POSITIVELY AWARE

HIV TREATMENT, PREVENTION AND HEALTH FROM **TPAN**
JAN+FEB 2022

‘IS HIV STILL A THING?’

CELEBRATING THE PICTURES OF A DAY WITH HIV

25 YEARS OF HAART

HERSHEY KRIPPENDORF
The Philadelphia Center,
Shreveport, Louisiana

STILL TESTING, STILL TALKING

How the pandemic and telehealth have changed HIV treatment and prevention

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LIVE LIFE **POSITIVELY AWARE.**

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

A SPECIAL MESSAGE

Then along came Fred

In 2010, Rob Garofalo, MD, a board member of TPAN, the Chicago-based organization that publishes POSITIVELY AWARE, was mugged and assaulted while walking down the street. Later that year, he was diagnosed with HIV.

"I spend my career helping hundreds of adolescents living with HIV to manage and navigate HIV-related stigma. How easily the advice always seemed when giving it to others. But when the proverbial shoe was on the other foot, I struggled. I felt alone. I didn't eat. I had trouble sleeping. I held my life together as best as I could, but make no mistake about it: My HIV diagnosis and the time that followed was the lowest point in my life."

Until along came Fred, a Yorkie who changed Rob's life at a time when he needed it most.

"Fred was instrumental in saving my life, and probably in making me a better doctor and person. This bundle of pure goodness filled with nothing but unconditional love brought peace and joy back to my life at a time I feared it was gone forever."

In 2011, Rob started Fred Says, a grassroots charity devoted to improving the lives of teenagers living with and affected by HIV.

"With the light he brought into my life, I rediscovered the passion I have to help those affected by HIV/AIDS and work to fight the stigma that too often accompanies an HIV diagnosis. No one, especially no teenager, should have to deal with HIV alone. Armed with Fred, the world's best wingman, I had the strength to continue the fight to make sure that all teens living with HIV can find the hope that I did."

Sadly, Fred passed away last year. On the day of Fred's death, an "Angel Donor" made a significant contribution to Fred Says with the message, "You and Fred have only just begun to change the world."

And that they have. Rob and Fred Says have generously committed $50,000 to TPAN this year.

To best honor Fred and Rob, we are asking you to contribute to TPAN and POSITIVELY AWARE. Your donation will not only help continue Fred's legacy, but it will also help get our publication directly into the hands of those who need it the most.

We thank you for your support of POSITIVELY AWARE and for helping us end HIV once and for all.

With so much gratitude,

Kara Eastman
CEO, TPAN

SUPPORT POSITIVELY AWARE in its mission. Scan this QR code to donate, or go to bit.ly/give-to-pa.

Text ISUPPORTPA to 44-321.

JAN+FEB 2022

POSITIVELY AWARE · VOLUME 32 NUMBER 1 · positivelyaware.com · @posaware

EVERY ISSUE

THIS ISSUE

ON THE COVER
HERSHEY KRIPPENDORF PHOTOGRAPHED BY EVAN STEVENS. READ ABOUT HER ON PAGE 21.

> *'Something that we regularly explore with folks is their relationship with sex and their own sexuality. What does someone's sex, sexuality, and identity mean to them.'*
>
> —Joshua Gutierrez, **PAGE 18**

THE CATEGORY IS...

VIRTUAL REALNESS

Have you used telehealth? What has been your experience? If you've not utilized telehealth services, why not?

That was what we asked our followers on Facebook, Instagram, and Twitter. They shared their experiences

“**Telehealth has** saved me a tremendous amount of money and time, not having to travel to my specialists. I go to Johns Hopkins for specialty HIV care. Where I live in Pennsylvania, there are zero HCPs here who are aware of the importance of my health history.”

—@KARIMMARQUETTE

“**It was** a nightmare. Good thing I followed my instincts and went to the ER for a face-to-face consult for my daughter. He said 24-48 hours more and she would have had a dull abscess leading to all sorts of complications.”

—XIO MORA-LOPEZ

“**Telehealth in** Texas is still lacking, and still heavily restricted depending upon what type of treatment you're receiving. Definitely would say, if you have anxiety or any sort of substance dependence issue, Texas is not friendly enough to you...nor are they for cancer and HIV/AIDS.”

—@JAREDVONBAREN

“**I've absolutely** loved it. I find it a lot more convenient and sort of insist on it now unless I or my doctor feels that an in-person visit is prudent.

—JEFFERY PARKS

“**Dr. Nwabara** and the entire team at Edgewater Health in both Griffith and Gary [Indiana] have been amazing. When COVID-19 happened, I didn't know how medical help would be able to be effective and sustain every need that a patient would have. I was blessed to find such a place and capable doctors.”

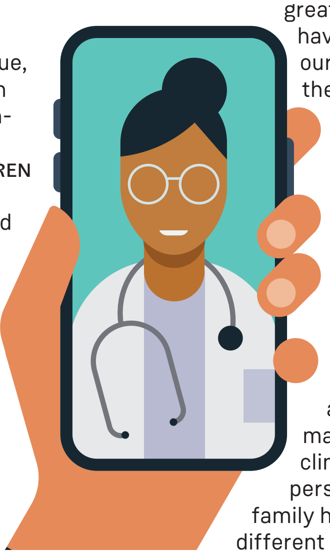
—JOSHUA BENTON STOVALL

“**I prefer** face to face. Even then, the provider sits behind a computer. During telehealth, you're looking eye to eye, assuming the technology works. But medicine requires physical proximity; looking at skin, nails, feet, etc. Routine ‘lab’ reviews are fine with telecommunicating, but otherwise it's a no for me.”

—JOHN DEGREGORY

“**Three people** in our family are living with HIV, and we have visits every 3 months. The first couple of times we thought this is great! We don't have to leave our home and the appointment was fast! But we still had to leave our house to have our labs drawn, therefore there was a trip to make to our clinic. Each person in our family has very different needs. It can be hard to address all those needs via telehealth. We also missed seeing the faces of our clinic staff in person. Sometimes it's hard to open up over the computer. Telehealth has its place but it's no replacement for the connection that you get by seeing your providers face to face and heart to heart.”

—JESS WIEDERHOLT



“**It's difficult** to navigate, even to get to medical results.”

—HAROLD BROWN

“**I've had** great experience with virtual appointments. Especially on days when I was not feeling well. I've been able to prevent cancelling or rescheduling appointments because of the convenience. Being a long-term survivor of HIV for 37 years with multiple comorbidities, these appointments have been a godsend! Too bad it took COVID-19 to get doctors to cooperate with insurance companies to provide this service that insurance companies were already willing to provide. I'm assuming the pay doctors received was less so that's most likely why they didn't provide it. I think it's essential to maintaining our health. Most of the time I don't think an in-person appointment is needed. Hopefully Medicare and insurance companies will bring the payments more in line with in-person visits to keep this service available even after the pandemic.”

—LONNIE SHELTON

“**I have** found it a relief and surprisingly just perfect for me at times when going outside to the doc would cause a level of anxiety.

—CHHAYA SUSANNA FEDER

JOIN IN THE CONVERSATION

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ISTOCK

EDITOR'S NOTE

JEFF BERRY
@PAeditor

Riding the wave

"You must live in the present, launch yourself on every wave, find your eternity in each moment."
—HENRY DAVID THOREAU

"The breaking of a wave cannot explain the whole sea."
—VLADIMIR NABOKOV

As I write this, we are on the verge of yet another wave of COVID-19, this one the omicron variant, which is much more transmissible than earlier versions of the virus, up to five times more according to one study. A recent report suggests that omicron multiplies 70 times faster in the airways (or bronchial tubes), probably one of the reasons why it's more transmissible. A study out of Johns Hopkins reported on in early December by *aidsmap* found that while COVID-19 is uncommon for those who are fully vaccinated, whether living with HIV or not, "fully vaccinated people with HIV are about 40% more likely to experience breakthrough cases than HIV-negative people, regardless of CD4 counts or viral suppression."

The jury is still out on whether omicron results in milder infections overall, but the sheer number of increased cases likely means the absolute number of hospitalizations and deaths will go up, regardless. And we need to be careful not to categorize it as a milder virus. "We know that people infected with omicron can have the full spectrum of disease, from asymptomatic infection to mild disease, all the way to severe disease to death," says Maria Van Kerkhove, the World Health Organization's (WHO's) COVID-19 technical lead, as reported by CNBC.

A wave of exhaustion is sweeping over many of us, with some carrying on their holiday travel plans and parties as usual, tiring of nearly two years of mandates and restrictions, while others are cancelling their plans, and accepting uncertainty as the new normal. But no one is as exhausted as the health care workers who have been battling this nonstop for the last 20 months, with no clear end in sight. We salute all of the doctors, nurses, and health care staff who continue to care for the sick and the dying, even though many hospitals are short-staffed, workers are demoralized and suffering from PTSD, and everyone is just plain overwhelmed and tired.

So how do we navigate or ride these waves, and keep from going completely under or even drowning? Here are some things that have helped me, so I'm sharing them here in the event they might help someone else.

Difficulty sleeping or staying asleep. Sometimes I wake up in the middle of the night and my mind starts racing and I can't get back to sleep. A few years ago I discovered the box breathing—or square breathing—technique, and it really works. Basically, you breathe in, hold your breath, breathe out, and hold your breath again, all for the same amount of time (for example you can slowly count to four each time). Then repeat, repeat, repeat. I'm usually asleep before I know it, because I'm focusing on the technique so the thoughts just fall away. It's even used by the Navy SEALs in stressful situations as a way to stay calm.

Limiting consumption of news and social media. This one is tough for me because it's part of my job to stay up to speed on what's going on, and to use social media to promote our work. But it's about finding the right balance. There are free apps and features on your smartphone that can help you limit your screen time and increase productivity and focus.

Getting out in nature. Even if it's just a walk around the neighborhood or the yard, the exercise alone will do you good. It doesn't hurt to get away from your screen and technology, and get in touch with the natural world around you. If your eyes are straining and dry, or your anxiety is going up, that's probably a sure sign you need a break. Finding quiet and solitude (no AirPods, please!) while walking through a forest preserve or public garden is free, and can be very healing.

Connecting with others. We've had to find different ways to connect these last two years, and nothing beats the face-to-face interaction with another human being. But if you can't see each other in person, using technology to stay in touch whether it's through phone/video calls, texts, Zoom or other virtual meeting platforms, finding connection is vital to breaking out of the isolation that can often lead to loneliness and despair if left unaddressed.

I'd love to hear from you about ways that you've found to help you keep centered and focused, and stay connected with others, while taking care of your mind, body, and soul. We'll get through this, one wave at a time, until the waves become ripples and have dissipated. Still and calm waters exist—we just have to search them out, be patient, and have faith that they lie ahead.

Until then, take care of yourself and each other.

How do we navigate or ride these waves, and keep from going completely under or even drowning?

Briefly

ENID VÁZQUEZ @ENIDVAZQUEZPA

Disappointing results lead to hold on HIV studies

A Phase 2 (early) study using the combination of two HIV drugs in development was stopped after decreases were observed in total lymphocytes and CD4+ T cell counts.

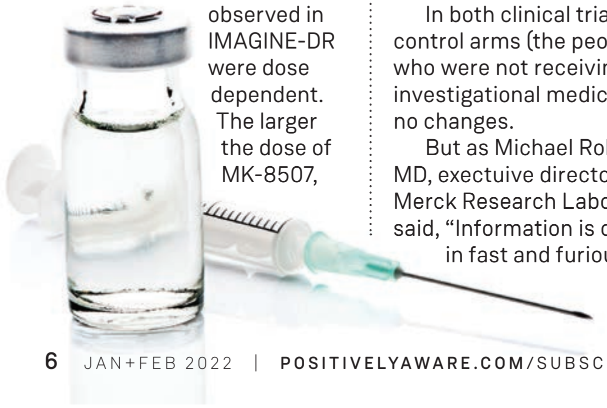
The two long-acting medications, islatravir along with a newer compound, MK-8507, were being studied in combination as a once-weekly complete oral regimen for HIV treatment.

Merck pharmaceutical made the announcement about its IMAGINE-DR (MK-8507-13) clinical trial in November. Merck will continue to monitor study participants. All were transitioned back to the original regimen they were on when they entered the study, Biktarvy. The participants had stable undetectable viral load when they entered the study and that did not change while they were in it.

In a conference call with community advocates, representatives of both the community and the company called the results disappointing. Merck spokespeople said the company is dedicated to continuing HIV treatment and prevention drug development safely, noting that new options are still needed.

The substantial decreases in immune system markers that were observed in IMAGINE-DR were dose dependent. The larger the dose of MK-8507, the greater the decrease.

The mean (average) decrease in total lymphocyte counts was 17% for the 100 mg dose of MK-8507, 26% for 200 mg, and 30% for 400 mg. For CD4+ T cell counts, the mean decrease was 11% for 100 mg, 23% for 200 mg, and 30% for 400 mg.



Looking at islatravir

As a result of the findings from IMAGINE-DR, Merck looked at all of its studies with islatravir, which are further along in development. Islatravir has oral and injectable formulations, and is being studied for both HIV prevention (PrEP) and HIV treatment.

At the time, Merck only found a total lymphocyte count decrease in one PrEP trial. The decreases were in the normal range and not considered clinically concerning. The mean decrease was 21% for the 60 mg dose of islatravir and 36% for the 120 mg dose. The people on a placebo saw an increase of 4%. All individuals, of course, were HIV-negative.

In both clinical trials, the control arms (the people who were not receiving the investigational medicine) saw no changes.

But as Michael Robertson, MD, exectuive director at Merck Research Laboratories, said, "Information is coming in fast and furious."

On hold

Then in December, the U.S. Food and Drug Administration (FDA) put clinical holds on islatravir trials. Six studies were put on a full hold and seven were placed on partial holds.

With a full hold, participants no longer received islatravir and were put on their previous HIV regimen (what they were taking when they entered the study), or they were put on an HIV regimen or a PrEP medication that is already FDA approved and on the market.

With a partial hold, people were allowed to continue taking islatravir, but enrollment of new participants was stopped.

Doravirine plus islatravir moves forward

All studies of islatravir in combination with doravirine moved forward under a partial hold. Doravirine is an FDA-approved HIV medication from Merck, sold under the brand name Pifeltro. Merck announced in October that a Phase 3 (advanced) study of the two medications, taken together combined in a once-daily fixed-dose pill, had maintained undetectable viral load out to 48 weeks in people who had switched from a stable HIV regimen. In the ILLUMINATE SWITCH A study people were switching from any HIV regimen, while in the ILLUMINATE SWITCH B study they were switching over from Biktarvy.

As of press time, information was still coming in fast and furious.

Another person cured?

Another case of someone who may have been cured of HIV through their own immune system has been reported in the November 15 *Annals of Internal Medicine*. **READ** more about the case from science writers Ben Ryan for NBC News at nbcnews.com/health/health-news/womans-immune-system-possibly-cured-hiv-rcna5610 and Tim Murphy for TheBody.com at thebody.com/article/the-esperanza-patient-immune-system-cured-hiv.

Helping recently incarcerated Black women living with HIV

In Chicago, a new program that helps recently incarcerated Black women living with HIV was announced by the AIDS Foundation of Chicago (AFC) during National Transgender Awareness Week, November 13–20. The Women Evolving Initiative offers critical reentry services, including economic opportunities, intensive case management, care coordination that includes behavioral health needs, and access to telehealth services.

"Studies show the imprisonment rate for Black women is more than 3.8 times the rate for White women and 2.4 times the rate of Hispanic women," reported AFC.

ISTOCK

“Roughly 1.8 million Black women are released annually from local jails with the goal of rebuilding a life post-incarceration. Black women face much higher rates of homelessness and unemployment, and are much less likely to have a high school education.” The program serves all women, whether cisgender or transgender.

For more information, call (312) 922-2322 or **GO TO** aidschicago.org.

HIV cases in children worldwide

On World AIDS Day (December 1), UNICEF reported that **at least 300,000 children were newly infected with HIV in 2020**, or one child every two minutes. Another 120,000 children died of AIDS-related causes, or one every five minutes. The organization noted that COVID has made things worse for women and children in regards to HIV. **READ** the UNICEF report at childrenandaids.org/2021-global-snapshot.

Ending the Epidemic, Equitable Access

An updated National HIV/AIDS Strategy (NHAS) for 2022-2025 was released on World AIDS Day. It’s “designed to re-energize a whole-of-society response to the HIV epidemic” and provides a framework for the **Biden Administration’s principles and priorities over the next four years**, including a new focus on people aging with HIV and long-term survivors. **GO TO** HIV.gov/topics/nhas.

In advance of World AIDS Day, White House Office of National AIDS Policy (ONAP) director Harold Phillips spoke about the day’s theme for 2021: “Ending the HIV Epidemic: Equitable Access, Everyone’s Voice.”

“[W]e need to pay attention to…the places in the country that we have health disparities, and where we have individuals and communities or geographic regions within our country that have a lot of HIV cases and HIV continues to increase in those areas as well. It means that we need to ensure that we leave no portions of our country and our populations behind.”

LEARN MORE about the NHAS at HIV.gov/topics/nhas, and **WATCH THE VIDEO** at bit.ly/HIV-strategy-2021-update.

Correction

In “Transforming Power” in the November + December 2021 issue, Lisa Spedalle, RN, works with the Visiting Nurse Service of New York (VNSNY), not the Visiting Nurses Society, which is a different group. POSITIVELY AWARE apologizes to Spedalle and VNSNY for the error.

New injectable PrEP given every two months: Apretude

The U.S. Food and Drug Administration (FDA) approved a new form of HIV PrEP (pre-exposure prophylaxis—a medication used for disease prevention) on December 20.

It’s not just new. Some may see it as improved—in some ways, at least.

Apretude is taken as one long-acting injectable dose every two months. It is the third medication on the market for the prevention of HIV. The first two, Truvada and Descovy, are both taken as one tablet once daily.

“Today’s approval adds an important tool in the effort to end the HIV epidemic by providing the first option to prevent HIV that does not involve taking a daily pill,” said Debra Birnkrant, M.D., director of the Division of Antivirals in the FDA’s Center for Drug Evaluation and Research, in a press release. “**This injection, given every two months, will be critical to addressing the HIV epidemic in the U.S.**, including helping high-risk individuals and certain groups where adherence to daily medication has been a major challenge or not a realistic option.”

The FDA went on to explain that according to the Centers for Disease Control and Prevention (CDC), “notable gains” in increasing PrEP use in the country have been made. Yet early data from 2020 show that only a quarter of the 1.2 million people for whom PrEP is recommended were prescribed it. Still, that compares with just 3% of the people for whom PrEP is recommended according to data back in 2015.

Noting that high levels of drug adherence are required for HIV PrEP use, the FDA said the new injectable could help increase prevention with PrEP, especially for some groups and for people who may be less likely to take daily medication correctly (be adherent).

Side effects occurring more often in people taking Apretude compared to Truvada in two clinical trials included injection site reactions, headache, pyrexia (fever), fatigue, back pain, myalgia (muscle aches and pain), and rash.

Apretude consists of the HIV medication cabotegravir (CAB). Cabotegravir is already on the market in the form of Cabenuva, which is made up of one shot of CAB and one shot of another long-acting medication, rilpivirine, taken once a month for HIV treatment.

For more information, see the upcoming POSITIVELY AWARE annual HIV Drug Guide.

Welcome to the battle, Apretude.

APRETUDE: VIIV HEALTHCARE

Updated PrEP guidelines

The U.S. Centers for Disease Control and Prevention (CDC) issued the following statement as it presented updates to its HIV PrEP (pre-exposure prophylaxis—prevention) guidelines on December 8.

This statement is from Demetre C. Daskalakis, MD, MPH, Director of the Division of HIV Prevention in the National Center for HIV, Viral Hepatitis, STD, and TB Prevention.

Dr. Daskalakis says here, "PrEP is one of the most powerful tools we have to prevent HIV transmission. Expanding access to PrEP will be critical to ending the HIV epidemic in the United States."

Statement from Dr. Daskalakis on updated CDC PrEP guidelines:

Today, the Centers for Disease Control and Prevention (CDC) published its updated *Clinical Practice Guideline for Pre-exposure Prophylaxis for HIV Prevention* and *Clinical Providers Supplement*. The updated guideline and supplement reflect the latest science and are intended to help physicians effectively prescribe all FDA-approved pre-exposure prophylaxis (PrEP) medications to patients and increase PrEP use among all people who could benefit.

The overall goals of the revisions are to update existing guidance using the current evidence base, incorporate recent and potential FDA actions on PrEP medications, clarify specific aspects of clinical care, and improve usability and increase implementation of the guideline.

Key revisions to the guideline include:

- A new recommendation for providers to inform all sexually active adults and adolescents about PrEP. This is intended to increase awareness of PrEP more broadly.
- A recommendation that, in addition to taking a very brief history to identify persons with indications for PrEP, providers prescribe PrEP to anyone who requests it, even if they do not report specific HIV risk behaviors. This recommendation is intended to make PrEP available to people who may be apprehensive about sharing potentially stigmatized HIV risk behaviors with their provider.
- A recommendation for F/TAF (Descovy) as an FDA-approved PrEP option for sexually active men and transgender women at risk of getting HIV, based on recent data showing its effectiveness for these populations.
- A new section on prescribing bimonthly intramuscular injections of cabotegravir (CAB) for sexually active men and women who could benefit from PrEP, pending FDA data review and potential regulatory action.
- Updated HIV testing recommendations that incorporate the latest and most effective methods for quickly detecting HIV infection among people using any PrEP medication.
- ❏ Specifically, it includes a recommendation that providers now require the following for people who have taken oral PrEP in the last three months or who have received a CAB injection in the last 12 months:
  - a positive antigen/antibody test and a detectable HIV-1 RNA test to confirm an HIV infection before transitioning the patient to an HIV treatment regimen; or
  - a negative antigen/antibody test and an undetectable HIV-1 RNA test before confirming the absence of an HIV infection to continue prescribing PrEP.

Please note there are ***no changes*** to the guideline regarding populations for whom PrEP is recommended nor to the section of the guideline pertaining to recommended daily dosing regimens for oral PrEP. There are also no changes to the sections of the guideline regarding frequency of HIV and sexually transmitted infection (STI) testing for daily oral PrEP.

PrEP is one of the most powerful tools we have to prevent HIV transmission. Expanding access to PrEP will be critical to ending the HIV epidemic in the United States. CDC is committed to increasing the use of PrEP by funding high-impact HIV prevention programs for health departments and non-clinical and clinical community-based organizations around the country, including through the federal Ending the HIV Epidemic (EHE) in the U.S. initiative.

CDC programs are designed to increase PrEP awareness and demand by funding: local organizations to conduct community-based outreach to people who could benefit most including gay and bisexual men of color, people in the South, Black women, transgender women, and persons who inject drugs; education campaigns that increase awareness and combat stigma associated with PrEP use; and tools such as CDC's PrEP Locator, which has information on public and private providers who offer PrEP.

CDC also aims to increase accessibility of PrEP through healthcare provider training, provider education campaigns, clinical guideline development, and by working with partners to offer PrEP and related services through primary care clinics, sexually transmitted disease (STD) clinics, TelePrEP services, pharmacies, and school-based health centers.

We have a once-in-a-generation opportunity to end the HIV epidemic in the United States, but to do so, we must maximize the use of effective prevention tools, such as PrEP. As the nation's leading HIV prevention agency, CDC is committed to working with providers, partners, and communities across the country to increase the implementation of this updated guideline and increase the uptake of PrEP to reach our shared goal of reducing new HIV infections by 90% by 2030.

GO TO bit.ly/cdc-prep-guidelines-2021.

U=U website revamped

Prevention Access Campaign (PAC) has redesigned and expanded its website, making it into **a clearinghouse for information and resources about U=U**. Launched five years ago by PAC, U=U (undetectable equals untransmittable) is the message that a person living with HIV who is on antiretroviral treatment and has an undetectable viral cannot transmit the virus to someone through sex.

Among the website's offerings:

- an interactive map to find U=U community partner organizations all over the world
- endorsements from a number of health organizations describing and explaining the significance of U=U, including UNAIDS, the World Health Organization, the Centers for Disease Control and Prevention, and the National Institutes of Health
- a link to *Can't Pass It On*, a training course from the UK's Terrence Higgins Trust to help health care professionals understand and discuss U=U with colleagues and patients
- an abstract article with companion video about how U=U improves the health and quality of life people living with HIV

Additional resources in other languages will be added, based on browser feedback.
GO TO preventionaccess.org.


DR. GAROFALO WITH PLUSH VERSIONS OF FRED

PHOTO COURTESY OF FRED SAYS

Fred Says donates over $200,000 to help young people around the world

On World AIDS Day 2021, the Chicago-based foundation **Fred Says announced over $200,000 in donations to help young people** around the world who are living with HIV or affected by it.

The awards were made in honor of Fred, the Yorkie who inspired the creation of the foundation. Fred passed away in August of last year, with his dad, Robert Garofalo, MD, at his side.

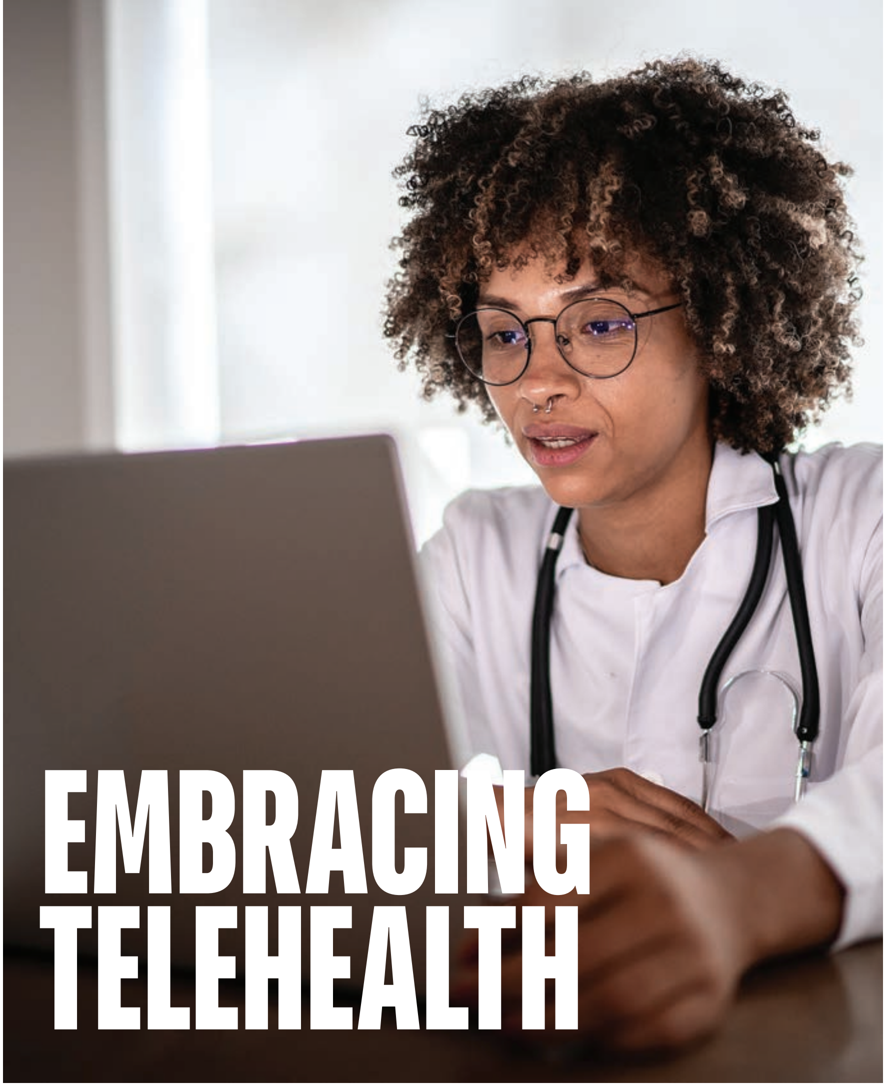
Fred Says awardees include TPAN, the non-profit HIV service organization that publishes POSITIVELY AWARE; the Broadway Youth Center of Howard Brown Health; and the Ann & Robert H. Lurie Children's Hospital of Chicago, where Dr. Garofalo is a pediatrician working with transgender youth. All three awardees are located in Chicago. Dr. Garofalo, who is a faculty member at Northwestern University's Feinberg School of Medicine, helped found the community-based Broadway Youth Center in 2003 and has served on the TPAN board of directors since 2016.

"Fred may no longer be by my side, but he is forever a part of me. I am grateful for all that he has given, not just to me but to the world," said Dr. Garofalo in a press release. "To that end, I have only just begun to fulfill the promise we made in 2013 to together make the world a better place for young people living with HIV. This year's $200,000 [multi-year commitment to TPAN] in giving is by far the largest in Fred Says' history and is the first of many that will honor my little man and help young people around the world who need just a little help to not just survive, but to thrive. Being able to support the work being done by TPAN, and our other awardees, with young people in the U.S. and abroad is a blessing and a gift in and of itself."

TPAN serves young people from throughout the city in addition to adults. The award will specifically benefit the Tea Room, TPAN's youth services and drop-in center, and Paws n' Effect, the agency's program linking people living with HIV with rescue pets.

Other donation recipients are the Callen-Lorde Health Center in New York, the Los Angeles Children's Hospital Adolescent HIV Program, Birmingham AIDS Outreach in Alabama, Children's Hospital of Philadelphia's Adolescent Initiative, Advocates for Youth, the University of Ibadan in Nigeria, and the Desmond Tutu HIV Foundation Youth Center in South Africa.

Fred's story has appeared in the pages of POSITIVELY AWARE several times, and he appeared with Dr. Garofalo on last year's cover of the January+February issue. His death was devastating, but his legacy lives on.



EMBRACING TELEHEALTH

A new hybrid model of healthcare emerges, combining technology with old fashioned in-person visits

BY **ENID VÁZQUEZ**

The year 2021 saw the United States emerge—carefully—from the COVID-19 shutdown of 2020. But the world has been forever changed. Healthcare has seen more patients interact with their doctors via the internet or phone instead of face-to-face visits. Many drop-in clinics for HIV testing—created for greater convenience—had been closed down. Appointments became the norm again to help space out the people coming in. Or home tests were mailed out. For HIV care, people could even prick themselves at home to obtain a blood sample and send that to their clinic. Telehealth and telemedicine—combining electronic information with telecommunication technologies to support remote healthcare—is here to stay and continues to evolve. “I do not feel that we’re going back to the way things were,” said June Gipson, PhD, president and CEO of My Brother’s Keeper, a non-profit HIV service organization in Jackson, Mississippi that also runs a medical clinic. “I *hope* we don’t go backwards.”

The virtual heartbeat

David Goodman-Meza, MD, an infectious disease specialist at the University of California-Los Angeles (UCLA) David Geffen School of Medicine, and colleagues and community advocates in September celebrated the launch of a new mobile unit that brings clinical care to people who inject drugs (PWIDs) in Long Beach. (See sidebar, *Needed Now More Than Ever.*) Ironically, the van was planned long before COVID-19 even hit. Providence.

While UCLA’s newest mobile clinic was just a few months old as this issue went to press, Dr. Goodman-Meza had by then a lot of experience with changing technology under COVID-19 and beyond.

“We all use electronic medical records where we capture our data, including every doctor visit,” says Dr. Goodman-Meza. “Other than that, there was very little use of technology other than the phone. COVID spurred the need for us as providers to adopt telemedicine for the protection of our patients, our staff, and ourselves. So we rapidly piloted it and now this is the norm. It’s going to become more common to see your provider over telemedicine compared to in-person visits.”

Dr. Goodman-Meza also sees a larger future for at-home monitoring tests. “A lot of the things that we ask people to come to the clinic for can really be done at home. Glucose monitoring is already done at home. Blood pressure monitoring can be done at home and maybe even better than if you come to the clinic. I’m part of a weight loss program where they sent me a scale that automatically transmitted my weight to the program. I know cardiologists use these remote systems as well.”

The flip side is providers becoming more comfortable using telemedicine services. “I think a lot about seeing somebody in person [is] to establish a relationship. I think of somebody who may be living far away in a rural area with no provider in a 50-mile radius. It’s burdensome for somebody to drive an hour or more to go see a doctor. That readiness to have a virtual visit over videoconferencing and connect to a provider creates convenience. The physical exam is the most limited piece, but for most interactions, you could probably go without one, especially with routine check-ups,” he says. “Of course, if someone has physical complaints, a physical exam is warranted and helpful. You need to palpate the stomach to measure pain, for example. But even then, there are going to be all these ways of doing a physical exam virtually in the near future. There’s probably already the development of a virtual stethoscope that patients place on their chest and the provider can hear wherever they are.”

Then there’s the decentralization of medical care. Providers are seen over the internet, labs are picked up somewhere outside the provider’s office, and vaccinations are done at the pharmacy. “So we’re getting services away from the

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doctor's office and much closer to where people are actually at," he says.

But electronic health records need to be further developed and then maintained.

"That's been the ever-present problem with electronic medical records, updating software. They're getting better. We're now employing some systems where we can share our records more seamlessly, but we still have a world of improvement to go."

Then too, the public needs to get more comfortable with telemedicine as well.

"As we rely more on technology, we make it more convenient for some but technology will create barriers for others," he says. "I'm totally for relying more on technology and using its benefits, but we also have to have the old school options always available to people."

Pandemic-ready

My Brother's Keeper operates the Open Arms Healthcare Center in Jackson, Mississippi, which focuses on the local LGBTQ community. Like many—maybe most—clinics, Open Arms uses electronic health records (EHR). But theirs had an important difference.

"Most electronic health record systems didn't have telehealth attached. We were just fortunate enough to have a system that has a built-in telehealth component. We've been doing telehealth since 2015. So you can essentially say that we were ready for a pandemic and didn't know it," says June Gipson. "We literally just flipped a switch. Everyone on staff was trained to do it and patients were familiar with it. So it wasn't a headache for us."

Electronic records help the clinic keep track of what patients need. "Data tells us everything. We don't move without data," Gipson says. "The electronic health record system is telling us what's happening with the patient. It's telling us what's happening in the community."

Got labs?

Open Arms also had a van travel out statewide, providing a program called Becoming A Healthier You. Blood draws were taken to measure glucose and cholesterol, and test for HIV, syphilis, gonorrhea, and chlamydia, as well as hepatitis B and C. Blood pressure was taken and body mass index measured. Many people used the program as their only health care access, and many transitioned into clinical care through it.

Then came COVID.

"When we started, I didn't have any idea of sending labs to your home. I was thinking that we would do telehealth visits, but you would still go to the clinic and have us draw your blood. And we did that. Then we found another way of doing it and that's another part of technology," Gipson says.

During the shutdown that began in spring 2020, lab kits were mailed to people's homes, where they took their own blood sample with a finger prick and mailed it back. "That's going to be a way that healthcare is going to be done with telehealth," she says. "It's going to make life a bit more convenient, and we can modify that kit to include screenings specifically for people living with HIV."

As stay-at-home orders lifted and more people were able to return to the clinic, things didn't go back to business as usual.

Gipson says she found that "people want a hybrid model. It can't really be a one-way street anymore in which you have to come in or you have to stay at home. You may have four visits a year as a Ryan White [HIV care] patient where you only do one at the clinic. You may decide you want to do two. There's a connection that patients like to have with their clinician where they want to see them, but they're living lives and they're going to be busy. So I think the hybrid model of healthcare is the way to go, where you're providing a face-to-face option and you have an online telehealth option. You can go back and forth."

Aging in place with dinner and a movie

Open Arms also runs a wellness program for older adults living with HIV that has a strong social aspect. The popular program sends people out to dinner and a movie. It provides free massages, facials, and pedicures. While My Brother's Keeper serves a primarily African American clientele, the wellness program attracts a diverse group of participants—Black, White, and Latinx, gay and straight, men and women.

"We do a lot of health care, but we want a component of wellness to make people happy. We're under the impression that when you are happier, you feel better. When you are happier, you take your medication," Gipson says. "We know there's a whole host of things like loneliness and getting sick with just getting older. But then when you add HIV on top on that, you're going to age differently. So we added wellness."

Then came COVID.

The group continued to watch movies together, but from home using free iPads provided to members. Food was also sent out to their individual homes. Participants were taught how to use Zoom for their gatherings over the internet.

They also used Zoom to attend fitness classes, with free Fitbits, dumbbells, and blood pressure cuffs sent to their homes.

PHOTO COURTESY OF JUNE GIPSON

'People want a hybrid model. It can't really be a one-way street anymore in which you have to come in or you have to stay at home.'
—**JUNE GIPSON**, MY BROTHER'S KEEPER

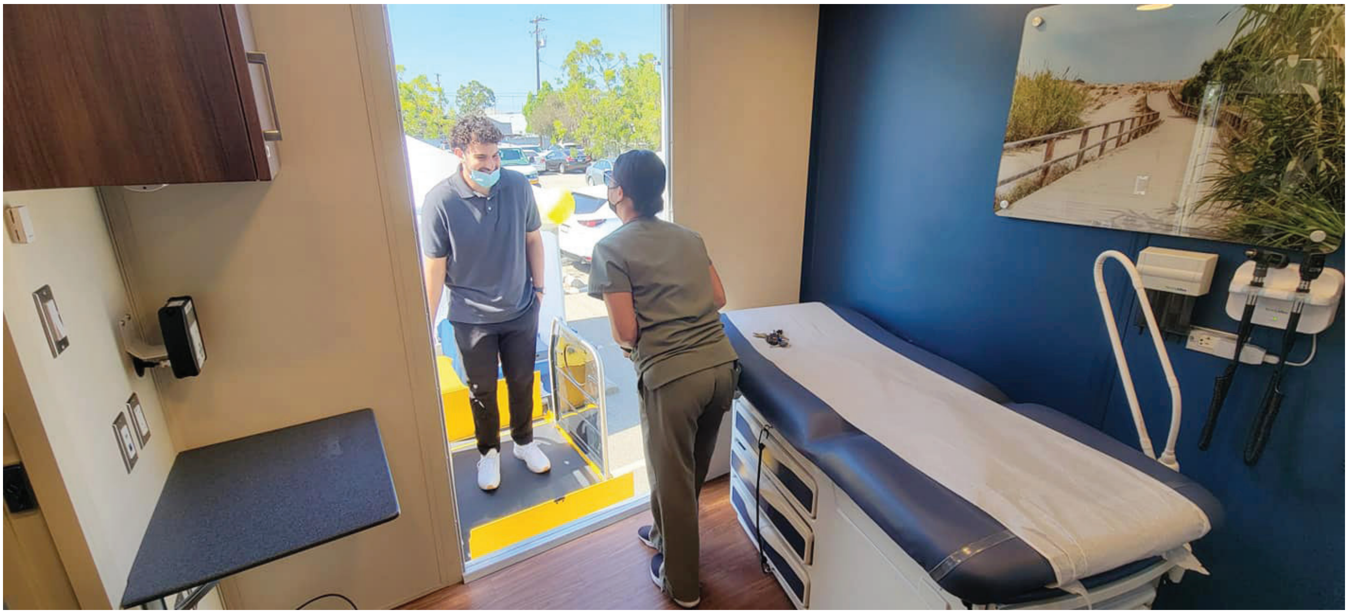
Today, they come together in person once again or through their computer, whichever they prefer at the time.

"It turned into a very successful component of the aging program that we have," says Gipson. "It's one of the good things that happened with COVID. COVID gave you the opportunity to think outside the box."

She noted that by 2050, the U.S. will have three times as many 100-year-olds as there are now. But healthcare is set up for babies, not the aging population, she says.

"Anybody who's getting older should be able to experience wellness and company, having someone to talk to daily, because that's a huge part of your health at some point. Nursing homes don't want to come see you. If we're going to be older, we need to have mechanisms that make sure that we're able to keep people in the loop regardless of how old they are."

Open Arms is on track to provide 100 free iPads this year. "I think telehealth is going to become a huge part of what we want to do. So it behooves us to put mechanisms in place to make sure that patients can get it." And, Gipson adds, this is in Mississippi, a state that hasn't even expanded Medicaid. "If Mississippi can do it, anyone can!"



A clinic on wheels serves people who inject drugs

As health care providers move further into telehealth services, clinics on wheels rolled out in five cities to serve people who inject drugs who are living with or are at risk for HIV.

"This is stigma-free and judgement-free integrated care for the needs of the population we're trying to serve in locations they can easily access," said David Goodman-Meza, MD, an infectious disease specialist at the University of California-Los Angeles (UCLA) David Geffen School of Medicine.

Dr. Goodman-Meza serves as principal investigator for the Los Angeles site of the HPTN 094 INTEGRA study. ("HPTN" is short for HIV Prevention Trials Network.) Preventing deaths from overdose is also part of the study. Medication to prevent HIV (PrEP, or "pre-exposure prophylaxis") will be offered. In addition to the medical care in the van, peer navigators will help participants access harm reduction and other services throughout the area. As a randomized controlled clinical trial, HPTN 094 represents the highest standard there is for a study.

Psychologist Steven Shoptaw, PhD, INTEGRA protocol co-chair and director of the Center for Behavioral and Addiction Medicine at UCLA, says that, "People who inject drugs and are not taking medication for opioid use disorder, or MOUD, face the nearly impossible task of trying to get care with limited or no financial resources from brick-and-mortar clinics that provide separate, siloed services for opioid addiction, HIV, and primary care. Breaking down structural barriers to accessing health care is essential to improving outcomes." He made his comments as the new clinics prepared to launch over last summer. The other cities are Houston, New York, Philadelphia, and Washington, D.C.

"It was actually difficult to roll out our mobile unit, especially during the peaks of COVID for us in L.A. in the last winter, because of all the uncertainty and the risks to the staff and the public, but now we're fully operational," said Dr. Goodman-Meza. The UCLA INTEGRA clinic operates in the nearby city of Long Beach.

The clinic, in its large beautiful van, launched in the fall of 2021, with special precautions taken for COVID, such as wearing masks and special cleaning procedures between participants, and having a telehealth component added. Once people are determined to be eligible for the study and go through a few visits where information and labs are taken, a lot of the continuing work can be done over the phone or through videoconferencing.

DR. GOODMAN-MEZA

Because of this new reality, INTEGRA helps people obtain smartphones. "Being on the streets, especially for those who are experiencing homelessness, means that having their stuff stolen or their stuff lost is of a way of life," says Dr. Goodman-Meza. "But that's the beauty of having a mobile unit near where they are living or where they're sleeping. That makes it easy for them to stop by."

Dr. Goodman-Meza says the study team was energized by the support for this innovative work from the HIV and substance use professionals, community members, and government officials and agencies in Long Beach. But there's even more work to do.

"One of the biggest difficulties for me is that the project is very specific in the people we're trying to recruit, so we're really only able to engage with people who are injecting drugs, particularly opioids," said Dr. Goodman-Meza. "Whereas at least here in L.A., a lot of people are still using methamphetamine and other substances. They might not necessarily be using opioids or injecting drugs and so it's just heartbreaking to not be able to provide them services."

Those services could be part of the future if the INTEGRA study can show that bringing the clinic out to the people can improve their health outcomes when they already have so many medical vulnerabilities.

Godspeed. —**ENID VÁZQUEZ**

GO TO hptn.org/research/studies/hptn094. Watch videos about the study from the different sites on YouTube.

PHOTOS COURTESY OF UCLA HEALTH CARES CENTER AND DR. DAVID GOODMAN-MEZA

25 YEARS OF HAART

THE LONG JOURNEY CONTINUES

BY **MICHAEL BRODER**

These days, it is quite possible to take for granted the fact that we have lifesaving medications for HIV. In fact, it is so easy to take for granted that I forgot to write this article for a whole year! That's right—as we entered 2021, I got it in my head to write an article about 25 years of effective treatment for HIV (what used to be called "highly active antiretroviral therapy," or HAART, but is now simply called ART—a reflection of how we now take the "highly active" part completely for granted). But I was so caught up with COVID (vaccines, good; delta variant, bad), and the presidential election, and the January 6 insurrection at the Capitol, and the trial of Derek Chauvin in the spring, and the wildfires in the West over the summer, and the spate of extreme weather events nationwide in the fall, and the wave of voter suppression laws, and the battle in Congress over infrastructure, and on and on and on, that I forgot to pitch the article to my editor until it was too late to run it in 2021.

Okay, so that lapse was largely due to my own scattered brain; but I really do think it is worth noting that we have so much momentous, historic, unprecedented "stuff" (by which I really mean an expletive known for hitting the fan) going on in this country and in the world right now, that the Herculean/Amazonian strides we as the human race have made against HIV since the AIDS epidemic began in 1981 can easily fade from our collective view. And maybe that's a good thing. Maybe that means HIV and AIDS are, though by no means in the rearview mirror, nevertheless something we more or less know what to do about—provided we can muster the political will and the human and financial resources to do it, whether in sub-Saharan Africa, or in hard-hit urban and rural parts of the United States, or elsewhere around the world.

Nevertheless, as a person who has been living with HIV for some 30 years now, while I may be a day (or a year) late, I am loathe to be even a single dollar short, and am grateful that POSITIVELY AWARE has agreed to publish my love letter to 25 years of HAART in this issue. And in fact, since HAART as we know it was more or less born at the XI International AIDS Conference, held in Vancouver, Canada, in early July of 1996, I guess I still have six months or so before HAART actually turns 26.

Anyone reading this article who wasn't living with HIV in 1996, or who was not otherwise involved in what we then referred to as the AIDS community—or, as I'm sure is the case for many readers, not even born yet—you may well be asking, *What is this HAART of which you speak, what is so important about it, what does it mean for me now, and what are its implications for my future?* Good questions! Let's address them one by one.

Let's start with what I like to think of as the catechism of the early AIDS epidemic. The first signs of the emerging epidemic appeared in the spring and summer of 1981, with the mysterious appearance of unusual infections and cancers predominantly among young gay men in New York, San Francisco, and Los Angeles, including *Pneumocystis carinii* (later renamed *Pneumocystis jiroveci)* pneumonia (PCP) and Kaposi sarcoma (KS). While it was not immediately clear what was behind these outbreaks, the unusual infections and cancers were all associated with compromised cellular immunity. Since the first outbreaks reported were among gay men, medical experts initially called the condition Gay-Related Immune Disorder (GRID). Soon, however, it became clear that the phenomenon was occurring among other groups as well, including injection drug users, the sexual partners of injection drug users, the newborn children of women who injected drugs or whose male partners may have done so, certain national groups (such as Haitians), and certain recipients of blood products (such as hemophiliacs). Consequently, the disorder was renamed Acquired Immune Deficiency Syndrome (AIDS). It became increasingly clear that AIDS was associated with an infectious agent that resided in certain cells (transmitted through blood, semen, vaginal fluid, and breast milk), which explained its transmission via sexual intercourse (anal and vaginal), through sharing needles to inject drugs, through receipt of contaminated blood products in medical procedures, and from mothers to infants either during delivery or when breastfeeding. At this point, the infectious agent remained unidentified, and without an infectious agent to target, the prospects for treatment were slim to none.

A virus that appeared to be associated with AIDS was isolated in 1983 by Luc Montagnier's team at the Pasteur Institute in Paris. In 1984, two other teams confirmed the association of this newly identified virus with AIDS—Robert Gallo's team at the National Cancer Institute in Bethesda, Maryland, and a team of scientists from the University of California, San Francisco, and the California Department of Health Services in Berkeley. Initially called lymphadenopathy-associated virus (LAV) by Montagnier and human T cell leukemia virus type III (HTLV III) by Gallo, a group of scientists eventually agreed on the name human immunodeficiency virus (HIV), the name we know it by today.

Now that a virus had been identified, the search for a treatment could begin in earnest. But that was much easier said than done. In 1983, the field of antiviral development was still in its infancy. The first antivirals to be approved by the U.S. Food and Drug Administration (FDA) and marketed for clinical use targeted the herpes simplex virus (HSV). Dendrid (idoxuridine), an ophthalmic solution (eye drops), was approved by the FDA in 1963 to treat eye infections caused by HSV. Then, in 1982, a decade into the genital herpes epidemic that came in the wake of the sexual revolution of the 1960s, the FDA approved Zovirax (acyclovir) ointment to treat genital herpes—and with that, the antiviral era entered high gear.

Herpes viruses belong to a large group of viruses called DNA viruses. A DNA virus is a virus that has a genome (the complete set of genetic material in a cell or microbial organism) made of deoxyribonucleic acid (DNA) that is replicated (reproduced) by an enzyme called DNA polymerase. The DNA polymerase makes new DNA by building up a chain of nucleotides, the basic building blocks of nucleic acids. Stick a wrench in the works of the DNA polymerase, and you stop the virus from replicating. That's what drugs such as idoxuridine and acyclovir do, in a process called *DNA chain termination*.

By contrast, HIV is a retrovirus. As the prefix "retro" suggests, retroviruses do things the reverse of how we usually think of cellular metabolism. In most viruses, as in most cells, DNA copies its genetic code into ribonucleic acid (RNA) in a process called "transcription," and RNA synthesizes all the proteins that carry out the life processes of the cell or virus. In the case of retroviruses, RNA, not DNA, is the basic genetic material. In a process called "reverse transcription," retroviral RNA encodes its genome into DNA, which the virus then inserts into the genome of the infected cell. The retrovirus, in essence, "hijacks" the host cell, turning it into a cellular factory for its own replication.

Now that a virus had been identified, the search for a treatment

The first drug to treat HIV infection

AT THE TIME HIV was identified as the virus that causes AIDS, medical science had developed a number of antiviral agents targeting DNA viruses, but no antiviral agents that targeted retroviruses. Now, the search was on for antiretroviral drugs to treat HIV. Medical scientists began screening a wide range of existing drugs to identify ones that might show efficacy against HIV. Researchers at the drug company Burroughs Wellcome (which later became Glaxo Wellcome, and later still GlaxoSmithKline, and most recently spun off a subsidiary called ViiV, focused on HIV drugs) struck it lucky with a drug called azithrothymidine (AZT), first developed in 1964 to treat cancer, but shelved when it failed to show any anticancer effect. The drug was later given the generic name zidovudine, and approved in 1987 under the brand name Retrovir, but will forever be known in popular parlance as AZT. It belongs to a class of drugs called reverse transcriptase inhibitors (NRTIs), which interrupt the stage in the viral life cycle where viral RNA transcribes its genetic code into DNA.

While AZT decreased opportunistic infections and deaths among people with AIDS, it had serious side effects, especially anemia (low red blood cells) and neutropenia (low white blood cells) at the initially prescribed dose of 1,500 mg daily. The word on the street in the AIDS community back then was that AZT was poison, a treatment worse than the disease. That anger and frustration is completely understandable given the circumstances. But the fact is, AZT is a good drug that was being used in a bad way. That was not anyone's fault, per se. At the time, ART was a whole new ball game, and researchers and clinicians alike were playing without much of a rule book. A clinical trial in 1990 not only reaffirmed the efficacy of AZT, but showed that it could safely and effectively be used at a much lower dose than before, and in fact, performed better overall because people taking the drug were no longer beset with such severe side effects.

The big problem that remained with AZT, however, was viral resistance. Viruses mutate, and retroviruses mutate at a much higher rate than other types of viruses. Mutations are changes in the genetic makeup of the virus that emerge in response to what is called "selective pressure." It's all about Darwinian principles of evolution—survival of the fittest. Over hundreds or thousands of years, people or animals may change their appearance or develop new behavioral traits (lighter or darker skin, greater running speed, sharper teeth, etc.) in response to new conditions or elements in their environment, like climate or predators. We say these environmental pressures "select for" particular genetic mutations. The same thing happens to viruses under what is called selective drug pressure. The virus is always mutating. Absent the presence of a drug like AZT, the HIV population is dominated by the "wild type" virus, with its sort of starter kit of genes—the Legos that come in the original box. But when a new drug comes to town, like AZT, the wild type virus gets displaced, while certain mutations confer a survival benefit—turn HIV into viral cockroaches that refuse to die. Over time, the mutant virus becomes the dominant strain over the wild virus. In the early days of AZT, this process begins to happen within a matter of weeks after starting treatment, and led to multiple mutations that conferred high-level resistance. People got better for a while, but then they got sick again, and eventually died of AIDS-related complications. AZT—at least when used by itself—improved health and extended survival, but only temporarily. In medical terms, we would say the response to AZT was remarkably robust, but not sustained. It worked, but only for a while.

More NRTIs and the advent of dual combination therapy

THE PHARMACOLOGISTS and research clinicians working to develop treatments for HIV were no dopes; in fact, they were some of the smartest, most resourceful, most dogged and determined medical scientists the world has ever known. They got the drill on viral resistance early in the fight, and moved right on to plan B, which was combination therapy—using combinations of antiretroviral drugs to stymie the emergence of viral resistance, setting up multiple genetic barriers, as it were, so that HIV could no longer mutate its way out from under the drugs. Of course, combination therapy required drugs to combine. That came to pass, but at an excruciatingly slow pace. After AZT in 1987, it took several years to roll out four more NRTIs: Videx (didanosine, ddI) in 1991; Hivid (zalcitabine, ddC) in 1992; Zerit (stavudine, d4T) in 1994; and Epivir (lamivudine, 3TC) in 1995.

After the introduction of the newer NRTIs, a series of large clinical trials showed that dual combination therapy with AZT and another NRTI was better than AZT alone at delaying disease progression and reducing mortality. These trials also suggested that combination therapy is beneficial for asymptomatic patients with CD4 counts less than 500 cells/μL. These studies—with arcane names like ACTG 175, Delta, CPCRA, and CAESAR—all released their preliminary findings in 1995, and their findings collectively brought an end to the era of antiretroviral monotherapy. In the wake of these findings, the International AIDS Society–USA in 1996 issued the first published guidelines for ART. The regimens recommended for initial therapy in these guidelines included AZT+ddI, AZT+ddC, and AZT+3TC.

On the downside—and it was a big downside—these trials also showed that there was no clear benefit to dual combo NRTI therapy for people with AIDS who had already been on AZT monotherapy. The same would prove to be true for people who had previously been on any NRTI monotherapy. This was a heartbreaking situation for the AIDS community at the time, as many people with AIDS "burned through" one NRTI monotherapy after another. As each new drug came to market, medical providers tried desperately to provide those in their care with even an additional year or two, in some cases even a few additional months of life. In each case, however, the benefits of NRTI monotherapy quickly waned in the face of viral resistance, and the new dual combination regimens did little or nothing to restore health or prolong life for these highly treatment-experienced individuals.

New drug classes and the coming of 'the cocktail'

MEANWHILE, something big—something *very, very big*—was brewing in the research laboratories of the major drug companies, the academic medical centers, and clinical trial sites across the country and around the world. Two new classes of antiretroviral drugs were being evaluated in clinical trials—nonnucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs). The investigational (that's shop lingo for *experimental*) NNRTIs targeted the reverse transcription stage of the HIV life cycle, just like the NRTIs, but via a different molecular mechanism. The PIs, as their name suggests, inhibit a viral enzyme called protease, a sort of viral scissors that cut long protein chains into shorter fragments during viral replication.

The crucial turn of events, however, was not merely the availability of two new drug classes, but also the fact that these new drugs could be used in triple drug combinations. Medical science already knew that two drugs were better than one, but still not quite good enough. Now, adding a third drug—that might prove to be a real game changer!

And in fact, it did. For several years, the international AIDS conferences had reported only incremental progress in the scientific and medical effort to treat HIV. New NRTI monotherapies raised the hopes of people with HIV and AIDS excited at the conference in Berlin in 1993, but were ultimately disappointing. Dual combination therapy showed promising results in Yokohama in 1994, but no brass ring. In fact, progress had become so incremental that the organizers decided to hold the international AIDS conference only every other year. I remember going to a meeting for community members in some big auditorium somewhere in New York, maybe the Great Hall at Cooper Union or someplace like that, where trusted messengers like Dr. Marty Markowitz presented data on the new PIs, all four of them—saquinavir, indinavir, ritonavir, and nelfinavir (none of them even had brand names yet). It was a very emotional time. We wanted to hope, but we were also afraid to hope. We had been disappointed so many times. We had buried so many friends and loved ones, attended so many memorials. And here were these experts telling us to hold on just a little longer. It wasn't just that a new drug meant a few more months of health or life; it was the idea that maybe finally, by erecting a high enough barrier to resistance, by closing off enough escape routes, we could achieve not only robust but also sustained suppression of HIV.

The XI International AIDS Conference in Vancouver in July 1996 was a moment of great hope and great expectation that for once, finally, did not run up against a cold, hard wall of disappointment, but rather made good on its promise. The findings reported on various combinations of a dual NRTI "backbone" plus either a PI or an NNRTI were not merely encouraging, they were exhilarating. The researchers called this new kind of treatment highly active antiretroviral therapy, or HAART, to distinguish it from all the previous incarnations of ART that had been stopgap measures at best, and cruel jokes at worst.

"From AIDS Conference, Talk of Life, Not Death," announced a headline in *The New York Times* on July 15, 1996. The media were abuzz with news of the revolutionary new "drug cocktail" that had been unveiled in Vancouver. While there were several triple-combination regimens that boasted good results, a clear winner did emerge from the conference—an NRTI backbone of AZT/3TC combined with the PI marketed as Crixivan (indinavir, IDV).

In the following years, there would continue to be ups and down, successes and failures, challenges as well as opportunities. For example, the initial NNRTIs had a very low genetic barrier to resistance. In fact, a single mutation could knock out not only the drug you were taking, but the entire NNRTI class (a phenomenon called cross resistance or, at this extreme, class resistance). The PIs, particularly Crixivan, appeared to be associated with disfiguring and debilitating types of fat redistribution, collectively known as lipodystrophy or lipoatrophy, and described by terms like "buffalo hump" and "Crix belly." Crixivan was also associated with kidney stones (which, in case you didn't know, are really awful things to have). Norvir (ritonavir, RTV) was associated with severe gastrointestinal (GI) side effects (nausea, vomiting, diarrhea). Invirase (saquinavir, SQV) had relatively low oral bioavailability, so they really had to push the dosage up as high as possible, which meant worse side effects. If none of this sounds like much of a picnic—well, it wasn't; but it was much better than the status quo ante, especially the sickness and (nearly) uniform fatality part.

could begin in earnest. But that was much easier said than done.

Moreover, while the PIs as a class had a higher genetic barrier to resistance than the NNRTIs or most NRTIs, they nevertheless did succumb to resistance eventually. That situation was remedied by a very fortunate coincidence that was discovered quite by accident. It turned out that ritonavir was a particularly powerful example of something called a cytochrome P450 3A4 inhibitor (abbreviated, by the grace of God, and science, to CYP3A4). That means it blocks the activity of an enzyme that plays a role in the metabolism of drugs in the liver. Somebody somewhere along the way had the very bright idea of using extremely small doses of ritonavir to boost levels of other PIs in the bloodstream. At such low doses, the GI side effects of ritonavir were much less pronounced, while the dose of the other PI could be greatly reduced and yet provide a much higher genetic barrier to resistance. That was a blessing—especially when it meant that folks on Crixivan no longer had to worry about taking their PI three times a day on an empty stomach (no food for two hours before or one hour after a dose); and a curse—increasing the risk of kidney stones for those on Crixivan, for example, as well as increasing the risk and severity of other Crixivan-related side effects such as loss of body hair (more of a problem for bears than for twinks, *but still*).

What we need now, in this world where we have the right tools, is the political will and the material resources to put those tools into action.

Anyway—this is getting a bit long-winded. Suffice it to say that HAART, aka triple-combination therapy, aka *the cocktail*—revolutionized the treatment of HIV, changing it from a nearly uniform death sentence ("nearly" because there is a very small proportion of people with HIV who manage to control the infection indefinitely without medication, a group called *long-term non-progressors* or *elite non-progressors*, who are to this day the subject of intense focus by scientists seeking clues to a cure for HIV) to a chronic, manageable condition (as people often used to say, "like diabetes," which I think undersells the seriousness and potentially life-threatening nature of diabetes). Today, we take new advances in HIV treatment (and prevention) almost for granted—the advent of pre-exposure prophylaxis (PrEP), the fact that undetectable equals untransmittable, the advent of long-acting drugs such as cabotegravir, promising research into new types of treatment like broadly neutralizing antibodies, and even progress, albeit incremental, towards HIV vaccines (both preventive and therapeutic). But in 1996, the advent of HAART was a virtually unimaginable gift.

Of course, the international HIV/AIDS community still faces tremendous issues of availability and access to state-of-the-art treatments and prevention strategies, especially in resource-limited countries, among marginalized populations, and particularly among women. We must never lose sight of this reality. At the same time, we can, I think, allow ourselves to be grateful for the fact that we are dealing with issues of access and availability, rather than dealing with the issue of whether or not effective methods of treatment and prevention even exist. I said it at the outset, and I'll say it again: HIV and AIDS are, though by no means behind us, nevertheless something we more or less know what to do about. What we need now, in this world where we have the right tools, is the political will and the material resources to put those tools into action, not just in wealthy countries or among those who have ready access to healthcare, but for everybody, everywhere in the world.

AND FINALLY... a personal reminiscence. I attended the Vancouver conference in 1996 as part of my job doing continuing medical education programming sponsored by leading academic institutions and funded by unrestricted educational grants from Glaxo. We worked not only with renowned research clinicians like Paul Volberding, Harrold Kessler, Robert "Chip" Schooley, and Mike Saag, but also with leading community-based AIDS advocates and activists. One of these was Moisés Agosto-Rosario, widely acknowledged to be the first person to come out as gay and HIV-positive on the island of Puerto Rico. The company I worked for organized a big bash in honor of Moisés in Vancouver that year. The reason for this celebration of his life and his work was grim: His AIDS was very advanced, and he was presumed to be near death. The party was meant to be a worthy sendoff for a young man who had given his all, and presumably his very life, to the fight against AIDS.

The reception was held at the incomparably beautiful Museum of Anthropology, on the traditional land of the Musqueam people, with its iconic Great Hall, a spectacular space enclosed within 45-foot-high glass walls. A tented podium was set up on the sprawling grounds behind the museum. A number of friends and colleagues took to the podium to speak about Moisés—his intelligence, his wit, his charm, and his fierce determination to fight AIDS. Finally, it was time for Moisés himself to speak. Up to the podium he strode, this slight, sexy, 35-year-old man whom we had come expecting never to see again.

But that was not how it was going to go down. Moisés flashed his devilish grin and spoke loud, clear, and strong into that microphone. He was alive, he was well, and he planned to stay that way for a long, long time, continuing this fight, and embarking on new fights for human rights and for racial and social justice. Moisés, it turns out, had been in a clinical trial of one of the groundbreaking new triple-combination HAART regimens (I have no idea which one). Moisés, like so many others, was there to do his best imitation of Lazarus. Moisés had literally risen from his deathbed, like hundreds of others who had participated in clinical trials of the new regimens, and like the thousands of others who would, within days, have access to these new, truly lifesaving treatments. He still works on behalf of all people living with HIV today. He even contributed to an article in this issue. The topic? An HIV cure.

We had come to a party that we expected to be bittersweet. We left a party that was pure magic.

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, Brooklyn with numerous houseplants and three feral backyard cats.

Inclusion is essential to a cure

An update on HIV cure research from the virtual 2021 U.S. Conference on HIV/AIDS

BY **DANIELLE M. CAMPBELL**, **PORTIA D. COWLINGS**, **MOISÉS AGOSTO-ROSARIO**, **WILLIAM B. CARTER**, **CECILIA CHUNG**, **MORENIKÉ GIWA ONAIWU**, AND **LUIS J. MONTANER**

A diverse group of advocates, scientists, and community representatives came together to host a session on HIV cure at the virtual U.S. Conference on HIV/AIDS this past December. The Master Series session, chaired by Danielle M. Campbell and Moisés Agosto-Rosario, provided an update on the latest in HIV cure-related research and discussed critical issues that affect how research is conducted and not always inclusive of all populations affected by HIV. Among the issues discussed: barriers and facilitators of participation in HIV cure-related research; inclusion of diverse populations like transgender women, Latinx, and youth; participant perspectives of HIV cure research; analytic treatment interruptions; and partner protection measures to minimize secondary HIV transmissions among sexual partners.

DR. LUIS MONTANER, vice president of Scientific Operations and a professor with the Immunology, Microenvironment and Metastasis Program at The Wistar Institute, opened the session with his HIV cure science presentation, “BEAT-HIV Program and the State and Future Directions in the Search for an HIV Cure.” Dr. Montaner is a leader in the BEAT-HIV Collaboratory, one of 10 newly-funded Martin Delaney Collaboratories (MDC) for HIV Cure Research, the flagship NIH program on HIV cure research. Its purpose is to foster dynamic, multidisciplinary collaborations between basic, applied, and clinical researchers studying HIV persistence and developing potential curative strategies. Dr. Montaner described the National HIV/AIDS Strategy for the United States, 2022-2025, Goal 2: Improve HIV-Related Health Outcomes of People with HIV, the importance of Section 2.6, to advance the development of next-generation HIV therapies and accelerate research for HIV cure. The BEAT-HIV collaboratory seeks to develop and test innovative combined immunotherapy strategies to eradicate and/or induce permanent remission (a cure) in the absence of antiretroviral therapy by trying to understand strategies to control HIV (functional cure) and to eradicate HIV (sterilizing cure), as well as how best to measure a functional cure.

He also discussed last November’s promising news of a woman whose own immune system may have cured her HIV without stem cell transplantation (see Briefly), and other determinants of HIV control. Next, he discussed topics related to immune responses, HIV reservoirs, and HIV rebound, including chromosome location, HIV tropism, intact and defective virus, memory T cells, broadly neutralizing antibodies (BNAbs), Type-I interferons, and plasma factors. A personal favorite, Dr. Montaner discussed the BEAT-HIV Model Community Education Group (CEG), composed of scientists, community-based organizations (CBOs), and community advisory boards (CABs). The collective published a position paper on cure-directed clinical research and analytical treatment interruptions. Finally, he rounded out his presentation with an update on BEAT-HIV trials and future plans for the BEAT 2.0.

WILLIAM B. CARTER, chairman of the Beat-HIV CAB, addressed diversity and inclusion in HIV cure clinical trials, sharing his perspective as a research participant in an HIV cure trial. Carter noted the need to continue to advance HIV cure research agendas by centering diverse communities affected by HIV. In the United States, HIV continues to disproportionately impact racial and ethnic minority and sex and gender diverse populations. That includes Black and Latinx communities, gay and bisexual men, women, and transgender persons. In 2019, Black and Latinx communities comprised 71% of the new HIV diagnoses in the U.S., but represented less than 30% of the total population. When an HIV cure becomes available, these groups should not be left behind. A cure for HIV would be a welcomed feature to enhance the lives of countless affected individuals. Several affected communities including women, transgender persons, and racial and ethnic minorities are still underwhelmingly represented among HIV cure trial participants. For example, transgender women are a population highly affected by HIV in the U.S., and to date, only a single participant in an HIV cure trial has ever identified as transgender.

HIV advocate **MORENIKÉ GIWA ONAIWU** spoke about the need to continue to include youth and young adults in our discussions about HIV cure research. She provided additional context on addressing HIV treatment in the lives of children, youth, and young adults who face their own unique set of challenges. Of note, the MDC program was further expanded in 2021 to include a collaboratory focused on HIV cure research in infants and children.

LASTLY, future HIV cure-related discussions should continue to address HIV analytical treatment interruptions (ATIs). ATIs involve a research study participant stopping their antiretroviral therapy while their viral load is carefully monitored. It is a critical and complex component of HIV research. Barriers and facilitators to participating in ATIs, including what types of considerations for sexual partners, or significant others of partners, should also be carefully examined.

This session, unlike any other, utilized a “for us by us” model, that focused on discussions about HIV cure research among highly-affected populations led by individuals representative of those populations. All too often racial and ethnic and sex and gender populations are disproportionately impacted by HIV but sadly, they are not appropriately, effectively, or even ethically engaged in conversations about HIV cure research activities or public forums, community advisory boards, or even in clinical research. It’s time we have a conversation about what’s really going on and where our communities fit in with what’s happening around HIV cure science.

DANIELLE M. CAMPBELL is a Los Angeles-based health equity and sexual health activist whose work centers minoritized communities of women and girls living with and affected by HIV/AIDS. She is a member of the AIDS Clinical Trials Group and several other advocacy-related efforts.

LET'S TALK

Doing right by sexual health

INTERVIEW BY **ENID VÁZQUEZ**

HIV testing remains key to ending the epidemic. Those who test negative can be offered PrEP (pre-exposure prophylaxis—medication to prevent HIV). Those who test positive can be linked to the medical care and effective treatment that can keep them healthy for a normal lifespan, and once their viral load is suppressed they can't pass HIV on to a sex partner (called U=U, for "undetectable equals untransmissible).

But a year after our article looking at testing during a time of pandemic ("Testing the Testers," January+February 2021), the U.S. still experiences a lag in people getting tested to see if they have any STIs (sexually transmitted infections).

One thing that remains the same: the need to have someone to talk to, and someone who will listen to and answer questions about what remains a sensitive topic: *sex*.

Joshua Gutierrez is the Prevention and Health Education Manager at TPAN, the non-profit HIV services organization that publishes POSITIVELY AWARE. He's had more than 10 years of experience discussing sexual health and wellness with people seeking an HIV test. He started at TPAN during the COVID-19 shutdown of 2020–2021.

ENID VÁZQUEZ **What do people most misunderstand?**

JOSH GUTIERREZ People have misconceptions about what STIs are and how you get them. So basically, education is missing, that is what I am finding. There are a lot of misconceptions and a lot of rumors, things that they've heard from friends or on Google.

Then when they're symptomatic, they may not know what it is. We know that STI symptoms come and go, but they believe that, "Oh, I'm no longer having symptoms so I'm okay." And obviously most STIs, in particular syphilis and HIV, can lead to serious health consequences if left untreated.

I had someone come in recently who asked me, "Can I still get HIV? I had bottom surgery [vaginoplasty]." Nobody had that conversation with her. That, yes, you can still get an STI or HIV. We discussed modes of transmission and prevention and I was able to make a Fast Track PrEP referral. She came in later to see me and tell me she was on PrEP and to pick up condoms and lube. She was very happy to have been given information about PrEP and wanted to tell me personally. That was one of my prouder moments.

I always ask clients, "Tell me what you know about how someone acquires HIV?" One young person told me they heard that if you take a slice of orange and rub it on a woman's labia and the orange turns green, that she has HIV.

EV **What year was that?**

JG This year [2021]. This was a relatively young person, 19. And I think when people are in high school, they just come up with random things that they read on Reddit or on the internet. They believe what their friends tell them. And that's what he really thought, and I explained that's not true. It was great that he trusted me, because then we can have an open and honest conversation. We give folks accurate, science-based information. I always tell them, make sure you tell your friends that no, you cannot acquire HIV that way.

One young person asked me, what's the best way to have anal sex? His partner was rather large and so we had a discussion about it.

We take the time to explain what the rectum is, how it works, and that anal sex can be pleasurable. We also teach how to care for your rectum and anus before and after sex, and talk about using toys, condoms, and lubes. As well as having conversations with your partner and stressing the importance of getting tested for STIs and HIV.

I had a very open conversation with a married mom. She's been married for 10 years and she gets tested two to three times a year. I had noticed her high anxiety and stress levels when I initially greeted her. So I'm asking her all the open-ended questions. How many sexual partners have you had? She had one sexual partner, in a monogamous relationship for the last 10 years. She explained to me that when she was younger that she had "a past." I assured her that most people have "a past," and she laughed, which made me feel better as a counselor because I felt she was getting comfortable with me and the session. So I started to ask about her baseline knowledge about HIV and about HIV and STI transmission. She was saying that she heard that HIV can incubate, so you should test at least once a year. Nobody had taken the time to explain the window period to her or what the tests look for and how to interpret them. Once I explained that her results and her information indicated that she did not have HIV, she released all this stress and fear that she had been dealing with for 10 years, and she started crying. She asked me, *Why didn't anybody ever tell me that?* I told her, "That was a failure in the testing process. I'm glad you came in today, and I'm glad that we had this discussion."

Once people feel safe to open up, you can begin to shape the conversation. I do ask people, "How many partners have you had in the last 30 days? In the last six months?" And one person said that they had 30 partners in the last 30 days. And then the client asked me, "Is that a lot?" And I said, "Is it a lot to you?" It's a

'I always tell people that this is a safe space.
You can ask me anything or you can ask me nothing. It's up to you.'
—JOSHUA GUTIERREZ

question of how do you feel about your sexuality—what concerns do you have about it? We're not here to judge you.

Something that we regularly explore with clients is their relationship with sex and their own sexuality. What does someone's sex, sexuality, and identity mean to them? Are you enjoying the sex you are having with your partner or partners? What do you use to prevent STIs and protect yourself? Does sex validate you in some way? Sex can be pleasurable or fun, or it can be a burden and stressful. Having good information can be vital in a person's overall health.

What information does this person need? What can the person leave with today to better help them protect themselves and their partners? It is very important to us that our clients are treated with respect and compassion, regardless of their baseline knowledge. For some folks, coming to get tested and be vulnerable is a giant step for them and we should acknowledge that and speak to that courage with our clients.

We offer more than just testing. We offer sexual wellness counseling. That young man was able to join our Lifeline program, which helps folks recognize their personal vulnerability for HIV/AIDS, come up with attainable risk-reduction goals, develop increased health awareness overall, improve their physical and emotional health, and create a healthier lifestyle for them. What is great about this program is that they can receive six free mental health sessions from one of our amazing therapists.

I have found that those who are in routine care don't get sexual health information from their providers. Their providers also may not test them for STIs. So I don't think they're having that conversation with their medical provider or care team regardless of age, gender, or sexual identity. That's probably

RICK GUASCO

the most astonishing thing that I find. That sexual wellness, sexual health, and STIs and HIV are not discussed during an office visit. We try to teach folks to initiate the conversation with their primary care providers and to advocate for themselves.

We try to create a conversation with clients that is age appropriate, but I also don't make assumptions. When I introduce myself, I always let them know that the questions I'm going to ask are questions I ask of everyone. If you wish not to answer, just say *pass*, and I will keep going, although if I need to circle back to the question, I will. I want them to know that we are here for them. That the sharing of information is confidential, if you feel comfortable. Often, folks don't want to talk about their sex life with their providers. Other people don't talk about their sex life with their sex partners. They don't know how to broach the topic or how to talk about it. They might not have the terminology they need for a discussion. But again, it's just information. We provide "coaching" with clients, providing a safe space for folks to practice what they want to say to their partners or medical providers. Hopefully, this tool, this skill, will allow them to feel comfortable having open and honest dialogue when it concerns their sexual health.

From the moment they walk through our doors, how we greet them, even asking about their preferred pronouns, is a great way to help folks relax.

Some folks are dealing with shame or stigma. I always tell people that this is a safe space. You can ask me anything or you can ask me nothing. It's up to you. In my experience, I feel that folks really like to talk about themselves. And some really like to talk about sex.

There's no negative language in the signage that we have. Nothing scary. We even have a nice little stress toy that people can squeeze when we're testing them.

Make it a positive experience, even fun! Because if you have a positive experience, you're more likely to come back. We are *sex positive* here. If you have a negative experience somewhere, you're more likely to never to go back. And that could be a reason why folks are not getting tested, and in some cases not getting treated.

I've had clients come in who didn't want to tell me anything. I don't force them to either. I hope that we are able to provide a warm, safe, and welcoming experience so that maybe the next time they come in, they'll be a little bit more open.

EV What are the STIs being seen the most now? Do we still have a syphilis epidemic in the country? Or is it only among MSM (men who have sex with men)?

JG Language is also very important. We do not have a syphilis epidemic. It is *endemic* in a lot of urban areas. It's just part of communities, particularly large urban communities, and in certain rural areas. But yes, part of the CDC data of 2018, I believe, did indicate a rise in syphilis, gonorrhea, and chlamydia, and particularly concerning was congenital syphilis [which is passed in utero to the child, before and during birth]. I believe that went up by 143% from the previous year.

STIs do not discriminate; bacteria and viruses are opportunistic. So it is very important that folks get tested, treated when needed, and also that partners are notified. The messaging sometimes goes back to the stigma and shame of acquiring an STI or HIV. I think sometimes the messaging could have a more positive spin on it.

With COVID-19, STIs and HIV testing services have been curtailed as people who were working as partner disease intervention specialists were pulled to work on COVID-19 contact tracing. Testing has been limited at some sites. It's sort of like a perfect storm. Behaviors may not have changed during COVID-19, but access to testing, PrEP, and HIV care did.

Making testing routine, as part of your overall health, could lower the rates of infections. I think we need to start early in schools and colleges and just make it part of your overall health checkup.

EV And being non-judgmental goes hand in hand with being comfortable.

JG Absolutely.

As part of the sexual wellness counseling session, we ask, "Are you having any signs or symptoms of an STI? Has a partner notified you that they tested positive for an STI? Do you believe you


GOLSON

A sense of trust— and a matter of access

"**Testing is still** a little light compared to what it was pre-COVID, but still, testing for HIV, syphilis, and hepatitis C is on the upswing," says **Leon Golson**, Prevention Manager for UNIFIED, in Detroit. During the COVID shutdown, the organization mailed out HIV home test kits, which were donated by the Greater Than AIDS campaign and by test kit companies themselves. On-site testing at the agency's two locations (the other is in Ypsilanti) went from walk-ins to by appointment only. Today, people can go to the UNIFIED website to make an appointment for testing or have a test kit mailed to them. "We're still seeing more people come in for appointments than asking for kits," Golson says. "For me personally, I want to talk with someone when I'm calling a company about a problem. So I think that's what's happening when it comes to HIV and STI testing. People want to have a sense of trust. They want to look at another person and have the information explained." As for setting up the test, "I'm so old school, but people who are familiar and comfortable with the technology don't have a problem making their appointments online. Our state health department is a big supporter of telemedicine, but it's just a matter of, do agencies like ours have the infrastructure? And do we have the financial support to step that up?" There's also the question of access for clients. "A lot of folks just don't have phones or access to a computer. So even though there's a shift toward more technology-based prevention or technology-based care, we still have to have room for the old school way of meeting folks face-to-face and you know, helping them out with what they need. Because not everyone is going to have access to that. And I would venture to say not everyone wants access to it. We want to always make sure that we're not losing that human element or the ability to meet individuals where they're at."

have may have been exposed to HIV in the last 72 hours?" I don't ask if they have ever had an STI because that could make people very uncomfortable. How you approach your clients and the questions asked lead to an understanding of respect and trust.

The 10 to 20 minutes waiting for an HIV test result can be a long time. So it is a perfect opportunity to have a relaxed conversation with someone. I like to ask questions like, "So, tell me what you know about PrEP?" "Tell me what you know about STIs?" But surprisingly, what they do tell me is that they don't test for STIs because they don't know where to go. Or they had a terrible experience at another facility. In a perfect world I would love to have express clinics around the city, like pop up clinics, where it would be very seamless. If we see in the data that there is a high prevalence of STIs or HIV in certain neighborhoods, then the pop-up clinic could move to that community. There they could offer comprehensive testing and treatment, PrEP, and HIV care for folks in real time at the point of care.

We need more testing clinics, better treatment options, and comprehensive sexual health services, such as PrEP, PEP, and free birth control. I could go on, but my point is that If services were offered, people would take advantage of them.

EV This is exactly what I was going to ask you, where do you send them?

JG In a perfect world I would love to have express clinics around the city, like pop up clinics, where it would be very seamless. If we see in the data that there is a high prevalence of STIs or HIV in certain neighborhoods, then the pop-up clinic could move to that community. There they could offer comprehensive testing and treatment, PrEP, and HIV care for folks in real time at the point of care.

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> **'Make it a positive experience, even fun!** Because if you have a positive experience, you're more likely to come back. We are sex positive here.'
>
> —JOSHUA GUTIERREZ

'Oh my gosh, I can't believe you talk like that!'

Hershey Krippendorf may be the director of development for the HIV service organization Philadelphia Center in Shreveport, Louisiana, but she ended up providing front-line services for the organization's new Syringe Service Program (SSP) during COVID-19. The program started in January 2020, just a couple of months before the nationwide shutdown. Other available staff members were leery about coming in.

"We continued with that service, through a window, because it was so new and we had told the community that *we're gonna have this for you guys*, so it was important for us to continue it," said Krippendorf. "Because you can't have a gap in service for that community. And they prefer in-person service." The work did her a lot of good. "I find so much joy from being able to just have conversations with our participants and learning about their lives, and just being there for them to listen. Because that's one thing about our participants, is that they don't feel like they're being heard or they don't feel like anybody cares about them. So we're not just a place for them to get sterile syringes, but also a place to feel like a human being and where they can talk openly about their drug use."

Open conversations are important to her. Once, a woman overhearing her discussion in a doctor's office said, "Oh my gosh, I can't believe you talk like that!" She says, "Being a first-generation Asian American, talking about sex was something that was very taboo. You know, I didn't learn about the birds and the bees from my mother. It's not something that you talk about in Asian cultures." Her family is from Cambodia.

During the COVID shutdown, the Philadelphia Center also kept up its work for PrEP and PEP prescriptions. This was also important in part because the organization serves many serodiscordant couples. Walk-ins for HIV testing were stopped and they switched to appointment only. However, many people failed to make their appointments, despite receiving reminders from the center.

STI testing, however, continued without a hitch. "We have another component to our agency, the GBT Health Center, that offers a panel of STI and hepatitis C testing. That is still by appointment only, but that is a service that people in our community know about, and so they know who to talk to," said Krippendorf. "There's a lot of relationship building in that particular department, because the GBT community is very small in Shreveport." In fact, she says, the center is walking distance for most of the people it serves.

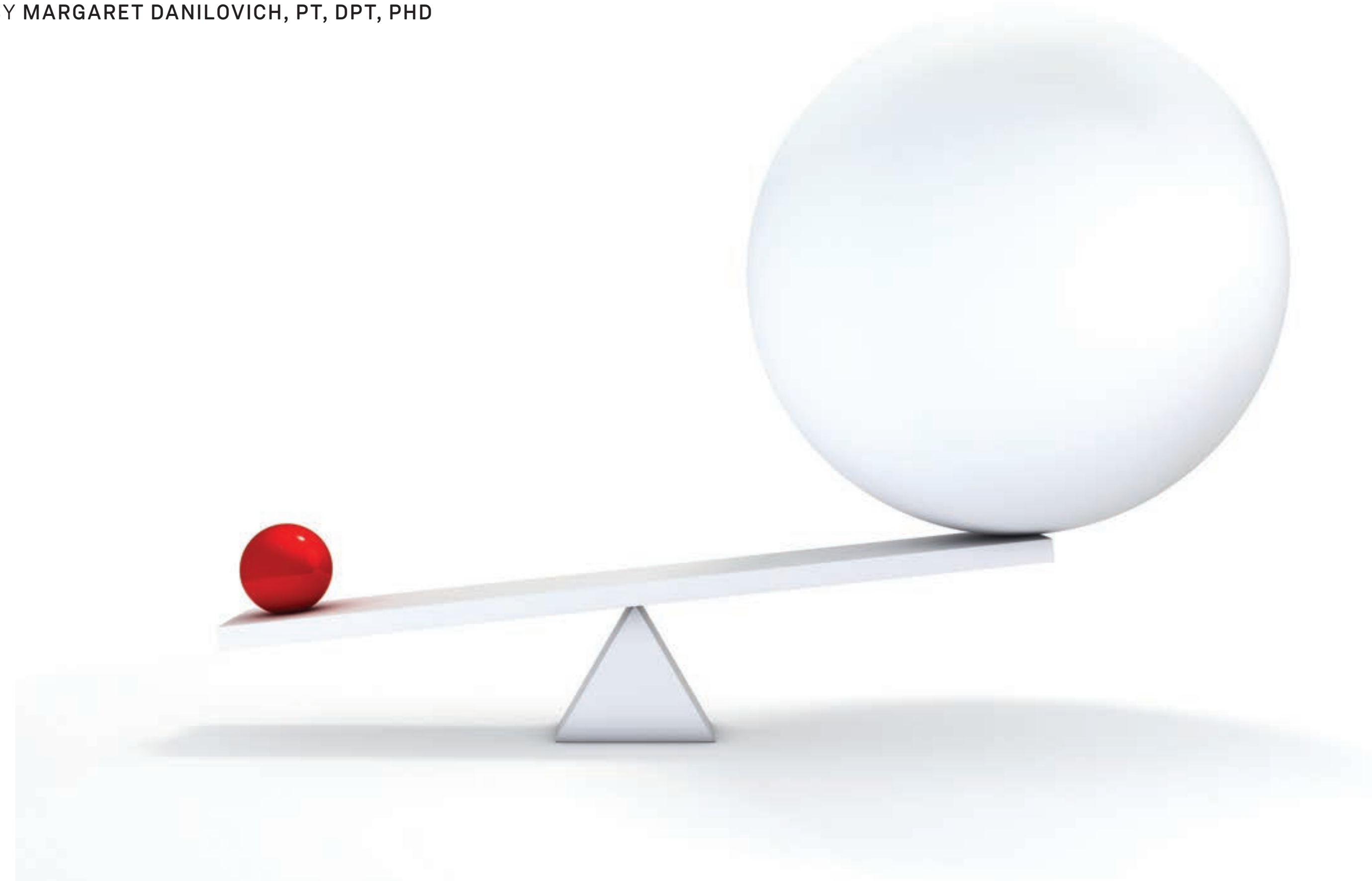
She has one great wish: an addiction specialist who accepts Medicaid and Medicare. Krippendorf has no one to refer the center's SSP clients to, because local providers for addiction services work on a cash-only basis.


KRIPPENDORF

LITTLE CHANGES CAN MAKE A BIG DIFFERENCE

Creating a pathway to better health in the new year

BY MARGARET DANILOVICH, PT, DPT, PHD



SKEGBYDAVE -ISTOCK

THE START of a new year is often a time of reflection and resolutions. Subsequently, we are bombarded with advertisements for diet plans, gyms, and smoking cessation products, setting people up with the expectation of making major changes to their lives. The reality is that, according to research from the University of Scranton, only 8% of people achieve their new year's resolutions; most people abandon their desired changes by January 19.

One reason for not achieving health goals is that we attempt changes that are too ambitious. We want to lose 100 pounds or never smoke a cigarette again. While the goal itself is fine, we have not planned for the daily actions that it will take to achieve that goal.

This year, don't make a dramatic new year's resolution. Instead, resolve to make a small daily change to your health habits to make changes that will truly stick and last all year.

One way to make a health behavior change is to create an action plan. First, imagine the outcomes you expect as a result of changing your health behaviors. These can be both negative and positive. For example, if you resolve to exercise for 30 minutes each day, the expected outcomes might be that you will feel less stress, and sleep better, but also that you might have some muscle soreness or joint pain. These potential outcome expectations can be identified through an if/then statement—*If I do "X", then I will have "Y"*. *If/then* statements for a new exercise routine might look like this:

1. **If I exercise for 30 minutes per day, then I will be able to sleep better at night.**
2. **If I exercise for 30 minutes per day, then I might have to give up spending 30 minutes with my friends.**

When setting goals for changing your health behavior, it is also important to think of the risks of *not* changing your habits. For example, the risk of not quitting smoking is a greater likelihood of getting cancer. Or the risk of not exercising is more difficulty managing blood sugars, which can create major health issues for people who are diabetic.

Once you have identified the expected outcomes and the risks of not changing behavior, it's time to set a small, achievable plan for behavior change.

The table shown below is a template for outlining the steps to changing behavior. In this example, the goal is to lose weight and eat a healthier diet.

As you think about changing your health habits, here are recent guidelines to give you potential goals to work towards.

PHYSICAL ACTIVITY

THE GOAL FOR ADULTS over the age of 18 is to achieve at least 150 minutes (two and a half hours) of moderate-intensity aerobic activity, like biking, brisk walking/jogging, or fast dancing. If you are not reaching 150 minutes each week right now, that's okay! Start where you're at and add seven to 15 minutes more time each week. Adults also need muscle-strengthening activity, such as lifting weights or doing push-ups, at least twice a week. Most importantly, find activities that you enjoy and that are accessible. There is good evidence that people will stick to physical activities they enjoy compared to those they don't. One of the most accessible ways to get physical activity is in your own home. There are a variety of Zoom-based exercise classes available through senior centers and YouTube. Thanks to a grant from the Administration for Community Living, there are also free Zoom exercise classes for people living with HIV through CJE SeniorLife in Chicago. To learn more about these classes, you can email Margaret.Danilovich@cje.net.

NUTRITION

ONE OF THE CHALLENGES with HIV is body changes from lipodystrophy (fat distribution syndrome), as well as medication side effects that can cause weight changes, increased cholesterol, fatigue, and muscle wasting. Nutritional principles for people living with HIV include eating a diet higher in fruits and vegetables (5–6 servings per day), whole grains, and lean proteins. Because of the muscle wasting that can occur in HIV, the protein recommendation is to aim for 100–150 grams per day for men and 80–100 grams per day for women. It is key to optimize vitamin and mineral intake especially with HIV because of the boost they provide to the immune system. One general recommendation is to "eat the rainbow"—consume a colorful variety of fruits and vegetables every day to get the full range of vitamins and minerals.

To make 2022 the healthiest year possible, set small, daily goals to improve your health. Make a detailed plan for how you will achieve your goals. And no matter the setbacks, remind yourself that tomorrow is a brand new day to begin again on your way to positive daily health habits.

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MARGARET DANILOVICH is the senior director of the Leonard Schanfield Research Institute at CJE SeniorLife and an adjunct assistant professor at Northwestern University, where she directs the dual degree Master of Public Health and Doctor of Physical Therapy program. A physical therapist by background, she has practiced her entire career with older adults. Her current research has been funded by the NIH, Retirement Research Foundation, and Third Coast Center for AIDS Research and focuses on exercise interventions for older adults with frailty.

THE BIG GOAL

Lose 25 pounds (this is a goal that, without details and small daily steps, is likely to fail)

MY DAILY GOAL

Eat one vegetable with every meal and in place of snacks (this change is smaller, more achievable, and will help achieve the big goal)

What I will do:	Eat one serving of vegetables with lunch and dinner, and eat vegetables in place of an afternoon snack.
How I will do it:	On Sunday nights, I will do "meal prep" and prepare a gigantic batch of green beans, brussels sprouts, and cauliflower. I will divide this up into small containers, leaving them in the fridge to eat throughout the week.
When and where I will do it:	I will do my meal prep on Sunday nights at 7 p.m. in my kitchen. I'll get groceries on Saturday mornings so I am prepared.
What I will do when I have a setback or relapse:	When I have a non-veggie snack, I won't get upset with myself and will remind myself to try again tomorrow. If I'm feeling very tempted to eat candy as a snack, I'll first make sure I don't have any in the house but if I do, I'll call a friend or go for a walk.
What resources I have to achieve this goal:	I'll need to get Tupperware containers. I'll want to find recipes for veggies so I can have some variety. I'll need to get groceries.

Once you have identified the expected outcomes and the risks of not changing behavior, **it's time to set a small, achievable plan for behavior change.**

The stories behind A Day

Positively Aware hosts an online celebration of *Resilience* told through pictures

BY RICK GUASCO

Ahead of World AIDS Day, POSITIVELY AWARE presented a webinar, *Resilience—Stories of A Day with HIV*, celebrating the photos that were posted for the magazine's social media-based anti-stigma campaign. "I think it's important to show us as living, and not dying, with HIV," Charles Sanchez said as the virtual program began. "Everything with this campaign, every picture that you see, is an example of people joyously living their lives, whether they're at their doctor's office getting their blood drawn, or they're with their families or their work. All the pictures are affirming and fantastic."

Accompanying Sanchez in the program were HIV advocates Davina Conner Otalor and Jax Kelly, who joined me in talking with a few of the people who took part in A Day with HIV to ask them about the story behind their photo and share their experience in overcoming stigma. **Held every year on the first day of autumn—September 22, last year—A Day with HIV depicts 24 hours in the lives of people affected by stigma** by encouraging everyone everywhere to take a snapshot of their day on that date and post it to their social media with a caption that mentions the time and location of their photo, and what inspired them to take it, accompanied by the hashtag #adaywithhiv. This year, about 250 pictures were posted, representing 15 countries around the world in addition to the U.S.

CHARLES SANCHEZ

There's a perception that people living with HIV don't *look* healthy, Sanchez said, so for A Day with HIV he wanted to show off the progress he'd made by regularly working out. On a whim, he took a shirtless selfie for the first time. Sanchez, who is a contributing editor for TheBody.com and contributing writer for *Poz* magazine, also created and stars in *Merce!*, a musical comedy web series about a flamboyant and optimistic middle-aged gay man living with HIV in New York City.

Sanchez introduced Elijah Palles, a trans gay man from Phoenix. Palles wears many hats and a variety of identities. In addition to his job as a mental health therapist at the Southwest Center for HIV/AIDS, he works with transgender youth in the community, and sits on a number of boards, including RipplePHX, a local HIV outreach organization, and the Jim Collins Foundation, a national trans affirmation surgery grant program. He is also a drag king, performing under the stage name Eddie Broadway for over 10 years; most recently, he became Mr. Trans USA.

"I have been out about eight or so years, I've been medically transitioning," Palles said. "I also was married for a little bit to a woman, and then I came out as gay. A year later, I was diagnosed with HIV. So, there're a lot of layers there. Stigma on top of stigma, right?"

He credits the activists that have come before him. "But there still is this layer of stigma when it comes to trans people, trans masculine people not being served but also being underrepresented," he said. "I know it's still out there. I experience it mostly with the medical community because they don't know what to do with me. It's kind of like, *Okay, well, you're trans but you're also positive*."

About a year and a half ago, he was diagnosed with HIV. For World AIDS Day 2020, he disclosed his HIV status in a video on social media. A colleague and friend at work urged him to take part in A Day with HIV. "He was like, *You have to be part of this!*" Palles said. So, he submitted a picture of himself at work, which was chosen for one of four versions of the foldout cover of the November+December 2021 issue of POSITIVELY AWARE.

"Most of my social media is primarily Eddie Broadway drag-related, and A Day with HIV spoke to me with me as a person," he said. "Because I am one of just a handful of trans masculine individuals that I know of who are HIV-positive and public about it, I wanted to make it about me, my mental health practice, who I am. It was really important to show me as a person, in my office in my center."

Whereas his disclosure video a year earlier drew a mixed reaction, with some acquaintances pulling away from him, there was a different response to his picture.

"This photo, after being a year positive, it brought a lot of people kind of out of the woodwork—who maybe aren't LGBTQ, aren't part of the community, aren't necessarily allies of the community, but people I've known since I was little—and the support and love that they had for me was eye-opening," he said. "They were able to reach out to me, ask me questions, feel kind of normal with having the conversation about what it means to be positive, what it means to be undetectable. It was a bridge between my community now and my former self. That was really nice."

with HIV

"One of the things that impresses me a lot about you is that you're so authentically you, and unapologetic about that," Sanchez responded as their portion of the program was concluding, "and I think when you are authentic, you give people permission to be who they are as well."

Davina Conner introduced herself for the next segment. Diagnosed at age 27, she has lived with HIV for 24 years, but had kept it secret.

"I actually lived 17 years of my life, not knowing one person who lived with HIV, not ever being able to have a conversation with someone who lived with what I lived with, and been able to share that with them—it was just me, myself, and I," Conner said. "When you live that way, you feel like you're the only person who is living with this. I knew I wasn't the only one. It's just that I was living in this little box, taking care of my children, and going through a rough marriage. That was all that I actually knew until I started to become an HIV advocate."

Today, Connor is a public speaker and the creative engagement outreach specialist for Prevention Access Campaign, the organization that launched U=U (undetectable equals untransmittable, the message that a person living with HIV who is on antiretroviral treatment and has an undetectable viral load cannot transmit the virus to someone through sex). She also hosts her own podcast, *Pozitively Dee's Discussion*.

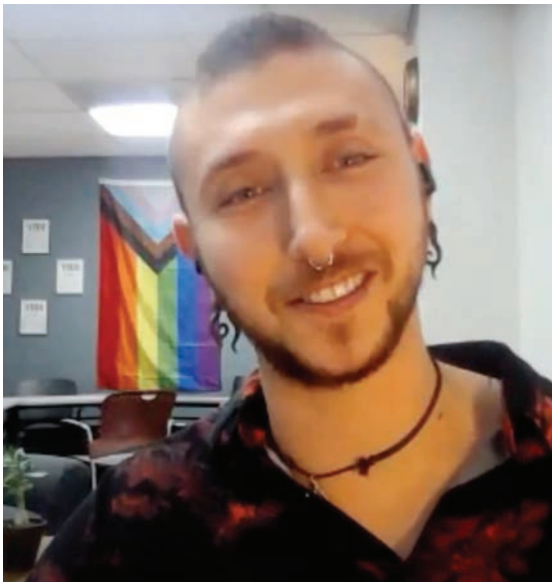
"When I [saw] A Day with HIV, it had only been some months that I had shared my diagnosis with the world, and A Day with HIV inspired me to be a part of it," she said. Driving with her sister that day in 2015, Conner suddenly told her to pull over to the side of the road so she could take an outdoors picture, which surprised her by becoming one of the covers that year.

Conner introduced Ciarra ("Ci Ci") Covin, who is a program coordinator for The Well Project and has written for the organization's *A Girl Like Me* blog since 2018. She also recently served as an ambassador for the CDC's *Let's Stop HIV Together* campaign. Diagnosed 13 years ago, Covin gave birth on A Day with HIV.

"The whole day before, I was in labor, in pain, and I had been sharing my personal journey of pregnancy with my Instagram family," she said. "Social media has been a great outlet for advocacy. On that morning, the 22nd at 9:48 a.m., I finally gave birth. Everyone had been anticipating this baby, so I was like, *Okay, let me share.* I got on Instagram and saw other advocates posting #adaywithhiv. I was like, *Wow!* It was powerful to me. I didn't realize how powerful it could be to someone else. It turned into this really big thing because my baby—my second HIV-negative child—was born on A Day with HIV."

Covin's Instagram picture of baby Zuri also became a cover photo. "If my younger self could have seen that, I would have been inspired sooner," she said.

She still wrestles with stigma, she admits. "To this day, when I speak of stigma, usually the first thing that pops in my head is the internal sigma that I feel, sometimes every day," she said. "The messaging that we receive from the outside world coming in can so heavily affect how you feel about yourself."



LEFT: THE ROADSIDE PHOTO **DAVINA CONNER** TOOK THAT BECAME A 2015 COVER. RIGHT: **ELIJAH PALLES**. BELOW: **JAX KELLY**.

But if the image of a newborn can make a powerful statement, Covin said she has felt its impact. "The response from the community—*how much you have helped me, how I'm inspired or, keep doing what you're doing*—you think that no one's listening to you, that you're just talking to yourself," she said. "To receive that validation back because of such a powerful post, it means a lot to me."

A Day with HIV was also the 80th birthday of Maurice Greenham, of Stoke-on-Kent, a city in England. "Not only am I now 80, but I've

ON A DAY WITH HIV, **CIARRA COVIN** (ABOVE) GAVE BIRTH TO **BABY ZURI**, WHILE **MAURICE GREENHAM** CELEBRATED HIS 80TH BIRTHDAY, MAKING ONE OF THE FOLDOUT COVERS OF THE NOVEMBER + DECEMBER ISSUE (BELOW).

been living with HIV for an awful long time,” Greenham said. “I’ve been with it for 37 years.”

“I changed careers in 1983, from education into professional theatre, so I was very keen in hearing what both Charles and Elijah had to say,” he said, referring to the earlier conversation between Sanchez and Palles, “because [performing] is a part of my life, too. In 1984, when I was given my HIV diagnosis, I just thought it was the end and that I was going to—I was angry because I thought I was going to lose my new career. But I was asymptomatic for the first 10 years. And then I got seriously ill. I developed AIDS, and was given six months to live. My AIDS-defining illness was HIV-related encephalopathy, which leads to dementia. It was after that, when I didn’t die, that I kept fighting. So, keeping my mind active was vital.”

The approval of the first protease inhibitors in 1995 marked a turning point in HIV treatment—and for Greenham. He started organizing concerts with the local choir and musicians for World AIDS Day and other events.

“It was incredible, that spirit of generosity of the folks of Stoke-on-Trent, that they were willing to give their time and their talents to the cause,” he said. “And that sort of empowered me. It was from that time onwards, that I started to speak out as someone openly gay living with HIV.”

Discovering POSITIVELY AWARE and its campaign, the simplicity of taking a picture and writing a caption appealed to him. “So, I was astonished when I wound up on the cover, opposite the picture of a newborn baby,” he said referring to the foldout cover he shares with Covin’s baby Zuri.

The final conversation was led by Jax Kelly, president of Let’s Kick ASS Palm Springs, an organization dedicated to the survivors of the early plague years of the AIDS epidemic. He is also treasurer of The Reunion Project. Calling out a pin he was wearing, Kelly said raising awareness of U=U had been an important part of his messaging when he was Mr. Palm Springs Leather 2018.

“I’ve been positive since 2006,” he said. “One of the things that I wanted to do was to break out of my shell. I didn’t like the idea that I was forced to actually come out again, having come out as a gay man years before, only to have to come out as an HIV-positive person. So, I did a billboard for an AIDS organization in Los Angeles. It was so empowering for me because I could pose in front of it, and point to it. It was just a great way to take all the stigma out of being HIV-positive.”

Kelly spoke with Sascha Rex, who lives in Bonn, Germany, and had taken his journey to become public about his HIV status. Rex, 45, was diagnosed with HIV in July 2020, at the height of the COVID-19 pandemic’s first wave.

“It was an interesting experience having a pandemic around and struggling with another virus,” he said, referring to the problems getting connected to support systems during the shutdowns. “I started talking about my diagnosis, in March, April [of 2021] on social media. I’m very active on Twitter, and there, I saw this initiative, A Day with HIV. I really liked the idea, so I took part.”

For his picture, Rex chose a place that was special to him, the garden of his cozy home in the middle of the former West German capital. “This always was a kind of paradise for me, especially in the time of the pandemic,” he said. He was very intentional about the time he took his photo—8:30 a.m. Tweeting out the photo soon afterward, because of the six-hour time difference between Bonn and the American east coast, it would be one of the first pictures to be seen in the U.S.

“That was the idea behind the time,” he said.

Rex’s photo was seen by many of his acquaintances—including the president of the German adult education association where he works, Annegret Kramp-Karrenbauer, who until late last year had also been the German minister of defense. She sent him a warmly worded direct message of support.

“All day I was showing everybody this direct message,” he said. “That really was a breakthrough for me.”

Rex acknowledged he had some privilege in getting to where he is now. “I’m a white, middle class gay man, so I had a very positive bubble around me,” he said. “And I had the help of friends. I built my own network. I also had therapy. It lasted one year, from the diagnosis to the moment when I could speak openly. It was a long journey, but a very good journey.” PA

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TO WATCH highlights of *Resilience—Stories of A Day with HIV*, go to positivelyaware.com/webinars. Some quotes in this article have been lightly edited for content.

POZ ADVOCATE

SCOTT SCHOETTES
@PozAdvocate

HIV privacy laws are about choice and control, not shame

“You make it worse,” said my young friend. “By bringing lawsuits to enforce the HIV confidentiality laws, you make it seem like HIV is shameful and should be kept hidden.”

Though I am a strong proponent of “owning” one’s HIV status—and being open about it when circumstances allow—I couldn’t disagree more with my friend’s statement. And it’s not that I don’t recognize how having HIV-specific privacy and confidentiality protections—a form of HIV exceptionalism—may contribute to the stigma surrounding HIV. It’s just that I firmly believe the benefit of such laws and prosecutions greatly outweigh any incremental amount of harm that might accompany them. The solution, in my view, is to better understand and explain the history and purpose of these laws.

Let’s start with the history. In considering the “chicken or the egg” problem that sits at the root of my friend’s statement—do we have stigma because we engage in HIV exceptionalism or do we need to engage in HIV exceptionalism because HIV-related stigma is so severe?—it is important to remember that the stigma clearly came first. What we now know as HIV was stigmatized from the moment it was first identified as a phenomenon primarily among gay men, and the stigma only grew as other disproportionately impacted populations—like injection drug users and sex workers—were added to the list.

HIV-specific privacy and confidentiality laws were a natural reaction to the stigma that surrounded HIV from the very beginning. And these laws were not simply a legal solution to the obvious violation of medical privacy involved in the disclosure. Rather, they were a public health strategy designed to encourage people to get tested. Remember that even getting tested for HIV was considered a tacit admission that one was engaged in an activity that put them at risk for HIV.

When most people thought that you had to be gay or an injection drug user or a sex worker to have HIV, ensuring that people would feel comfortable getting tested was of paramount importance. Even though there were no effective treatments in the late 1980s and early 1990s, knowing one’s HIV status allowed people to mitigate the risk of passing it on to others. Hence, the HIV-specific privacy and confidentiality laws—with their strict protocols for disclosure and enhanced civil penalties for unauthorized disclosure—were a critical part of early efforts to combat the epidemic.

ISTOCK

The natural question that follows is whether these laws are still necessary. After all, we’ve come so far in our understanding of HIV and the routes of its transmission—and we know that almost anyone from any walk of life can contract HIV. Not to mention the fact that there are effective treatments, as well as preventive medicines that serve as a quasi-vaccine. One could mount a plausible argument that HIV-specific privacy and confidentiality laws are a relic from a time when we had less understanding and compassion regarding HIV.

That would be a plausible argument but not a winning one. Unfortunately, HIV is still a highly stigmatized medical condition—currently the most stigmatized medical condition today and perhaps the most stigmatized condition of all time. Other conditions are much more deadly—cancer is one example—but there is a shame in the acquisition of HIV that does not exist at the same level for any other serious medical condition. And there are persistent myths about how—and how easily—HIV is transmitted that harken back to the earliest days of the pandemic. Stigma still discourages some people from getting tested, others from remaining in treatment, and still others from accessing the support they need to live successfully with HIV. Maintaining a strong disincentive to the unauthorized disclosure of what can still be highly stigmatizing information is as important as it ever was—both for people living with HIV and to keep potential disclosers in line.

With an ever-greater understanding of HIV and greatly reduced mortality for people living with HIV, it can be easy for those holding HIV-related private information to start thinking that strictly maintaining its confidentiality is not as important as it once was and to grow lax in their practices involving such information. But there is a disconnect between those important advances and the persistence of public misperceptions and ongoing stigma. Enforcement of HIV privacy and confidentiality laws serves as a bulwark against relaxing the standards for handling HIV-related confidential information and keeps the individuals living with HIV in control of when such information is disclosed.

Ultimately, that is what the HIV privacy and confidentiality laws are designed to do—allow the individual to make the choice as to when this information is shared. Some people will choose to share this sensitive personal information very rarely, while others may share it freely. But these laws are not about buying into shame around HIV or fostering the perception that this information should be kept hidden. They are about giving people living with HIV control over when and how their HIV status is shared.

I could not be more out about my HIV status—it is in my bio and appeared on my former employer’s website for years and years—but I still want to make the decision about where, when, and how it appears elsewhere. The HIV privacy and confidentiality laws are an attempt to give all of us living with HIV that important choice.

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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.

What we need to know about advanced aging

If you don't address social determinants of health, you're not going to improve health outcomes, says a leading geriatrician

COMPILED BY **ENID VÁZQUEZ**

ISTOCK

"Our society really treats aging as a disease, but it is not a disease," said Dr. Meredith Greene, an associate professor of medicine in geriatrics at the University of California San Francisco. "It is actually a physiologic process that we're all going through from the time we're born." Dr. Greene spoke to medical providers on World AIDS Day on *Geriatric Principles for People with HIV*, including psychosocial changes. Her virtual presentation to the Midwest AIDS Education and Training Center (MATEC) is adapted here.

Everybody's different

PEOPLE AGE DIFFERENTLY. There's a saying in geriatrics, "If you've seen one 80-year-old, you've seen one 80-year-old." You cannot make assumptions that the next person will be the same.

Not all older people are frail. Not all are unable to think for themselves. I wanted to highlight that as people age, that is a time when there's more heterogeneity than at any other age. If you think of pediatrics, there are certain milestones. There are certain ages that pediatricians track, but for older adults, it is actually the opposite. People age based on their whole life experience, and so everyone ages very differently.

You have to ask about geriatric conditions. Older adults might not volunteer the information. Frailty and other geriatric syndromes add up to vulnerability. Addressing polypharmacy and exercise—non-pharmacologic interventions—can address multiple concerns.

We need to understand what is a normal part of the aging process, and what is not normal. Knowing that can help combat stigma as well.

Physical changes

AT SOME OLDER AGES, there's a decline in kidney function. There is a decrease in lean body mass and an increase in fat mass. There is decreasing bone density. There are changes that happen in our cardiovascular system, in our blood vessels, which means the arteries are sometimes stiffer. There are changes in blood pressure, and there are changes that occur via output from our heart. And then there are changes in our eyes and in our ears, which is why some people need a screening process and some people need to get hearing aids for high-frequency sounds, because that is a normal part of aging that affects hearing.

Some of these things are also impacted by HIV, or its treatment. We talk a lot about medication changes and kidney function—the way that body mass changes will absolutely affect how medication metabolizes and processes in the body.

We talk about individuals who are age 50 and older. Not that 50 is old, but the literature [study data] supports the idea that comorbid conditions and geriatric conditions do tend to occur at relatively younger ages in people living with HIV compared to the general population. A lot of this may be in part because of chronic inflammation.

Psychosocial needs

IT'S IMPORTANT TO RECOGNIZE that in HIV care, you're already often dealing with complex psychosocial situations. Both the fields of HIV medicine and geriatrics are essentially good at acknowledging that if you don't address the social determinants of health, you're not really going to be able to improve health outcomes. There are actually a lot more similarities between the two fields than are often recognized or talked about.

One piece of the complexity with psychosocial aspects is that often there is not just depression, but there is the trauma that long-term survivors, especially, might be facing. We think about COVID retriggering trauma, especially for the patients I work with. There is the intersection of stigma, COVID, and HIV. So racism, homophobia, transphobia—all of these things contribute to significant trauma.

There were people isolated before COVID. How do we address that?

First, it is important to know that

loneliness is different from social isolation. You could be alone and not feel lonely, or you could be surrounded by lots of people and feel completely alone. So again, it's subjective. It's usually more about the quantity of relationships—and the quality of those relationships—and in general, feelings of loneliness, that have the most impact on health.

In the general population, isolation has been related to depression, loneliness, cognitive decline, and even increased mortality similar to smoking 15 cigarettes a day, according to one often-touted figure that came out of a meta-analysis. Again, you don't have to be isolated to feel lonely.

There's controversy over directly asking, "Do you feel lonely?" Some people see it as stigmatizing. You can ask about social support. "How many people do you feel you can depend on or feel close to?" You can use the three-item UCLA loneliness scale: *I feel left out. I feel isolated. I lack companionship.* The responses are *hardly ever*, *some of the time*, or *often*.

In people with HIV, there's evidence behind combatting loneliness through online support groups, mindfulness-based cognitive therapy, and group interventions for smoking cessation. And also notably, interventions that were not meant to address loneliness, for example, peer-to-peer counseling around sexual risk behaviors.

We should recognize resilience, and partner with community organizations for direct interventions reaching people who are the most lonely. I think more and more we have to break down the silos between health care and community organizations.

This is even more important during COVID-19. Other consequences of COVID include increased isolation, increase in mental health concerns and substance use, decreased physical activity (fear of leaving home), and difficulty keeping caregivers. These may lead to decline in cognitive and physical function, and falls.

Ask about who else is around who can be an emergency contact, so that somebody could be a surrogate decision maker, if someone is ever too sick to make decisions or speak for themselves. Many people may not be able to identify a single person—normalize that, because it is, unfortunately, far too common. But I think if we can normalize it, then we can talk about ways we can document their preferences, without having a decision maker.

Many parts of geriatric assessment can be adapted to telehealth. With video, we can look at their gait and see how they get up from a chair.

Related to telehealth, especially in current times, we can ask about access to phone and video when asking about social support. We do so much online. But not everyone has internet access, and unfortunately, that's [another aspect of health disparities]. We have to think through strategies to address the digital divide.

But I will say there are some upsides to telehealth, including helping improve access for some patients, especially people who have limited mobility.

Physiological changes with aging

- Decreased GFR (glomerular filtration rate, a measure of kidney function) and decreased lean body mass (with resulting increased fat mass), both of which can affect pharmacokinetics
- Decreased bone density
- Decreased cardiac output and increased myocardial and arterial stiffness
- Decreased vision and hearing

Why do we need a different approach for older adults?

Diseases often present atypically. May not have the "usual" signs and symptoms.

Older individuals have less physical reserve—small insults (injuries) can cause significant problems.

Ockham's razor (the idea that in problem solving, a simple explanation may be preferable to a complicated one): one unifying diagnosis may not apply.

The 5 Ms of Geriatrics

Multicomplexity: describes the whole person, typically an older adult, living with multiple chronic conditions, advanced illness, and/or with complicated biopsychosocial needs

Mind: mentation (thinking); dementia; delirium; depression

Mobility: amount of mobility and function; impaired gait and balance; fall injury prevention

Medications: polypharmacy, deprescribing; optimal prescribing; adverse medication effects and medication burden

What matters most: Each individual's own meaningful health outcome goals and care preferences

"Mobility" includes being able to navigate around the home or out in the community. Mobility is associated with "activities of daily living" (ADLs), which include bathing, dressing, toileting, transferring (being able to get in and out of bed, a chair, or a wheelchair), and feeding. There are also "instrumental activities of daily living" (IADLs), which include telephone services, finances, transportation, laundry, housekeeping, shopping, meal preparation, and medications.

RESOURCES

STEADI—Older Adult Fall Prevention website includes other clinical resources such as brochures for patients and caregivers.
cdc.gov/steadi/index.html

STEADI Algorithm for Fall Risk Screening, Assessment, and Intervention among Community Dwelling Adults 65 Years and Older.
cdc.gov/steadi/pdf/steadi-algorithm-508.pdf

Selected top 10 drug classes to avoid in elderly PWH, from the European AIDS Clinical Society:
eacs.sanfordguide.com/drug-drug-interactions-other-prescribing-issues/other-prescribing-issues/selected-top-10-drug-classes-to-avoid-in-elderly-plwh

HIV Drug Interactions Checker:
hiv-druginteractions.org/checker

Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV:
https://aahivm.org/wp-content/uploads/2017/02/Aging-report-working-document-FINAL-12.1.pdf

HealthHIV's National Resource Center for Care Coordination and Pozitively Aging with HIV:
healthhiv.org/pozitivelyaging

The Veterans Aging Cohort Study Index (VACS Index) from the Yale School of Medicine predicts all-cause mortality, cause-specific mortality, and other outcomes in people living with HIV. It features a calculator, summary of validation work to date, and a clinical interpretation of index scores.
medicine.yale.edu/intmed/vacs/cohorts/vacsresources/vacsindexinfo

State of Illinois Senior Health Insurance Program (SHIP) offers free counseling for seniors or their caregivers about available Medicare and insurance options. Services available throughout Illinois.
(800) 252-8966
uofi.box.com/v/seniorhealthinsurance

SOURCE: MIDWEST AIDS TRAINING AND EDUCATION CENTER (MATEC)

BRIDGETTE PICOU

'Is it still a thing?'

> **It's the people *in* HIV work that fight apathy to keep trying to pull us out of the epidemic. Because *it most certainly is still an epidemic*. It's still a 'thing.'**

I'm disappointed every time someone says something ignorant or ill-informed about HIV. I'm shocked every time I hear someone say they didn't know HIV was still a "thing." How people can possibly still believe after 40 years that it's transmissible by kissing or sharing silverware is beyond me. With information so readily available, it annoys me to hear that people still think it's only a gay man's disease or that only "down low" heterosexual Black men get it. All I can do is roll my eyes and shake my head that people think if you are heterosexual and have HIV you are a drug user or sex worker. My eyelid twitches when I hear people who think those with HIV should live in some kind of quiet shame without a healthy relationship or healthy sex life. The pervasiveness of Magic Johnson jokes and memes 30 years later makes me want to pinch people on the soft part of the inside of the arm. You know, where your parents pinched you so you would be still in church?

Then I have to take a breath and gather myself—a deep, long breath. Sometimes I have to count to 10 and pray to the tiny eight pound, seven-ounce baby Jesus. Just because I knew the basics about HIV even before I was diagnosed doesn't mean everyone does. The reality is most people don't *want* to know. Ignorance is bliss, and plausible deniability means folks can take risks without guilt. Sadly, if you aren't in HIV care or don't know someone directly affected by it, chances are you know next to nothing about it. It falls to advocates and activists to keep the conversations going, which is in direct contrast to the abundance of fear and misinformation that was everywhere in the beginning. That drives me crazy! People are so quick to perpetuate fear, and whisper lies and half-truths. The media coverage peaked in the '80s and '90s, shouting with fear-driven, sensationalized headlines about AIDS, lifestyle choices and taboo culture and sexuality, but whispers about living and thriving with HIV now. HIV information, the truth and facts of it, have mostly been relegated to specialty cause magazines or scholarly and medical journals. I'm thankful for the medication commercials making their way to mainstream TV and magazine ads which at least can help spark a conversation. It's the people *in* HIV work that fight apathy to keep trying to pull us out of the epidemic. Because *it most certainly is still an epidemic*. It's still a "thing."

I really wanted to take this moment to give a shout out to the activists and advocates. The doctors, nurses, and scientists. The pharmacists, researchers, and scholars. The writers, editors, and publishers. The countless faces of knowledge and heart and hope that go into fighting HIV every single day. I see you. Even if few on the outside do. I hear you even though you get hoarse from saying the same thing over and over. I fellowship with you and send you hope and light and encouragement to keep doing what you do. Doesn't matter if it is one person at a time or 10 people at a time. I promise you, the efforts you make matter. Keep shouting about PrEP and PEP, and TasP, and staying in care, and U=U. Teach about harm reduction and reducing self-stigma. I'm hugging your life and am grateful for what you do. I believe in you. I thank you. You matter.

Be well.

PICOU: CHAD SAIN · IMAGE: IZUSEK-ISTOCK

2022 POSITIVELY AWARE READER SURVEY

Tell us about yourself, and what matters to you

Take a few minutes to fill out the survey below. Tear out this page, fold, tape, and mail it. You can also scan or take a picture of the page and **email it to** inbox@tpan.com—or go old school and **fax it to** 773-989-9494. **Take the survey online at** positivelyaware.com/2022survey **or scan this QR code** at left. All responses are completely anonymous. **Thank you!**

1. I primarily read POSITIVELY AWARE:
☐ in print
☐ on a desktop or laptop computer
☐ on my smartphone, tablet, or other mobile device

2. How do you get POSITIVELY AWARE?
☐ I have a subscription
☐ I pick it up at my doctor's office/clinic
☐ I pick it up at an HIV/AIDS service organization
☐ Other: ______________________

3. I read POSITIVELY AWARE because (check all that are applicable):
☐ I am living with HIV
☐ I work at an AIDS service organization or community-based organization
☐ I am a healthcare provider
☐ I am incarcerated and need current information
☐ I know/care for someone living with HIV
☐ Other: ______________________

4. I would like to read more in POSITIVELY AWARE about (check all that apply):
☐ The latest HIV-related scientific/medical information
☐ HIV treatment and drug information
☐ Stories about people living with HIV
☐ Information related to HIV and aging
☐ HIV advocacy and policy
☐ HIV prevention/PrEP
☐ HIV cure research
☐ Stories about TPAN, the publisher of POSITIVELY AWARE
☐ Other: ______________________

5. If it were available, I would be interested in reading POSITIVELY AWARE in Spanish:
☐ Yes ☐ No

6. I live in ZIP code: ______________

7. My relationship status (check all that apply):
☐ Single ☐ In a relationship
☐ Married ☐ Divorced ☐ Widowed
☐ It's complicated ☐ I prefer not to say

8. I am receiving, or have received, treatment for (check all that apply):
☐ Alcoholism or substance use
☐ Arthritis ☐ Cancer
☐ Depression, anxiety, or other mental health conditions
☐ Diabetes ☐ Heart disease
☐ Hepatitis B or C
☐ High blood pressure
☐ STIs (sexually transmitted infections)
☐ None of the above
☐ I prefer not to disclose
☐ Other: ______________________

9. What is your age?
☐ Under 20 ☐ 50–64
☐ 20–29 ☐ 65–74
☐ 30–39 ☐ 75 and up
☐ 40–49 ☐ I prefer not to say

10. What is your gender identity?
☐ Female ☐ Male
☐ Queer ☐ Non-binary
☐ Gender non-conforming
☐ I prefer not to say
☐ I prefer to self-describe:
____

Transgender is an umbrella term that refers to people whose gender identity or expression differs from what is typically associated with the sex they were assigned at birth. Other identities considered to fall under this umbrella can include non-binary, gender fluid, and genderqueer—as well as many more.

11. Do you identify as transgender?
☐ Yes ☐ No
☐ I prefer not to say
☐ I prefer to self-describe:
____

12. What is your race and/or ethnicity? (check all that apply):
☐ American Indian or Alaskan Native
☐ Asian
☐ Black or African American
☐ Latinx, Latino/a, or Hispanic
☐ Native Hawaiian or other Pacific Islander
☐ White
☐ I prefer not to answer
☐ I prefer to self-describe:
____

13. What is your sexual orientation?
☐ Bisexual
☐ Gay or Lesbian
☐ Straight/Heterosexual
☐ I prefer not to say
☐ I prefer to self-describe:
____

14. My annual household income is:
☐ Less than $15,000
☐ $15,000–$34,999
☐ $35,000–$49,999
☐ $50,000–$74,999
☐ $75,000–$99,999
☐ $100,000 or more
☐ I'd rather not say

15. What is your HIV status?
☐ HIV-positive ☐ HIV-negative
☐ I don't know
☐ I prefer not to disclose

16. I have been living with HIV for:
☐ Less than 5 years ☐ 5–10 years
☐ 11–20 years ☐ 21–30 years
☐ More than 30 years
☐ I am not living with HIV

17. How likely are you to share what you read in POSITIVELY AWARE with your health care provider?
☐ Likely
☐ Somewhat likely
☐ Not at all

18. As someone living with HIV, my greatest concern is:
____
____
____
____

19. What social media platforms are you on?
☐ Facebook ☐ Instagram
☐ Twitter ☐ WhatsApp
☐ Tik-Tok ☐ LinkedIn
☐ Other(s):
____

CUT ALONG THIS LINE

CUT ALONG THIS LINE

FOLD THIS PANEL DOWN FIRST

POSITIVELY AWARE
5537 N BROADWAY
CHICAGO, IL 60640

PLACE
STAMP
HERE

POSITIVELY AWARE READER SURVEY
5537 N BROADWAY
CHICAGO, IL 60640-1405

FOLD THIS PANEL UP. TAPE FLAPS TOGETHER. **DO NOT STAPLE!**

SUPPORTING POSITIVELY AWARE HAS NEVER BEEN EASIER.

TEXT ISUPPORTPA TO 44-321.

When you text to give, you help ensure that the latest, accurate and dependable information and inspiring personal stories are delivered every issue to people affected by HIV.

Join TPAN's mission. There's never been a more critical time for information you can trust.

POSITIVELY AWARE
positivelyaware.com/**donate**

NMAC
leads with race

biomedical HIV prevention summit

April 20-21 Chicago, IL
biomedicalhivsummit.org #2022BHPS