil Rights Act of 1964

The Civil Rights Act of 1964 prohibits discrimination on the basis of race, color, religion, sex or national origin.

In the 2020 case of *Bostock v. Clayton County* the plaintiff, a gay man, sued Clayton County, Georgia, claiming that he had been fired from his county job for being gay. He claimed that under Title VII of the Civil Rights Act, protections against discrimination on the basis of sex, the firing was unlawful. The U.S. Supreme Court agreed, ruling that firing him for being gay amounted to discrimination under Title VII, that he had been fired because of his sex. Thus, the Civil Rights Act of 1964 could be used to combat discrimination that LGBTQ+ people living and aging with HIV face in employment if it is due to their LGBTQ+ identity.

The Fair Housing Act

It applies to all “housing-related transactions” which include: renting, buying, selling, applying for a loan, appraisal services, and homeowners insurance. It “prohibits discrimination by direct providers of housing, such as landlords and real estate companies as well as other entities, such as municipalities, banks



Not every federal law protects every identity category from discrimination ... some laws, such as the Fair Housing Act, provide protection only within a specific area.

or other lending institutions and homeowners insurance companies.” Discrimination is broadly defined by the FHA to include all of the kinds of conduct it was passed to combat, such as trying to steer a member of a protected class away from a particular neighborhood.

As of the 1988 amendments, there are seven “protected classes” under the Fair Housing Act: race, color, national origin, religion, sex, disability, and families with children.

Section 1557 of the Affordable Care Act

The purpose of Section 1557 of the Affordable Care Act (ACA, aka “Obamacare”) is to improve access to healthcare, primarily by reducing barriers and through strengthening protections against discrimination on the basis of race, color, national origin, sex, age, or disability.

Important interpretations and expansions under the Biden rule [interpreting this section] are:

- Healthcare providers and suppliers who receive Medicare Part B payments are subject to the anti-discrimination requirements of Section 1557. ...
- Interprets the definition of “sex” in Section 1557 to include protecting people from discrimination on the basis of gender identity and sexual orientation. ...
- Provides protections on the basis of sex characteristics (including intersex traits), and pregnancy-related conditions, including termination. ...
- Forbids benefit designs that do not provide health insurance coverage for qualified individuals with disabilities (which includes people living with HIV) in integrated (“Olmstead”) settings. What this means, practically speaking, is that covered providers (currently including covered

insurance providers) cannot treat people living and aging with HIV differently from other older people with insurance on the basis of their HIV status, regardless of the cost of their care.

Since HIV is a covered disability under the ADA, as amended in 2008, protections from discrimination based on HIV status are integrated directly into Section 1557 through its explicit incorporation of the definition of disability used by the ADA. But the category of “covered provider,” or who is subject to the nondiscrimination clauses of Section 1557, depends upon the interpretation by different presidential administrations.

A looming threat: The Religious Freedom Restoration Act

The Religious Freedom Restoration Act (RFRA) as it has been interpreted and applied by the courts, including the Supreme Court, lurks on the horizon as a threat to many of these protections. RFRA was passed ... in an effort to shield ... a person’s sincerely held religious beliefs and practices from even inadvertent infringement by the government. [However] it is currently being wielded by the religious Right to challenge laws with which they do not agree. Challenges have ... been raised to state laws that protect against discrimination in public accommodations for lesbian and gay people, [the contraceptive mandate under the ACA and preventative care—including (HIV) PrEP under the ACA].

What is troubling about these attacks is that even if the Supreme Court does address the RFRA claim, justices have indicated strongly that they believe that RFRA should give people the right to discriminate on the basis of religion. ... As of 2011, 14% of all hospitals in the U.S. were religiously affiliated—meaning 17% of all hospital beds nationally could be impacted by licenses to discriminate under RFRA. **FA**

For CHLP’s 76-page guide, which includes footnotes, **GO TO bit.ly/aging-and-law-primer.**



BEING BRIDGETTE

Bridgette Picou

Just enough hope

“Beginnings are scary, endings are usually sad, but it's the middle that counts the most. You need to remember that when you find yourself at the beginning. Just give hope a chance to float up.”

—Birdee Pruitt, from the 1998 film, *Hope Floats*

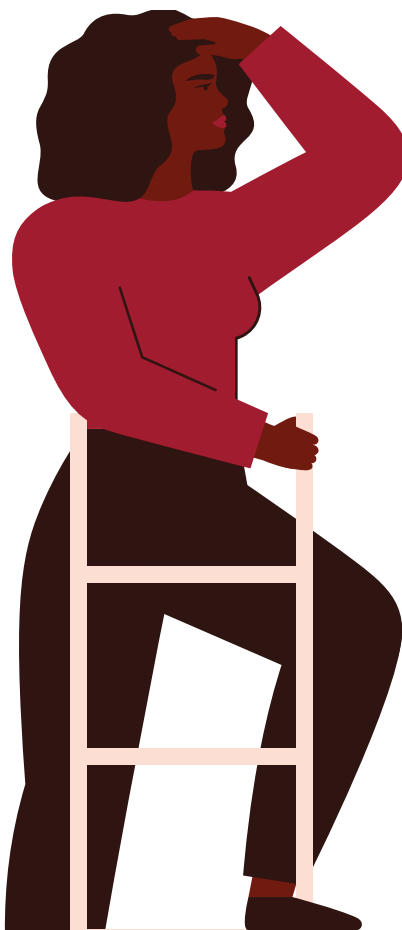
Hope is something you can work toward while prayers involve a higher power leaning in to help you.

I stopped watching TV and going to movies with sporadic exceptions in 2013 when I started nursing school. I wanted to devote my energy to study, and in doing so fell out of the habit of moving pictures. Life itself feels like a movie often enough to keep me entertained and on the edge of my seat. Some things still stick with me though from my love of cinema—movie quotes mainly. I think of that one from *Hope Floats* around the end of one year or beginning of the next nearly every year.

Every year in January we reset to start over again. Some folks make resolutions to set them on track. This year, though, it feels like they carry extra weight. My end of the year is always fraught with a mash-up of trying to remain positive and coping with the grief of holiday loss. The beginning of 2025 feels a bit overwhelming for me. There is no need to get political or divisive, but the fact is there are a lot of scary things facing us in 2025. I can share that I feel concern for friends who are scared for their very existence and identity. I worry for them, their safety and their mental health. As a nurse working in HIV and (more to the point) as a woman living with HIV, I worry about an already broken healthcare system and if we will see an end to the Affordable Care Act (“Obamacare”) and therefore, an end to not only affordable healthcare, but a return to denials because of pre-existing conditions. I also know without doubt this would widen the gap in health disparities and equitability. So many things to think about. Funding for HIV both in the U.S. and abroad,

the fate of community-based organizations and AIDS service organizations, the list goes on.

It's necessary for me, my sanity and my well-being to *focus on what the middle might be*. To give hope a chance to float up. Hope is hard for many people. There are so many actions and emotions tied up in such a short four-letter word. *Hope* has an element of dreaming in it. There is anticipation in hope. There is the desire for change and the need to plan for it to happen, in addition to trust. To hope means *waiting*—but acting while waiting, as if the



thing you hope for is coming to pass so you are prepared. Hope is also trying to let go of the “what-ifs.” Do you just hope for the thing and trust that it will be? Or should you plan for the outcome with the hope it comes out alright? Hopes are different from wishes and prayers. I think hope implies a more practical outlook and application than wishes or prayers, which often are for the impossible or unlikely. Hope is something you can work toward while prayers involve a higher power leaning in to help you.

I've shared before that I think laughter is hope. I will never *not* believe that. I also think there are pragmatic ways to employ hope in life so that you keep trust in hope *and in yourself*. In 2025, I hope you have just enough of the things you want and need. I hope you have just enough success to keep pushing for more. I hope you make just enough money to pay your bills and have a little extra for those shoes or that hobby you love. I hope you feel just enough support from those around you to let go of “what-if” and revel in the “let's do it.” I hope you have just enough love and light to remind you that you are blessed and worthy. I hope that *just enough hope floats up for your new beginning*. 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.

Tell us about yourself, and what matters to you



Knowing you better helps POSITIVELY AWARE serve you better. Please take a few minutes to fill out the survey below. Tear out this page, fold, tape, and mail it. You can also scan or take a picture of the page and email it to inbox@positivelyaware.com. Take the survey online at positivelyaware.com/2025survey or scan this QR code at right. All responses are completely anonymous. Thank you!

1. I primarily read POSITIVELY AWARE:

- in print
 on a desktop or laptop computer
 on my smartphone, tablet, or other mobile device

2. How do you get POSITIVELY AWARE?

- I have a subscription
 I pick it up at my doctor's office/clinic
 I pick it up at an HIV/AIDS service organization
 Other: _____

3. I read POSITIVELY AWARE because (check all that apply):

- I am living with HIV
 I work at an AIDS service organization or community-based organization
 I am a healthcare provider
 I am incarcerated and need current information
 I know/care for someone living with HIV
 Other: _____

4. What topics would you like to read more about in POSITIVELY AWARE? (check all that apply):

- The latest HIV-related scientific/medical information
 HIV treatment and drug information
 Stories about people living with HIV
 Information related to HIV and aging
 HIV advocacy and policy
 HIV prevention/PrEP
 HIV cure research
 Other: _____

5. Are the articles that are translated into Spanish useful to you?:

- Yes No

6. I live in ZIP code: _____

7. My relationship status (check all that apply):

- Single In a relationship
 Married Divorced Widowed
 It's complicated I prefer not to say

8. I am receiving, or have received, treatment for (check all that apply):

- Alcoholism or substance use
 Arthritis Cancer
 Depression, anxiety, or other mental health conditions
 Diabetes Heart disease
 Hepatitis B or C
 High blood pressure
 STIs (sexually transmitted infections)
 None of the above
 I prefer not to disclose
 Other: _____

9. What is your age?

- Under 20 50–64
 20–29 65–74
 30–39 75 and up
 40–49 I prefer not to say

10. Do you identify as transgender?

- Yes No
 I prefer not to say
 I self-describe as: _____

11. What is your gender identity?

- Female Male
 Queer Nonbinary
 Gender nonconforming
 I prefer not to say
 I self-describe as: _____

12. What is your race and/or ethnicity? (check all that apply):

- American Indian or Alaskan Native
 Asian
 Black or African American
 Latinx, Latino/a, or Hispanic
 Native Hawaiian or other Pacific Islander
 White
 I prefer not to answer
 I prefer to self-describe as: _____

13. I have been living with HIV for:

- Less than 5 years 5–10 years
 11–20 years 21–30 years
 More than 30 years
 I am not living with HIV

14. What is your sexual orientation?

- Bisexual
 Gay or Lesbian
 Straight/Heterosexual
 I prefer not to say
 I prefer to self-describe as: _____

15. What is your HIV status?

- HIV-positive
 HIV-negative
 I don't know
 I prefer not to disclose

16. My annual household income is:

- Less than \$15,000
 \$15,000–\$34,999
 \$35,000–\$49,999
 \$50,000–\$74,999
 \$75,000–\$99,999
 \$100,000 or more
 I'd rather not say

17. How likely are you to share what you read in POSITIVELY AWARE with your health care provider?

- Likely
 Somewhat likely
 Not at all

18. What social media platforms are you on?

- Facebook Instagram
 Bluesky X (Twitter)
 Tik-Tok LinkedIn
 Other(s): _____

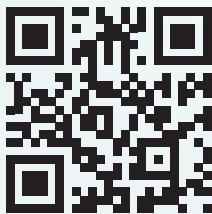
19. As someone living with or affected by HIV, my greatest concern is:

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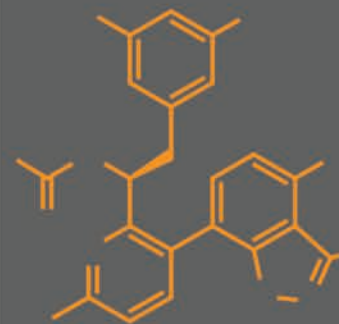
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