

PA

POSITIVELY AWARE

HIV TREATMENT, PREVENTION AND HEALTH FROM TPAN
SEP+OCT 2021

THE BASICS
LIVING YOUR
BEST LIFE
WITH HIV

SEX+DATING
WITH HIV
IN THE AGE
OF U=U

IAS 2021
CONFERENCE
HIGHLIGHTS

On the eve of the release of his new memoir, activist **Peter Staley** talks about ACT UP, the early days of the AIDS epidemic, and Tony Fauci

NEVER SILENT



Jeff Berry
EDITOR-IN-CHIEF
@PAeditor

Enid Vázquez
ASSOCIATE EDITOR
@enidvazquezpa

Andrew Reynolds
HEPATITIS C EDITOR
@AndrewKnowsHepC

Rick Guasco
CREATIVE DIRECTOR
@rickguasco

Scott Schoettes
LEGAL COLUMNIST
@PozAdvocate

PROOFREADER
Jason Lancaster

PHOTOGRAPHERS
Habeeb Mukasa
John Gress
Chris Knight

ADVERTISING MANAGER
Lorraine Hayes
L.Hayes@tpan.com

DISTRIBUTION MANAGER
Denise Crouch
distribution@tpan.com

SUBSCRIBE OR ORDER COPIES
positivelyaware.com/subscribe

LIVE LIFE POSITIVELY AWARE.

FOR OVER 30 YEARS, PUBLISHED BY



5537 N. BROADWAY
CHICAGO, IL 60640-1405
(773) 989-9400
FAX: (773) 989-9494
inbox@tpan.com
positivelyaware.com
@PosAware

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.



On Wednesday, Sept. 22, become part of a 24-hour event. Here's what you do:

1. **Take a photo of your day Wednesday, Sept. 22.**
 2. **Post it to your social media.** Include a caption that gives the time and location of your photo—and what inspired you to take it. Add the hashtag **#adaywithhiv**.
 3. **Upload your picture and caption to adaywithhiv.com,** and it'll be included in our online gallery. Select high-res pictures will be featured in the NOV+DEC issue of *Positively Aware* magazine.
- PLUS,** four print quality photos will be chosen for different versions of the cover!

A DAY WITH HIV captures 24 hours in the lives of people affected by HIV—that's all of us, regardless of status.

Join us on Wednesday, Sept. 22. Get in the picture, and share your story with the world.



9/22/2021

ON SEPT. 22, GET IN THE PICTURE!



#adaywithhiv
adaywithhiv.com

SEP+OCT 2021

POSITIVELY AWARE · VOLUME 31 NUMBER 6 · positivelyaware.com · @posaware



EVERY ISSUE

4

THE CATEGORY IS... BASIC REALNESS

What are the basics of your life with HIV?

COMPILED BY RICK GUASCO

5

EDITOR'S NOTE

Reflections.

6

BRIEFLY

Third COVID shot urged for people living with HIV. Update on opportunistic infections. Syphilis PrEP? \$122 million grant to advance monthly PrEP pill.

U.S. Conference on HIV/AIDS goes virtual—again.

38

POZ ADVOCATE Decriminalizing sex work is good public policy

BY SCOTT SCHOETTES

39

BEING BRIDGETTE When it clicks

BY BRIDGETTE PICOU

40

POSITIVELY AGING Report: Meeting the needs of people aging with HIV

THIS ISSUE

10

Living your best life with HIV

You have your whole life ahead of you. What to know, and what to consider.

BY MICHAEL BRODER

14

Sex + dating with HIV in the age of PrEP and U=U

A personal perspective.

BY MICHAEL BRODER

16

An interview with HIV specialist Dr. W. David Hardy

For nearly 40 years, Dr. Hardy has been one of the leading figures in HIV clinical research and practice.

BY MICHAEL BRODER

21

HIV basics: U=U

'Undetectable equals untransmittable' means you can't sexually transmit HIV while on successful therapy.

BY ENID VÁZQUEZ

22

Never silent

On the eve of the release of his new memoir, activist **Peter Staley** talks with editor-in-chief **Jeff Berry** about ACT UP, the early days of the AIDS epidemic, and Tony Fauci.

28

Children's HIV research continues to grow up

With success comes new issues.

BY ENID VÁZQUEZ

CONFERENCE UPDATE

IAS 2021

33

Another international HIV conference goes virtual amidst a global pandemic

WHO finds increased risk of severe disease and death from COVID-19 in people living with HIV, while a U.S. study finds no increased risk of severe disease or death from COVID-19 in people living with HIV. Latest study results on islatravir for PrEP and lenacapavir. Adherence with vaginal rings and oral PrEP. Closing the gaps for trans and gender-diverse people.

BY ENID VÁZQUEZ

36

Aging with HIV: Moving beyond treatment

Now that HIV is a treatable chronic condition, dealing with what comes next.

BY JEFF BERRY

37

Highlights from the 2021 HIV Cure and Gene Therapy Forum

Disrupting the CCR5 gene to make cells resistant to HIV infection. Strategies to bring cell and gene therapy to resource-limited parts of the world. CAR T cell trials. An overview of the new HIV Cure Africa Acceleration Partnership. Funding announced for 10 Martin Delaney Collaboratories.

BY KARINE DUBÉ, LYNDA DEE,
AND MICHAEL LOUELLA



ON THE COVER
PETER STALEY
PHOTOGRAPHED
BY EMIL COHEN

THE CATEGORY IS...

BASIC REALNESS



JOIN IN THE CONVERSATION

inbox@tpan.com



@posaware

POSITIVELY AWARE
5537 N.
BROADWAY
CHICAGO, IL
60640-1405

ALL LETTERS, EMAIL, ONLINE POSTS, ETC. are treated as letters to the editor unless otherwise instructed. We reserve the right to edit for length, style, or clarity. Let us know if you prefer not to have your name or city mentioned.

GET YOUR SUBSCRIPTION OR ORDER BULK COPIES



SCAN THIS QR CODE with your smartphone, or go to positivelyaware.com/subscribe

The basics of HIV are different for each person. Getting into care and staying on treatment are the beginning. The question we asked our followers on Facebook, Instagram, and Twitter: **What are the basics of your life with HIV?**

"I've been living with HIV for so long that it really isn't in and of itself a significant part of it (albeit, other than my HIV advocacy roles, which are my life). It's now really the multi-morbidities that shape my life... and take so much of my energy. But the same things that are good for them are also good for any person living with HIV. My belief is that a person needs to feed the three important elements of oneself in order to thrive. Those elements are your body, mind, and soul. You aren't truly whole unless you're incorporating strategies to keep these parts of yourself in balance. So, my focus is on nutrition, exercise, love, laughter, helping others, expanding my mind (knowledge), music, arts, socializing, nature, and generally just following the things I'm passionate about."

—JEFFERY PARKS

"As a woman senior my way of living positive is staying in treatment. Also, eating right, sleeping seven to eight hours a day, living

life with a true mindset of spiritual healing, meditation, tai chi, yoga, and treating myself with love, family, friends. Living with HIV is healthy."

—@CYNTHIATAYLORG2

"What's basic for me living with HIV/AIDS is to never, ever give up! I remember the early 1980s and a time when there were no meds and we were most fearful. Volunteering and helping others who were struggling made me appreciate my own life. I sought out an AIDS-knowledgeable physician to give me a fighting chance. I attended support groups and made poz friends. I'll always remember those who are gone forever reminding me to appreciate and enjoy every second! 40+ year poz survivor."

—ARTURO C. JACKSON III

"My basics: 1. It's daily. Each day, every choice I make is connected directly or indirectly to my HIV status. 2. It contributes to my creativity. I have a story to tell that is much more interesting

because of what I have learned from living with AIDS. 3. It has made me a better person. I can be more empathetic because I have been there. I can be more grateful because I know what I could have lost. 4. I have a positive attitude about life. I believe my positive attitude is there because I have survived AIDS for over 30 years. The positive attitude also contributes to helping my body fight the virus. 5. I have a purpose. My experience in living with AIDS may help someone else, just like the experiences of others have helped me."

—HARRY C S WINGFIELD

"Adherence, labs, doctor discussions as a long-term survivor, and living life."

—LARRY FRAMPTON

"Live every day to the fullest."

—DEREK CANAS

"Always trust your instincts. Be proactive. Choose the best provider available."

—KATHY CALLAGHAN

"The basics of my HIV life start with ensuring I do my part to keep my viral load undetectable—one pill a day. The rest appears no different from a non-HIV living individual. Vitamins, some daily activity, and good food with good people."

—MARISSA GONZALEZ

"HIV is a virus. I am a human. They are different. I live my life with HIV. It doesn't run my life."

—BRIDGETTE PICOU

"One pill per day. Two doctor visits per year for labs and monitoring. Otherwise, live my life and my HIV goes along for the ride."

—XIO MORA-LOPEZ

©2021 POSITIVELY AWARE (ISSN: 1523-2883) is published bi-monthly by Test Positive Aware Network (TPAN), 5537 N. Broadway, Chicago, IL 60640. TPAN is an Illinois not-for-profit corporation, providing information and support to anyone concerned with HIV and AIDS issues. POSITIVELY AWARE is a registered trademark of TPAN. All rights reserved. Readership: 100,000. For reprint permission, email inbox@tpan.com. Six issues mailed bulk rate for \$30 donation; mailed free to those living with HIV or those unable to contribute.

We accept submission of articles covering medical or personal aspects of HIV/AIDS, and reserve the right to edit or decline submitted articles. When published, the articles become the property of TPAN, POSITIVELY AWARE, and its assigns. You may use your actual name or a pseudonym for publication, but include your name, email address, and phone number with your story. Although POSITIVELY AWARE takes great care to ensure the accuracy of all the information it presents, POSITIVELY AWARE staff and volunteers, TPAN, and the institutions and personnel who provide us with information cannot be held responsible for any damages, direct or consequential, that arise from use of this material or due to errors contained herein. Opinions expressed in POSITIVELY AWARE are not necessarily those of staff or TPAN, its supporters and sponsors, or distributing agencies. Information, resources, and advertising in POSITIVELY AWARE do not constitute endorsement or recommendation of any medical treatment or product. TPAN recommends that all medical treatments or products be discussed thoroughly and frankly with a licensed and fully HIV-informed medical practitioner, preferably a personal physician. A model, photographer, or author's HIV status should not be assumed based on their appearance in POSITIVELY AWARE, association with TPAN, or contributions to this journal.



EDITOR'S NOTE

JEFF BERRY
@PAeditor

Reflections

This issue was a joy to put together, and not least because in mid-July I was able to sit down and have a nice, long conversation with Peter Staley to talk about his new memoir, *Never Silent: ACT UP and My Life in Activism* (see page 22). The book is a fascinating read, from his youth when growing up as a “precocious child” in Southern California to the troublemaker in the “ritzy” suburbs of Philadelphia, then coming out as gay and HIV-positive as the AIDS epidemic took hold, to his life in activism, and looking back on it all as he’s had time to reflect. I couldn’t help but draw parallels to my own life—Peter and I are about the same age, both gay, white, cis men diagnosed with HIV around the same time, but from there our lives took completely different paths. Well, maybe not completely, but I came around later to activism and was never part of ACT UP. After I tested positive, I continued working in the bars in Chicago as a deejay while going back to finish my degree, and started working at TPAN and eventually became editor of POSITIVELY AWARE. Peter became a fierce advocate, along with many others, who fought and sometimes died to save our lives.

So, it was somewhat surreal and humbling to be sitting and having a casual chat with Peter about his book, and his life—our paths have crossed a handful of times over the years, but this was the longest conversation I’ve ever had with him, and it felt so comfortable, and fun (thanks, Peter!). The parts we couldn’t fit into this issue due to space constraints (what he really wanted to do at Jesse Helms’ house, the scruffy UPS guy who made a delivery in the middle of the interview, the humanity of Tony Fauci), you’ll just have to buy the book to find out about (well, all except the UPS guy). But it’s all there, he’s very candid in his memoir, which is what makes it so enjoyable to read.

Sometimes it’s good to step back, take stock, and reflect upon your life. In this issue we talk about some of the basics of HIV that we think will be helpful for people today—such as U=U and PrEP—which we didn’t have back in 1989 when I tested positive for HIV. Had I known then what I know now, I don’t think I would have felt nearly as much stigma or shame around sex and being HIV-positive. Michael Broder gives his personal perspective on sex and dating in the age of PrEP and U=U on page 14.

Also in this issue, Dr. David Hardy talks about some of the changes in treatment, and shifting public attitudes towards HIV and people living with HIV, compared to the early days. Associate Editor Enid Vázquez provides perspectives from both providers, and younger long-term survivors who acquired HIV around birth or at a young age, on children’s research and lessons learned. Scott Schoettes explains why decriminalization of sex work is good public health policy; and Bridgette Picou talks about what she has learned as a provider and a person living with HIV, and has an empowering message for others.

So many voices, so many perspectives, but ultimately one goal. Improving our lives and the lives of people around us in whatever way we can, by empowering ourselves with the tools and the knowledge to live better with HIV and other conditions.

I fully intended when I sat down to write this editor’s note that I would put everything in the context of COVID, but that didn’t happen. For now, the one thing I will say is, if you’re not vaccinated and eligible, please get vaccinated. If you have friends, family or people you know who are not vaccinated, try listening to them and attempt to gain an understanding of what it is that is holding them back. We may not be able to persuade everyone, but for each person we can get vaccinated, we are one step closer.

When we look back on COVID years from now, we will have an opportunity to reflect and pause, and celebrate our successes, while reconciling with our shortcomings and failures. Just as we had hope back in the early days of AIDS in the face of death and despair, we must strive to have hope now. It’s the only way through this.

Take care of yourself and each other.

So many voices, so many perspectives, but ultimately one goal. Improving our lives and the lives of people around us in whatever way we can.



ENID VÁZQUEZ  @ENIDVAZQUEZPA

Briefly



Third COVID shot urged for people living with HIV

As this issue went to press, the U.S. Food and Drug Administration was expected to approve COVID-19 vaccine booster shots for people with weakened immune systems. This group includes people living with HIV or cancer and organ transplant recipients. They may not be adequately protected against COVID. That's because people with a weakened immune system are often unable to achieve the protective immune response that vaccinations are supposed to elicit.

In early August, Anthony Fauci, MD, director of the U.S. National Institute of Allergy and Infectious Diseases (NIAID) and chief medical advisor to President Joe Biden, said it has become clear that this has happened with COVID-19 vaccinations. He called a third vaccination shot “a very high priority” for these individuals and said the government was working hard to authorize it.

Update on opportunistic infections

The U.S. Department of Health and Human Services (DHHS) recently updated its guidelines on opportunistic infections (OIs) in HIV. Specifically, changes were made to information on cryptococcosis (“crypto” for short), cytomegalovirus (CMV), coccidioidomycosis, and bartonellosis.

The section on immunizations was also updated, on June 11. GO TO clinicalinfo.hiv.gov/en/guidelines/adult-and-adolescent-opportunistic-infection/recommended-immunization-schedule?view=full. The guidelines noted that the only vaccine now available to prevent shingles is Shingrix (recombinant zoster vaccine, RZV). Zostavax (attenuated

zoster vaccine live, ZVL) is no longer available for use in the U.S.

The DHHS expert panel recommends that for the treatment of crypto, there be an increased fluconazole dose from 400 mg to 800 mg daily “for consolidation therapy. For clinically stable patients who have been started on ART [HIV antiretroviral therapy] and whose CSF [cerebral spinal fluid] culture results return with no growth, the dose can be decreased to 400 mg daily.”

In addition, the updates “Clarified that the treatment of non-CNS [central nervous system] extrapulmonary [outside the lungs] cryptococcosis and diffuse pulmonary disease should be the same as that for meningitis and that treatment of mild-moderate focal pulmonary infection should be with fluconazole, 400–800 mg daily.” Also, in the table of treatment for cryptococcosis, treatment recommendations for the various forms of crypto have been clarified.

There is also information on people with antigens to cryptococcosis (a sign of exposure to the disease), but no crypto symptoms. “For patients whose serum titer is <1:320 using a lateral flow assay, treatment can be with fluconazole 400–800 mg daily. For patients whose serum titer is >1:640, the likelihood that meningitis is present or will develop is high, and treatment should be the same as that for cryptococcal meningitis.”

Toxicities of alternative antiviral medications for treating CMV are now highlighted.

For coccidioidomycosis, changes include “revised section on serology for the diagnosis,” “added PCR as a commercially available diagnostic test,” and revised a section on people who are “asymptomatic with a positive serological test.”

For bartonellosis, there's an updated section on diagnostics, including the role of PCR-based testing, and an updated section on treatment for endocarditis.

DHHS updated the guidelines on July 22. See the June and July updates in “What's New in the Guidelines” at clinicalinfo.hiv.gov/en/guidelines/adult-and-adolescent-opportunistic-infection/whats-new-guidelines. GO TO hivinfo.nih.gov.

Syphilis PrEP?

Many people say “PrEP” when they're referring to HIV prevention drugs. The movement towards STI prevention drugs may help clarify the meaning of “PrEP.”

It stands for “pre-exposure prophylaxis.” PrEP indicates prevention, not just HIV prevention. “Prophylaxis” refers to medication used to prevent disease. For example, people traveling to areas where malaria is endemic can take pills before their visit to prevent getting it.

Other interventions that are used to prevent disease also serve as prophylaxis. That's why, for example, condoms are called “prophylactics.”

So, a new PrEP may be coming soon to a clinic near you. The antibiotic doxycycline holds promise for the

prevention of syphilis and chlamydia, among other STIs, including some strains of gonorrhea. It is already used for the prevention of several bacterial infections.

As is done with HIV medications, doxycycline is also being looked at for PrEP, or post-exposure prophylaxis, intended to prevent an infection after a potential exposure.

Going back to HIV PrEP, there have been several reports of increased incidence of STIs related to its use, since it does not protect against other infections.

Read Mallory Harrigan's comprehensive article on the doxycycline possibilities, including research findings, in *CATIE Prevention in Focus* newsletter, from the Canadian AIDS Treatment Information Exchange, at catie.ca/en/pif/fall-2020/prep-and-pep-sexually-transmitted-infections-what-do-we-know-about-doxycycline-strategy.

\$122 million grant to advance monthly PrEP pill

The Bill & Melinda Gates Foundation has awarded a \$122 million, five-year grant to the University of Washington for Phase 3 study of islatravir as a once-a-month pill for the prevention of HIV (see page 33). The IMPOWER 22 study compares islatravir to a daily PrEP medication in 4,500 cis-gender women in southern Africa and the U.S.

The Gates Foundation has previously funded the university's research of the medication for use as pre-exposure prophylaxis, or PrEP,

as part of a collaboration. The university announced the newest award on July 23.

Islatravir for HIV PrEP is also being studied in other populations. It is also being tested as a once-weekly oral medication for treatment, for use in combination with another HIV drug.

'Unmet' HIV needs in Eastern Europe and Central Asia get funding

The Elton John AIDS Foundation and Gilead Sciences announced a new wave of its funding application for the RADIANT "unmet need" fund.

The RADIANT Partnership was formed by the foundation and the pharmaceutical company to promote HIV prevention and care, education, and community empowerment efforts in Eastern Europe and Central Asia (EECA).

According to a July 21 press release issued by the foundation, "There are an estimated 1.6 million people living with HIV in EECA. It is one of the few regions in the world where the annual rate of HIV infections continues to rise, having seen a 43% increase in annual new HIV diagnoses between 2010–2020, while rates have declined by around 30% globally. Each day in EECA over 400 people acquire HIV, and around 100 people die from AIDS-related illnesses. Factors contributing to the HIV epidemic are manifold including late diagnosis, low treatment rates, and HIV-related stigma."

LEARN MORE at radianhiv.org.

U.S. Conference on HIV/AIDS goes virtual

Responding to the increasing spread of the COVID-19 virus' Delta variant, NMAC announced that the U.S. Conference on HIV/AIDS (USCHA) is going virtual and has been pushed back to Dec. 2–3. This is the second year in a row that USCHA has gone online-only as a result of the pandemic.

"This is not the announcement we wanted to make," said NMAC executive director Paul Kawata. "We were very hopeful that we could hold an in-person USCHA this year. However, the health and safety of our constituents must be our primary concern. The continued spread of the Delta variant and the data from both the Provincetown outbreak and the study released at the IAS conference in Berlin about the impact of COVID on people living with HIV led us to this decision. We are as disappointed as everyone else by the need to make this decision, but we could not, in good conscience, potentially put attendees at risk of exposure."

U.S. Assistant Secretary of Health Rachel L. Levine, MD, was originally scheduled to appear at USCHA, and will address the virtual gathering. She is the first transgender official to hold a government position requiring U.S. Senate confirmation.

"We've made so much progress—from testing to treatments—but there is still a long way to go," Levine said in an initial statement announcing her attendance at USCHA. "We need to increase access to testing



LEVINE

and treatment (including PrEP), and expand telehealth services."

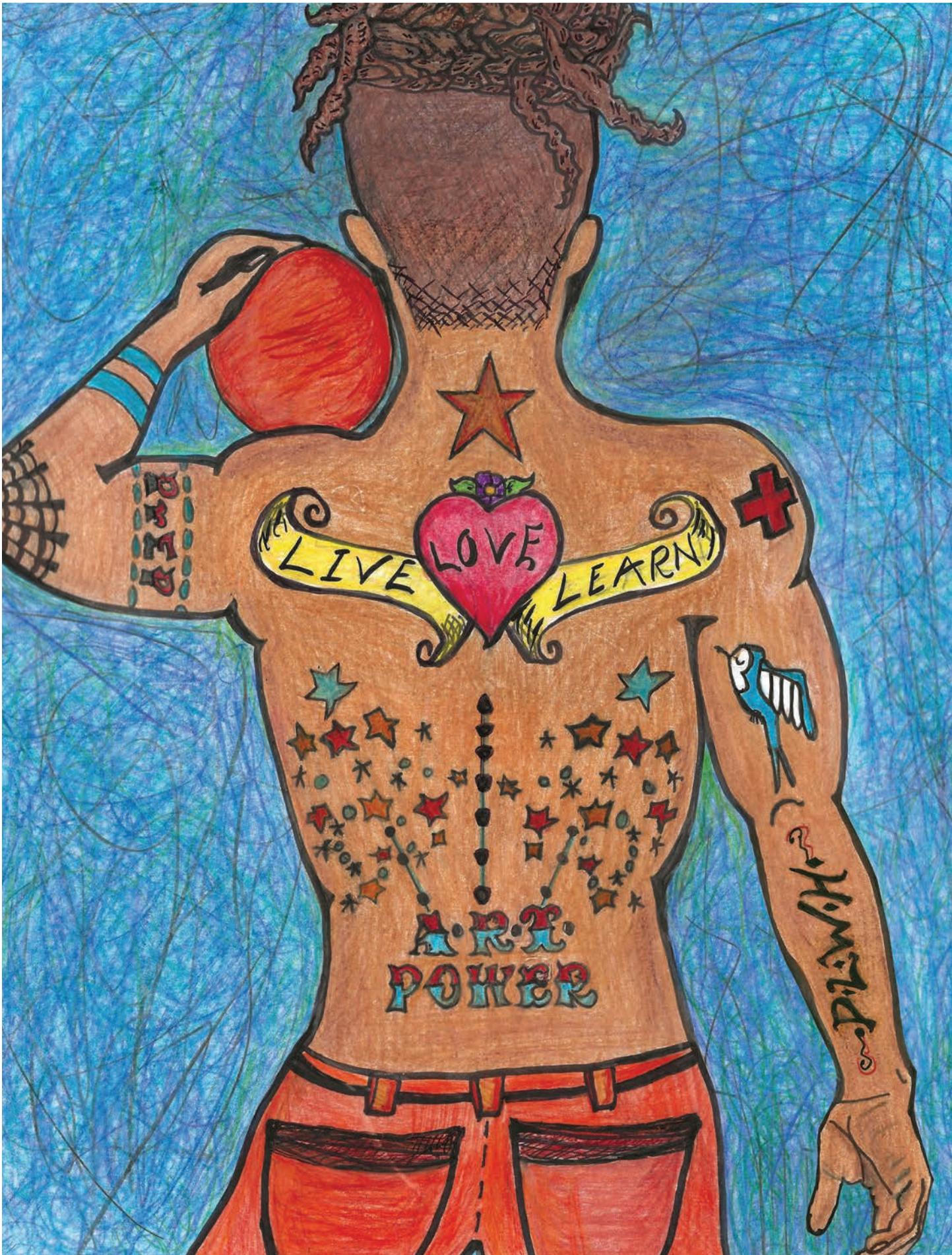
Prior to her appointment as assistant secretary of health, Levine served as Pennsylvania's secretary of health, where she issued a standing order on naloxone, allowing law enforcement officials and civilians to carry the opioid overdose reversal medication.

Joining Levine for USCHA's virtual opening plenary will be Dr. Anthony Fauci; his remarks will be made in a recorded address.

Pushing back the virtual conference date will allow for discussion of the Biden administration's Plan to End the HIV Epidemic, set to be released on World AIDS Day, Dec. 1.

With a lowered \$295 registration fee for the virtual conference, NMAC hopes to draw many more participants. Registrants prior to the Aug. 10 announcement who want to cancel their registration have a number of options: transferring their registration to the virtual conference, with a refund for the difference; transfer registration to the 2022 conference set for Puerto Rico; cancellation with a full refund; or donating their registration fee to NMAC.

REGISTER AT uscha.life.



LIVING YOUR BEST LIFE WITH HIV

You have your whole life ahead of you. What to know, and what to consider

BY MICHAEL BRODER

About 35,000 people in the United States test positive

for HIV each year. That's a far cry from the peak of 130,000 new cases in 1984. But the day you got your positive test result, it probably didn't matter if you were one of a kind or one in a million. You may have been scared; you may have been angry; on some level, you may not even have believed it could be true. But whatever you felt, you knew your life was never going to be the same. Well, you know what? You're right—your life never will be the same. We can't always choose what happens to us, but we can choose how we respond. And take it from me—someone who, at age 60, has been living with HIV for over 30 years: There's never been a better time to be living with HIV. Today, treatment for HIV not only keeps you healthy, but also prevents you from passing the virus to sexual partners. So, please sit back and relax, and let me share some information about living with HIV. No, scratch that—let me share some information about *living your best life with HIV*.

The newly diagnosed HIV two-step

I want to make it super clear that there are two—and only two—things that are absolutely essential for you to do as soon as possible after you receive a positive HIV test result, also called an HIV diagnosis:

- Find a doctor or other medical care provider who specializes in HIV.
- Get on HIV treatment, also called antiretroviral therapy (ART).

Sure, these are not the only two things you need to know about, or to do,

in order to live your best life with HIV; but they are the two most essential things that you need to do as soon as humanly possible after you get an HIV diagnosis. Why are these two steps so important, and why is it so important that you do them right away? It's really pretty simple. You need to have a medical provider to get on treatment, and you need to get on treatment in order to live a long, healthy, happy life with HIV. Let's take a look at these two steps in reverse order: first, what is treatment and why is it so important; and second, how you find the right doctor or other care provider to prescribe and monitor your HIV treatment.

HIV treatment—What it is and why it matters

As you may know, HIV (human immunodeficiency virus) is the virus that causes AIDS (acquired immune deficiency syndrome). AIDS is a complete and devastating breakdown of the human immune system that leaves a person with AIDS (PWA) unable to fight infections and cancers that are usually no bother to people with normal immune systems. HIV attacks an important part of the immune system called T cells or CD4 cells.

HIV barges into your CD4 cells, hijacks their genetic material (DNA), and uses it to make copies of itself (replication). Once HIV has set up shop in a CD4 cell, it destroys that cell. Over time, the CD4 cell population is severely depleted. That's what leads to severe immune suppression, which in turn provides an opening for various infections and cancers—known as opportunistic infections and cancers, because they take advantage of the opportunity afforded by the destruction of the immune system.

Ultimately, nobody really dies from HIV itself; rather, it is this onslaught of opportunistic infections and cancers that leads to death if HIV is left untreated.

When AIDS first made the scene in 1981, it appeared in the form of rare infections and cancers among specific groups including gay men and people who injected drugs, as well as among their sexual partners, and among infants

born to mothers with HIV (this kind of transmission could take place during pregnancy, delivery, or breast feeding). Nobody knew what was causing this strange outbreak of rare infections and cancers. It wasn't like COVID-19, for example, where the first four cases of a mysterious new form of pneumonia were identified on December 29, 2019, and the virus that caused the pneumonia was identified nine days later on January 7, 2020 (the virus is called SARS-CoV-2, and the disease is called COVID-19).

By contrast, it took two years after the first known appearance of AIDS for virologists to identify HIV as the cause (1983). It took four more years for pharmacologists to develop the first drug to fight HIV (1987). But while that drug (Retrovir, also known as azithrothymidine, zidovudine, and AZT) slowed the destruction of the immune system, it did not stop it altogether. Not until 1996—15 years into the AIDS epidemic—did researchers come up with combinations of three drugs that would suppress HIV sufficiently to stop the destruction of the immune system.

With this kind of maximally suppressive ART, HIV became a chronic, manageable condition rather than a death sentence. That's why many people today, especially young people who have come of age in the past 25 years, do not always realize how serious HIV infection can really be. And that is why I need to impress upon you here the very, very, very great importance of getting on ART as soon as possible after your HIV diagnosis. You see, within six months on any one of a number of different treatment options available today, the virus generally becomes undetectable in your circulating blood. This is called viral suppression. Viral suppression is the primary goal of ART. Viral suppression on ART leads to two very important benefits:

- Your immune system is protected from the damaging effects of HIV.
- You can no longer transmit the virus to your sexual partners.

With your immune system protected from the ravages of HIV, you have your health and your life back—barring complications unrelated to HIV, you can now live a normal, healthy life for decades to come.

Just as important for most people living with HIV (PLWH), viral suppression means you can no longer transmit the virus to your sexual partners. This is now often called “undetectable equals untransmittable,” or U=U. It means you can feel free to meet people, date people, enjoy sex, and even fall in love and enter

into long-term relationships, regardless of the HIV status of your partner.

So, again, in case I have not already single, double, triple underlined this enough: It is vitally important that you get on ART as soon as possible after your HIV diagnosis, both for the sake of your own health, and for the protection that viral suppression gives to your sexual partners.

Why you need an HIV doctor or other healthcare provider



feel fine when you are first diagnosed with HIV, because it can take years for untreated HIV to cause the kinds of infections or cancers that can make you ill and threaten your life. Even if you do not feel sick, if you have HIV, the virus is doing damage. But you can prevent that damage by getting on ART. Early treatment has been proven to extend life and good health. That's why you need to see an HIV medical provider as soon as possible after receiving your HIV diagnosis.

When it comes to choosing your HIV medical provider, experience matters. There is evidence that PLWH who have medical providers with more experience in HIV care tend to do better than those who see a provider who has only limited HIV care experience. As someone who has seen his share of both good and bad HIV care providers, I can confirm—you definitely want a doctor or other medical provider who has experience caring for patients with HIV.

Your HIV care provider may be a

In order to get on ART, you need to be in the care of a doctor or other medical provider who knows how to care for PLWH. You may very well

The [HIV.gov](https://www.hiv.gov) website includes a page that provides other ways to find an HIV care provider ([hiv.gov/hiv-basics/starting-hiv-care/find-a-provider/locate-a-hiv-care-provider](https://www.hiv.gov/hiv-basics/starting-hiv-care/find-a-provider/locate-a-hiv-care-provider)). These include calling your state's toll-free HIV/AIDS hotline (find it at hab.hrsa.gov/get-care/state-hivaids-hotlines), or searching the referral link directory (providers.aahivm.org/referral-link-search) on the American Academy of HIV Medicine website. Finally, if you received an HIV diagnosis by using an HIV home test kit, you were provided with a telephone hotline that provides confidential counseling and can give you a referral to an HIV care provider in your area.

I'm in care and on treatment—now what?



As I stated at the outset, there has never been a better time to be living with HIV. We live in an era when treatment for HIV is very

effective, as well as safe, easy to tolerate, and convenient. It's often just one pill once a day (this is still combination therapy, but all the components of the combination are included in a single tablet). Now there are even injectable drugs that only have to be taken once a month. Soon, this may even become every two months. There are even implantable drug formulations in development that will go under the skin, like some forms of birth control do now, and may be able to provide effective treatment for a year or longer following a single implant. The search for a vaccine to *prevent* HIV has been long and largely fruitless; but the possibility of a vaccine to *treat* HIV is just over the horizon, and other antibody-based treatments

As I like to put it as a PLWH who often has HIV-negative partners, “My treatment is your prevention.”

medical doctor (MD), an osteopath (DO), a nurse practitioner (NP), or a physician assistant (PA). If your HIV medical provider is an MD, their specialty may be internal medicine (an “internist”) with a subspecialty in infectious diseases (ID). But doctors with other specialties, such as family medicine or OB-GYN, can also be great HIV specialists.

Finding an HIV care provider

If you already have a primary care provider, they may be able to manage your HIV care and treatment. If your primary care provider cannot manage your HIV care, they may be able to refer you to an HIV specialist.

are also on the way. While a cure for HIV is still years away, it is no longer mere fantasy to talk about a cure—the fundamental scientific underpinnings of one or more different approaches to curing HIV are already in hand.

With all that said, some of the greatest challenges in living with HIV today are not issues of physical health, but rather emotional issues. Those of us living with HIV must still confront stigma, and may often deal with feelings of shame. Shame and stigma interact with what to me is perhaps the most challenging part of living with HIV, namely, issues of intimacy—dating, sex, love, and relationships. I believe this is

CONTINUED ON PAGE 15 >>

12 things TO KNOW ABOUT HIV

HIV: WHAT IT IS AND SYMPTOMS

1. What exactly is HIV?

Is it the same thing as AIDS?

HIV, which is short for Human Immunodeficiency Virus, is a virus that attacks the body's immune system, weakening it over time. **This makes it difficult or impossible for the body to fight off infections and some diseases, if left untreated.** Sometimes people with HIV can get an opportunistic infection or their CD4 count goes below 200. If either of these things happen, your HIV may be categorized as AIDS. Talk with your medical provider for more information.

2. What are some of the symptoms of HIV? When do these symptoms start after exposure?

Many people don't show any symptoms at all; however, some initial HIV symptoms can occur between 2 and 4 weeks after exposure and may include chills, fever, rash, muscle aches, fatigue, sore throat and more. **Some say it's like having a case of the flu or a bad cold.**

3. Is there a cure for HIV?

Although there is no cure for HIV, modern medical treatments are extremely effective at controlling HIV. When taken routinely, treatments help people live long, healthy lives.

TREATMENT AND LIFE BALANCE

4. Can HIV affect how long I live?

In most cases, HIV can only impact your lifespan if you are not receiving treatment. As long as you take your HIV medications correctly, you can live a long and healthy life.

5. What are my options for treatment?

Antiretroviral therapy, aka ART, is a combination of medication that your medical provider will give you. It can greatly reduce the level of HIV in your blood. **ART may come in the form of one pill or two or more to be taken together.**

6. When should I start treatment?

You should begin treatment as soon as possible after receiving an HIV diagnosis. Delaying treatment may cause you to become seriously ill with infections that your body is unable to fight off on its own.

7. How often do I need treatment?

Your healthcare provider will prescribe your treatment as a medication to take on a daily basis. There is also now a once-monthly injectable ART available.

8. Do I need treatment even if I'm feeling OK?

Yes, even if you aren't experiencing active symptoms of HIV after receiving your diagnosis, **you need to keep up with your treatment plan.**

9. Can I skip my treatments?

What should I do if I miss a treatment?

Missing or skipping your HIV treatment allows HIV the opportunity to multiply and weaken your immune system. This increases your chances of becoming sick. If you forget to take a dose or miss several doses, consult with your healthcare provider or pharmacist immediately to determine the best course of action.

10. Do I need to tell my employer about my HIV?

You aren't required to disclose having HIV to your employer.

You are protected by the Americans with Disabilities Act (ADA), which prevents any employer from discriminating against your HIV status.

WORK AND RELATIONSHIPS

11. How is HIV spread?

HIV is spread through semen, vaginal fluid, blood, and breast milk. **Most commonly, people get HIV through anal or vaginal sex or sharing needles.** HIV can't be transmitted via air, water, saliva, sweat, tears, insects, pets, or sharing toilets, food, or drinks.

12. Does living with HIV mean I can't have sex anymore?

You can still enjoy a fulfilling sex life with HIV by taking extra steps to practice safer sex. This begins with taking your treatment as prescribed by your healthcare provider, as doing so can lower the levels of HIV to levels that are undetectable in your blood, which means you can't transmit HIV to a sexual partner (U=U, see page 21). Using condoms and dental dams can also help prevent HIV and other STIs.

.....
ADAPTED FROM "You're In Control: We're Here to Help" booklet from Family Health Council of Central Pennsylvania, Inc. (FHCCP). For more information GO TO TakeControlHIV.com.





SEX + DATING WITH HIV IN THE AGE OF PREP AND U=U

A personal perspective

When I tested positive for HIV in 1990, AIDS was considered a death sentence, and my first concern was for my health. Early on, my gut told me that AIDS was not going to kill me. That may have been what is often called “healthy denial,” a kind of lie we tell ourselves so we can get on with our lives in desperate circumstances. As it turned out, my gut was right: AIDS did not kill me, and HIV became a condition you can live with if you take your medication as prescribed, presumably (as we are still awaiting a cure) for the rest of your life. At that point, the issues that came to the forefront of my life again were those that occupy the attention of most people who believe they have their whole life ahead of them—love, commitment, family, and, of course, sex. There’s so much to say about these issues from my perspective as a 60-year-old gay man who has been living with HIV for over 30 years; but for now, I will focus on how PrEP and U=U have affected my sex and dating life.

Once upon a time, social networking apps gave users the option of indicating whether they were HIV-negative or HIV-positive. That raised a lot of moral, ethical, and practical issues, and allowed both deception and stigma to have free reign. Today, things are different. Social networking apps now allow users to indicate in their profiles not only whether they are HIV-negative or HIV-positive, but also whether they are HIV-negative and on PrEP, or whether they are HIV-positive, on ART, and undetectable. This way of doing things provides a lot more incentive for users to

disclose both their HIV status and their HIV prevention method of choice (or lack thereof). Of course, users can always leave any or all relevant information off their profile completely; but even silence can provide useful insight to other users, who have the opportunity to decide how they feel about interacting with people who choose not to share this information.

My experience is that many guys on PrEP are very open to linking up with men who are living with HIV. The app Daddyhunt even gives users an option to indicate that they “live stigma-free,” which means they

are open to dating someone of any HIV status. I know that I’m reaching out to people with whom I can feel safe in terms of the whole HIV disclosure issue.

It remains important for me to disclose my own HIV-positive status on my profile, and sometimes even to reiterate it in the course of in-app chat, depending on the sense I get of how carefully someone might or might not be paying attention to issues of HIV status.

Some men on gay social networking apps actually fetishize men who are living with HIV. Some HIV-negative people think that sex with a person living with HIV is “hot,” while others fantasize about actively seeking to become infected by having unprotected sex with a PLWH. This is referred to colloquially as “getting pozzed.” I sympathize with PLWH who find this fetishization of HIV offensive. Personally, while I recognize how potentially “messed up” it is when guys want to “get pozzed,” I tend to shrug it off. For one thing, I’m undetectable, so I’m incapable of “pozzing” anyone.

For the most part, however, I find that my dynamic with guys on PrEP exemplifies the promise of PrEP, which was to make it safe for people to choose their sexual partners without regard to HIV status. (Of course, PrEP does not protect its users from STIs including gonorrhea, chlamydia, or syphilis, but that is a separate issue that merits its own in-depth exploration.)

The advent of U=U (if you’re on HIV treatment and virally suppressed, you can’t pass on HIV to your sexual partners) has the potential to reduce the stigma associated with HIV. Much of that stigma arises from the fear that PLWH pose a danger to people who are HIV-negative, especially when it comes to sexual connections within the most affected communities. As a PLWH who has an active sex life and uses social networking apps, I have seen this new dynamic played out in my own experience. Just as social networking apps give you the option to indicate that you are HIV-negative and on PrEP, the major apps now

also let you indicate that you are HIV-positive, on ART, and undetectable. I find that most of the guys who hit me up on the apps are HIV-negative and on PrEP, and our chat often reveals that they noticed the “positive, undetectable” status indicated on my profile—in fact, they often say this is one of the reasons they reached out to me. Whether fantasy or reality, there is a perception among some people—and perhaps especially among some younger people who are HIV-negative—that older PLWH make for “better” sexual partners. Regardless of HIV status, younger men often seem to value the company of older men because they find them to be savvy both about sex and about interpersonal relations compared to their own younger peers. Some younger guys seem to extend this notion to HIV status, believing that older PLWH are more sexually adventurous and are more likely to be able to “show them a thing or two.” Again, I have no evidence for or against this presumption, but as an older PLWH, it certainly rings true to me.

Overall, I believe the greater the awareness of U=U, the greater the likelihood that people who are HIV-negative will feel safe and comfortable connecting sexually with PLWH who are on meds and undetectable. This has certainly been my experience. If anything, I find that some people in my community, especially young gay men, are sometimes not aware of the distinction between PrEP (a prevention strategy) and ART (a treatment strategy). While my HIV status is in all of my profiles on social networking apps, I often make sure to disclose my status in chat as well. When I do so, some guys will ask me if I am on PrEP. I assume they mean to ask whether I am on ART—but I don’t think they really know the difference. When this happens, I will say, “I’m on treatment. PrEP is for people who are negative; treatment is for people who are positive.” In most cases, they will simply reply, “Oh okay,” and we then get back to the matter at hand—by which of course I mean a cup of coffee!

—MICHAEL BRODER

>> CONTINUED FROM PAGE 12
 an area where much has changed in recent years, largely because of two game-changing developments:

- pre-exposure prophylaxis (PrEP)
- treatment as prevention (TasP, the same thing as U=U, as we shall see below).

PrEP and how it has changed life with HIV



As you may know, PrEP is HIV medication you take if you are HIV-negative to protect yourself against acquiring HIV during sex.

The first PrEP regimen was approved in the U.S. in 2012. In the early days, PrEP was controversial and often stigmatized, with people on PrEP being viewed as promiscuous or eager to engage in risky sexual activity. The medical literature continues to document PrEP-related stigma today.

According to the CDC, there were about 1.7 million new cases of HIV worldwide in 2018. By comparison, from 2016 to today only about 1 million people have started taking PrEP the world over. The

This increased access to a larger pool of potential partners is at least part of the motivation behind some people's choice to go on PrEP. Of course, PrEP does not protect its users from STIs including gonorrhea, chlamydia, or syphilis. People who use PrEP must continue to evaluate their risk for STIs, and to use condoms if they wish to reduce their risk of acquiring an STI.

How U=U is changing life with HIV

What we now generally call U=U was originally called “treatment as prevention” (TasP) by doctors and other medical providers. By 2010, many experts in the science of HIV realized that ART not only improved the health of PLWH, but also prevented transmission of HIV from PLWH to their HIV-negative sexual partners. As I like to put it as a PLWH who often has HIV-negative partners, “My treatment is your prevention.”

Before the idea of TasP could become widely accepted, evidence was needed from large, randomized clinical studies designed specifically to demonstrate its validity. Four key studies published between 2016 and 2019 have proven definitively that a PLWH who is on ART and whose viral load is undetectable for at least six months cannot transmit HIV to their sexual partners.

associated with HIV. Much of that stigma arises from fear on the part of people who are HIV-negative—fear that PLWH pose a danger to them, especially when it comes to sexual connections within communities with the greatest incidence of HIV.

Getting on with your life

To conclude, my 3-step plan for living your best life with HIV can be summarized as follows:

- Get into the care of an experienced HIV medical provider.
- Get on ART as prescribed by your medical provider.
- Get on with your life.



Becoming HIV-positive is never good news in and of itself. But there is good news about living with HIV in 2021.

Today, treatment for HIV not only keeps you healthy, but also prevents you from passing the virus to sexual partners. In addition, as public health agencies and health advocacy organizations spread the U=U message, potential partners are coming to understand that they are at no risk of getting HIV from PLWH who have been unde-

On an individual level, PrEP allows people to choose their sexual partners without regard to HIV status.

goal set by UNAIDS was to have three million people on PrEP globally by 2020, with a focus on the groups most affected by HIV, including men who have sex with men (MSM), sex workers, and people who inject drugs (PWID). Policymakers hoped that 90% of people in these key populations, as well as 90% of adolescent girls and young women in the hardest-hit regions, would be taking PrEP by now, but these goals are nowhere near met. In the U.S., only 147,000 people initiated PrEP between its approval in 2012 and 2016. By contrast, the CDC estimates that 1.1 million people in the U.S. would benefit from PrEP, including 175,000 women and 780,000 people of color.

Nevertheless, for people who have made PrEP a part of their HIV prevention plan, the impact is profound. A study found that PrEP uptake was significantly associated with declines in HIV diagnoses in the U.S. between 2012 and 2016. On an individual level, PrEP allows people to choose their sexual partners without regard to HIV status. From the perspective of PLWH, PrEP increases the likelihood that a potential sexual partner will feel comfortable exploring sexual intimacy with a person living with HIV.

In 2016, an advocacy organization called Prevention Access Campaign coined the slogan “undetectable equals untransmittable” and began promoting the U=U message to medical providers, public health agencies, and affected communities.

The U=U message fundamentally changed the way public health policy the world over views ART for HIV. Before U=U, some policymakers saw treatment and prevention as competing interests, especially when considering how to allocate scarce financial resources between these two urgent needs. Once U=U was proven and accepted, treatment itself became a prevention strategy. Financial resources put into treatment were viewed as doing double duty, because treatment and prevention were now known to be one and the same.

In addition, the U=U message gave people newly living with HIV additional incentive to get on treatment immediately: Not only would ART protect their health, it would also protect their HIV-negative sexual partners from infection.

Perhaps most important for the quality of life of PLWH, U=U has the potential to reduce the stigma that continues to be

tectable on ART for at least six months.

Moreover, the advent of PrEP has ushered in a generation of people in affected communities who now feel secure in their ability to protect themselves against acquiring HIV, whether they know their partner's status or not. Together, U=U and PrEP are beginning to chip away at the stigma associated with HIV, particularly the stigma around sex with PLWH in affected communities.

What's more, while a cure for HIV is still years away, the fundamental scientific knowledge that will underlie any approach to a cure is already in hand.

It's a good day to live your best life with HIV, and from where we sit right now, it looks like it's only going to get better. **PA**

MICHAEL BRODER is a gay, white, poz, Jewish, male, late-Boomer Brooklyn native (b. 1961). Columbia undergrad, MFA in creative writing from NYU, and PhD in classics from the CUNY Graduate Center. He tested HIV-positive in 1990, and started doing AIDS-related journalism while collecting unemployment insurance in 1991. He lives in Bed-Stuy with his husband and several feral backyard cats.

INTERVIEW WITH VETERAN HIV SPECIALIST DR. W. DAVID HARDY

BY MICHAEL BRODER

W. *David Hardy, M.D., is director of infectious diseases at Cedars-Sinai Medical Center in Los Angeles and an associate professor of medicine-in-residence at the David Geffen School of Medicine, University of California, Los Angeles (UCLA). For nearly 40 years, Dr. Hardy has been one of the leading figures in HIV clinical research and practice. The following are excerpts from a wide-ranging discussion we had about how living with HIV has changed since the beginning of the epidemic.*

MICHAEL BRODER: What would you say is new or different about being newly diagnosed with HIV now compared to the past? How would you say the medications themselves have changed since the beginnings of ART over 30 years ago?



DAVID HARDY: I would say there's a huge difference being diagnosed now versus being diagnosed even 10 years ago. The antiretrovirals today are much, much better. They are better in terms of potency and the ability to keep the virus suppressed. They have much less toxicity. And they're much easier to take. You know,

right now, the state of the art is single-tablet regimens, one pill once a day. But we've already seen licensure of the first monthly injectable back in January. And before the end of this year, I will wager that we're going to see an extension of that to injection every two months, because the data actually support it from another study that ViiV [the manufacturer] did. There's basically four pharmaceutical companies now that work in HIV: Gilead, ViiV, Merck, and Janssen. Those are kind of the last four standing of the 12 that were there before. So, you know, coming down the pike, all of those companies now are taking the same line of developing long-acting injectable or implantable treatments.

What has changed about the basic approach to starting HIV treatment?

What is great about today is that a person who is diagnosed can look forward to initiating therapy almost immediately. The back and forth we used to do about should we start now, should we start later, how much the T cells have to fall, *blah, blah, blah, blah, blah*, is over. It's been over since 2012, almost 10 years. But you know, it's—you get diagnosed, you get treated like any other STI. It's different, but it's still kind of the same principle.

What does the future hold for medications?

There are much, much better medications on the horizon, so that the interference that taking medications for HIV has caused in many people's lives, is going to get less and less and less. In terms of treatment, that's a big difference.

What has changed about community and public attitudes towards HIV and PLWH?

In terms of stigma, and sort of living and coping with HIV, there is a difference now compared to the 1980s and 1990s, when there was a great amount of compassion. Red Ribbon compassion for persons who are positive, a lot of that has sort of passed. And that sort of, *I'm special because I'm HIV-positive* sort of feeling, or *I deserve this because I'm HIV-positive*, or *feel sorry for me because I'm HIV-positive* I think has also changed. It has now become, *this is part of my life. I accept it. I deal with it. I try not to hide it. I disclose it when necessary, and I no longer live in the state of fear, or shame, that someone's gonna find out, because it is just a fact of life.* Like if I had diabetes, hypertension or anything else, it just is what it is. And I get treated for it and take care of myself.

So, I think there's been a huge evolution in terms of what people who are HIV-positive are being exposed to now, compared to what went before. In years past it was always, *I can't tell this person, I can't tell that person, and I'm holding this big, nasty secret. I'm hiding my pills as best I can, and making sure no one ever sees them*—those days hopefully are over. I think there's a whole brand-new sense of openness, and acceptance. What they used to call "AIDS exceptionalism," the idea that persons with HIV should be granted extra sort of privileges, because they're HIV-positive, I think is also passed, and become more about yes, you're HIV-positive, here are the medications, take advantage of them, and move on through your life because data are showing that your chances of living a long time are very good.

The antiretrovirals today are much, much better. They are better in terms of potency and the ability to keep the virus suppressed. They have much less toxicity. And they're much easier to take.

ASK YOUR DOCTOR
ABOUT DELSTRIGO

I NEVER LET MY HIV HOLD ME BACK

LEARN WHY DELSTRIGO MAY BE RIGHT FOR YOU

Your HIV-1 treatment isn't only about getting to undetectable.*
Where you go from there is just as important.

As you age, your health changes. Maybe you change your diet. Maybe you need
to take more medications. These factors can impact your HIV-1 treatment.

A LOW RATE OF SIDE EFFECTS

DELSTRIGO is a once-daily treatment option for HIV-1 that can be
taken with or without food and has a low rate of side effects.

At week 96 of a study of adults who were new to treatment,
the most common side effects were: dizziness (7%),
nausea (5%), and abnormal dreams (5%). These
are not all the possible side effects of DELSTRIGO.

*Undetectable means that the level of HIV in your
blood is so low it cannot be detected.

HIV-positive
model.



WHAT IS DELSTRIGO?

DELSTRIGO is a complete, one-pill
prescription HIV medicine used to treat
human immunodeficiency virus-1 (HIV-1)
infection[†] in adults who have not taken
HIV-1 medicines before or to replace
their current HIV-1 medicines for adults
whose healthcare provider determines
that they meet certain requirements.

[†]HIV is the virus that causes Acquired Immune
Deficiency Syndrome (AIDS).

**Please read the adjacent Patient
Information for DELSTRIGO and
discuss with your doctor.**

IMPORTANT SAFETY INFORMATION

Worsening of hepatitis B virus infection (HBV).

If you have both HIV-1 and HBV and stop taking
DELSTRIGO, your HBV may suddenly get worse. Do
not stop taking DELSTRIGO without first talking
to your doctor, as they will need to monitor your
health. Your doctor should test you for HBV infection
before you start treatment with DELSTRIGO.

**Please see additional Important Safety
Information continued on next page.**


Delstrigo™
doravirine/lamivudine/
tenofovir disoproxil fumarate
100 mg/300 mg/300 mg tablets

DELSTRIGO AND OTHER MEDICATIONS

DELSTRIGO can be taken with a wide range of common, non-HIV-1 medications, such as:



HEARTBURN

PROTON PUMP INHIBITORS
(pantoprazole)



BIRTH CONTROL

ORAL CONTRACEPTIVES
(ethinyl estradiol and levonorgestrel)



PAIN

METHADONE
DELSTRIGO should be avoided if you are using or have recently used nonsteroidal anti-inflammatory drugs (NSAIDs).



CHOLESTEROL

STATINS
(atorvastatin)



DIABETES

METFORMIN
(metformin hydrochloride)

Do not take DELSTRIGO if you are currently taking any of the following medicines: carbamazepine, oxcarbazepine, phenobarbital, phenytoin, enzalutamide, rifampin, rifapentine, mitotane, or St. John's wort. Do not take DELSTRIGO if you have ever had an allergic reaction to lamivudine.

STARTING THE CONVERSATION

Only you and your doctor know which HIV-1 treatment is right for you. Here are some questions you can use to start a conversation with your doctor about your treatment options.

- When should I start or change treatment?
- What are the possible side effects of HIV-1 treatments?
- Will taking an HIV-1 treatment interfere with my day?
- Do I need to eat when I take my medication?
- How might my HIV-1 treatment interact with the other medications I take?
- What information do you have on weight changes and my HIV-1 treatment?
- Other: _____



Take a pic of these questions and discuss them with your doctor.

IMPORTANT SAFETY INFORMATION (CON'T)

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

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

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

Do not take DELSTRIGO if you have ever had an allergic reaction to lamivudine.

New or worse kidney problems, including kidney failure, can happen while you are taking DELSTRIGO. Your doctor should do blood and urine tests to check your kidneys. If you develop new or worse kidney problems, your doctor may tell you to stop taking DELSTRIGO.

Some people who take DELSTRIGO experience bone problems such as pain, softening, or thinning of the bone. Tell your doctor if you have any of the following symptoms during treatment with DELSTRIGO: bone pain that does not go away or worsening bone pain; pain in your arms, legs, hands or feet; broken bones; or muscle pain or weakness.

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

The most common side effects of DELSTRIGO include: dizziness, nausea, and abnormal dreams.

These are not all the possible side effects of DELSTRIGO. For more information, ask your doctor or pharmacist.

QUESTIONS ABOUT WEIGHT?

LEARN MORE AT
DELSTRIGO.COM



Are you concerned about weight change? Talk to your doctor about how you can manage your health, weight, and HIV.

Department of Health and Human Services (DHHS) guidelines support changing HIV treatment regimens for several reasons, including:



Food requirements



Potential drug-drug interactions



Tolerability/side effects



MY HIV IS UNDETECTABLE.

**UNDETECTABLE IS
JUST THE BEGINNING.**

HIV-positive models.

Before starting DELSTRIGO, tell your doctor about all your medical conditions, including if you have hepatitis B virus infection; kidney problems; bone problems, including a history of bone fractures; are pregnant or plan to become pregnant; or are breastfeeding or plan to breastfeed. It is not known if DELSTRIGO can harm your unborn baby. Do not breastfeed if you take DELSTRIGO. Women with HIV should not breastfeed because their babies could be infected with HIV through their breast milk.

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines,

Please read the Patient Information for DELSTRIGO on the following page, including an important warning about the potential worsening of hepatitis B after stopping DELSTRIGO, and discuss it with your doctor.

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

vitamins, and herbal supplements. **Some medicines interact with DELSTRIGO.** Keep a list of your medicines to show your doctor and pharmacist. **Do not start taking a new medicine without telling your doctor.** Your doctor can tell you if it is safe to take DELSTRIGO with those other medicines.

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



INVENTING FOR LIFE

Copyright © 2020 Merck Sharp & Dohme Corp., a subsidiary of Merck & Co., Inc. All rights reserved. US-DOR-00602 11/20


Delstrigo[™]
doravirine/lamivudine/
tenofovir disoproxil fumarate
100 mg/300 mg/300 mg tablets

Patient Information
DELSTRIGO™ (del-STREE-go)
(doravirine, lamivudine, and tenofovir
disoproxil fumarate) tablets

What is the most important information I should know about DELSTRIGO?

DELSTRIGO can cause serious side effects, including:

Worsening of hepatitis B virus infection (HBV). If you have Human Immunodeficiency Virus-1 (HIV-1) and HBV infection, your HBV infection may get worse (flare-up) if you stop taking DELSTRIGO. A "flare-up" is when your HBV infection suddenly returns in a worse way than before. Your doctor will test you for HBV infection before you start treatment with DELSTRIGO.

- Do not run out of DELSTRIGO. Refill your prescription or talk to your doctor before your DELSTRIGO is all gone.
- **Do not stop taking DELSTRIGO without first talking to your doctor.** If you stop taking DELSTRIGO, your doctor will need to check your health often and do blood tests regularly for several months to check your liver. Tell your doctor about any new or unusual symptoms you may have after you stop taking DELSTRIGO.

For more information about side effects, see **"What are the possible side effects of DELSTRIGO?"**

What is DELSTRIGO?

DELSTRIGO is a prescription medicine that is used without other HIV-1 medicines to treat HIV-1 infection in adults:

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

HIV-1 is the virus that causes Acquired Immune Deficiency Syndrome (AIDS). DELSTRIGO contains the prescription medicines doravirine, lamivudine and tenofovir disoproxil fumarate. It is not known if DELSTRIGO is safe and effective in children under 18 years of age.

Who should not take DELSTRIGO?

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

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

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

Do not take DELSTRIGO if you have ever had an allergic reaction to lamivudine.

What should I tell my doctor before treatment with DELSTRIGO?

Before treatment with DELSTRIGO, tell your doctor about all of your medical conditions, including if you:

- have hepatitis B virus infection
- have kidney problems
- have bone problems, including a history of bone fractures
- are pregnant or plan to become pregnant. It is not known if DELSTRIGO can harm your unborn baby. Tell your doctor if you become pregnant during treatment with DELSTRIGO.

Pregnancy Registry: There is a pregnancy registry for people who take DELSTRIGO during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk to your doctor about how you can take part in this registry.

- are breastfeeding or plan to breastfeed. Do not breastfeed if you take DELSTRIGO.
 - You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.
 - Two of the medicines in DELSTRIGO (lamivudine and tenofovir) can pass into your breast milk. It is not known if doravirine can pass into your breast milk.
 - Talk with your doctor about the best way to feed your baby.

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

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

How should I take DELSTRIGO?

- Take DELSTRIGO every day exactly as your doctor tells you to take it.
- Take DELSTRIGO 1 time each day, at about the same time every day.
- DELSTRIGO is usually taken by itself (without other HIV-1 medicines).
- If you take the medicine rifabutin during treatment with DELSTRIGO, your doctor will also prescribe an additional dose of doravirine for you. You may not have enough doravirine in your blood if you take rifabutin during treatment with DELSTRIGO. Carefully follow your doctor's instructions about when to take doravirine and how much to take. This is usually 1 tablet of doravirine about 12 hours after your last dose of DELSTRIGO.
- Take DELSTRIGO with or without food.
- Do not change your dose or stop taking DELSTRIGO without talking to your doctor. Stay under a doctor's care when taking DELSTRIGO.
- It is important that you do not miss or skip doses of DELSTRIGO.
- If you miss a dose of DELSTRIGO, take it as soon as you remember. If it is almost time for your next dose, skip the missed dose and take the next dose at your regular time. Do not take 2 doses of DELSTRIGO at the same time.
- If you have any questions, call your doctor or pharmacist.
- If you take too much DELSTRIGO, call your doctor or go to the nearest hospital emergency room right away.
- When your DELSTRIGO supply starts to run low, get more from your doctor or pharmacy. This is very important because the amount of virus in your blood may increase if the medicine is stopped for even a short time. The virus may develop resistance to DELSTRIGO and become harder to treat.

What are the possible side effects of DELSTRIGO?

DELSTRIGO may cause serious side effects, including:

- See **"What is the most important information I should know about DELSTRIGO?"**
- **New or worse kidney problems, including kidney failure.** Your doctor should do blood and urine tests

to check your kidneys before you start and during treatment with DELSTRIGO. Your doctor may tell you to stop taking DELSTRIGO if you develop new or worse kidney problems.

- **Bone problems** can happen in some people who take DELSTRIGO. Bone problems include bone pain, softening or thinning (which may lead to fractures). Your doctor may need to do tests to check your bones.

Tell your doctor if you have any of the following symptoms during treatment with DELSTRIGO: bone pain that does not go away or worsening bone pain, pain in your arms, legs, hands or feet, broken (fractured) bones or muscle pain or weakness. These may be symptoms of a bone or kidney problem.

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

The most common side effects of DELSTRIGO include dizziness, nausea, and abnormal dreams.

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

How should I store DELSTRIGO?

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

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

General information about the safe and effective use of DELSTRIGO.

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

What are the ingredients in DELSTRIGO?

Active ingredients: doravirine, lamivudine, and tenofovir disoproxil fumarate.

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

THE BASICS OF U=U

‘Undetectable equals untransmittable’ means you can’t sexually transmit HIV while on successful therapy

BY ENID VÁZQUEZ

“U=U” stands for “undetectable equals untransmittable.”

It means that people with an undetectable viral load cannot transmit HIV through sex.

Undetectable viral load means **bringing the amount of HIV in blood down to such a low level that it can’t be measured** on a viral load test.

HIV therapy should bring viral load down to less than 20 or 50 (copies per milliliter, or mL, of blood plasma). (The lowest amount of HIV that can be measured depends on the viral load test being used.)

To be untransmittable, your viral load doesn’t actually have to be undetectable. It just needs to be less than 200! This is called **“virally suppressed.”** And it’s the level found to make HIV untransmittable in research.

U=U has a scientific name: TasP, which stands for **treatment as prevention**.

There’s more to U=U/TasP than being virally suppressed. A person must be on the same HIV regimen (stable therapy) and virally suppressed for at least six months, according to the U.S. Department of Health and Human Services (DHHS) HIV treatment guidelines. Other guidelines have other considerations, such as two undetectable viral load test results in a row (at least several weeks apart), according to the New York State Department of Health AIDS Institute (GO TO hivguidelines.org). Most people achieve undetectable viral load in about two weeks. Maintaining that status is obviously key.

Medical providers should tell people about U=U, according to the DHHS guidelines. It may help motivate people to maintain their care, but also help overcome the stigma that blocks testing and treating, DHHS writes.

But, says DHHS, providers should remind people that not taking their meds correctly or having a treatment interruption can make transmission possible.

Viral load can go back up within about two weeks of stopping treatment. **There’s a lot of help available around adherence.** SEE bit.ly/NIH-adherence-factsheet.

Remember that **an undetectable viral load does not stop anyone from picking up other STIs or from passing those on.** Condoms help if you want to prevent STI transmission.

It’s **not yet known if undetectable viral load can prevent transmission through needle sharing** or the use of other injection equipment. (Although there is some evidence that it does lower the risk.)

And while it definitely lowers transmission to infants, **a very small risk of transmission during pregnancy remains and has also occurred during breastfeeding** (less than 1%) despite undetectable viral load.

Some people refer to **a third “U”:** **“universal access”** to healthcare.

Credit goes to Bruce Richman and the Prevention Access Campaign for creating the U=U educational and advocacy campaign; GO TO preventionaccess.org.

There are two major biomedical **strategies for ending HIV today: U=U and PrEP.** PrEP stands for pre-exposure prophylaxis, which means taking medicine to prevent infection before a possible HIV exposure. There is also PEP, or post-exposure prophylaxis, in

which medication is taken for 28 days starting within 72 hours of a potential HIV exposure.

GO TO hiv.gov/tasp. Read the section on TasP from DHHS HIV treatment guidelines at clinicalinfo.hiv.gov/en/guidelines/adult-and-adolescent-arv/antiretroviral-therapy-prevent-sexual-transmission-hiv. The TasP section begins on page F-1 of the guidelines.



“The science is clear.

People living with HIV can feel confident that if they have an undetectable viral load and take their medications as prescribed, they cannot pass on HIV to sexual partners (Undetectable = Untransmittable, U=U).

“U=U offers freedom and hope.

For many people living with HIV and their partners, U=U opens up social, sexual, and reproductive choices they never thought would be possible.”

—PREVENTION ACCESS CAMPAIGN

NEVER SILENT

On the eve of the release of his new memoir, activist **Peter Staley** talks with editor-in-chief **Jeff Berry** about ACT UP, the early days of the AIDS epidemic, and Tony Fauci

JEFF BERRY: It's rather surreal to be sitting here talking to you. If it weren't for you, and the work of ACT UP and other treatment activists, I probably wouldn't be here to do this interview. I just want to say thank you and acknowledge that.

PETER STALEY: Same here. If it weren't for ACT UP, I wouldn't be here.

JB: I'm very excited and honored to be the first person to interview you for the book [*Never Silent: ACT UP and My Life in Activism*!] I know it sounds cliché, but I literally could not put the book down. I have to ask you, why this book, and why now?

PS: Ever since *How to Survive a Plague* came out, I've been blown away how, to this day, it continues to inspire folks, especially younger LGBTQ people who discover this history for the first time. Even today, a week doesn't go by where at least one person reaches out to me on social media letting me know how impacted they were by watching it. Some of those who reached out years ago went on to become activists themselves. And it's not hero worship. They're inspired by how people power—a community-based movement—changed the world. They rightly view it as one of the most inspiring moments in queer history.

So this notion that a historical work, be it a documentary or a book, can have this endless shelf-life that will outlive all of us and continue to inspire young people for years to come—that's a beautiful thing. Our AIDS movement needs to fill a few shelves at every bookstore. All of us who have stories to tell need to write them down or find a place for them online. And even though others have tried to show some highlights from my activism, they were just the tip of my iceberg. I've been sitting on some great untold stories, and it was high time I wrote them down in my own words.

JB: I love that the book is so sex-positive. Is that something that your editors encouraged you to do, or were you intentional from the get-go?

PS: Are you kidding? Those were some of my best untold stories! I've been an openly proud slut my entire life, and the book would have been a lie if I left that out of it. Also, my activism was rooted in the most sex-positive movement in world history. I think this gets lost a little bit—ACT UP's amazing, in-your-face politics around sex. We were born in '87 at the peak of a backlash against queer Americans because of AIDS, saying, 'These people deserve it. They should be quarantined. They are dirty, should never have sex again, their buttocks should be tattooed,' you name it. Instead of timidly managing that backlash and not making things worse—what the mainstream gay establishment was trying to do all through the '80s—ACT UP said, fuck that shit. We know that safe sex works, so we're gonna have lots of safe sex. And we're gonna let everyone know that we're having lots of safe sex. We're gonna do kiss-ins in straight bars, and put posters around town saying *MEN: Use Condoms Or Beat It* next to a picture of a huge erect penis. Safe sex became a religion for us. It kind of got transplanted into the DNA of ACT UP.

That's the stuff that doesn't get told in some of the other narratives. That's one of the reasons I wanted to write the book, was to fill in the blanks on how we lived during those years, and in a sense, thrived.

JB: In chapter five, *Searching for ACT UP*, you talk about Griffin [Gold], the co-founder of People with AIDS Coalition, Michael Callen, who's also another co-founder, and then Michael Hirsch, its executive director who later founded Body Positive. You say, "With Gold, Callen and Hirsch, I had found the beating heart of AIDS activism in New York, HIV-positive gay men who demanded to be heard, and to live without stigma." This is really the heart of the book in some ways, isn't it, the lens through which you view the epidemic?

PS: It was. I mean, it was such a stroke of luck that Griffin Gold was at the first support group I walked into. I didn't stick with the group because it mostly resonated an intense level of victimhood, which

EMIL COHEN



makes total sense, but didn't jive with how I was feeling. Griffin was across the room from me and was having none of it, and just seemed very self-empowered. He was the tip of the spear of this self-empowerment movement I knew nothing about that started years earlier, and culminated in 1983 with the Denver Principles, a bunch of gay men just laying down the law, rejecting victimhood. I did a beeline to him after the support group to say, let me

I found a good shrink. Dixie Beckham was a psychotherapist who had earned a reputation working with people with AIDS, another shining example of the lesbians who fought for and took care of gay men at death's door." You make sure to give credit where credit is due, including the lesbians who stepped up early in the epidemic when no one else would—talk a little bit about why that's important to you.



ACT UP would not be ACT UP if it weren't for this beautiful combination of desperate gay men and

take you out to coffee, and he became a very good friend. Within weeks I caught a stroke of luck. I was meeting these founders of the HIV self-empowerment movement, and that was the beating heart of AIDS activism at that time. GMHC [formerly Gay Men's Health Crisis], [activist and writer] Larry Kramer, *The Normal Heart*—that's '81 to '83—that's chapter one of AIDS activism in New York. Chapter two is the self-empowerment movement, which is very much San Francisco and New York in combo, and while it overlapped with chapter one, its peak was mostly '83 to '87. Chapter three was street activism, ACT UP, which spread around the world with over a hundred chapters. I got lucky to meet the founders of chapter two, before chapter three started. It was one of the things that saved me, and it showed where my head was at, which was, *reject victimhood*. I was ready for chapter three.

JB: After the meltdown, you write, "I did what any unstable New Yorker with a savings account does,

PS: Well, Dixie was my first example. As I joined ACT UP, that one example with Dixie became a couple dozen examples of dykes who were about the same age. Definitely older than I was, who were there based on this impulse to take care of their gay brothers. They were losing their friends but also had this movement memory that gay guys like myself had none of. They had been through the battle with the Equal Rights Amendment. They had been with the reproductive rights movement. Some of them had been part of the post-Stonewall radical gay activism during the first few years after Stonewall, some of them were with the anti-[Vietnam] war movement, and they had lots of experience with civil disobedience. So that allowed ACT UP to hit the ground running. We didn't have to start from scratch. We had this movement memory transplanted mostly by these lesbians. That allowed us to take to the streets immediately, and do it as radically as we'd like in a semi-safe way, and that was absolutely crucial. ACT UP would not be ACT UP if it weren't for this

RICK REINHARD

beautiful combination of desperate gay men and wise lesbians coming together to fight this together.

JB: You talk about the inside-outside game. You write, “We were always willing to meet with government officials and pharmaceutical executives to push our demands. If they refused to meet or ignored our demands we’d take to the streets, the outside game.” You



wise lesbians coming together to fight this together.

get to have the final say, or at least your say, on topics that are still being debated today, such as your perspective on AZT. Some said it killed their friends and was poison, but you have a different take. Why was it important to include that? Because, some people will disagree.

PS: Yeah, I know, the AZT chapter is going to be a bit controversial.

JB: But that never stopped you before—controversy.

PS: Exactly. I've been privately fuming about that and telling people one-on-one for decades now, but because I loathed writing, I never sat down and wrote out some defense of AZT. Until now, I hadn't pushed back against what became an incorrect historical memory of that drug's place in the history of treating HIV. I explain my theories of why this inaccurate reputation took hold. I did a lot of activism around AZT, so it made sense to tag that

onto that chapter. I'm not going to give it away here, but if there's a little side debate that happens within the community, I anticipate there might be on what I say about AZT, and whether it did kill all your friends. Let's have it, because frankly, it's overdue.

JB: You alluded to the schisms in ACT UP that caused the treatment activists to break away, in chapter 10, resulting in the creation of the Treatment Action Group [TAG]. Some of the rifts were really deep and painful, and they still exist to this day. How does that affect or inform the work you do today? Or does it?

PS: It does. I haven't had to really live through that type of internal activist conflict since then. AIDS activism became a bit more professionalized in the aughts and ever since. Most of the AIDS activists out there work for an AIDS organization or public health institution. Now, because of the internet and travel, it's fully international and representative of those who are infected with HIV, unlike the ACT UP days, where we had some real diversity issues of representing those who were infected. There's a real consensus among today's activists, now that we have tools to actually fight AIDS. We didn't back then. We were taking to the streets in an effort to force society to find those tools—a very different type of activism. When all the activists agree on the science that undergirds those tools, then it's really easy to do the work together; you're all playing from the same book, you're all on the same page. I briefly mention in the memoir one kind of conspiracy movement that tried to push a narrative after PrEP was approved in 2012, led by Michael Weinstein and AIDS Healthcare Foundation. The rest of the community, 90% was on the same page, but we had this horrible morality argument that we had to win after 2012. I took that on, as did many, but I was at the forefront of pushing back against that conspiracy movement. It took a few years to kind of silence it, and prove them wrong. But that's really been the only major spat that I can remember since ACT UP split, and that split was horribly, horribly painful. And you're right, it's still debated now. Among ACT UP alumni, and as a for instance, I finished my book before Sarah Schulman's new book—[a] deep dive into ACT UP history—came out, *Let the Record Show*, and I read that after I had finished writing my memoir. Not surprisingly, we were members of ACT UP, and we were in the two respective camps that collided. Her take on the split in her book is very different from mine, so it'll be a great thing for people to read both and contrast and compare. It's still a very, very lively debate. My opinion is definitely not the end of it; people shouldn't take it as truth by any means, but I hope it adds to the debate.

JB: In the chapter, *Surviving Survivor's Guilt*, you write, “I made it to 1996 without a serious illness or a diagnosis of AIDS. When discussing long-term survivors today, I'm careful not to claim membership in its most resilient fellowship, those who survived AIDS itself.” Why is it important to you to make that distinction?

PS: I just think it's night and day, and, you're in that club?

JB: I'm on your team.

PS: You never had an AIDS diagnosis? Ah...

JB: My T cells dipped below 200 for like, one month.

PS: You're in my club. We both dealt with lipodystrophy, and, our stories are very similar.



ACT UP CO-FOUNDER
LARRY KRAMER,
AMFAR CO-FOUNDER
MATHILDE KRİM,
AND STALEY

It was the gauntlet hanging over me the entire time. I talked about how dropping below 200 T cells is the beginning of a two-year clock tick-down. But you could get back over 200 T cells and stop the clock again for a little while, and I was able to do that. But with an OI [opportunistic infection], the clock starts and it doesn't stop. You end up in a hospital, you obviously must be thinking, is this the first hospital visit? Is this the last? It's just fucking night and day, and not just mentally, but physically. All the things that you and I went through are compounded exponentially on how your body gets beat up. There's this category of individuals who went through something I did not go through. I did everything I could to avoid going through that, including some very selfish stuff that I feel a lot of shame about. I write about all of that. I think every person, including HIV-negative people who went through those years, did some sort of self-protection at some point that they feel guilty about. They avoided something, they just couldn't take it all in. They couldn't be there. I know very, very, very, very few saints from the AIDS years. Frankly, the saints, they probably all died. We're all human. I really want to open up a conversation for all of us to be able to talk about that, and find some space for us to find self-forgiveness. Writing this book was part of that process for me.

JB: In the last chapter, *Dinner with Tony*, you write “There’s a bond among all of us who survived those years, not just those of us with HIV, but also our friends, family, lovers, researchers, civil servants, nurses, and doctors. We all carry the memories of those we lost, a deep scar that will never heal.” I’m really glad you bring this up in the book. At *The Reunion Project*, we’ve always included these folks in our definition of long-term survivors.

PS: Exactly.

JB: I like to say to our allies [from those years] who are not living with HIV, that they are long-term survivors in their own right. All that trauma, and all that loss takes its toll whether you’re living with HIV or not. HIV just adds more layers to it, more complexity.

PS: After the death rate plummeted in the U.S. and developed countries around the world in the late '90s, a lot of

us did some mental jujitsu to tuck all this away or try to move on, and so a lot of this is buried for many people. It was for me; it was, for periods, for almost everybody I know. Then there’s a moment where there’s a discussion with a friend about a memory from those years, and all of a sudden, it floods back. [In the book] I described this moment of witnessing someone get caught off guard by those hidden scars, which I think points to the value of remembering. This period that we’ve entered, starting with *How to Survive a Plague* in 2012 and other works since then, remembering those years, which is still—thank God—flourishing right now, with, finally, many additional perspectives from women and people of color. While I was writing, during the past three years, my white cis, gay male narrative, I read and saw a bunch of novels and theater from women and people of color with major AIDS narratives. I don’t remember seeing much of that in 2012, so I think we’re making progress.

JB: You talk about Spencer Cox [who died in 2012] in the book. Spencer represents a whole community of people who are still struggling, or [were] struggling and haven’t survived. Even later in life they weren’t all able to overcome those demons. Is there something you want to say about Spence that you want people to know?

PS: I wanted to highlight how brilliant an activist he was, as well as describe the character that he was; I hope I did that. One of the most crucial debates in treatment activism, probably the biggest split among AIDS activists, not within ACT UP, but after the split between ACT UP and TAG, was this debate before the protease inhibitors got approved around access versus answers. Spencer became the ethical leader of the right side of that argument, and took a lot of shit for it. That took amazing strength from somebody that young—I thought I was a young member of ACT UP, but he was seven years my junior. After his death, it shocked the AIDS community, and I think that we did what we do best, which was to turn these hard emotions into action. It spawned some new activism that still has legs to this day, of looking at long-term survivors, not forgetting them, making sure all our AIDS organizations have programmatic focuses on this group, because there is a very mixed bag for those who lived through the '80s and '90s. Some eventually adjusted, some went through really rough bumps before adjusting—I’m in that camp—and some are still struggling. The struggling ones are often isolated and alone. As a community we have to push back against that, we have to do something about it, and that’s what Spencer’s death spawned.

JB: In the epilogue, about Tony Fauci, you write, “He’s a brilliant scientist, especially with infectious diseases, and knows how to explain that science to lay people, a rare talent.” What do people not know about Tony that you’d like them to know?

PS: The guy’s being examined right and left, there are documentaries coming out now, including a big one with a theatrical release set for this fall from Disney Nat Geo. It’s very interesting to me, he’s become a symbol for the far right in this country. He is enemy number one for Fox News and other far right surrogates and the Tea Party Caucus in Congress and the Senate. They’re just foaming at the mouth right now, and their critique of him is just all bullshit. But for AIDS activists, it’s a completely different set of issues and they remain to this day. I’ve always told him, you’re a great scientist, but you’re a lousy

administrator. I haven't stopped saying that to him. He's a control freak. He doesn't delegate well, and the assets, the stuff he does bring that he's great at, this explaining new bugs to the American people and to the President, whatever president that is—he's now on his seventh, I believe. Those are two amazing and unique assets, he's one of the best infectious disease specialists in the world.

Whenever he lashed out at me in recent decades, the first words out of my mouth were, *Fuck you, Larry.*

But his faults are that he focuses on it to the detriment of getting behind public health programs in an aggressive way, being an activist about implementing new public health programs to get things done as quickly as possible, which is what we do as activists. It's very hard to get him to do things on our timeline.

JB: You talk about the fact that you don't necessarily believe in God or any religion, but you do talk about spirituality and forgiveness, and how you've come to understand the role that plays in your life. I'm curious, if you don't believe in God, what does spirituality mean to you?

PS: When I went through the 12-stepping notion of higher power with the help of a great sponsor, given my kind of proud atheism, I decided that the guys in the room—and they were almost all guys—this unconditional, selfless love that these men were showing me, giving to me, and that I, in turn, started giving back—that was power. It felt very spiritual. There's a scientific evolutionary argument about how we are capable of loving and being selfless. It's obviously real. It's in almost every human, it's something that can be tapped, but a lot of people don't. When you tap it as a group it becomes beautiful, just absolutely beautiful. And life-saving. It saved me. I hope I honored it.

JB: About your first meeting at ACT UP you said, "While the cruising was fun, what smacked me in the face the hardest at that first, long meeting was a sense of community. Sure, I had been with throngs of gay men on dance floors, where I felt that beautiful bond of sexual freedom, but this was something entirely different. The stakes were enormous, because our fucking survival as a people was on the line. By now it was obvious that no one else would save us. We realized that our only chance to stop the slaughter was in this room." That's some powerful stuff.

PS: I remember that feeling in that meeting, it really was palpable. I showed up at ACT UP's third or fourth meeting, after its first action on Wall Street. It was already over 100 people. There was such an energy, and confidence, and getting-down-to-business about it, the confidence was manifest as, we know that what is happening here now is like lightning in a bottle. We know that we are going to make history. We don't know what that history is going to be, but Larry Kramer lit the match as well as the Silence Equals Death Project, with the posters going up all over New York City. Both of those things came together and lit the match. We were off and running, and nobody

had any doubts that we were going to be a big splash, we were going to make waves, that the dam had burst. The dam was this closet the community had lived in, half lived in, or some guys maybe just one toe was still in the closet. But by and large the community was very much closeted except in our gay ghettos in major cities in the U.S., where we felt safe enough to be open with each

other. But on the national scene, we were very cautious and calculating, too calculating, and frankly too timid a community, always afraid of a backlash, and that was our dam. That was what was holding us back, this fear of a backlash. We took our national activism as a community, which is very careful and quiet and almost all inside work, and ACT UP said we're done with that. We can't afford that. Time's up. We crashed through closet doors, and blasted out onto the national scene and grabbed history by its throat and said, *We're here. We're queer. Get ready! 'Cause we're gonna start appearing on your nightly news for the next few years.*

JB: You mentioned Larry, and you write, "To this day, I never saw a happier and more alive Larry Kramer than the one sharing toasts with us at Woody's in the summer of '87. If I was one of his children, then it is equally true that he was a father figure to me, one whose approval I would seek from that time forward."

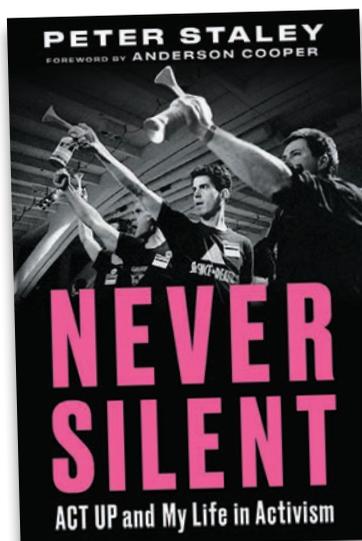
PS: Ain't that the truth. There's a cost to be paid when you're seeking approval from your dad. As the years go by he starts withdrawing it, and that's what happened in our relationship. He was not happy with the split. Actually, initially, he was okay with the split, but when he was not invited into TAG, eventually he started turning against us. I don't think [his activism] kept up with the evolution of AIDS activism in recent decades. He was in that 10% who were on the wrong side of history on the moral debates about PrEP. We had a lot of arguments, but thank God, continued to come together and remain friends. I never got totally pushed out of the way, like he did with Tony Kushner and others. Maybe it's because I got to a level where I would instantly push back. Whenever he lashed out at me in recent decades, the first words out of my mouth were, *Fuck you, Larry.* Most people are very intimidated by Larry Kramer. I don't think he heard a lot of

that, one-on-one, from others, and when I said it, he would instantly back off a bit, and then we'd start talking about the issue. It could be explosive and very argumentative, but the "Fuck you, Larry," that really helped keep the relationship going. Because he'd roll over you, boy, if you showed any weakness.

I miss the guy. **PA**

.....
This interview has been edited for length and clarity.

Never Silent: ACT UP and My Life in Activism is available to pre-order now on [amazon.com](https://www.amazon.com), and is scheduled for release on October 12 at wherever you like to buy your books. Published by Chicago Review Press.



Children's HIV research continues to grow up

With success comes new issues
BY ENID VÁZQUEZ

Forty years ago, children didn't come to mind when most people thought about AIDS. But children were also being affected. They were born with HIV, or they acquired it through a blood transfusion or from receiving a blood product.

Today, it's a different world for everyone, thanks to drug developments and the research participants who helped make the medications possible. Some of those research participants were children.

"What an amazing, complete change, to see the tremendous difference in children's care," says Rohan Hazra, MD, who has dedicated his life's work to pediatric HIV. "When I was an intern at Boston Children's Hospital's AIDS ward, half of the children were sick or dying," he recalls. "Now we talk to children to plan a normal lifespan."

Dr. Hazra points to the advances in drug development and other research, including basic science, arising from HIV work. But, he adds, "I'm equally moved by the patients and families themselves. They've been through so much and they still participate. Living with HIV is still stigmatized even now."

In 2007, Dr. Hazra joined the National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health (NIH), and since 2008 he has overseen the Pediatric HIV AIDS Cohort Study (PHACS, pronounced *facts*). Last year, he was named the acting associate director for extramural research, which serves as an umbrella group overseeing studies and clinical trials from different



NIH institutes. Many of the studies include children from around the world.

At first, medications were difficult for children to take, he says. There were many side effects and the medications didn't taste good. In 1990, he says, there was the promise of better treatments to come. But at the time, "It was a real struggle to get kids to take medicine. Now our antiretrovirals are much better."

"We're still looking at the medical effects on organs—the heart, brain, kidneys, liver. But we're really not finding any major effects. That's really heartening," says Dr. Hazra.

Stigma, however, continues to matter greatly in pediatrics because with health care involving any serious condition, clinics tend to concern themselves much more with the welfare of the kids and their families than adult clinics would with their patients. Pediatric HIV research clinics will help families deal with disclosure and other stressors. Special summer camps for children facing a serious disease in themselves or their families might be made available. Other family outings could be on the agenda. Some of the studies, including PHACS, have sites around the country. The site located at the Children's Hospital Colorado, in Denver, has arranged for young participants to go horseback riding.

The sites have to go above and beyond to work with families in other ways as well. For example, they may offer snacks and beverages. They may guide family members through hospital corridors to get to where the clinic is located.

It's part of what makes transitioning to an adult clinic difficult. In pediatrics, "transitioning" refers to leaving the cocoon of your pediatric clinic to entering a clinic for adults where they don't know you. And they have no idea what you've been through in your young life. And suddenly, you're on your own for dealing with your medical care, without the extra handholding (and kindness) associated with specialized pediatric care.

Nurse practitioner Julia B. Purdy, MSN, CRNP, who has also dedicated her work at NIH to children who acquired HIV around the time of birth, agrees that children's survival is no longer the overriding concern it was long ago, but that the stigma associated with HIV remains nearly as strong as ever.

"I started out 20 years ago with patients who were very young, and the issue was survival, but we also helped families deal with disclosure and stigma. Fast forward 20 years and we don't have to worry as much about survival," says Purdy, who today serves as a Senior Research Nurse Specialist at the NIH.

Back then, children participating in research were receiving free expert care at a time when so little was known about the disease or possible treatment.

Now there are fewer and fewer children being born with HIV in the U.S. In the latest statistic from the U.S. Centers for Disease Control and Prevention, there were 35

"Being an adolescent and healthy is a challenge, but being an adolescent with HIV is much more challenging," Purdy says. But, she adds, "Many of our now-adult patients are having families and doing really well."

These now-grown adults participating in a longitudinal NIH study travel yearly to the NIH Clinical Center for study-related tests and procedures. They may also participate in other NIH studies and even stay overnight. The NIH campus of teaching hospitals is located in Bethesda, Maryland, just 10 miles from the center of Washington, DC.

"You can't be a patient unless you're enrolled in a study," says



'When I was an intern at Boston Children's Hospital's AIDS ward, half of the children were sick or dying. Now we talk to children to plan a normal lifespan.'

DR. ROHAN HAZRA

children born with HIV in 2018 (*HIV Surveillance Report*, 2019).

Dealing with disclosure is still important, but family planning has also taken on greater importance with the options now available and the desire of younger long-term survivors who are now adults to have a family.

There are also more conversations between provider and patient and between patients and their sex partners, thanks to the use of HIV treatment as prevention (TasP), which stops the virus from being transmitted to sex partners. (See "U=U" on page 21.)

These advancements don't necessarily make the conversations easy.

Purdy. "This is the largest hospital dedicated to research in the U.S. There are 27 research institutions and centers focusing on particular diseases or conditions. Our research is under NIAID [the National Institute of Allergy and Infectious Diseases].

"Many of our study participants have been coming here to the NIH since they were young," says Purdy. "The goal of our current research is to understand the clinical outcomes and impact of HIV infection and its treatment on this unique cohort of individuals. Patients in our study, the NIH COPE study, undergo laboratory, cardiac, and metabolic evaluations and more recently, our work is focused on reproductive health

and decision making, topics which are very important to our aging population. Participation in the study is free of charge. We also advise the patients' local health care team when requested."

Evaluating the metabolic effects of treatment, the team found weight gain and observed more fatty liver, as is seen with people who acquired HIV as adults. "For a long-time people couldn't gain weight," says Purdy. "Now the antiretrovirals are so good that people can gain too much weight."

Still, she notes, "We don't know what it's going to be like being on antiretrovirals for 40, 50 years and longer."

Research studies can provide access to cutting-edge medical services that could one day become standard of care, years ahead of time. They can perform sophisticated procedures that insurance may not cover. And it's all free because studies cannot charge people for the costs of participation.

In addition to physical conditions, PHACS and other pediatric HIV studies look at mental health, as well, such as depression.

This year and last, there was a lot of work added to look at COVID. Dr. Hazra said that because of the quarantine, there was an increase in telehealth and other remote health care techniques.

For example, testing kits were sent out to study participants. They received a device they attached to their upper arm to draw a small amount of blood. Then they mailed it back.

"It doesn't even hurt," says Dr. Hazra. "It doesn't leave a scar. So they don't have to come to the clinic and sign in and wait. We can engage individuals in a way that's much less burdensome now," he says.

These long-term studies can be hard to keep going, especially those that keep track of children.

"Some had very involved parents," says Purdy. "But now, as adults, they have to take their meds on their own, travel on their own. It's hard to keep people in a longitudinal study, especially with work and school. This is a very mobile group. We are grateful for the important contribution our patients make to the research and its impact on the care of others."

Dr. Hazra referred to the early pediatric study participants as "the first wave."

"Through their participation,

they've helped millions of children around the world," Dr. Hazra says. "Some of it may not have even helped them, but they wanted to do what they could to help others as well."

I've been very blessed.

—BEN BANKS

At age 40, Ben Banks continues to participate in the clinical research studies at the NIH.

Banks had a deadly form of cancer at age three, and because he was from a military family, he was treated at a naval hospital. But during follow-up years later, it was found that he had contracted HIV from a blood transfusion he needed for cancer treatment. He was 11.

He continued to be treated for his newly-discovered virus at the military hospital, initially receiving AZT. But when he was 17, his doctor told him he should get medical care at the NIH next door in Bethesda.

"They can do a lot more for you across the street," his doctor said.

"I was only on ddl [Videx] at the time, for two or three years. It was a chewable horse pill. I can still remember the horrible taste," Banks says, something that he discusses with other friends who lived through the experience as children.

He remembered that the first nurse to take his blood at NIH didn't wear gloves. At a much later date, she explained to him that she didn't want him to feel as if he was a danger to others. She said the risk to her from a blood draw was extremely small. "I wanted you to feel accepted by me," she told him.

That experience helped him to balance his other encounters in the outside world.

"She wanted me to feel normal," says Banks. "There's still so much stigma and discrimination. The people who got involved in pediatric HIV, it's because they wanted to. They lost people close to them. The compassion level is so high. I knew that in the hospital, at home, and in church I was accepted no matter what."

Today, the Bethesda campus is a two-hour drive from his home. He continues to participate in multiple studies. "MRIs. DEXA scans. EKGs. All kinds of things. In one study, they were checking to see how much of my medicine was being absorbed. So I had blood taken every hour for eight hours. They've taken 25 tubes of blood before. I go

in every three months because of multiple studies. I'm one of those people who take full advantage of opportunities. I'm a firm believer that we're always supposed to be learning. And we're supposed to share what we learn. I tell people what's science fiction today will be science 10 years from now. We've got brilliant minds. They're unlocking doors for diseases and new ways to treat people.

"It's really cool. Even the researchers go from one study to another. I'll go down the hallway and I saw Wendy, who was my nurse 20 years ago. She asked me, 'How old is Finley [his daughter] now?' 'She's eight.' 'Wow.' Banks married his high school sweetheart and has been married for 18 years.

"What I like about NIH is that it's multidisciplinary," Banks says. "It's not just medical. It's the emotional aspect. It's the spiritual aspect."

"Through NIH, I've spoken at symposiums. I've gone into research labs. When I talk with medical students, I tell them the amount of HIV in my body is about the size of my fingernail. So, treat the whole person. That's my message," he says, "treat people, not diseases."

He gives talks through his college, James Madison University in Harrisonburg, Virginia, and has served on committees for HIV treatment guidelines.

Yet as an adolescent, he was silent about his HIV status throughout high school, even when his class discussed the movie *The Ryan White Story*. Like Ryan White, Banks had to receive permission from the school superintendent to attend high school, although unlike White, he didn't have to fight for it. "The only people who knew my status were the principal, the guidance counselor, the school nurse, and the physical ed teacher. I had to keep my AZT on me for confidentiality." He remained silent throughout college. But he's long past that now.

"When I started, they told us to keep it hush-hush," Banks says. "Because of that, many of the kids didn't know why they were there. Parents told them they had cancer."

"I've had conversations with a friend, remembering: 'Man, that was some crazy stuff we went through in our lives. How did they get us to take something that tasted so bad and convince us that it was good for us?' The approach I take is that this may not benefit me,

BEN AND KASIAH BANKS
WITH DAUGHTER FINLEY



‘Even the researchers go from one study to another. I’ll go down the hallway and I saw Wendy, who was my nurse 20 years ago. She asked me, ‘How old is Finley [my daughter] now?’ ‘She’s eight.’ ‘Wow.’ Banks married his high school sweetheart and has been married for 18 years.

but it may benefit others.” But the medications did benefit him.

“I’ve been very blessed,” he says.

He’s also proud about serving as an ambassador for the Elizabeth Glaser Pediatric AIDS Foundation, speaking to Georgetown University medical students every year. As an ambassador, he also mentors younger people living with HIV. “Some of them call me ‘Grandpa,’ because I’ve survived 40 years. I think that’s a sign of respect. I love my grandpa. ‘You paved the way for me’ is how I see it.”

He understands the stigma they face from classmates. “I believe stigma comes from two places: fear and lack of education. I want to educate people. These kids, I can’t

fault them,” Banks says. “They don’t know better. How can you fault them when they don’t have the knowledge to understand this?”

He tells the world, “Listen to the children. Let them have a voice. Sometimes children are much wiser than we give them credit for. The guardians and parents sign the permission forms. Let children express their opinions and value those opinions.

“As a child, a lot of times there’s anger. ‘What did I do to deserve this? Why did my mom and dad do those things and not think about me?’ They’re afraid. So, sometimes they build a wall. But they’re fragile inside.”

Some of the kids he mentored

from grade school are now getting married.

Many kids living with HIV don’t look like Banks, who is white and middle class.

“Inside we’re all the same. We have a brain. We have a heart. I relate to people of color. I relate to the gay community. Because I’ve been discriminated against. So I tell some of these children, ‘Don’t let anything be a handicap. Push through it. Show the world what you have to offer.’

“I’m coming from the cancer world and the HIV world. It’s an instant bond. It’s hard to describe, but it’s an instant bond for people who have survived something that’s trying to kill them.” >>

I want to be normal.

—ALI

Ali, 35, was three when her family learned that she had HIV. The youngest of five children, only she and her sister who was four had the virus. Her five-year-old sister did not have HIV, but was born with fetal alcohol syndrome. The three sisters were placed in a foster home after their mother died of AIDS-related causes. Their two oldest siblings were teenagers and unable to care for them. As Ali sees it, "I've been in foster homes all my life."

Ali and her sister were enrolled in NIH research studies by their first foster mother, but were later removed from that home. They remained in their new home, with the foster mom Ali stays in touch with to this day. As children, Ali and her sister traveled from their Florida home to NIH in Bethesda.

"That's where I began the whole journey with medications and therapy," Ali says. "I've been undetectable since 2007 to this day thanks to new drugs on the market."

It's been a long journey.

"I remember my [foster] mom waking us up in the middle of the night to give us medication," Ali says. "In 1990 was when AZT was available and ddI was coming out. So I was on all of that. I felt I couldn't be normal because I couldn't go to slumber parties. Couldn't even spend the night. Even now I say I have to take my vitamins when there are other people around."

She and her sister participated in several studies. Sometimes they had DEXA scans and MRIs at the NIH.

She also saw a therapist because she was very angry, she says. "Case managers had to follow us. They had to do a chart review because we were in a medical foster home. My mom—I call her my mom—was a nurse. We had home visits all the time and always had to talk with the case managers. That's probably where the moodiness came in, because that's a lot for a kid to adjust to. I have memories of being in second grade and going on the stage behind the curtains in the cafeteria and having my teacher give me my medication. It became the norm. As a kid, I wondered why do I have to be here [at the NIH] and talk to these people? But it becomes the norm too," Ali says.

Ali and her sister enjoyed the excitement of flying between Florida and the NIH in Maryland, and taking

sightseeing side trips. There was even a school at NIH, helping them with their homework from back home. But like the other children taking pills, Ali and her sister hated the taste of their medications.

"But my mom made sure we had the best life. We went to the movies, the skating rink, to Busch Gardens. She made sure we had birthday celebrations, and all of that. And that's what I'm doing for my son today," says Ali.

Ali did better as she grew older and didn't have to travel as often to NIH. Her sister, however, was often sick.

"My sister and I were in the same studies, but she was not responding as well. She would sometimes stay for months [at NIH]," says Ali.

Then, her sister died at age 14. Ali was 13. It was then that she found unused pills in her sister's dresser.

"Her body didn't have as good a response to the medications. She was tired of fighting. I'm getting emotional," Ali says, and starts to cry. "She gave up. There's only so much you can take."

Ali continued to tolerate her medications, both physically and mentally. She was diligent about taking them.

"I've been very healthy," she says. But she also had setbacks.

"Yes, I was hospitalized. I had kidney stones. I had pneumocystis pneumonia [PCP]. I was hospitalized for esophageal candidiasis," she says.

In spite of all that, she graduated from high school with honors, thanks to her foster mom, she says. They remain in touch. "I talked with her today," says Ali.

Ali obtained legal emancipation at the age of 17 and would sign herself out of high school to attend medical appointments and then sign herself back in. "I was responsible," she says. "I wasn't playing hooky." She even moved out into her own apartment at one point, when she was 18, but ended up moving back home. "It was a bit much," she says. Today she lives in a beautiful apartment with her son.

Ali went straight to college, and continued to receive high grades. She took a few semesters off. She also gave birth to a healthy, HIV-negative boy while in college, at the age of 25, and went straight back to her classes. She hired babysitters and had a lot of help from her partner. Today, her son is "super healthy and active. He's tall for his age and he's now in the fourth grade." She pushes him to do well in school the way her foster mother used to push

her. She wants to be sure he goes to college.

But at one point before she had her son, her HIV medications had stopped working for her.

"That was the worst part, waiting for new drugs to be on the market. My mental health was deteriorating," she says. "I've been on Cymbalta [an antidepressant] since 2007. I was depressed. I had mood changes because I had no HIV medications in me. It affected everything. I was like, dying. I was really sick and I was in the hospital. Then the new drugs were approved, and here I am."

She continues to participate in NIH clinical research. "Because of COVID, I've been doing Zoom," she says, having virtual telehealth appointments using her smartphone.

She also takes care of her health on her own. Because she's healthy, she only sees her HIV specialist every six months. "I also see a psychiatrist. I see a cardiologist. I see a dentist. I see a rheumatologist. I got a referral because of joint pain. It's not carpal tunnel—I had that before.

"And then I find time to exercise. That's my stress relief," Ali says. "I try to eat right. That all goes into my mood."

Ali has always disclosed her status to the men she dated. She found a lot of misunderstanding. "People have not been educated about it," she finds. "One guy told me, 'I want to live and have kids.' Well, so do I. It's not a death sentence anymore the way people still think it is, even today. They don't know. I am now with an amazing man who loves me for me and is supportive and even went with me to my doctor appointments.

"I want to be normal, just keep going—and there are people older than me who also started the medications when they were kids. If you are positive, follow through on your medication. Follow through on your doctor visits. Be healthy. Exercise. Don't think that because you're feeling good you can stop medication. I don't do that," Ali says. She knows that in spite of enjoying good health, "There are going to be sad days, depressing days. Get support. I used to be in support groups too."

Ali continues to need support: "I'm still wondering, how am I going to tell my son one day?"

Medications are here, but so is stigma. That's another journey. **PA**

.....
TO FIND information on NIH studies, go to clinicaltrials.gov.

"That was the worst part, waiting for new drugs to be on the market... Then the new drugs were approved, and here I am."

Another international HIV conference goes virtual amidst a global pandemic

This year's 11th IAS Conference on HIV Science (IAS 2021), held July 18–21, moved online, dropping its original plans to take place in Berlin. It was a change that once again was made necessary due to the COVID-19 pandemic.

Last year, the 23rd International AIDS Conference (IAS 2020) went virtual. Both conferences are organized by the International AIDS Society (IAS), in alternating years.

"It's been 40 years since the first reported cases of the disease now called AIDS, one of the worst pandemics in human history. To date, we have lost nearly 35 million people to AIDS," said IAS president Dr. Adeeba Kamarulzaman, dean of the faculty of medicine at the University of Malaya and an adjunct associate professor at Yale University, and IAS 2021 co-chair, as she opened the conference.

"Thanks to scientific inquiry—including the dogged determination of many IAS Members—a positive HIV test no longer means a death sentence," said Dr. Kamarulzaman. "A mother living with HIV can give birth without passing it on to her child, and an undetectable viral load is untransmittable between partners. Each year, our treatment and prevention efforts improve. And each year, we continue to unlock the mysteries of how HIV interacts with the human body."

When HIV doctors around the world elected Dr. Kamarulzaman last year to lead IAS, she became the organization's first Asian president. Moreover, the governing council became

female-majority—also for the first time—with 13 women and 12 men.

At the time, the society announced that, "The International AIDS Society views racism, wherever it occurs around the world, as one of the greatest threats to public health and greatest obstacles in ending AIDS. Stigma and discrimination drive health disparities worldwide and determine whether or not someone has access to health care, effective treatment, and lifesaving information to stay healthy. We stand in solidarity with those personally facing racism and discrimination and with those calling for meaningful change. The IAS pledges to confront racism, stigma, and discrimination, and contribute to ending disparities, wherever we see them."

Once again, HIV doctors don't play.

Professor Hendrik Streeck, director of the Institute for HIV Research at the University Hospital, Medical Faculty University Duisburg-Essen, in Germany, and IAS co-chair, spoke of the disappointment of not being able to host the international conference in his country and of the continuing devastation of COVID-19. In spite of the setback, Berlin managed to include a face-to-face hub for many

providers, scientists, and community people.

"We do not know yet the precise impact of the COVID-19 pandemic on HIV and AIDS, but what we already know is nothing but alarming," Dr. Streeck reported during the conference opening. "The COVID-19 pandemic has exacerbated many inequalities worldwide. UNAIDS programs and activities of joint partners were interrupted or could not be implemented, despite all efforts and best intentions. HIV infections have gone undetected. Life-saving drugs have not been distributed. While the COVID-19 pandemic is a devastating catastrophe for so many, so are the collateral damages in health, economic, and social inequalities that put many in precarious situations.

"While HIV cannot be compared to SARS-CoV-2 in structure and complexity, one point is clear: with political will, we can achieve more in the fight against HIV and AIDS. HIV is still a global problem. While we are hopefully on our way to end one pandemic, the other has endured far too long," Dr. Streeck said. "The time is now to end HIV and AIDS. We have the means and we have the opportunity."

WHO finds increased risk of severe disease and death from COVID-19 in people living with HIV

Large-scale analysis from the World Health Organization (WHO) showed that people living with HIV were at greater risk of severe illness during hospitalization due to COVID-19.

There was also an increased risk of dying while still in the hospital.

The risk of severe illness

or death due to COVID-19 more than doubled for people living with HIV. These are global statistics that may look much different in resource-rich countries like the United States (see next item).

Based on the WHO findings, the IAS called on countries to add people living with HIV to their lists of groups prioritized for receiving COVID vaccination.

"The global community must also do much more to bring COVID-19 vaccines to countries around the world with high prevalence of HIV and other diseases. It is unacceptable that as of today, less than 3% of the entire African continent has received a single dose of the vaccine and less than 1.5% have received both doses," Dr. Kamarulzaman said in a press release.

According to the statement, "Previous evidence regarding the impact of HIV infection on the severity and mortality of COVID-19 has been limited and sometimes conflicting, and most analyses have been based on relatively small cohorts of individuals in specific settings. In this report, WHO researchers analyzed clinical data submitted to the WHO Global Clinical Platform for COVID-19 from 24 countries on more than 15,500 people living with HIV who were hospitalized for COVID-19. The mean [average] age of these patients was 45.5 years. About 37% were male, about 92% had received antiretroviral therapy, and about 36% had severe or critical COVID-19 illness on admission. Their most common underlying chronic conditions were hypertension, diabetes, and obesity. Among patients with a known outcome, 23% died in the hospital." >>



IAS PRESIDENT DR. ADEEBA KAMARULZAMAN

U.S. study finds no increased risk of severe disease or death from COVID-19 in people living with HIV

Unlike the global report from WHO, a team of U.S. HIV researchers found no increased risk of dying in the hospital for COVID-19 patients who also had HIV.

Matthew S. Durstenfeld, MD, of the University of California, San Francisco and Zuckerberg San Francisco General Hospital's Division of Cardiology, presented the findings on behalf of his study colleagues. The research group included all adults hospitalized with COVID-19 from March to December 2020 at 107 hospitals participating in the American Heart Association's COVID-19 Cardiovascular Disease Registry.

"Whether HIV infection is associated with differences in clinical outcomes among people hospitalized with COVID-19 is uncertain," the team noted. "Therefore, the objective of this study was to evaluate the impact of HIV infection on COVID-19 outcomes among hospitalized patients."

There were 21,528 hospitalization records of confirmed COVID-19 cases. Of these, there were 220 people living with HIV (PLWH).

"In this registry-based study of over 21,000 people hospitalized for COVID-19, HIV was not associated with adverse outcomes including in-hospital mortality, MACE [major adverse cardiac events], or severity of illness," the group reported.

Thirty-six of the 200 PLWH (16.4%) died in the hospital compared with 3,290 HIV-negative individuals (15.4%). This was not a statistically significant difference. Nor were there differences in terms of admission, ventilation, or length of stay.

After adjusting for age, sex, race, and insurance,

HIV was not associated with in-hospital deaths, even after considering body mass index (basically, obesity) or co-morbidities (other medical conditions).

The study found that the people living with HIV were younger (average age of 56 vs. 61) and more likely to be male (72% vs. 53%), non-Hispanic Black (51% vs. 25%), on Medicaid (45% vs. 25%), and active tobacco users (13% vs. 7%). The registry did not include data for CDC counts, treatment, or length of time for positive HIV status.

Lenacapavir

Lenacapavir is a long-acting HIV drug in development that can be used orally or via injection, and has shown the potential to be taken just once every six months.

That six-month possibility was demonstrated with results from early Phase 2/3 study in the Capella clinical trial. At half a year (26 weeks), 81% of people given a subcutaneous shot of lenacapavir achieved undetectable viral load (less than 50). This was 29 out of the 36 individuals in the randomized part of the study.

It wasn't just lenacapavir doing the work, however. These were heavily-treatment experienced (HTE) people with drug resistance to HIV medications they had previously taken. So in addition to the lenacapavir shot, they were also put on an optimized background regimen (OBR). This meant changes to the daily HIV treatment regimen that they were taking when they entered the study.

So it's not a big surprise that four of the 36 randomized participants had some emergent drug resistance observed to lenacapavir. Three of them later suppressed that emergent resistance. Two of them suppressed that resistance with yet another OBR, and one did it without further optimization.

Options are always needed, especially for people with drug resistance. Also, lenacapavir is being studied in combination with another long-acting HIV medication, islatravir. It's hoped that these two can be given as twice-yearly injections as the entire HIV regimen.

A separate group of 36 individuals who were not randomized in Capella all received oral lenacapavir in addition to having their HIV therapy optimized.

Islatravir for PrEP

Like lenacapavir in the previous item, islatravir is a long-acting HIV drug in development that is also being studied for PrEP (pre-exposure prophylaxis—prevention).

Early safety and PK (pharmacokinetic) results were presented out to 26 weeks on once-monthly oral islatravir for PrEP.

Of 242 participants, 60% reported an adverse event (AE). The most common were headache (9%), diarrhea (5%), and nausea (5%).

However, AEs that the researchers considered related to islatravir were reported in 15% of participants. These AEs were all considered mild to moderate.

Two participants stopped islatravir because of an AE considered related to the medication. One was a "mild foreign body sensation in the throat." The other was moderate rash and pruritis (itchiness).

The PK results demonstrated the levels needed to prevent HIV infection. *Woo-hoo!*

Participants were randomized 2:2:1—for every two individuals given a 60 mg once-monthly oral dose, two received a 120 mg once-monthly oral dose and one received a placebo (inactive pill).

"All sexes" were included, with people ages 18 to 65 allowed in the study. The median age (half of the

participants were younger and half older) was 31. Women made up 67% of study participants. Whites made up 53% of participants while Black or African American participants made up 42%. Participants were from the U.S., Israel, and South Africa. Of the 242 study participants, 189 completed dosing, 15 discontinued their participation, and 38 were still continuing in the study as of April 5.

There are two current HIV prevention medications commercially, Descovy and Truvada, each to be taken as one pill a day. There are some expert guidelines allowing less than daily use, but none calling for once-a-month oral dosing. If approved, long-acting injectable cabotegravir would be the first long-acting HIV prevention drug, taken every other month.

So stayed tuned for more from islatravir as another option. Options are always needed. (Did we say that already?)



Adherence with vaginal rings and oral PrEP

"Adolescent girls and young women (AGYW) account for more new HIV infections in sub-Saharan Africa. WHO has endorsed oral PrEP and dapivirine vaginal ring (ring) for women at substantial risk of HIV infection," noted an international team of researchers. "However, adherence to both products was lower among younger

women in randomized placebo-controlled trials.”

The team studied the use of a vaginal ring containing the medication dapivirine or the use of a daily pill for HIV prevention, containing tenofovir disoproxil fumarate (TDF) plus emtricitabine (sold under the brand name Truvada in the U.S.).

In this study, the team found that, “Adherence to oral PrEP and dapivirine ring was higher than previously observed among African AGYW, and both were well-tolerated and highly acceptable. Dapivirine ring is a viable, promising new HIV prevention method, and adherence to both products can be achieved with support strategies.”

Dr. Gonasagrie Nair of Stellenbosch University, Center for Medical Ethics and Law, in Cape Town, South Africa, presented on behalf of the MTN-034 (REACH) study. The study enrolled 247 young women ages 16 to 21. Their average number of sex partners in the last two-and-a-half months at the time of enrollment was 2.5. Nine percent of the women said they were “very worried” about acquiring HIV and 39% said they were “not at all worried.” Nearly a quarter of them, 24%, thought that their primary sex partner had other partners. About a third of them had at least one STI at baseline (28.7% had chlamydia and 8.5% had gonorrhea).

A little more than two years into the study, the young women overwhelmingly continued to make their study visits (94.4%).

Most participants had at least moderate adherence—78% to the ring and 59% to oral PrEP. A high level of adherence was demonstrated by 50% of the women using the ring and 22% of those taking oral PrEP.

GO TO ias2021.org.

Closing the gaps for trans and gender-diverse people

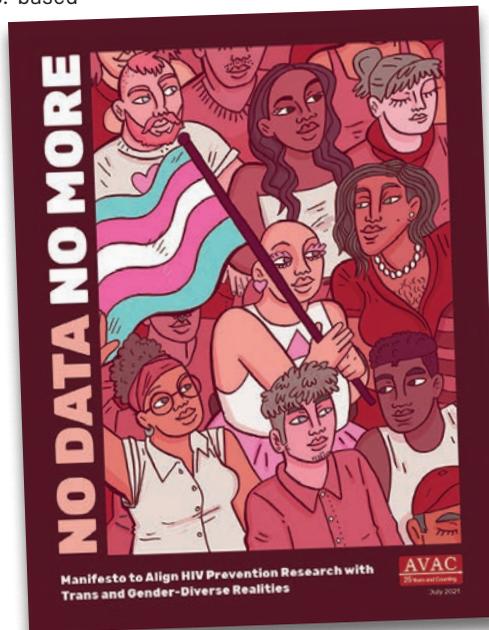
Activists produced a manifesto calling for changes in HIV programs and research to better serve the “trans and gender-diverse (TGD)” community, and making recommendations to do so.

“Whether through ignorance or bias, the engagement of trans and gender-diverse people in HIV research and responses continues to fall behind the devastating impact of the pandemic on our communities,” said Tshepo Ricki Kgositau of Accountability International, in Cape Town, South Africa, in a press release.

According to the release from AVAC, a U.S.-based global advocacy group for HIV prevention, in partnership with the global group of activists, “No Data No More analyzes how TGD communities are left out of HIV prevention research and responses through structural barriers such as discriminatory attitudes and punitive laws, non-inclusive language, failure to recognize the diverse and unique identities of different members of TGD communities, and a lack of understanding of the role of gender-affirming hormone therapy (GAHT) in TGD health. The need for change in HIV research and prevention for TGD people is clear. Trans women, for example, are 49 times more likely to

as among trans male sex workers in Zimbabwe. And data on HIV impact on gender nonbinary people, which may make up 25-30% of trans populations, is virtually nonexistent.”

Said longtime HIV activist JD Davids, of JD Strategies and The Cranky Queer Guide to Chronic Illness, “The gap between the extremely high impact of HIV on TGD communities and the extremely



low level of engagement of our communities in HIV research and responses can only lead to more infections and a prolonged epidemic. *No Data No More* is a global wake-up call for HIV prevention researchers, funders, and program implementers.” Davids, formerly

of Philadelphia, lives and works out of Brooklyn.

Immaculate Mugo, also of Cape Town, who serves as a consultant on gender, inter-sectional sexual

and reproductive health and rights, called efforts such as the Cross-Network Transgender Working Group at NIAID (National Institute on Allergy and Infectious Diseases) “laudable,” but said much more needs to be done around the world.

The *No Data No More* recommendations:

- Track epidemiological data on HIV incidence and prevalence that accurately reflects the large and growing HIV acquisition rates of TGD populations.
- Support best practices in language use, informed by TGD researchers, advocates, and trial participants.
- Address fundamental structural barriers that limit TGD people’s access to HIV research and prevention.
- Provide GAHT across the HIV research, prevention, and care continuum, resolve existing questions about potential interactions between HIV PrEP and GAHT, and ensure future studies address potential interactions between HIV prevention products and GAHT.
- Improve TGD-inclusion in randomized clinical trials and ensure that these recognize, address, and evaluate the impact of differences among subgroups of TGD people.
- Include TGD leadership in clinical research, including study design and implementation.
- Fund and strengthen the capacity of local research sites to recruit TGD participants in alignment with the Good Participatory Practice Guidelines.

GO TO avac.org/no-data-no-more, which includes a press conference video from the group.

The manifesto includes a table of drug interactions between gender-affirming hormone therapies and medications used for HIV prevention (PrEP).

Aging with HIV: Moving beyond treatment

BY JEFF BERRY

Linda-Gail Bekker, director of the Desmond Tutu HIV Center based in Cape Town, South Africa, provided an excellent overview of some of the challenges facing people aging with HIV. Bekker explained that aging with and living long with HIV is made up of three distinct groups: “Individuals who are exposed to ART, over a long period of time, [including] adults diagnosed in the last thirty-odd years who are still alive today...because of early ART and careful care; adults who due to good control or recent diagnosis are now requiring ART; and adolescents, finally, who were diagnosed in childhood or adolescence.”

With HIV now having moved into an era as a chronic, treatable condition, Bekker says we are, in some ways, victims of our own success. “People are now living with HIV long, and they need certain special considerations,” with some who

have had HIV for a long time experiencing accelerated aging, geriatric syndromes and frailty, and chronic exposure to antiretrovirals that may have some impact. “Higher rates of comorbidities, the socio-economic challenges that go often with individuals who find themselves in tricky situations, and the loss of support structures including family and friends, all having an impact on mental health, mental well-being, and social support.”

A geriatric syndrome is a variety of conditions that predict adverse clinical outcomes, says Bekker. “They may include falls, urinary incontinence, difficulty with activities of daily living, slow gait, sensory deficits such as hearing or sight loss, and neurocognitive impairment. There was a high incidence of geriatric syndromes in people living with HIV who are older than 50. And people living with HIV susceptible to frailty occurs at younger ages. The risk factors for this include low current and nadir CD4s, other comorbidities,

The challenges across the board are physical, internal, stigma, and a sense of loss—a shrinking kind of life.

obesity, and social factors, and the strategies to prevent these syndromes [are] early treatment, identifying and treating comorbidities, and insisting on some form of exercise.”

Bekker put forward some key management considerations. “It is advisable to think HIV, and offer testing, in people over 50—immediate antiretroviral therapy following diagnosis is important to these individuals, and missing a diagnosis could have severe impact.

Also remember adolescents may have slipped through childhood diagnoses, and where there is a sense that an HIV test should be done, then we should go ahead and offer one. Offer ART that takes into consideration other comorbidities and also the potential for drug-drug interactions; be wary of treatment fatigue, especially in adolescents. Screen for comorbidities and treat appropriately; avoid polypharmacy and simplify medication when possible. Always think about mental health considerations and maybe well-being; and recognize life events and offer opportunities and referrals for social support.

Quality of life is a key critical consideration, says Bekker. “You need to be thinking of these individuals’ physical disabilities and morbidities, but at the same time their psychiatric illness, the possibility of a loss of

partners and friends. With that social isolation and stigma and social stressors such as unemployment and poverty, all of these leading to reduced quality of life and health span, and the challenges really across the board are physical, internal, stigma, and a sense of loss—a shrinking kind of life.”

Bekker also spoke about adolescents living long with HIV. “They need to either continue in pediatric services with inherent complications and confusion, or get them transferred to adult service; so what we’re talking about is health care transition. This often is a problem for young adults and teenagers. We know that they struggle with adherence to appointments, and to medication.”

A geriatric syndrome is a variety of conditions that predict adverse clinical outcomes.

They may include falls, urinary incontinence, difficulty with activities of daily living, slow gait, sensory deficits (such as hearing or sight loss), and neurocognitive impairment.

There’s a high incidence of geriatric syndromes among people living with HIV over age 50.

People living with HIV are susceptible to frailty, and at younger ages.

Risk factors include low current and nadir CD4 counts, other comorbidities, obesity, and social factors.

Prevention strategies include early treatment, identifying and treating comorbidities, and exercising.

In a Canadian study of 360 patients with congenital heart disease ages 19 to 21, “attendance as an adult at an adult clinic resulted in a 47% successful transfer. So, this is often dependent on

documents, recommendation, and people introducing patients into the adult clinic and enabling self-reliant behaviors. Healthcare transition after all is the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems. In my experience it’s discussed frequently, but studied very rarely, and the barriers to successful healthcare transition often sit within the health system with an inherent inertia. The pediatric provider won’t let go, or [the adult] won’t be released; the adult provider lacks expertise, feels this will be extra demand on time and resources; and the patient

and the family or caregiver feels abandoned, they feel anxiety and loss of control.”

Healthcare transition is often not done well at all, says Bekker. In a study of more than 4,000 adolescents, “50% had discussed transition, 30% had a plan, but only 16% had a comprehensive plan that resulted with a good relationship and a great number of needed services to a successful transition.”

Bekker concluded by stating that it’s “most important to emphasize the need for differentiated service delivery for folks who live long

with HIV, whether they are getting older, or whether they are adolescents transitioning into adulthood. They deserve our differentiated care, our tailored care, our comprehensive care.”

Highlights from the 2021 HIV Cure and Gene Therapy Forum

BY KARINE DUBÉ, LYNDA DEE, AND MICHAEL LOUELLA

The International AIDS Society (IAS) held a virtual pre-conference meeting focused on HIV cure and gene therapy, July 20–21, 2021. The meeting focused on leveraging advances in cell and gene therapy towards an HIV cure and for sickle cell disease, and ensuring that these interventions be made globally available. A few highlights:

Hans Peter-Kiem [fredhutch.org/en/faculty-lab-directory/kiem-hans-peter.html] from the Fred Hutchinson Cancer Research Center in Seattle, WA, provided an overview of cell and gene therapy as a strategy to enhance control or elimination of HIV. The two HIV cure cases of Timothy Ray Brown (known as the Berlin patient) and Adam Castillejo (known as the London patient) provide a proof of concept that an HIV cure may be possible. During the last 10 years, the defeatHIV Collaboratory [defeathiv.org] has worked to develop gene editing of hematopoietic stem cells (the cells that give rise to other cells in the blood) as an approach towards HIV cure. The desired outcome would be disruption of the CCR5 gene, which acts as a doorway for HIV to enter cells, to make cells resistant to HIV infection. The approach is also being investigated as a strategy to cure sickle cell disease and other gene-based diseases.

Dr. Kiem also spoke about the work his lab has conducted towards the development of chimeric antigen receptor (or CAR) cells. CAR cells are made through cell and gene therapy to boost their ability to detect only the cells infected with HIV and kill them. Stem cell-based CARs can overcome the limitations for T cell-based HIV CARs. Kiem's lab has figured out a way to improve the manufacturing of these kind of cells, and has tested ways to increase how long these cells will last, as well as how well they will perform in the body of non-human primates. The next big step is to move these techniques into humans.

Jennifer Adair [research.fredhutch.org/adair/en/lab-members/jennifer-adair-phd.html] from the Fred Hutchinson Cancer Research Center in Seattle, and **Cissy Kityo** [virology-education.com/cissy-kityo-mutuluza-md] from the Joint Clinical Research Center in Kampala, Uganda, discussed strategies to bring cell and gene therapy to resource-limited parts of the world. Advances in cell and gene therapy have opened new opportunities for patients in high-income countries. To date, low- and middle-income countries have been

excluded from these developments. Drs. Adair and Kityo's vision is to make gene therapy available to everyone who needs it, especially in places around the world where diseases like sickle cell disease or HIV are most prevalent. Dr. Kityo presented the new Global Gene Therapy Initiative (GGTI) [caringcross.org/ggti-impact-project], an alliance of key stakeholders including clinicians, scientists, engineers, advocates, and community members brought together to enable access and implementation of gene therapies as curative medicines for presently incurable diseases in low- and middle-income countries. GGTI has four key pillars: 1) new technology development (e.g., sustainability), 2) clinical readiness and implementation (e.g., training and capacity building), 3) regulation and policy (e.g., infrastructure for commercialization), and 4) community outreach and education. The GGTI Working Group will focus on establishing a sustainable pathway to implement cell and gene therapy in Uganda and India.

Carl June [pathology.med.upenn.edu/departments/people/447/carl-h-june] from the University of Pennsylvania gave an overview of chimeric antigen receptor (CAR) towards HIV and cancer cure. Kymriah was the first gene therapy approved by the U.S. Food and Drug Administration for the treatment of acute lymphoblastic leukemia (ALL). CAR T cell trials are being explored as a strategy towards an HIV cure. The University of Pennsylvania is currently studying CAR T cells in combination with zinc finger nucleases (ZFN)—a type of gene therapy [clinicaltrials.gov/ct2/show/NCT03617198]. Study results will be made available in 2025.

Boro Dropulic [caringcross.org/board-of-directors], executive director and founder of Caring Cross, presented his organization's mission for making cell and gene therapies globally available. Caring Cross' vision is to use place-of-care manufacturing to significantly reduce the cost of cell and gene therapies globally. The ultimate goal

would be to develop safe and effective in vivo products (administered directly inside the body) that could help improve access to cure-related interventions globally. More information about Caring Cross is at caringcross.org.

Izukanji Sikazwe [cidrz.org/dr-izukanji-zuzu-sikazwe] from the Centre for Infectious Disease Research in Zambia (CIDRZ) gave an overview of the new HIV Cure Africa Acceleration Partnership (HCAAP).



HCAAP is a public-private partnership aimed at catalyzing HIV cure research and implementation by coordinating a forum of different stakeholders—including community, regulators, pharmaceutical companies, philanthropy, and academic institutions, among others. HCAAP has developed a target product profile [[thelancet.com/pdfs/journals/lanhiv/PIIS2352-3018\(20\)30232-0.pdf](https://thelancet.com/pdfs/journals/lanhiv/PIIS2352-3018(20)30232-0.pdf)] for a globally scalable HIV cure. This provides a vision for how a cure could be made available to all those who need it globally.

Francis Collins, MD, PhD, director of the U.S. National Institutes of Health [nih.gov/about-nih/who-we-are/nih-director/biographical-sketch-francis-s-collins-md-phd] announced that 10 Martin Delaney Collaboratories for HIV Cure Research would be funded in the next round of the program, including one collaborative focused entirely on pediatric research. Funding for the MDC program is expected to increase by 80% in 2021–2026. Increased investments will aid in the search for an HIV cure. They also can contribute to increased knowledge about HIV pathogenesis and control, as well as benefit public health globally.



FOR MORE INFORMATION the IAS 2021 HIV Cure and Gene Therapy Forum, go to iasociety.org/HIV-Programmes/Programmes/Towards-an-HIV-Cure/Events/2021-HIV-Cure-Gene-Therapy-Forum.



POZ ADVOCATE
SCOTT SCHOETTES
@PozAdvocate

Decriminalization of sex work is good public health policy

Sex work needs to be decriminalized in the United States. My desire to see this come to pass is not (completely) self-interested. It is a matter of human rights and personal autonomy, and a natural extension of *Lawrence v. Texas*, the landmark 2003 Supreme Court case that established the constitutional right to engage in same-sex sexual activity. Just as importantly, however, decriminalization of sex work is an HIV prevention and public health strategy.

First, criminalization drives sex work underground and impedes public health efforts to reach sex workers and their clients with HIV prevention, treatment, care, and support programs.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) has documented that, in large part due to the criminalization of sex work, sex workers frequently have insufficient access to adequate health services, male and female condoms, water-based lubricants, post-exposure prophylaxis (PEP) following condomless sex or rape, management of STIs, drug treatment and other harm reduction services, protection from violence and abusive work conditions, and social and legal support.

Due in part to the illegal nature of the work, sex workers often face discrimination and rejection in accessing healthcare, with damaging health results. Occupational stigma of criminalized work increases vulnerability to stress and diseases, compounding health care needs while simultaneously acting as a barrier to healthcare services essential to prevention. When sex workers do seek out healthcare services, they often are regarded in ways that reinforce criminal stigma, which can deter sex workers from seeking care at all and from disclosing their occupation for fear of discrimination by their healthcare provider and disclosure of their identity and activities to law enforcement. For sex workers living with HIV, these concerns are compounded.

Second, the use of condoms as evidence undermines prevention of HIV and other

sexually transmitted infections, as well as other public health goals. Though a few jurisdictions have reformed their practices in recent years, many

‘...the criminalization of sex work means the violence that occurs in the context of sex work has been largely unmonitored, resulting in few to no legal protections afforded to sex workers by police and judicial systems.’

jurisdictions still view the mere possession of condoms as evidence of the intent to engage in prostitution or other prostitution-related crimes. Arresting and prosecuting people who carry condoms reduces use of an extremely effective and affordable prevention tool, particularly for people engaged in (or profiled as likely to engage in) “street level” sex work. And using condoms as evidence makes managing sexual health more difficult because

it forces individuals to weigh the risk of prosecution for a prostitution-related crime against the risk of transmitting or acquiring HIV and other STIs.

Third, criminalization increases violence against sex workers. Where sex work is criminalized, there are alarmingly high rates of physical and sexual violence against sex workers by clients, individuals posing as clients, police, exploitative “pimps,” and others. Abuse is fueled when perpetrators recognize the barriers criminalized sex workers face in seeking justice, perpetuating physical and sexual violence with impunity. Furthermore, abusive intimate partners can exploit the illegality of sex work and may threaten to expose their partners to police as tactics of control.

To avoid police detection, criminalized sex workers often displace themselves to isolated (and more dangerous) settings,

effectively forcing them to trade away their safety and well-being. When criminalization prompts sex workers and their customers to move their encounters off main streets and into less trafficked areas, they are exposed to greater risk of violence, more pressure to engage in unprotected sex, and other hazards.

Violence against sex workers is often not registered as an offense by the police and in some cases is perpetrated by police. Sex workers report severe sexual violence, including forced unprotected sex by police officers, both at the time of arrest for prostitution-related crimes and while in custody on those criminal charges. And the criminalization of sex work means the violence that occurs in the context of sex work has been largely unmonitored, resulting in few to no legal protections afforded to sex workers by police and judicial systems.

In countries where sex work has been decriminalized, access to care improves, STI rates decrease, and safer sex practices increase. Though the UN has identified sex workers as a “key population” in the global fight against HIV for many years, the current National HIV/AIDS Strategy fails to include them among the “priority populations” in the United States. Here’s hoping sex workers are identified as a priority population in the next iteration of the NHAS and that the barriers to prevention, care, and treatment identified above are addressed while progress is made toward full decriminalization.

.....
This column has been adapted from a legal brief co-authored by Schoettes, Kara N. Ingelhart, and Richard Saenz in *Erotic Service Provider Legal, Education & Research Project v. Gascon*, available at lambdalegal.org/sites/default/files/10.7.16_esplerp_v_gascon_amicus_brief_filed_by_lambda_legal_et_al.pdf.

SCOTT SCHOETTES is an attorney and advocate who lives openly with HIV. He engages in impact litigation, public policy work, and education to protect, enhance, and advance the rights of everyone living with HIV.



BEING BRIDGETTE
BRIDGETTE PICOU

When it clicks

One of the most powerful things a patient said to me was, “Just because I hear you doesn’t mean I understand what you’re saying.” His regimen was changing because he had developed some drug resistance, and I was doing the nurse education part of the visit right before discharge when we reiterate what the doctor said and ask if there are questions. After having discharged patients a hundred gazillion times, I could tell by the look on his face that something wasn’t clicking. His response also resonated with me because I could remember leaving appointments with doctors early on in my diagnosis, and scouring the internet to make sense of some of the things I was told. I didn’t have a nurse to follow up and explain what I missed, or to get my doctor back in for five more minutes to help it click.

It took a while before I was comfortable enough to ask clarifying questions of my provider. For me, I was still trying to absorb all the changes and information coming at me hard and fast. I wasn’t crazy about my first provider because I could tell he wasn’t crazy about me, so those conversations were *waaaay* more brief than they should have been. I can say the more I learned, the looser the knot of uncertainty in my stomach was.

People of all types, backgrounds, education level, maturity, and socio-economic history get HIV. People like me, or you. It’s crucial we get comfortable with being uncomfortable, in order to ensure we begin to thrive as early on in our new life process as we can. I purposely choose the phrasing of “new life process” as opposed to “disease process” because your life is yours, it doesn’t belong to HIV. There are parts and pieces about HIV that can be overwhelming, especially for the newly diagnosed. I have cared for patients who don’t care to learn anything but the basics because it’s easier to not give it a lot of energy—they take their meds, do their labs, and go about their business. They have a trusting patient/provider relationship with their clinician, and trust them to have the knowledge piece down. Others learn all the ins and outs and nuances because they feel safer and better informed. Neither is a wrong approach. Like I said, it’s your life, not HIV’s.

My wish is that no matter what your approach is—how much or how little you choose to learn about the life cycle of the virus, medication innovation, treatment options, or advocacy—remember you matter. Remember your questions have weight and relevance. Ask them. Repeatedly until you understand. Discuss your fears. You aren’t alone. Reach out for help if you need it. It’s not a weakness. On the contrary, it’s wise. HIV has the potential to upset the balance of everything in your life—your health, your relationships, your mental well-being. Because HIV affects so many lives, the likelihood that someone has been where you are and understands how you feel is greater than not. The help is there if you want it. You most certainly deserve it.



Another powerful thing I learned from patients is that sometimes people “nurse the nurse” without even knowing they are doing it. Something they say, do, or make me feel, makes a “click.” Your questions, fears, epiphanies, and triumphs could be someone else’s click. Remember that.

Be well.

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

‘...no matter what your approach is—how much or how little you choose to learn about the life cycle of the virus, medication innovation, treatment options, or advocacy—remember you matter. Remember your questions have weight and relevance. Ask them. Repeatedly until you understand.’

‘Meeting the needs of people aging with HIV’

A new report issues policy recommendations to improve the health of older people living with HIV



O’NEILL INSTITUTE’S JEFF CROWLEY (LEFT) AND SEAN E. BLAND PRESENT THEIR REPORT.

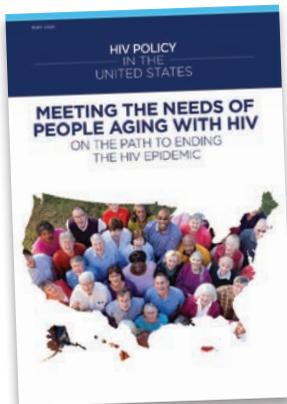
In July, NMAC held a webinar to discuss the findings of a recent report by the O’Neill Institute, “Meeting the Needs of People Aging with HIV on the Path to Ending the HIV Epidemic (May 2021).”

The report, prepared by Sean E. Bland and Jeff Crowley of the HIV Policy Project of the O’Neill Institute for National and Global Health Law, puts forward five key policy recommendations that would improve the lives of older people living with HIV, lists existing resources that can be leveraged, and provides examples of successful models of care including Positively Aging, the collaboration among TPAN, The Reunion Project, POSITIVELY AWARE, and National Working Positive Coalition.

At the start of the webinar, Crowley said, “A couple years ago, I started doing a little work in this area, and then Sean and I convened a meeting, and we produced this follow-up report. I want to say when I first got started, I was struck, and when we had our convening some of the national policy advocates were also struck, and it’s really troubling, just the level of despair experienced by so many people who are aging with HIV, people 50 and older, the feeling that in some ways, our movement’s forgotten them, or just feeling neglected in some ways...I think we all need to acknowledge that and do better.

“The other observation I’d make is that some of the challenges we face are so big, it can be immobilizing. In all the work we do, but in this report as well, we say this is a huge topic, but here’s a manageable number of recommendations... The other point I would leave you with, is with the existing programs and services and resources we have today, we can do better to deal with the needs of people aging with HIV.”

During his webinar presentation Sean Bland pointed out that one particular challenge faced by older people living with HIV is being able to access aging programs. “Some programs have age cutoffs, and that can sometimes be a problem for folks,” so ensuring that individuals “are not only aware of the program, but that we have advocacy to make sure that these programs are accessible to people aged 50 and older, and maybe even younger than that, to make sure that we’re really meeting the complexity of their needs.” Bland continued, “we also need this commitment to health equity and intersectional policy approaches, so when



thinking about equity issues, we need to be responsive to the experiences of people of color to women to trans folks who are immigrants, folks who lack access to housing or face other economic or social challenges.”

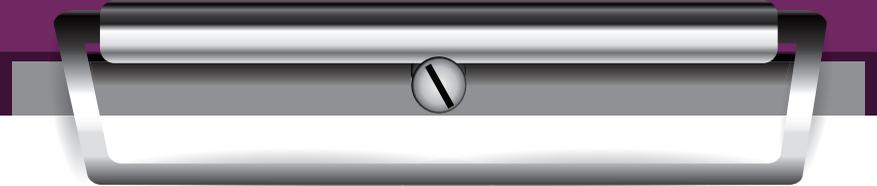
According to the report, “More than half of people living with HIV in the United States are aged 50 or older, and a growing number of people are living and aging with HIV into their 70s and beyond. Concerted action is needed to meet the needs of older people living with HIV. The burdens of HIV, aging, and related health comorbidities, combined with the social and structural challenges that people aging with HIV face, necessitate not only a focus on HIV-related outcomes, but also a comprehensive response aimed at treating comorbidities and improving long-term health and quality of life.”

The following policy actions are recommended by the report:

- 1. Develop models of care and prevention** for people aging with HIV and train and equip the clinical and non-clinical workforce
- 2. Expand opportunities** for older people living with HIV to make social connections through community-based programs that address isolation, stigma, and trauma
- 3. Maintain Medicare Part D** drug access protections (e.g., Six Protected Classes) and expand focus on high-quality care and quality of life
- 4. Allocate more funding** to programs that support financial security and access to employment, housing, food, and public benefits for the aging HIV population
- 5. Promote the meaningful participation** of older people living with HIV in the Ending the HIV Epidemic (EHE) Initiative and in broader advocacy efforts.

READ THE FULL REPORT: oneill.law.georgetown.edu/projects/ryan-white-policy-project

WATCH THE WEBINAR: bit.ly/aging-webinar-2021-07-08



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

Have I lost weight?

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

Do I have less energy?

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



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

Care you can trust.

“Over the years I’ve learned a lot about myself and grown more comfortable in my skin. But there are still many days where I feel like I don’t belong. Sometimes it’s hard to be kind to yourself, and I’m constantly working to be better at that. For those who trust us in their vulnerable moments, it is an honor and privilege to serve you.”

Andy Doan
PharmD, AAHIVP
Pharmacist-in-Charge,
Avita 1036 (Austin, TX)



Avita is a national pharmacy services organization with deep expertise in HIV, PrEP, and LGBTQ+ care. We want you to feel deeply understood, cared for, and empowered to reach your full potential for health. [Visit *avitapharmacy.com* to learn more.](https://www.avitapharmacy.com)