POSITIVELY AWARE
HIV TREATMENT, PREVENTION + HEALTH FROM TPAN
NOV+DEC 2022

7:00 PM: SOUTH PADRE ISLAND, TEXAS

"When having an undetectable viral load is sexy AF!"
—**MICHELLE ANDERSON**

A DAY WITH HIV

EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

ONE OF THREE SPECIAL EDITION FOLDOUT COVERS

9:04 AM: CHICAGO, ILLINOIS

"Today I'm in my neighborhood Starbucks, taking an hour that I put aside daily to work on my book of short stories. These stories make up moments of my life that bring me joy, caused me pain, left me confused, and of course the ones that I look to for strength. I have been thriving while living with HIV for 16 years, and that is worth celebrating!"
—**COLEMAN GOODE**

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—ALEXI DÍAZ

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3:05 PM: ASHLAND, OREGON

"A beautiful day in southern Oregon, in the community garden where I tend vegetables and flowers with friends. I celebrate living with untransmittable HIV for 20 years. As a Positive Sunbeam, I embrace being an HIV advocate to end HIV and self-stigma. I am lovable. I am free to be me. I am worthy of joy, family and connection. My life is worth living, and so is yours."

—GRETCHEN ROBERTS

P+A
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1:00 PM:
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"As we age with HIV, we may find ourselves being a caregiver to our elderly parents. Remember to take time to care for yourself and do whatever brings you peace, joy and happiness!"
—ASHA MOLOCK

8:00 PM:
NEW HAVEN, CONNECTICUT

"A Day with HIV is being the healthy, loving and proud Papa of this little guy, Sebastian."
—BRANDON M. MACSATA

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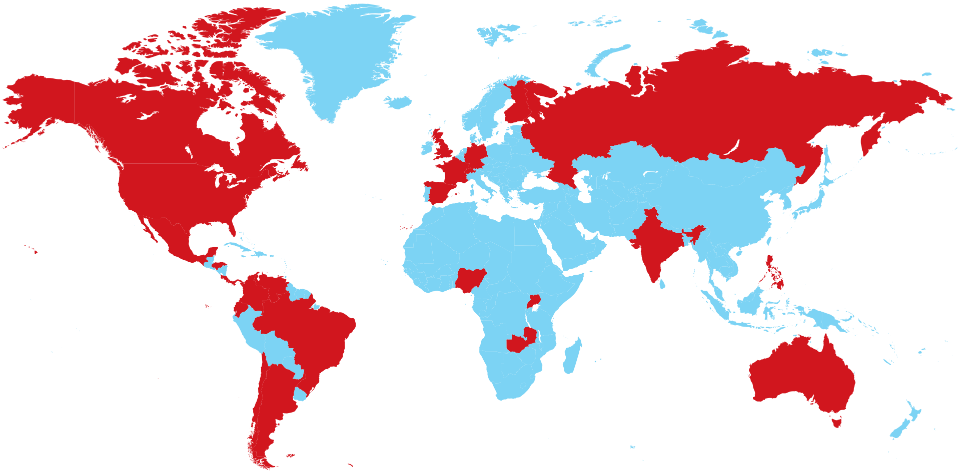
TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals living with HIV gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission to share accurate, reliable, and timely treatment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

BE GREEN.
SHARE OR RECYCLE
THIS MAGAZINE.

10:11 AM: THE BRONX, NEW YORK
Yonce Jones: I'm living and thriving with HIV. And the fact that I can't pass it on to others is priceless.
A SPECIAL SECTION OF PHOTOS FROM A DAY WITH HIV **BEGINS ON PAGE 33**.

Twenty-four countries were represented in photos taken on A Day with HIV:
Argentina • Australia • Canada • Chile • Colombia • Costa Rica • Brazil
Ecuador • Finland • France • Honduras • India • México • Nigeria • Panama
Peru • The Philippines • Russia • Spain • Uganda • The United Kingdom
The United States • Venezuela • Zambia



NOV+DEC 2022

POSITIVELY AWARE · VOLUME 32 NUMBER 8 · positivelyaware.com · @posaware

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BY **RICK GUASCO**

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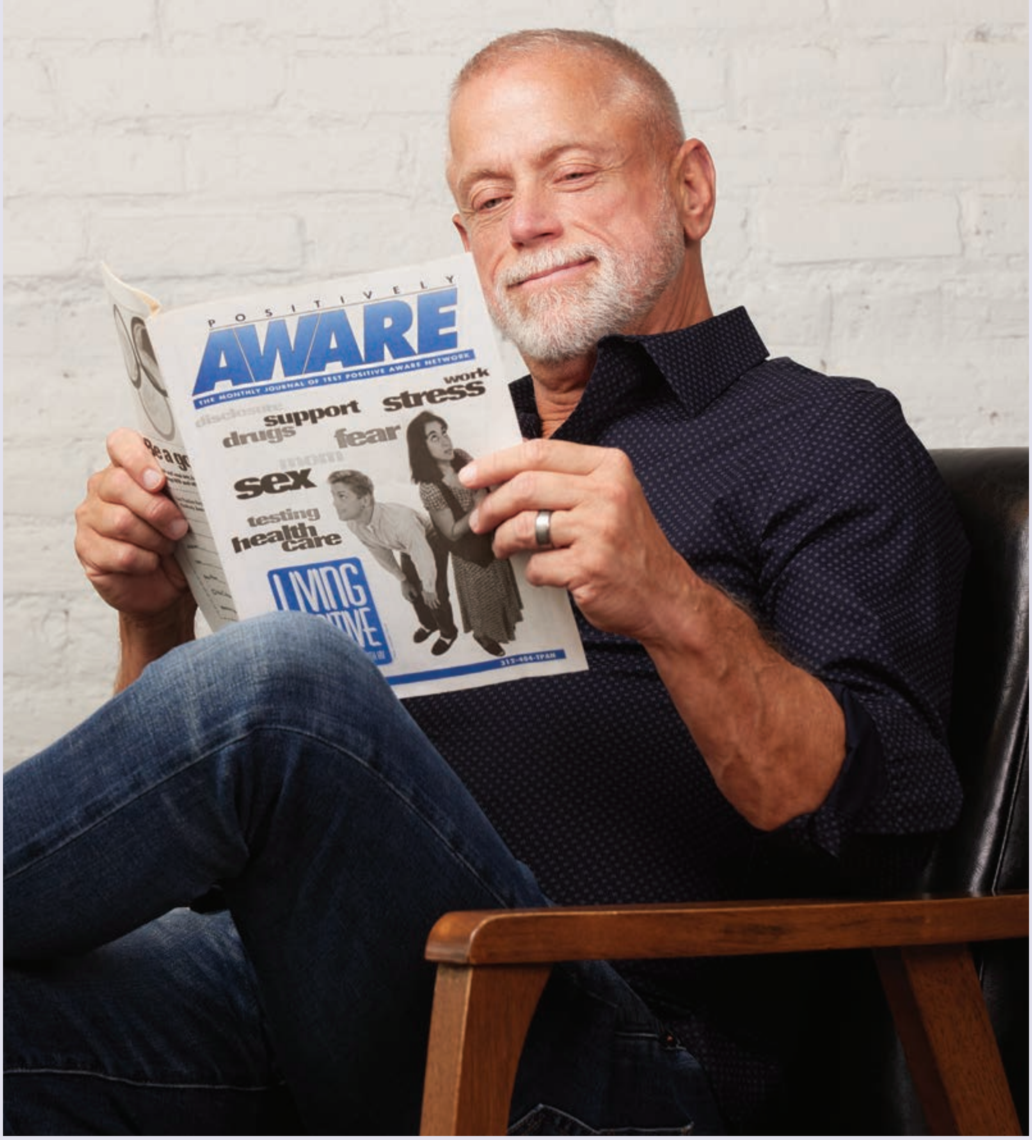
THE JEFF BERRY FUND
FOR POSITIVELY AWARE



As editor-in-chief of POSITIVELY AWARE for more than 18 years, Jeff Berry defined this publication. **The Jeff Berry Fund** will help continue the legacy of POSITIVELY AWARE in his honor.

Jeff was diagnosed with HIV in 1989 when he saw a copy of POSITIVELY AWARE in his doctor's waiting room. It was through the magazine that he came to TPAN as a client. He then started volunteering at TPAN, working on POSITIVELY AWARE, and eventually became editor-in-chief.

DID YOU KNOW:

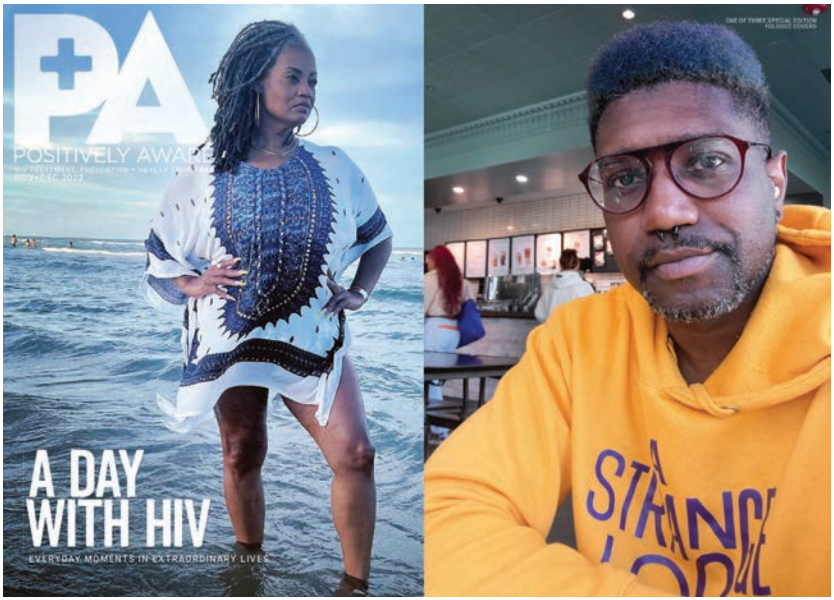
- POSITIVELY AWARE is the only nonprofit magazine in the U.S. that focuses specifically on HIV/AIDS.
- It is produced by TPAN, Chicago's oldest nonprofit social services organization serving people living with and vulnerable to HIV.
- One of its key purposes is to showcase the stories of people living with HIV and reduce stigma.
- More than half of the magazine's writers and contributors are people of color.
- POSITIVELY AWARE's annual HIV Drug Guide is an essential reference for people living with HIV and healthcare and social service providers.

THE GIFT YOU MAKE TODAY will help us achieve our vision for the magazine:

- Ensuring that everyone diagnosed with HIV in the U.S. has ***free access*** to POSITIVELY AWARE.
- Expanding the magazine's digital presence with webinars and podcasts and exclusive content.
- Offering a Spanish-language version of the magazine and the HIV drug guide.
- Expanding student access to POSITIVELY AWARE through colleges and universities.

Make your gift to **The Jeff Berry Fund**
positivelyaware.com/jeffberryfund

ONE ISSUE, THREE FOLDOUT COVERS. For POSITIVELY AWARE's annual anti-stigma campaign, this issue offers three versions of the cover featuring photos from A Day with HIV.



A Day with HIV portrays 24 hours in the lives of people affected by HIV. On September 22, 2022, people photographed a moment of their day, posted the pictures to their social media and shared their stories with the hashtag #adaywithhiv. An online gallery is on view at adaywithhiv.com.

<< 7:00 PM: SOUTH PADRE ISLAND

Michelle Anderson: When having an undetectable viral load is sexy AF!

< 9:05 AM: CHICAGO, ILLINOIS

Coleman Goode: Today I'm in my neighborhood Starbucks, taking an hour that I put aside daily to work on my book of short stories. These stories make up moments of my life that bring me joy, caused me pain, left me confused, and of course the ones that I look to for strength. I have been thriving while living with HIV for 16 years, and that is worth celebrating!

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Brandon M. Macsata: A Day with HIV is being the healthy, loving and proud Papa of this little guy, Sebastian.

Equity in vaccine development needs to be at the forefront

I agree with the arguments made by hepatitis C editor Andrew Reynolds in his guest editor's note, "Lessons Learned: Viral hepatitis in the COVID-19 pandemic" published in the July+August 2022 issue. I think it is essential, however, when highlighting problems of equity and health disparities to do it in a way that is systematically integrated into each point discussed instead of mentioning it at the end.

There is a lot to learn from the response to COVID-19, specifically in the domestic and global mobilization to develop a vaccine. The early and continuous public health guidelines and activities were impactful in containing the pandemic's spread. Yet, even with the addition of the vaccine, the U.S. surpassed more than one million deaths from COVID-19. Equal access to the vaccine was and continues to be a problem. The availability of the vaccine was a problem early on, as well as medical mistrust by some populations, dysfunctional health systems, and the stigma that resulted from the COVID-19 pandemic.

We might also have plenty to learn from COVID-19 around science and public health, but not in helping the HIV community overcome medical mistrust, stigma and access to functional healthcare systems. These critical issues affect access; it is not enough to educate and make the vaccine accessible. Some communities need to gain trust in a medical system that has constantly failed them and continues to do so. As the editor says, "The social determinants of health—including racism, poverty and access to healthcare and other services—had a dramatic impact on our COVID-19 outcomes." The same is said about HCV; we continue to see health disparities that, instead of being overcome, get exacerbated. It is good that we acknowledge it, but I believe it is time to give these issues the priority they need. Community mobilization and meaningful involvement must be front and center when confronting any epidemic or infectious disease. It needs to happen from the beginning of government and industry planning and implementation of responses. I believe the lessons learned from COVID-19 could influence our efforts to develop a vaccine for HCV, but I doubt that those lessons would help eradicate HCV.

—MOISÉS AGOSTO-ROSARIO
NMAC, WASHINGTON, D.C.

On a cool autumn morning, I wish I was snuggled on the couch with my furballs drinking a large mug of coffee while reading. Last Friday, I visited a handful of locally located Little Free Libraries in Oak Park [Illinois]. I snagged some copies of POSITIVELY AWARE to learn more about sexual health and mental health awareness. I recognize that I need more information and language to meet my clients where they are and to better inform myself with these communities. **—DOMINIQUE RODRIGUEZ** VIA INSTAGRAM

Associate Editor Enid Vázquez responds: Ironically, I go to three Little Free Libraries near POSITIVELY AWARE each week, and I thought people wouldn't be interested in an HIV publication. You have inspired me to contribute copies.

WHERE DO YOU FIND POSITIVELY AWARE?
Post a picture of where you find us and tag @posaware.

JOIN IN THE CONVERSATION
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JOHN GRESS

NOTE FROM THE ACTING EDITOR-IN-CHIEF

RICK GUASCO
@rickguasco

Hello

"Good luck," said the worried-looking post-test counselor as he told me my HIV test had come back positive. He handed me three publications—all produced by a Chicago HIV/AIDS services organization called TPAN—including this magazine. That was 30 years ago this December.

My body was already being covered by an ever-growing number of Kaposi sarcoma (KS) lesions, but I had been in denial since that first spot Memorial Day weekend. At the time, KS was classified by the Centers for Disease Control and Prevention as an end stage AIDS-defining illness. If you've seen pictures from the early "plague" years of people with AIDS who are covered in spots, that was me. That's why I've never seen *Philadelphia*, the 1993 film starring Tom Hanks as a gay man with AIDS who has KS; it hits way too close to home. Ultimately, I would have 150 lesions—50 on my head alone. I was 28 and scared; I didn't expect to see 30.

But the publications I was given were a clue, a hint. I realized that information—learning about HIV—was key to my survival. One of the TPAN publications contained a listing of local clinical studies, and I found a study that treated KS. Another publication was a listing of HIV-related services and programs available in the area. And the third publication was POSITIVELY AWARE.

It would take more than a year before the lesions faded and started to disappear that I felt comfortable enough to go out during the day beyond my monthly doctor's appointment and other necessary excursions. Once I did, I wanted to get close to the source of this lifesaving information, so I went to TPAN with the idea of volunteering to work on their magazine. Turned out they were looking for someone to do page layout—although they called the job *production coordinator.* And that's how I became art director—the first time.

That was the mid 1990s. While working on POSITIVELY AWARE, the first highly effective HIV treatments, protease inhibitors, were developed. We produced the first annual HIV drug guide. I left in 1997 to work for an LGBTQ newsmagazine. I didn't last long there, but I also didn't feel the sense of purpose I had at POSITIVELY AWARE. So, in 2010 when I was essentially offered my old job back, I jumped at the chance to return, this time as creative director. I felt connected to myself again.

That's what POSITIVELY AWARE does. It gives people living with HIV, and the people who care for them, a sense of connection. Readers have a relationship with our magazine. For more than 30 years, POSITIVELY AWARE has been a trusted resource; a connection to accurate, reliable information about HIV treatment while affirming the lives of people living with HIV by telling their stories.

In this new position as acting editor-in-chief, you'd think much of the job would have to do with... well, *editing*. But I've found that the key word is *in*. As in *in* meetings, *in* conversations, *in* conferences, *in* rapt attention listening to people living with HIV as they share their experiences, hopes and ideas.

As creative director, as editor and as an advocate for *all* people living with HIV, I believe in the power of creativity and collaboration.

People have told me that POSITIVELY AWARE is a platform. I rather see it as a stage for people living with and affected by HIV, spotlighting them, their stories and what matters to them. My place is backstage, behind the scenes.

It feels like I've come to, if not a destination, then a meaningful point in my journey with HIV. This magazine helped save my life, and I'm here now at a place to pay it back and return the favor.

You are not alone.

Rick

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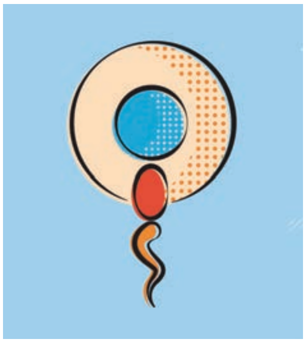
Briefly

ENID VÁZQUEZ @enidvazquezpa



Dolutegravir again found to be safe and effective in pregnancy

A study published online in the *New England Journal of Medicine* in September found that dolutegravir did better at reducing viral load than other preferred drugs for pregnant people living with HIV.

The research team noted that this was **the first study directly comparing the medications on the preferred drug list in U.S. perinatal HIV guidelines**.

At the time of delivery, the rate of undetectable viral load was

- 96.7% for people taking dolutegravir
- 89.2% for raltegravir
- 84% for ritonavir-boosted atazanavir

Results for the fourth preferred drug, darunavir, were not provided.

"We think the observed differences are due to dolutegravir's ability to rapidly decrease viral loads and its ease of use as part of a once-daily regimen that's available as a fixed-dose combination," said lead author Kunjal Patel, a senior research scientist at the Harvard T.H. Chan School of Public Health, in a press release.

The observational study looked at pregnancy data from the Pediatric HIV/AIDS Cohort Study here in the U.S. About half of the individuals were already taking HIV medications at the time of their pregnancy. Altogether there were

- 120 individuals on dolutegravir;
- 464 on ritonavir-boosted atazanavir;
- 185 on ritonavir-boosted darunavir;
- 243 on rilpivirine (Edurant, found in Odefsey and Complera);
- 86 on raltegravir; and
- 159 on cobicistat-boosted elvitegravir (found in Genvoya and Stribild)

There were also supplementary analyses from data in the Swiss Mother and Child HIV Cohort Study.

"No clear differences in adverse birth outcomes were observed with dolutegravir-based ART as compared to non–dolutegravir-based ART, although samples were small," the team reported. Among adverse outcomes the study looked for were preterm birth, low-birth weight, and small size for gestational stage.

DHHS preferred ARVs in pregnancy

The **preferred HIV drugs for use in pregnancy**, according to guidelines from DHHS (the U.S. Department of Health and Human Services), are:

- the single-tablet regimen Triumeq (consisting of dolutegravir/abacavir/3TC) or one of the following drugs plus a preferred background medication:
  - Tivicay (dolutegravir)
  - Isentress (raltegravir, must be taken twice daily in pregnancy)
  - Norvir-boosted Reyataz (atazanavir/r)
  - Norvir-boosted Prezista (darunavir/r, must be taken twice daily in pregnancy)

Dolutegravir is the newest of these medications. The other single-tablet regimens for HIV treatment, which are also newer meds, are not recommended in pregnancy because of lacking or limited data (such as with Biktarvy and Delstrigo) or data showing less efficacy in pregnancy (as with medications that include cobicistat, such as Genvoya and Stribild). The two-in-one single-tablet regimens containing dolutegravir, Dovato and Juluca, don't have much pregnancy data, but DHHS noted that the separate medications in these pills are approved for use in pregnancy.

Nevertheless, pregnant individuals taking these other medications at the time of conception may not need to switch them—more frequent viral load testing may be all that's required. See the considerations for individuals already taking HIV antivirals at the time they conceive at bit.ly/pregnancy-guidelines-whats-new. It is recommended, for now, that the long-acting complete injectable regimen Cabenuva be switched in pregnant individuals.

GO TO clinicalinfo.hiv.gov for treatment guidelines. **READ** about the HIV medications at positivelyaware.com/2022-hiv-drug-guide. Pregnant individuals can voluntarily enroll in the Antiretroviral Pregnancy Registry through their provider; **GO TO** apregistry.com.

'Monkeypox' is out, 'mpox' is in

The World Health Organization (WHO) in late November changed the name of the monkeypox virus to "mpox." "When the outbreak of monkeypox expanded earlier this year, racist and stigmatizing language online, in other settings and in some communities was observed and reported to WHO. In several meetings, public and private, a number of individuals and countries raised concerns and asked WHO to propose a way forward to change the name," the international agency reported. Both names will be used over one year as "monkeypox" is phased out. For more information, **GO TO** bit.ly/3GPwCZv.

Expanding mpox testing

The U.S. Food and Drug Administration (FDA) in September announced it has published **new guidance to expand the country's ability to test for the mpox virus**.

"Today's important actions further aid the monkeypox response by working toward expanding vital testing capacity and facilitating the detection of cases nationwide in an effort to stem the spread of the virus," said Jeff Shuren, MD, JD, director of the FDA's Center for Devices and Radiological Health, in a press release. "The policy

VÁZQUEZ: JOHN GRESS · ILLUSTRATION: ISTOCK

TOP OF THE NEWS

➤ “Monkeypox” is out, “mpox” is in ➤ Dolutegravir again found to be safe and effective in pregnancy ➤ DHHS preferred ARVs in pregnancy ➤ Most mpox hospitalizations were in people living with HIV ➤ Expanding mpox testing ➤ Jeff Berry joins The Reunion Project ➤ The Center for HIV Law and Policy’s new leader ➤ Federal judge rules against PrEP ➤ Barlesque celebrates life as a community ➤ Trans-led center receives 340B funding

announced today is intended to support the development of more validated monkeypox tests and expand access to testing.”

The FDA also granted Emergency Use Authorization (EUA) to Quest Diagnostics for a test to detect monkeypox and other viruses.

To subscribe to the agency’s mpox response page, **GO TO** fda.gov/emergency-preparedness-and-response/mcm-issues/fda-monkeypox-response.

Most hospitalizations due to mpox were in people living with HIV

Most people hospitalized with severe cases of mpox virus have been gay, bisexual and other men who have sex with men (MSM) who were also living with HIV, and most of them were Black men, according to a recent report from the U.S. Centers for Disease Control and Prevention (CDC).

“**Monkeypox and HIV have collided with tragic effects**,” said Jonathan Mermin, MD, PhD, in a news release from the agency.

The CDC reported that, “During August–October 2022, CDC provided clinical consultation for 57 hospitalized patients with severe manifestations of monkeypox, most of whom were Black men with AIDS. Delays were observed in initiation of monkeypox-directed therapies. Twelve patients died, and monkeypox was a cause of death or contributing factor in five patients to date, with several other deaths still under investigation.”

CDC advises that, “Clinicians should consider early treatment with available therapeutics for those at risk for severe monkeypox disease, particularly patients with AIDS. Engaging all persons with HIV in care remains a critical public health priority.”

The CDC recommends that all sexually active people with suspected mpox infection be tested for HIV unless they already have a positive diagnosis.

- Forty-seven (82%) of the 57 hospitalized patients were living with HIV.
- Of the 43 individuals, 31 (72%) with a known CD4 count had less than 50.
- Only four of the individuals living with HIV (9%) were on HIV therapy.

Overall, most of the individuals were men (95%), and 68% were non-Hispanic Black. The median age (half of the group were above this number and half were below) was 34 years old, with an age range of 20 to 61 years. Seventeen patients (30%) were treated in the ICU (intensive care unit).

All of the individuals had severe skin infections, as to be expected, but 39 (68%) also experienced severe mucosal lesions. Some had the mpox virus spread to other organs, including the lungs (12 individuals, or 21%), eyes (12, 21%) and brain or spinal cord (four, 7%).

In terms of other conditions:

- three individuals were solid organ transplant recipients
- three individuals were pregnant
- nearly one in four of the individuals (23%) were experiencing homelessness
- two individuals (one of whom was living with HIV) were undergoing chemotherapy for a hematologic malignancy

These are cancers that begin in blood-forming tissue such as bone marrow and in cells of the immune-system. These include leukemia, lymphoma and multiple myeloma.

The 12 deaths represented 21% of the 57 cases, a little more than one in five of the patients.

In terms of treatment:

- 53 (93%) received oral tecovirimat (TPOXX or ST-246), and 37 (65%) received intravenous tecovirimat
- 29 (51%) received the medication vaccinia immune globulin intravenous (VIGIV), and 13 (23%) received intravenous cidofovir
- all of the individuals who received cidofovir or VIGIV also received tecovirimat

GO TO the November 4 *Morbidity and Mortality Weekly Report* (MMWR): bit.ly/3UNfbwE.

Trans-led center receives 340B funding

Arianna’s Center in Fort Lauderdale, which serves a large immigrant base, has become **the first trans-led organization in Florida to receive 340B funding**. The pharmacy-support program is set to start in early 2023. “We’re helping to lead the way for other trans-led organizations,” said founder and director Arianna Lint. The center will help its clients receive PEP and PrEP as well as hormones in addition to HIV medication. (See story on providing free PrEP to undocumented immigrants on page 18.) **GO TO** ariannas-center.org.

Jeff Berry joins The Reunion Project

Former POSITIVELY AWARE editor-in-chief Jeff Berry has been named **the first executive director of The Reunion Project** (TRP), leading a coalition that he helped establish for long-term survivors of HIV.


BERRY

After 30 years of working for TPAN, the nonprofit HIV services organization in Chicago that publishes

TEST TUBE: ISTOCK · BERRY: JOHN GRESS

POSITIVELY AWARE—the last 18 of those years as editor—Berry turned increasingly towards advocacy for long-term survivors of HIV. He co-founded The Reunion Project with several other community advocates, holding get-togethers for survivors around the country.

According to their website, “Founded in 2015 by activists living with HIV, The Reunion Project (TRP) is the national alliance of long-term survivors of HIV, collaborating with local and national HIV advocates, providers and researchers. Together, we convene and connect individuals and communities, sharing our experiences of survival and loss while honoring our past, and developing successful strategies for living and supporting one another—today and into the future.”

"I am thrilled to be a part of this great organization, and grateful to the funders who helped make it happen," Berry said in a press announcement. “We are on the cusp of a silver tsunami of people living and aging with HIV who require services tailored to their unique needs. Isolation and other mental health issues have been exacerbated by COVID-19, so there is no time to waste and no better time for renewed focus on the myriad issues facing long-term survivors and people aging with HIV."

Shortly after his HIV diagnosis in 1989, Berry saw an ad for volunteers to distribute POSITIVELY AWARE during a monthly gathering. He was soon hired as the magazine's distribution coordinator. His talents and skills led the agency to give him increasing responsibilities over the years, including advertising and proofreading—earning him the nickname “Eagle Eye” after catching typos following publication. He led website development efforts at the dawn of the internet era, working his way up until becoming editor-in-chief in 2005. He handled it all with grace and expertise.

"We were honored to support The Reunion Project and know that Jeff and the steering committee will build on the body of work to elevate the voices, experiences, and needs of long-term survivors in our national dialogues around ending the HIV epidemic,” said Marc Meachem, head of U.S. External Affairs for ViiV Healthcare. "I'm excited and encouraged to see the tireless work of a diverse group of long-term survivors evolve from an all-volunteer effort to the naming of a full-time executive director.”

Darwin Thompson, director of Corporate Giving at Gilead Sciences, Inc., said, "We are proud to support The Reunion Project and its network of long-term survivors. Gilead knows the importance of facilitating organic connections and empowerment opportunities for long-term survivors through creative programming. The work of The Reunion Project has been critical to cultivating these safe spaces.”

Berry’s editorials in POSITIVELY AWARE over the years brought his kindness and light to an often-troubled world seeking solutions. As Lynda Dee, co-founder of AIDS Action Baltimore, put it perfectly, “He’s all Zen.” And that’s a good thing.

LEARN MORE about TRP at reunionproject.net.

HIV law center names new leader


MOORE-O’NEAL

The Center for HIV Law and Policy (CHLP), in New York, has named S. Mandisa Moore-O’Neal as its new executive director. The national organization **battles stigma and discrimination, particularly within the criminal justice and public health arenas**.

A civil rights attorney, Moore-O’Neal oversaw her Black feminist law and policy practice in New Orleans focusing on advocacy and litigation around HIV criminalization, family law, public accommodations discrimination, and police accountability. CHLP founder Catherine Hanssens will step up from executive director to the new role of chief strategy advisor.

“CHLP has always centered a bold political analysis that expands our collective understanding of systemic oppression against

Barlesque: Sexy for ourselves
Celebrating life as a community

In more than three decades of service, the nonprofit HIV services organization that publishes POSITIVELY AWARE, TPAN, has always been sex-positive. We have consistently reflected sex positivity in our images and education and our special events and fundraisers.

Community partners have always played an important part in these activities. For our most recent sexy fundraiser, Barlesque, were some of Chicago’s most faithful gay bars. Over the past couple of years, sexy bartenders and barbacks went online to perform a virtual burlesque photo slideshow, revealing more as they raised funds. This year, **performers were paired with professional choreographers to create a live revue** that was held September 30 at Center on Halsted, the city’s LGBTQ community center.

Craig Cherry of Sidetrack won the crowd favorite award for stepping onto the stage dressed as a boxer—with a couple of hot assistants to help him out of his robe. Ross Harrington of the Lucky Horseshoe performed as an alien who’d fallen to Earth a la Bowie, also with a hot assistant who helped him out of his coat. Viktoria Kay-Frost (Sebastian Velmont, originally from England) from Replay Andersonville was joined by a bodacious butch female assistant to act out a sexy “Skin Mix.” Marcus Stephen of Hydrate performed a stupendous butch/femme dance number titled *This is Me*. And the bartender who raised the most money, representing the leather community, was Luís Eudave of Cell Block, with choreographer Cocoa Pearlesque, performing a vampire seduction mix (featuring a riff off the sensuous “Sucker for Pain” by Lil Wayne, Wiz Khalifa, Imagine Dragons, Logic, Ty Dolla $ign and X Ambassadors).

We needed this after the pandemic’s lockdowns. Out in the community, together again. In previous years, Chicago’s dance community staged a fundraising performance for TPAN called Chicago Takes Off—use your imagination. The theme one year was *Under a Big Top*—what fun.

More than $50,000 was raised. “I’m excited to raise money for TPAN,” said Stephen, who came from Manilla, the Philippines as a child. He was inspired to dance because of the cheerleading he did as a high schooler in the U.S. “I’m extremely competitive and love supporting important causes for myself and my community.”

So thank you, community, for always being there for us. For helping us reject the harms of repression. For celebrating life, in all its glory. For as long as we’re here, let’s dance. And so much more.

BARLESQUE PHOTOS: JEFF RAMONE

people living with HIV while simultaneously leading the strategies to remedy the oppression," said Moore-O'Neal in a press release. "I came to know CHLP as a formative partner in our statewide work. Now is the political moment for continued transformative and accountable leadership and that is what I will carry forward."

READ her brilliant article on abolition and HIV criminalization at positivelyaware.com/issues/september-october-2020. CHLP coordinates the Positive Justice Project, which works state-by-state to change harmful laws. **SIGN UP** for its newsletter at hivlawandpolicy.org.

Judge rules against PrEP

A Texas federal judge ruled in September that **requiring employers to provide health coverage that includes HIV prevention drugs is unconstitutional**, saying that it violates the religious freedom of a Christian-owned company.

The ruling by Judge Reed O'Connor of the U.S. District Court for the Northern District of Texas could jeopardize the ability of the Affordable Care Act (known as Obamacare) to require which preventive health services and drugs must be fully covered by private health insurance. Under the ACA, employers must provide insurance coverage for drugs prescribed for HIV prevention, known as PrEP. Braidwood Management, Inc., a company based in Fort Worth, filed suit in 2020, charging that requiring the company to offer PrEP "facilitates and encourages homosexual behavior."

The Los Angeles LGBT Center issued a statement saying, "While the ruling is incredibly disturbing, we first want our community and allies to understand that its scope is currently limited to Braidwood, the Texas employer named in the lawsuit, and its 70 employees. It also undermines the bipartisan plans of the United States government to end HIV by 2030."

"As a person of faith who also appreciates logic and reason, it is clear this decision is not about religious animus or freedom, but the continuation of politics, partisanship, and a supremacist ideology designed to maintain marginalization by advancing the heterosexual agenda," said Dr. David J. Johns, executive director of the National Black Justice Coalition. "Medication to prevent the transmission of HIV is less accessible to Black same-gender loving men like me."

"This shocking ruling defies evidence, logic, public health and human rights, and sets back enormous progress made in the fight to end the HIV epidemic in the U.S. and globally," said Mitchell Warren, executive director of AVAC, a global advocacy organization for HIV prevention. "It is a blatantly homophobic and misogynistic ruling that will endanger the lives of many gay men and others who rely on PrEP to protect themselves from HIV."

Carl Schmid, executive director of the HIV+Hepatitis Policy Institute, said he expects the case will soon be appealed. —**RICK GUASCO**

I haz teeth

For the 20 years I've had my photo used for *Briefly*, I have never smiled. It's not because of my big gap. I love my gap. People kept wanting me to smile for my photo, but I said I didn't want to write "AIDS continues to kill people," and then I'm laughing in the pic. Over the years I came to use a slight upturned, closed-mouth smile, just to show a little warmth.

But with my new photo on page 10, you see my teeth. (I actually have all 32 of them, which my dental hygienist says is unusual for someone my age.) The epidemic has over the past several years finally come to the point where I can present overwhelmingly good news about treatment. That's something to smile about. New medications that are easier to take! People are living longer, healthier lives!

No doubt that there are still difficult stories to tell. Just before we went to press, I spoke with DeMarc Hickson, PhD, executive director of Us Helping Us in Washington, D.C. I told him I had long wanted to write the story of how young Black gay men are still dying from complications of AIDS. (We're talking out of proportion to their numbers.) He told me, "We just had a member die two and a half weeks ago because he wouldn't take his medications." This is tragic.

So there's still much work to be done—as everyone knows. But there's also so much to be grateful for. So, smile. It even makes you feel better. Maybe it can give us all fuel for the work to be done.

Volunteers assemble fentanyl kits to save lives

Just three days after TPAN's Barlesque finale, we went from stripping to strips—fentanyl test strips, that is. We welcomed **volunteers from all over the city to put together kits of fentanyl test strips and Narcan nasal sprays to reverse overdoses**. The kits will be distributed by the Chicago Department of Public Health (CDPH). And we had fun doing it. A couple of the volunteers said they had been interested in giving back after after receiving their monkeypox vaccine at TPAN. Thank you, community.

Narcan Nasal Spray: When an overdose occurs with fentanyl, a higher amount of Narcan is needed to reverse it. After calling 911, give the first Narcan spray. If the symptoms continue for two or three more minutes, give another dose.

Fentanyl test strips: Use a few drops of water. Add a very small amount of the substance. (For pills, scrape the side). Dip the white side of the strip for 10 to 15 seconds. Remove it and wait 60 seconds. *One red line—even a very light color—means that fentanyl is present.* Two red lines means it's not.

According to CDPH outreach material, "Fentanyl is an opioid *50 times more potent than heroin.* When illegally made, fentanyl comes in a *white/gray powder* that can be injected, smoked or snorted. Fentanyl is found in meth, cocaine, heroin and other pills. Fentanyl is *not* resistant to naloxone (Narcan).

VOLUNTEERS ASSEMBLING KITS AT TPAN

You *cannot* overdose simply by touching fentanyl. Symptoms of overdose include slow, shallow breathing, choking, limp body, skin that is pale, blue or cold, falling asleep or loss of consciousness, and very small pupils. *Call 911 if you think someone is overdosing.*"

Overcoming

What have you done to overcome HIV stigma?

We asked our social media followers, and they responded

COMPILED BY **RICK GUASCO**

“I confront it head on from a place of strength. They can’t stigmatize me because I’ve always been open about my status. But I understand that comes from a place of privilege. So, I stand up for others who aren’t where I am.”

—**JEFFERY PARKS**

“I pause, I take a breath, then I educate!”

—**WANDA BRENDLE-MOSS**

“The virus does not define me and I have many things to give, but I can't give anybody HIV!”

—**@sascha_rex**

“I educate. That’s how I overcome stigma.”

—**@smash719019**

“My perception of stigma is that it is based on misunderstandings and ignorance. It’s in people’s heads, and it’s just an opinion, and each one's opinion is their problem. Not mine.

“One cannot disagree with facts. I confront stigma with information. I educate myself and I know what is true and what is not about HIV and AIDS. This knowledge kills the fear.

“I was diagnosed with HIV already in the last stages of AIDS. Today, just a bit over two years later, I live a completely normal life. I’m healthier than I've ever been. I disclosed my HIV status publicly a few months ago and since then I can not only control the narrative but I can also help other people living with HIV feel more confident about themselves. HIV doesn't bring me any more harm; why would I let the opinion of others make any difference in my life? The stigma doesn't affect me because I don’t let it. It has no power over me.”

—**positivetalkwithmaya**

“Stare them in the eye and ask, ‘What’s up?’ Educate!”

—**DHORUBA KHALI**

“Educate people on what living with HIV is like now—no longer a death sentence.

“Yes, women with HIV can have babies who are HIV negative. Men with HIV, who are virally suppressed, can make babies without fear of passing the virus to the baby's mother or their baby.”

—**XIO MORA-LOPEZ**

“I overcome by living life as the normal person I am. I’m very open about my HIV status because I want no person to go through that diagnosis or disclosure alone. If people can hear my story and know that life can still be okay after HIV and hear my experience without having to go through it themselves, I feel I’m doing my job as a person with a voice in this world. I hope people know that whatever they are going through they will be okay as well. I overcome by being a mom to my three HIV-negative children and being a good wife to my husband who loves me so much and who sees me beyond my HIV. This year, I’m 19 years positive and I look forward to seeing what life throws at me because I know I will overcome. I’m Tamara and I am the Face of HIV.”

—**TAMARA D. MAYFIELD**

“As a heterosexual married couple with us both 16 years into living with this diagnosis, we've had wild conversations with people dealing with external as well as internal stigma. Our answer to this question is confidence and education. First, being confident in your own skin and in knowing the real truth about people living with or someone in alliance with people living with HIV. Second, being educated on the subject and willing to educate those that only have incorrect or outdated information including myths and rumors about HIV. That is our formula for confronting and overcoming stigma.”

—**KALVIN AND EUNICE MARSHALL**

“I overcome by being part of a great heterosexual men with HIV group that just had a great event at the International Conference on Stigma.”

—**DEREK CANAS**

“My expectations make a difference in how others perceive me. I try to expect positive reactions, which means I don’t try to hide my HIV status or to be confrontational about it. I try to care more about others than about what others think. I show others I’m proud and grateful for my long-time survival status. And they respond accordingly most of the time.”

—**HARRY C S WINGFIELD**

“I am open about who I love and my HIV status, and I will not give someone else power over my life. Besides, as I share my status, I become more free with very little push back. Stigma may be what you fear happening holding you back.”

—**ROY FERGUSON**

“I stomp on stigma by showing my face and humanizing this condition.”

—**MARIA HIV MEJIA**

“I am Latino, I am gay, I am an immigrant, I am undetectable, I am a father, I am a grandfather, I am a Christian man, I am married. I love helping others because that's how I help myself. One thing I am not is HIV, because the virus I share my body with does not define me; I am a just a very normal human being living with HIV! *Comprende*?”

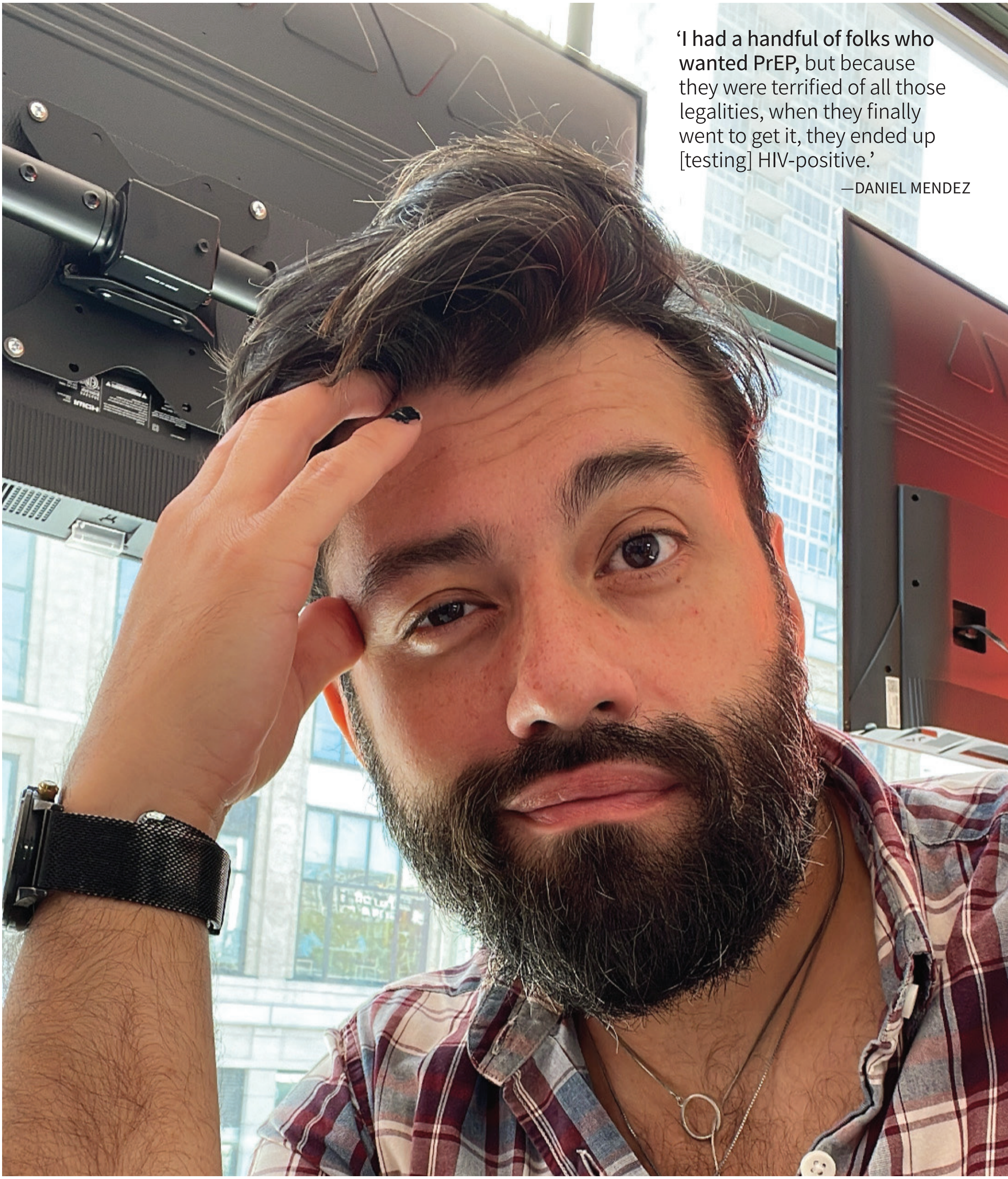
—**VICTOR CLAROS**

LEMONO-ISTOCKPHOTO

Yes, undocumented immigrants

But legal confusion continues to feed the HIV epidemic

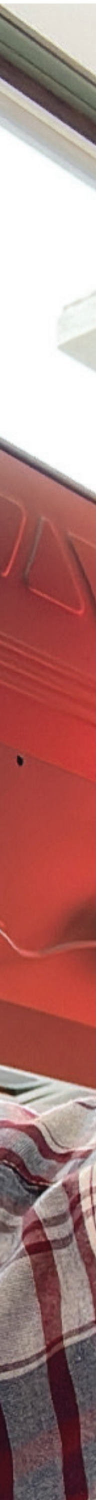
BY **ENID VÁZQUEZ**



‘I had a handful of folks who wanted PrEP, but because they were terrified of all those legalities, when they finally went to get it, they ended up [testing] HIV-positive.’

—DANIEL MENDEZ

can get free PrEP



It’s sad that HIV can spread simply because people are confused about prevention.

That’s the reality for undocumented immigrants and by extension, their sex partners. To be clear, we’re talking primarily about gay and bisexual men. Too often they’re given incorrect advice, being told that they do not qualify for free PrEP medication for the prevention of HIV because of their immigration status. That’s just not true, whether they’re visiting to attend the White Party or staying to work.

“Anyone in the United States over the age of 14 weighing at least 77 pounds can get free PrEP, whether they’re undocumented or not,” says Joshua Gutierrez, the prevention and health education manager at TPAN, the community-based HIV/AIDS nonprofit that publishes POSITIVELY AWARE (see “Let’s Talk,” January+February 2022). “I can’t tell you how many times visitors to the United States would call Howard Brown [Health Center, the Chicago LGBTQ clinic where Gutierrez worked as a PrEP navigator] and say, *I’m here from the Netherlands for three weeks and I want PrEP*. Well, *No problem*. Or, *I’m here from Germany on a student visa for six months and I want PrEP, but I don’t have insurance*. Again, No problem.”

Daniel Mendez also worked at Howard Brown for years as a PrEP program manager, and was successful at getting many undocumented clients onto HIV prevention medication. “In terms of people who are undocumented, I never ran into any issues helping folks access medication,” Mendez says. Today he works as a program manager at EDDR Foundation, which focuses on workforce job development to enhance the lives of Black and Brown people, assistance that includes housing, transportation and recovery coaching.

Undocumented immigrants are often advised by lawyers, family members and friends not to access “government services.” Err on the side of caution, they say, to avoid being identified by the federal government. But not taking advantage of PrEP can be a big mistake.

“I had a handful of folks who wanted PrEP, but because they were terrified of all those legalities, when they finally went to get it, they ended up [testing] HIV-positive,” says Mendez. “And they themselves said, *I just wish I would have spoken to somebody*.”

But who they talk to makes all the difference. A PrEP navigator would explain their eligibility for PrEP and help them get it.

Seeking help

Mendez did have one instance with Gilead Sciences, getting the company to donate one of its PrEP medications, in which the company asked why the client didn’t simply use his health insurance. When Mendez checked, his client said, *Hey, listen, this is not my Social Security number*. He had been using a friend’s number to apply for work.

“It was a simple thing that Gilead was able to address,” says Mendez. “This is maybe about four years ago, and this person is still on PrEP.” He says it shows the benefit of having an advocate in your corner.

Accessing free PrEP and prevention services does not jeopardize a person’s immigration status. That’s because the U.S. Citizenship and Immigration Service (USCIS) cannot access medical records, period—*punto*. The Health Insurance Portability and Accountability Act (HIPAA) prevents it. HIPAA protects everyone’s medical privacy. PrEP navigators are in a perfect position to explain that.

It’s the work of PrEP navigators to stay up to date on everything that’s available for clients in their area. Contrary to legalistic fears, that does include services using government funds.

Many roads

“There are different ways to get PrEP,” explains José Javier, a former PrEP navigator who is now a community coordinator and trainer with Holy Cross Health in Fort Lauderdale.

A federally qualified health center (FQHC) can provide PrEP services. Organizations and clinics can use 340B program revenue—government funds intended to help covered entities stretch their health dollars. They can use general revenue or donation dollars. People can get assistance for prevention meds through the “Ready, Set, PrEP” program from the U.S. Department of Health and Human Services (DHHS). They can help individuals register for free PrEP medications through pharmaceutical companies (in addition to Gilead’s oral medications, ViiV Healthcare has an injectable PrEP drug, Apretude, administered once every two months).

Having so many options can lead to confusion. “That’s why we advocate for using PrEP navigators, because they will take them there the easiest way possible,” said Javier. No matter how capable a case manager or other social worker may be, he says, a PrEP navigator is best equipped.

Immigration

Lawyers, however, are not PrEP navigators. They cannot be expected to have that level of knowledge or expertise. They aren’t expected to work with pharmaceutical companies, local health departments, HIV service organizations, federally qualified health clinics, or the federal government’s Ending the HIV Epidemic (EHE) initiative. Lawyers who work in health, especially HIV rights, however, do often talk with these organizations on a regular basis.

Immigrants of any status are advised against using public benefits because they are supposed to demonstrate self-sufficiency or sponsorship—to not be a burden on the government. But public health and public benefits are two different things. Again, PrEP navigators are in a perfect position to explain that.

The public health arena focuses on *public health*. In HIV, that means preventing transmission (in addition to protecting the health of people already living with the virus—which also prevents transmission in its own way). HIPAA privacy promotes the use of health care services.

“Immigrants who receive cash or long-term institutional housing may be considered a public charge, which can derail efforts to get a green card. Receiving other benefits like Medicaid or SNAP [Supplemental Nutrition Assistance Program] does not make an immigrant a public charge,” explains

Ronda Goldfein, executive director of the AIDS Law Project of Pennsylvania.

LGBTQ immigrants

Numbers for the undocumented U.S. population are not easy to determine. Among adult LGBTQ-identified immigrants, there were approximately 267,000 who were undocumented, researcher Gary J. Gates reported in a 2013 study published by the Williams Institute of the UCLA Law School. Of these individuals, 71% were Latinx and 15% were Asian or Pacific Islanders.

A new recommendation on “the critical role of peer navigators” to guide people through health services was added by the World Health Organization in July to its updated Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations.

Moreover, the Centers for Disease Control and Prevention (CDC) is practically going hoarse reporting that not enough people considered most eligible for PrEP in this country are taking advantage of it.

Dealing with fear

PrEP navigators working with immigrants are not downplaying their fears. They’ve heard horror stories of the bad things that have happened to friends of their clients. The barrier to prevention is real.

For immigrants who are undocumented, there’s fear of imprisonment and of deportation, legal matters that can cause great harm. This includes being returned to regions where they face violence. In the HIV community, transgender women imprisoned while awaiting deportation have been killed.

“They might rather be safe in terms of their immigration status than be safe sexually because of fear about the government coming after them,” says Mendez. “We still need to alleviate that fear. People would be like, *Hey, I don’t want to say this, but now that I lied, is it going to come back to me? Are they going to have documentation that I lied by using somebody else’s information?* And that’s not at all how that works.

‘I always like to point out and stress that they need to put their health first.’

“A lawyer is going to say, *Err on the side of caution. Don’t access these services. Don’t activate benefits.* So it makes sense for somebody to do that,” Mendez continues. “But what happens over time is that there are always either new laws and new amendments, or even just updates on existing policies.” He found that when people received incorrect or confusing information, they stopped trying to access PrEP. “The assumption is, I can’t get it.”

Says Javier, “At some point it was prohibited for people to migrate into the U.S. if you were living with HIV. Then President Obama changed that. Now [some] people make it more difficult to prevent new transmissions of the disease that you didn’t want to come in in the first place.”

College students

Andrea Rivera, a PrEP navigator at The Damien Center in Indianapolis, says that she always explains to people that, “*We don’t need to know your status per se.* But if someone is seeking asylum, we could even help with things like finding which community partners can provide free or discounted legal help, having interpreters, and finding immigration lawyers. If clients come in needing more than just PrEP, we must utilize our other community partners to meet those needs. Most clients prioritize their legal needs over their health, and we must be able to provide some help for them to want to take care of their health.”

She has helped dozens of undocumented individuals obtain PrEP. Many are from local colleges, most of them gay or bisexual men. Some were raised in the U.S., having been brought over as children without documents. “You wouldn’t be able to distinguish that they’re not necessarily from here because they grew up speaking English,” she says. “So they’ll tell me, *Technically, I was born in Venezuela. Now because of this, I can’t receive all the benefits anyone else can.*”

She tries to reassure them about their PrEP options. “What I like to say to people that I’m meeting for the first time is, *Know that everything is confidential. Nothing ever gets leaked or sent out to anybody. So the government doesn’t know that you’re coming to us trying to get free services. You are protected by HIPAA privacy laws. Despite your immigration status, you are still somebody who gets treated with dignity. You are someone*

What is PEP?

PEP—post-exposure prophylaxis—is medication to prevent acquiring HIV after a possible exposure. PEP must be started within 72 hours of possible exposure.

Immediately contact your health care provider, an urgent care provider or an emergency room about PEP if you think you’ve recently been exposed to HIV:

- during sex (for example, if the condom broke)
- if unsure of partner’s status
- through sharing needles, syringes, or other equipment to inject drugs (for example, cookers)
- as a result of sexual assault

The sooner you start PEP, the better. Every hour counts. If you’re prescribed PEP, you’ll need to take it daily for 28 days.

PEP is primarily for unexpected exposures to HIV; it is not a substitute for regular HIV prevention methods—namely, PrEP (pre-exposure prophylaxis). As such, PEP is not the best option for people who may have frequent exposure to HIV. These individuals would do well to talk with their health care provider about PrEP.

If taken within 72 hours after possible exposure, PEP is highly effective in preventing HIV. But to be safe, you should take other actions to protect your partners while you are taking PEP. This includes using condoms with sexual partners and not sharing needles, syringes or other equipment to inject drugs.

PEP is safe but may cause side effects such as nausea in some people. In nearly all cases, these side effects can be treated and aren’t life-threatening.

Health insurance covers most costs for PEP. If you are uninsured or under-insured you can utilize a copay card.

To find an HIV specialist, check the referral list of the American Academy for HIV Medicine: providers.aahivm.org/referral-link-search or call (202) 659-0699.

The CDC has a YouTube video about PEP basics: bit.ly/CDC-PEP-basics.

who is able to receive services just like anybody else. No one is judging you for taking that initiative in protecting yourself. In fact, I admire it.

"And I always like to point out and stress that they need to put their health first. *If you're here six months, a year, two years, 20 years, it doesn't matter. If you want to protect yourself and you're taking that initiative, that is a big step. You have that right to protect yourself.*"

She still struggles to explain to people that they are safe. "I'm not sure exactly how to explain it to them in terms of how they're not jeopardizing their immigration status by getting services. Even explaining that HIPAA protects against government officials knowing what is happening with their health, I feel the hesitation is still there with certain people. They'll say, *Okay, but I'd rather not.* And those are some of the most vulnerable, most of the time. I can only tell them that I cannot force them to do anything, but I know this would be a great benefit. But I know that people don't want to play with the process of trying to obtain citizenship or even residency. I've heard horror stories from people of many nationalities. Then they say that one little mishap can jeopardize everything."

Javier points out that, "When you go to a clinic, they're always going to collect data from you. You can always leave the line for a Social Security number empty. If they need to collect data from you, they can always connect with you. If they ask on the spot, you can say you don't remember it. Some people don't remember their Social Security number. I don't think in public health you can be denied service based on immigration status."

Advocates over the years have cited unnecessary documentation as a barrier to prevention for all people, but perhaps especially immigrants. Some organizations no longer ask for a Social Security number or they make it clear that it's optional.

For anyone with limited resources, clearly the best way to get to HIV prevention with PrEP is through a navigator. They can even advocate for people with private insurance who face stigma in their clinic or expensive co-payments for access. They know best what's available—for everyone.

'What I like to say to people that I'm meeting for the first time is, *Know that everything is confidential.'*

—ANDREA RIVERA

A new world can be scary

"An immigrant's avoidance of the healthcare system is not just about whether they are documented or not," says Oswaldo Mendoza, an intern in medical case management at TPAN who's here on a student visa from Colombia. "They usually face two problems: fear and concern about economic resources."

Mendoza notes that in many cases, immigrants from Mexico and from Central or South America have such a low level of education, they don't know how to read or write in Spanish, much less English. On top of which, he says, the healthcare system is much more complicated in the United States than in their home countries. As a result, whether they're from rural regions or from urban—more sophisticated—areas, they may prefer to avoid clinics because they fear the complexity and the language barriers as well as the potential costs. They just don't know how the system here works.

OSWALDO MENDOZA

"So they only move in Latino circles, where they can speak Spanish and be understood. They'll go straight to La Villita [Little Village, a well-established Mexican neighborhood in Chicago] for medical care," he says.

They will also rely on friends, family and acquaintances for information and advice. "So if those people don't have accurate information, that can hurt them," he says.

Lots of things here can be scary. "I'm here legally and I'm afraid of the cops," Mendoza admits.

For people who say "learn English," I told him about the year I worked part-time at Instituto del Progreso Latino, between the border of my predominantly Mexican neighborhood, Pilsen, and Little Village. I was astounded at the hundreds of Spanish-speaking immigrants who worked all day long and then came to Instituto four days a week to study English from 5–9 p.m., Monday through Thursday. These were invariably people who were married and raising children. They were killing themselves—as I saw it—with this exhaustive schedule to make a better life for themselves and their families. Learning a foreign language is just not that easy, especially for people who are working. It's because of their amazing fortitude that my heart breaks every time I hear the words "learn English." I realized too, from my own parents and other immigrants (my parents are from Puerto Rico but I see our community as immigrants as well though they are U.S. citizens), that they know how to speak a lot of English, but are afraid to use it because they often stumble over their words when they do. It was something I also noticed among the highly educated students from around the world at the University of Wisconsin at Madison where I attended journalism school as an undergraduate. Their English was magnificent, but it was never to the level of their native language and that bothered them. And that's why my mother would ask me to translate for her.

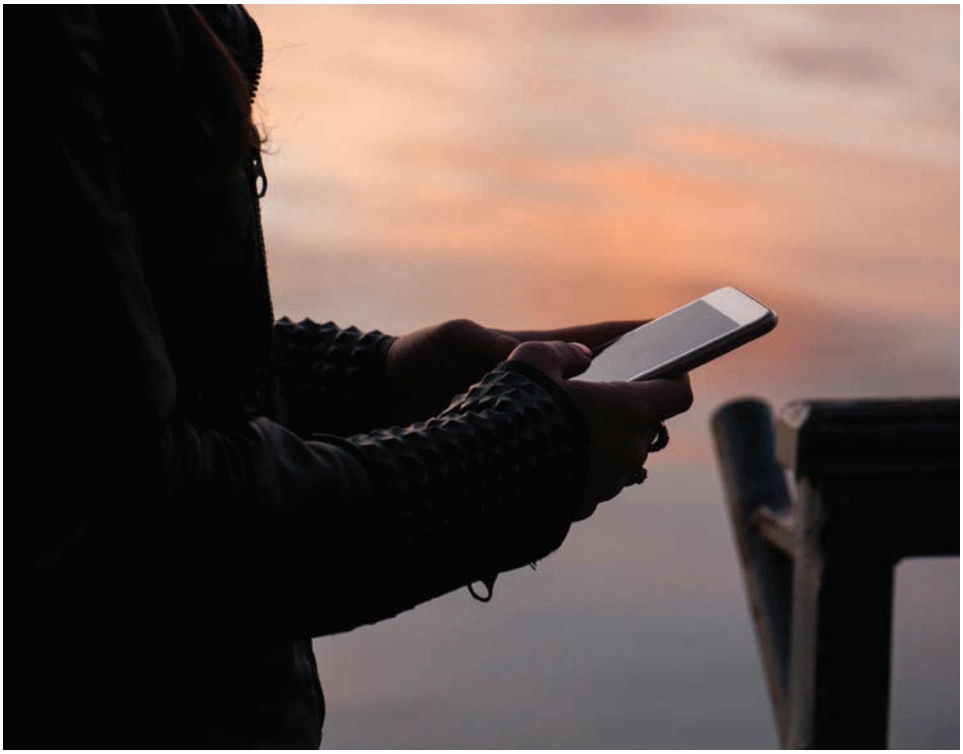
So please stop saying "they should learn English." Many already know it.

—ENID VÁZQUEZ

PUBLIC HEALTH AND INDIVIDUAL PRIVACY

Concerns about individual privacy surround the use of molecular HIV surveillance

BY KRISHEN SAMUEL



ISTOCK

There is ongoing debate about the ethics of using individuals' data in order to track HIV outbreaks at a molecular level, specifically related to concerns around the informed consent and confidentiality of people living with HIV.

Of particular interest is the use of a specific form of molecular epidemiology, phylogenetics, in this regard. Phylogenetics refers to the study of evolutionary relationships among entities, such as viruses. It can be used to identify two or more sequences that are closely related, the origin of outbreaks and factors associated with high rates of transmission, as well as helping to track drug resistance.

There is a difference between the use of phylogenetics in research contexts and for public health surveillance. Both applications were discussed at the recent 24th International AIDS Conference (AIDS 2022) in Montreal, with some believing it can be a highly beneficial technology when used with community consultation. However, community representatives were wary of the use of phylogenetics, and were quick to point out the potential for misuse—especially in instances where key populations are criminalized.

"The increasing clarity that these tools are giving us may allow for increased public health impact and improvements in our efforts to combat disease but there are also, of course, challenges that come with these new tools," stated Professor Charles Holmes from Georgetown University. "Challenges around educating ourselves about their appropriate use, and challenges understanding where the appropriate ethical boundaries may lie, so that we protect the rights of individuals."

Research vs. public health surveillance

Professor Christophe Fraser from the University of Oxford highlighted the immense benefits of phylogenetics in research contexts. For instance, if it were not for phylogenetic technology, we would not be able to say with certainty that Undetectable = Untransmittable (U=U).

In the studies that cemented the U=U finding, such as PARTNER 2, phylogenetic evidence was used to show that any HIV transmissions that occurred were not linked to the primary, undetectable partner. Phylogenetic analysis was required to prove that these transmissions occurred outside the relationship.

Phylogenetics provides information from the perspective of the virus, as opposed to more traditional epidemiological methods that rely heavily on the perspective of the individual.

However, the U=U studies were not without critique. Fraser highlighted that there is a degree of both observation and experimentation that occurs in these types of studies. This raises certain ethical questions: should more have been done to intervene prior to HIV transmission occurring? Also, despite the participants providing consent for their data to be used in this way, revealing that an HIV transmission happened outside the relationship certainly raises issues of trust between the partners and exposes potential infidelity for the purposes of scientific advancement.

Fraser argued that privacy is not the main issue. Instead, the ethical principles of beneficence (doing good), confidentiality and informed consent are the central principles that need to be upheld. While he emphasised the promise that phylogenetic research holds for HIV prevention in contexts such as sub-Saharan Africa, he said less about how research techniques could be misused when linking networks of members of key populations. Often, cluster detection may reveal behaviours that may be criminalized, such as same-sex relationships, injecting drug use and sex work. Instead, he suggested that the harms of molecular HIV surveillance can be mitigated through weighing potential risks and benefits in both research and public health surveillance, well-designed consent forms, anonymisation, and secure database storage.

Professor Peter Godfrey-Faussett, from the London School of Hygiene and Tropical Medicine, provided an alternative viewpoint, emphasising that while there may be strict ethical protocols in place for research with people, the same ethical protocols do not apply to public health surveillance. Consent is not always mandated and ethical principles such as beneficence (*Is the use of this technology more beneficial than more traditional methods?*) are less frequently discussed than in research. Additionally, there tends to be a trade-off between protections for an individual's freedoms and perceived public health benefits; one prominent example of this is public health agencies using COVID-19 testing data to enforce quarantines.

Godfrey-Faussett stated that this is a much wider conversation than just HIV and phylogenetic surveillance, as it speaks to multiple, broader issues. It is crucial to recognize that there are asymmetries of power, and that public engagement and dialogue is urgently needed to ensure that governance and regulation of a technology like phylogenetics catches up with its potential uses. Additionally, those using phylogenetics need to demonstrate strong evidence of actual benefits of doing so.

While some may take comfort in the idea that data is de-identified or anonymized for the purposes of public health surveillance, Godfrey-Faussett drew our attention to media headlines such as, "Five clusters of HIV identified in San Antonio, Hispanics affected most." While no individuals may specifically be named, the potential for stigmatization and harm to specific communities is evident.

Professor Bluma Brenner from the Lady Davis Institute provided an example of the insights gained from molecular HIV surveillance. Much of the 26% increase in HIV transmissions in Canada between 2014 and 2020 was attributable to immigration (subtype B arising from Haiti, Latin America and the Caribbean) and failures to prevent clusters of new infections in men who have sex with men (MSM).

Quebec has some of the largest clustering in the world, with 70% of transmission occurring among MSM in clusters, with 50% in large clusters, averaging 40 individuals who share a common virus. Large cluster variants tend to have a higher viral load than single infections, which means that there is an increased likelihood of transmission. Large clusters tend to be made up of younger people with more recent transmissions. All these are important factors when designing targeted HIV prevention campaigns or urging individuals from affected subgroups to get tested.

"All our data are anonymised and we don't know who infects who—or direction of transmission," Brenner said. "I believe it is important that all of this should be done anonymously."

Community perspectives on phylogenetics

Yvette Raphael, an HIV activist from South Africa, recognized the distinction regarding the use of phylogenetics in research versus public health surveillance, but noted that communities do not always see this difference between research and surveillance. This may be because it has never been fully explained to them, or because community engagement has been lacking. Instead, they hear that their biomarkers are being collected and may be fearful or distrustful about the reasons why. "Data are collected and being used," Raphael said. "The question is what are they being used for?"

Naina Khanna, from the Positive Women's Network, pointed out that one of the pillars of Ending the HIV Epidemic in the U.S. is focused on molecular surveillance and rapid cluster detection. However, this is occurring against a backdrop of HIV criminalization for non-disclosure of HIV status or alleged transmission in most states.

Khanna summarised specific activist concerns, such as the lack of informed consent for the collection of genomic sequences and the fact that data protections, storage and data sharing agreements vary widely from state to state. Given the criminalization of HIV exposure, sex work and drug use, key populations in some states may be much more vulnerable than others.

Khanna was also critical of how the media reports on cluster detection efforts. She cited one example where an HIV transmission cluster was reported among drug users and homeless people in Seattle, and the exact street that homeless people were living on was named by media outlets.

"I think in any situation we must center those who are most directly impacted, and who are most at risk for harm," Khanna concluded. "All stakeholders are not the same, they do not need to be brought to the table in equal ways. The implications of this type of data collection and the vulnerabilities in this data are different for people living with HIV, for people who are sex workers, for people who are using substances, for people who are queer and trans, for migrants. The vulnerabilities are very different."

If it were not for hylogenetic technology, we would not be able to say with certainty that **Undetectable = Untransmittable (U=U)**

KRISHEN SAMUEL is working on his PhD in public health in the U.S. He is originally from South Africa and obtained a Master's degree in Global Public Health and Policy in London. He is particularly focused on the social determinants of health in relation to HIV.

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A call for improved care and better living while aging with HIV

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The Glasgow Manifesto demands better care, improved quality of life and empowerment for people aging with HIV

At the 2022 International Congress on Drug Therapy in HIV Infection—known as **HIV Glasgow**—a coalition of older activists living with HIV issued the Glasgow Manifesto, a call to action urging greater services and care for people over age 50 who are living with HIV.

The Glasgow Manifesto was developed by founding members of the International Coalition of Older Poeple with HIV (iCOPe HIV), comprised of representatives of European AIDS Treatment Group (EATG, Belgium), National AIDS Treatment Advocacy Project (NATAP, USA), Realize (Canada) and UTOPIA BXL (Belgium).

Among the statement's demands:

- Developing new models of care that are multidisciplinary, integrated, proactive and preventive.
- Requiring individuals and organizations that care for older adults to be knowledgeable about HIV and understanding of the specific needs of people aging with HIV.
- Ensuring age-affirming community responses that include peer support and intergenerational understanding.
- Establishing meaningful inclusion in decision-making about the response to HIV.

"We decided to form a global network of older people living with HIV (PLWH) to fight for better care, improved models of care, better quality of life, and empowerment." said Jules Levin, co-author of the manifesto and executive director of NATAP. "We realize that without better care elderly PLWH are at risk for premature mortality and morbidity, and it's unacceptable that our governments are not responding to the coming 'silver tsunami'."

HIV Glasgow was held Oct. 16–19. **FOR MORE INFORMATION** about the Glasgow Manifesto and iCOPe HIV, email Kate Murzin at Realize: kmurzin@realizecanada.org.

—**RICK GUASCO**

The Glasgow Manifesto

PRESENTED BY iCOPE HIV AT HIV GLASGOW 2022

Preamble

At AIDS 2022 in Montreal, Canada, we—aging and older adults living with HIV, long-term survivors of HIV/AIDS and our allies from around the world—gathered in The Silver Zone, the first-ever global village networking zone to hold dedicated space for us. Our six-year struggle for visibility within the International AIDS Conference is representative of the challenges we face every day to have our living expertise acknowledged and our needs addressed by our peers living with HIV, our community-based organizations, our healthcare teams, our government officials and global leaders in the HIV response.

Older people with HIV are *not* collateral damage to be left behind in the pursuit of "ending the HIV epidemic." We are a *silent majority.* In 2020, there were an estimated 7.5 million of us (age 50+) around the world. Close to 40% of us who live in high-income settings will be at least 60 years old within the decade, and by 2040, over 9 million of us who live with HIV in sub-Saharan Africa will be over 50. If we speak in unison, we cannot be ignored.

Our bodies, hearts, minds and pocketbooks reveal scars earned building the modern HIV response. As we age, many of us are living with multiple chronic health conditions, coping with frailty, disability and/or cognitive changes, becoming more socially isolated and experiencing ageism in addition to HIV stigma and other forms of discrimination. Our independence, quality of life, and longevity are compromised and yet the HIV response has not evolved with us. It is past time for us to assert our rights to health, dignity and support!

Equitable health outcomes for aging and older people living with HIV will only be possible if we work in collaboration. Those of us with lived experience and living expertise must be at the centre of any decision or action taken in response to our self-identified needs. We call on healthcare providers, researchers, community-based HIV organizations, frontline providers of aging-related services and policy- and decision-makers to work in partnership with us to fund and implement the following calls to action.

Calls to action

We, aging and older adults living with HIV, call for:

Care

1. Tailored care. Work with us to develop new models of care for aging and older people living with HIV that account for the health and social complexity we experience. At a minimum, this model should be multidisciplinary, integrated, proactive and preventive, and organized around our priorities. We need more time with our care providers.

2. Wholistic care. We demand access to services and technologies that can help prevent and reduce the disabling impact of chronic illness, frailty and cognitive changes (e.g., rehabilitation services, vision and hearing care, dentistry, mental health services, mobility/hearing/vision aids, cognitive supports, personal care, in-home support for activities of daily living, etc.) regardless of our ability to pay.

3. Access to care. We insist on low-barrier care and services, whether delivered in the clinic, community or virtually. We have a right to reasonable accommodation.

4. Safe aging care. We demand that individuals and organizations providing care and services to older adults be knowledgeable about HIV, the lived experiences of people living long-term with HIV, our distinct support needs as aging persons living with HIV and the impact of HIV stigma. Individuals and organizations providing HIV care and services should be similarly conscious and renounce ageism. Service providers require education on our clinical and social needs to support us better. We have the right to respectful, informed aging care without discrimination.

Quality of life

5. Dignity. We expect that our sexual health is considered a vital part of our overall health.

6. Respect for our living expertise. We are self-aware, take responsibility for our well-being and demonstrate great resilience, having developed effective strategies for maintaining wellness in the face of adversity. We want care providers and researchers to ask us about our quality of life, and to prioritize what we deem most important.

7. Age-affirming community responses. We urge HIV organizations to address ageism within; work with us to develop responses that are relevant to our needs, including companionship and peer support; and foster intergenerational understanding and community-building.

8. Healthy living conditions. We demand that our right to an adequate standard of living and social protection, as guaranteed by the United Nations Convention on the Rights of Persons with Disabilities (Article 28), be realized. We implore policy makers to respond to the unmet needs of aging and older adults in their jurisdiction who struggle to afford adequate housing, food and/or other resources for health because of HIV-related disability.

Empowerment

9. Targeted research and education. We expect that aging and older adults are represented in all HIV research and that people living with HIV are included in aging research, so we are clear on what the findings mean for our well-being. We insist on more research focused on HIV, aging and older adults that responds to our community-identified priorities. We demand access to the most up-to-date information on aging with HIV to inform our decision-making, self-care activities to prevent illness and maintain health, and planning for the future.

10. Meaningful involvement. We demand that aging and older people be included in decision-making about the HIV response, including priority- and target-setting, funding allocation, and messaging about the impact of HIV on aging and older adults.

We—aging and older people living with HIV—are not a homogenous group between nor within countries around the globe, so we expect these Calls to Action to be implemented in ways that are equitable and account for intersectionality. We all deserve age-friendly and age-affirming information, care, services and support that considers the impact of our HIV status, gender identity, sexual orientation, citizenship, ability, race, ethnicity and place of residence, among other factors.

It is with great urgency that we, the International Coalition of Older People with HIV (iCOPe HIV), implore all stakeholders to work *with us* to implement these Calls to Action without further delay.

The 2022 International Congress on Drug Therapy in HIV Infection—known as HIV Glasgow 2022—was held October 23–26 in the Scottish capital. Following are reports by aidsmap.com on two of the many notable sessions.

A better second-line of defense

After viral rebound, dolutegravir-based treatment is more likely to suppress HIV

BY **KEITH ALCORN**

Dolutegravir-based treatment is significantly more likely to result in re-suppression of HIV after viral rebound than treatment containing efavirenz, a meta-analysis of four large clinical trials has reported.

The findings were presented by Dr. Andrew Hill of Liverpool University.

The capacity of an antiretroviral regimen to re-suppress HIV after viral rebound above the limit of detection is an especially important question for lower- and middle-income settings where a limited number of regimens are available.

If first-line treatment fails, second-line treatment is considerably more expensive, so it is critical to understand the likelihood of viral re-suppression when people continue with their existing regimen and receive enhanced adherence counselling, in line with World Health Organization guidelines for the management of viral rebound.

The question becomes even more critical in second-line treatment, where there are fewer options for replacement treatment.

Dolutegravir-based treatment is recommended as a preferred option for first-line treatment due to its high barrier to resistance. Treatment with dolutegravir is also better tolerated than efavirenz-based treatment.

To evaluate whether dolutegravir-based treatment is more likely to lead to re-suppression of HIV after viral rebound, investigators pooled data from four large studies that compared dolutegravir to efavirenz-based or protease inhibitor-based treatment in sub-Saharan Africa.

Studies included in the analysis were:

ADVANCE, a comparison of dolutegravir or efavirenz, paired with either tenofovir disoproxil/emtricitabine or tenofovir alafenamide/emtricitabine, carried out in previously untreated people in South Africa.

NAMSAL, a comparison of dolutegravir or lower-dose efavirenz, paired with tenofovir disoproxil/lamivudine, carried out in previously untreated people in Cameroon.

DOLPHIN-2, a comparison of dolutegravir and efavirenz, paired with tenofovir disoproxil/lamivudine, carried out in previously untreated pregnant women in Uganda.

VISEND, a comparison of several NRTI combinations when switching to second-line treatment containing dolutegravir or a boosted protease inhibitor.

The analysis looked at viral re-suppression rates in participants in the four studies who had experienced viral failure (a viral load above 1,000 copies after week 24) and did not change treatment. Participants with viral failure could be classified either as re-suppressing HIV, having persistent virus levels above 1,000 copies or lost to follow-up.

In ADVANCE, viral failure rates were similar across the three study arms (8–13%) but re-suppression rates ranged from 23% in the efavirenz study arm to 41% and 59% in the dolutegravir arms. The same pattern was evident in NAMSAL; 15% and 17% experienced viral failure in the two study arms but whereas 60% in the dolutegravir arm re-suppressed viral load, only 27% in the efavirenz arm did so.


ANDREW HILL, MD, AT HIV GLASGOW 2022

HILL: ALAN DONALSON PHOTOGRAPHY

In VISEND, people who entered the study with viral load above 1,000 copies/ml were more likely to experience viral failure than those with baseline viral load below 1,000 copies/ml. Viral failure occurred more often in the boosted protease inhibitor study arms (20–27%) than in the dolutegravir arms (12–18%). Re-suppression occurred less often in the boosted protease inhibitor arms (17–19%) than in the dolutegravir arms (34–41%).

In DOLPHIN-2, viral failure and re-suppression did not differ substantially between the dolutegravir and efavirenz arms.

In the meta-analysis, the rate of viral re-suppression was significantly higher for dolutegravir than efavirenz (p=0.04).

In three of the four studies, sustained viraemia above 1,000 copies/ml was more common in those with viral failure who did not receive dolutegravir. For example, in ADVANCE, 52% of those with viral failure in the efavirenz arm had a sustained viral load above 1,000 copies/ml after week 24 of the study, compared with 14% and 27% in the dolutegravir arms. The same pattern was seen in NAMSAL and VISEND, but not in DOLPHIN-2.

Presenting the study findings, Dr. Andrew Hill said that more research was needed to assess how much adherence counseling and sustained viraemia are required before people taking dolutegravir are offered a new regimen. He pointed out that new South African treatment guidelines only recommend a switch from dolutegravir if integrase inhibitor resistance is detected.

Professor Linda-Gail Bekker of the Desmond Tutu HIV Centre at the University of Cape Town said that long-term follow-up of people who re-suppress viral load on dolutegravir is needed. She asked whether people who re-suppress ultimately fail on dolutegravir, as has been previously shown for NNRTI-based treatment.

Untreated heart risk

People with HIV aren't getting medication to prevent heart disease, despite high risk

BY **KEITH ALCORN**

Almost half of a large European cohort of people with HIV were at very high risk of heart attack by 2019, but a substantial proportion were not receiving medication to lower blood pressure or lipid levels, investigators from the RESPOND study reported.

One-third of people eligible for medication to reduce their blood pressure were not receiving it in 2019 and 43% were not receiving medication to reduce lipid levels, the study found. A similar proportion were not receiving medication to control their blood sugar.

European AIDS Clinical Society guidelines recommend that all people with HIV who have a greater than 10% risk of heart attack, stroke or major heart surgery as a result of heart disease in the next ten years should be prescribed lipid-lowering medication, such as a statin. Treatment for raised blood pressure is especially recommended for this group too.

People with HIV have a higher risk of cardiovascular diseases (diseases of the heart and circulation) than others of the same age, partly due to HIV but also because they are more likely to smoke.

Guidelines recommend a variety of measures to reduce the risk of serious cardiovascular disease, but studies have shown that individual measures are unevenly applied. However, as cardiovascular disease is caused by multiple factors, it is important to understand where there are gaps in risk reduction and whether those gaps disproportionately affect specific groups of people.

The RESPOND cohort is a large international cohort collaboration designed to investigate long-term health outcomes in people with HIV taking antiretroviral treatment in Europe and Australia. RESPOND investigators at the University of Copenhagen, Denmark, used the cohort data to look at the use of preventive measures against heart disease in people with HIV.

The study investigators assessed whether any of seven preventive measures had been adopted to reduce cardiovascular risk in people with a very high risk of heart attack or stroke. A very high risk was defined as a 10% or greater risk within ten years of a serious cardiovascular event such as heart attack, stroke or death from a serious cardiovascular event, or surgery for major heart disease caused by hardening of the arteries or blockages due to raised cholesterol.

The preventive measures were:

- Weight loss (>7%) for people with body mass index of 30 or above (clinical obesity)
- Stopping smoking
- Discontinuation of antiretrovirals previously associated with cardiovascular disease (lopinavir/ritonavir, darunavir or abacavir)
- Use of medication to reduce blood pressure in people with high blood pressure
- Use of ACE inhibitors or angiotensin receptor blockers (ARB) in persons with high blood pressure and/or diabetes
- Use of antidiabetic medication in people with diabetes
- Use of medication to lower cholesterol or triglycerides in people with raised lipid levels.

The study looked at the risk of heart disease and the use of preventive measures in 22,050 cohort participants between 2012 and 2019. The absolute number of participants differed year by year as people joined or left cohorts.

Overall, 75% of participants were male, 45% had acquired HIV through sex between men and 14% through injection drug use. Seventy-five percent were white. Forty-four percent were smokers, 42% had elevated lipids, 19% had high blood pressure, 25% were overweight and 8% were clinically obese. Five percent had diabetes. At baseline, 33% had been exposed to abacavir, 26% to lopinavir and 16% to darunavir.

The proportion with very high risk of heart disease rose from 31% in 2012 to 49% in 2019. People with a very high risk of heart disease differed from the overall cohort in several ways. They were more likely to have raised lipid levels (63%), high blood pressure (38%) and diabetes (15%) and were more often smokers (57%) than the cohort as a whole. They were more likely to have been exposed to lopinavir (36%), abacavir (52%) and indinavir (33%) (a marker of living with HIV for longer, as indinavir was largely replaced by other drugs after 2000).

People at very high risk of heart disease were older than the cohort as a whole (a median age of 55 years vs. 45 years).

The use of three measures significantly increased between 2012 and 2019:

- Discontinuation of lopinavir/ritonavir
- Discontinuation of darunavir
- Discontinuation of abacavir after more than six months of treatment with the drug.

But there was no significant change in the proportions who received medication to treat high blood pressure (66%) between 2012 and 2019, nor in the proportion receiving lipid-lowering drugs (57%) or ACE inhibitors or ARBs (42%).

There was no change in the proportion of smokers who stopped smoking between 2012 and 2019 (7%) and the proportion with weight loss actually fell slightly in the same period (from 11.5% to 10.5%), as did the proportion receiving medication to treat diabetes (from 63% to 57%).

Multivariable analysis of preventive measures by subgroup showed that the use of medication was more common in older people, whether comparing over- and under-50s, or over and under-40s. But there was no age-related difference in the use of other preventive measures.

Women were less likely to receive ACE inhibitors or ARBs, but otherwise, there was no gender difference in the use of preventive measures.

Participants with a viral load below 200 copies/mL, and people who acquired HIV through injection drug use, were less likely to use lipid-lowering drugs or to stop smoking.

The study investigators say that their findings highlight the need for increased awareness of guidelines for management of cardiovascular risk factors.

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A MOKHTARI-ISTOCK


GREEN AND OTHER MEMBERS OF THE CLINIC STAFF CELEBRATE THE UNVEILING OF *THE KEY TO ENDING THE HIV EPIDEMIC*.

J.A. TOVAR, FROZEN LAKE PHOTOGRAPHY

THE BIG PICTURE

Bringing a message of hope to life

BY **RICK GUASCO**

A PrEP coordinator who's also an artist, Demetruis R. Green had never painted anything so big. Covering one side of the Wayne Health building in Detroit is a mural titled *The Key to Ending the HIV Epidemic*.

Green, as he prefers to be called, works for Wayne Health, the physicians group affiliated with Wayne State University in the Motor City. When the Michigan Department of Health and Human Services' HIV prevention awareness program funded a mural project to make the Detroit public health STI clinic where he works more noticeable, his colleagues convinced him to join. Green envisioned creating a vivid message of hope and growth.

"I started thinking about my friendships, about my clients, and I was like, *well, if I do this, let me really pull at some heartstrings*," he says. "I didn't want to be so direct when it comes to talking about HIV and U equals U because, in the field, I feel like we often get sterile information; we don't get to see the bright side of things. We don't get to see what it looks like when a person is living with HIV fabulously. I wanted to make

people feel like they were at a peaceful place."

Covering the exterior wall is a painting of a magical garden containing three portals, linked by a red ribbon that spans the mural. Each portal has a different theme and symbolic meaning. Bright gears turn with sunflowers, symbolizing progress and hope in "PrEP Works," the mural's left portal. Poised on a toadstool is a purple butterfly. "Butterflies represent freedom," Green says.

The middle portal is a tribute to his hometown. "I'm a Detroit native, born and raised, so I had to give a shout out to the 313," he says. With the city skyline in the background, another butterfly hovers above a beaker; the flask is spilling out a liquid rainbow. "It represents modern science," he adds, "how it touches our city and gives us hope toward ending the HIV epidemic."

The third portal is a celebration of U=U, Undetectable equals untransmittable, the scientific principle that if the viral load of a person on antiretroviral HIV treatment is too low to be measured, then the virus cannot be transmitted through sexual contact.

A heart, with the message *U=U*, sits atop a bed of purple feathers. To one side is a golden key; next to the key, a keyhole leading to the Detroit portal. At the mural's left edge floats another butterfly. This butterfly, though, symbolizes metamorphosis, Green says. In addition to escape and independence, the purple color of the feathers represents intuition. Nervous about taking on the entire project alone, he asked local muralist Lindy Shewbridge to paint the featherbed, knowing that her favorite color is purple.

The mural is filled with personal symbolism and double meanings. A ladybug appears on the Detroit portal, referring to his nickname for his sister. Roses adorn the mural's garden motif. "They take over the painting because that's my grandmother's maiden name," he says. A ceramic artist, Green's grandmother was a major and early influence in his life.

> ***'...if I do this, let me really pull at some heartstrings.'***

"My grandmother lived to be 101 years old; she passed away last year," he says. "She worked with ceramics a lot. I watched her go to the kiln and make these beautiful pieces. When I got to high school, my first job was at a pottery house."

Recognizing her son's creative talent, his mother started buying him art supplies, and he got into painting. "I developed a sense for surrealism—you know, when you have this alternate universe of what you think reality is," he says. "I like to think about artists like Salvador Dali. He was like a huge inspiration. I grew up looking at his images of melting clocks and how he would make abstract landscapes come to life."

Green brought *The Key to Ending the HIV Epidemic* to life in about 12 hours over the course of four days, using spray paint instead of his usual oil paints. The formal unveiling was held in July. Sometimes during his lunch break, he likes to stand outside near his mural and anonymously listen to people's comments or watch as they take photos. He won't reveal himself as the artist, because he thinks they might react differently if they knew who he was.

As a PrEP coordinator and early intervention specialist, it's Green's job to give people the information they need to know. Through his art, he wants to draw from them what they feel.

"Before I even tell somebody what something means, I want to hear how they feel when they experience or see it," he explains. "I feel like that's what art is all about."

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The Detroit Public Health STI Clinic is located at 50 E. Canfield St. **FOLLOW** Demetruis Green on Instagram and TikTok: @mrvenus0000.

6:19 PM: MEXICO CITY, MÉXICO **ALBERTO PEDRAZA:** Who among us lives with HIV? All and none. Because of our friendship, it makes no difference between us.

Everyday moments in extraordinary lives

Snapshots from around the world tell the story of ‘A Day with HIV’

The day got off to a different start, depending on where you were. Ángel Luis Hernández in Arecibo, Puerto Rico, was busy directing volunteer emergency assistance efforts in the wake of Hurricane Fiona having hit the island. Ferd Garcia was enjoying a beautiful morning in California’s wine country as he walked his dog Lana. In England, London police officer Steve Thornhill was starting his shift. Activist Cameron Brittany had just stepped out of the shower, pushing back against the stigma of a person’s HIV status. It was Wednesday, September 22, 2022—A Day with HIV.

POSITIVELY AWARE’s annual anti-stigma campaign coincides with the first day of autumn, signifying a change of seasons, and in some cultures, a change in thinking. Now in its 13th year, A Day with HIV depicts a single 24-hour period in the lives of people affected by HIV—regardless of their status.

The campaign is meant to normalize living with HIV. On A Day with HIV, everyone everywhere is encouraged to take a snapshot of their day and post it to their social media with a caption that includes the time and location of their photo, what inspired them to take it and the hashtag #adaywithhiv.

About 250 pictures were posted across Facebook, Instagram and Twitter and uploaded to the campaign’s website, adaywithhiv.com. This year, two dozen countries—the most ever—were represented in photos.

A number of photos were submitted from Latin America, the result of enthusiastic Instagram followers in South America who asked to promote the campaign. The result: a dozen photos with captions in Spanish accompanied by the hashtag #UnDiaConElVIH. A couple photos from Brazil were posted in Portuguese, the country’s official language. (The captions of these photos appear here in their original language, followed by the English translation.)

The photos capture personal moments of joy, accomplishment, vulnerability and daily routine. And as the day came to an end, there were moments of reflection and resilience.

In Detroit, Calire Gasamageria said, “Resilience is bringing back to our awareness good memories of foods, people and places to get through tough times.”

Ana Oliveira in Greater Manchester, England ended her day by taking her HIV medication. “I hope this picture reaches those who are afraid to start or continue antiretroviral treatment,” she said.

“Doing one of the things I love—traveling!” said Evany Turk, taking her picture at an airport terminal in Chicago. “Living in gratitude, love and peace. It’s been amazing seeing all the photos today. Love y’all!” — **RICK GUASCO**

THE FOLLOWING EIGHT PAGES of this issue feature pictures from A Day with HIV. Some captions have been edited for brevity and clarity. An online gallery is on display at adaywithhiv.com.

<<< 7:29 AM: PETERBOROUGH, ONTARIO; CANADA

Cameron Brittany: *Are you clean?* is how some people ask about a person's HIV status. People living with HIV are *not* dirty. In fact, I just bathed.

<< 8:00 AM: FORT WORTH, TEXAS

Jeffery Parks: As a 54-year-old long-term survivor and person aging with HIV, having a daily routine is important to my overall well-being. I'm especially enjoying today's coffee at 8 a.m. on the first day of autumn.

< 8:26 AM: ARECIBO, PUERTO RICO

Ángel Luis Hernández: Puerto Rico was hard hit by Hurricane Fiona. As a volunteer with the local AARP office, I started my day early to coordinate some urgently needed assistance at a hospice for bedridden people living with HIV.

<< 8:38 AM: NAPA, CALIFORNIA

Ferd Garcia: Walking my dog Lana!

< 9:31 AM: PALM SPRINGS, CALIFORNIA

Jax Kelly: A Day with HIV for me is about working hard and giving it my all.

<< 9:30 AM: LONDON, UNITED KINGDOM

Steve Thornhill: Me, doing my thing, at work. Proud to be a cop, proud of who I am, proud to be an out HIV-positive cop!

9:32 AM: FORT WORTH, TEXAS >
Junior Collins: Sixteen years later...

9:52 AM: HELSINKI, FINLAND >>
Maya Viecili: Sou muito grata por poder viver a minha vida linda, ser produtiva, saudável e feliz. Sou grata pelo propósito que o HIV trouxe para minha vida.

I'm so thankful to be able to live my beautiful life, be productive, healthy and happy. I'm grateful for the purpose that HIV brought to my life.

10:00 AM: SAN JOSÉ, COSTA RICA >>>
Kar A. Esquivel: Working wearing my Positive Latin America Youth hoodie (J+LAC). I love people with HIV; their courage to be visible gave me the courage to be visible as a trans person. Thank you, friends. Being an ally is being a safe place, listening and promoting the fight against stigma and discrimination.

Trabajando muy groupie de la @jovenesposlac

Yo amo a personas con VIH, y su visibilidad me dio el valor para yo ser visible. Gracias amigues

Ser aliadx es ser un lugar seguro, aprender a escuchar y promover la lucha contra el estigma y la discriminación
#adaywithhiv
#undiaconvih

10:15 AM: EAST GADSDEN, ALABAMA >
Marvellus S. Prater: In the media room of 6:52 Project Foundation. Not knowing just how long that I would live after my HIV diagnosis (31 years so far). Living with stigma and shame, I chose to be the change that I wanted to see in the world—to Live, to Thrive, to Love Life—with HIV.

10:20 AM: LE POULIGUEN BEACH, FRANCE >
Kevin Kelland: Living with HIV was unthinkable when I was diagnosed in 1986; now, I recently had my 71st birthday and I've lived with HIV for 35 years. We're on holiday from Plymouth, UK.

10:35 AM: NATURAL BRIDGE, VIRGINIA >>
Heather Rhea O'Connor: I feel insecure about my dancing body because it has been so long since I've trained, it feels foreign to me—almost like I'm not allowed to do it anymore and that part of my life has been lived. I'm posting this as a reminder to myself to be present and to immerse myself in the now. I worry too much. Worry is for the birds. (Plot twist: I'm the birds.)

< 10:20 AM: CHICAGO, ILLINOIS

Charlie Peterson: HIV should always be an open conversation without stigma. This year I have biked hundreds of miles with TPAN for their Ride for Life Chicago, and I have run for days on end with TEAM TO END AIDS (T2 CHICAGO) for AIDS Foundation Chicago. Join the dialogue. Help your community! We are all affected by HIV.

También es un dia para recordar la fragilidad, habitar el malestar, entendernos y comprender que la vivencia con el VIH acarrea otros temas de los que nos tenemos que ocupar. Como la salud mental y el cuidado.

<<10:38 AM: BOGOTÁ, COLOMBIA

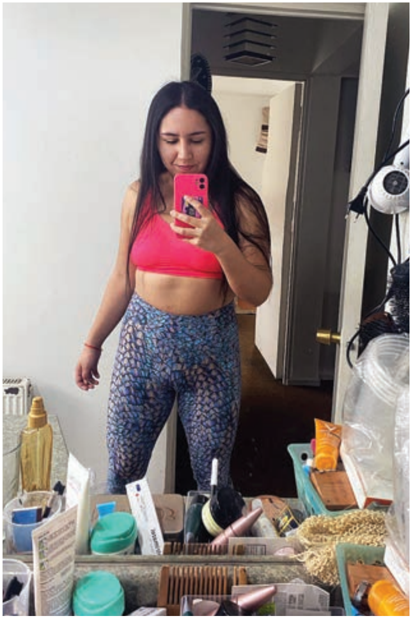
Juan De La Mar: Fragilidad.

< 10:41 AM: ATLANTA, GEORGIA

Nina Martinez: I finished it! Novel coronavirus phase III vaccine trial with a 39-year retrovirus tenure on board, completed after two years.

<<< 10:43 AM: LONDON, UNITED KINGDOM

Tresca Wilson: I'm a prevention and testing coordinator at Positive East, an HIV charity that supported me when I was diagnosed with late stage HIV in August 2015, after having been admitted to hospital with PCP and a CD4 count of 11. I started as a peer mentor, progressed to outreach, then testing; all of which were voluntary. On June 21 of this year, I was offered a full-time job.



<< 11:00 AM: BIOBÍO, CHILE

Sara Hernandez: Hace siete años que me acompañas.

You have been with me for seven years.

< 11:00 AM: CHULA VISTA, CALIFORNIA

Raul Robles: A positive and healthy lifestyle is the key for a long-term survivor. HIV-positive since 1985, and will be 64 years old in five months.

11:01 AM: FORT MYERS, FLORIDA >
Sharon Murphy: Making condom packets for community distribution with the most awesome outreach team ever!

11:33 AM: VALENCIA, VENEZUELA >>
Jhonatan Mendoza: Hoy junto a mis compañeras realizando prevención ante el VIH llevando en mensaje de inclusión a la sociedad dónde nos deben aceptar con mi condición de salud y que ser VIH+ no me hace diferente a los demás.

Together with my colleagues, doing HIV prevention outreach, a message of inclusion to society that they should accept us. My health status and living with HIV do not make me different from other people.

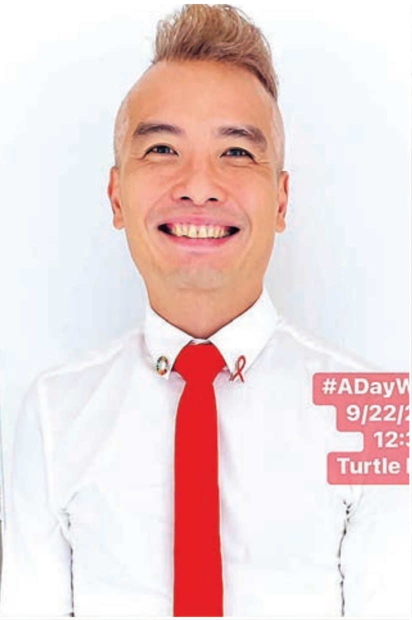
11:57 AM: ST. HELENS, OREGON >
Brenda Chambers: Taking meds is an important part of my day.

12:00 PM: KAZAN, TATARSTAN; RUSSIA >>
Svetlana Izambaeva: I have lived with HIV for 20 years. I talk about it openly to all people to remove the stigma. I am a happy woman. I am a mother; I have two children. I am a psychologist.

12:17 PM: MECHANICSBURG, VIRGINIA >>>
Melissa Blackwell: He said he wanted to ride a horse, so we found a horse for him to ride.

12:18 PM: NEW ORLEANS, LOUISIANA >
Jim Berman: Thirty-five years ago, I was told I'd be dead in a couple of years. Now, here I am all these years later and getting my life back. U=U has given me the ability to have a family and they are all HIV negative! HIV is now manageable, and truly nothing but a footnote in my life.

12:27 PM: WILTON MANORS, FLORIDA >>
Anthony Johnson: Enjoying lunch with my baby in blue. We're heading into our tenth year as a serodifferent couple, and looking forward to the next ten (and more) together!



**<< 12:30 PM:
TORONTO, CANADA**
Christian Hui: As a poz, BIPOC, post-HAART, long-term survivor and HIV/AIDS activist, I've lived 19 years with this now-manageable chronic condition. HIV taught me how to be strong and compassionate, and to speak truth to power on the injustices and inequities we face daily.

**< 12:59 PM:
HENDERSON, NEVADA**
Chris Reynolds: Enjoying a vacation day with my little man. Just being me, healthy with HIV. U=U.

**<< 1:00 PM:
MANILA, THE PHILIPPINES**
Artemus Cadlum Arojado: Yes, data and numbers are important, but HIV is more than that. We live, we breathe and we get hurt. We deserve to be treated equally.

**< 1:01 PM:
CLEVELAND, OHIO**
Bryan C. Jones: A Day with HIV is knowing your meds, so when they send you the wrong meds you can correct them.

**<< 1:10 PM:
SARASOTA, FLORIDA**
Debbie Sergi-Laws: At the infusion center getting my monthly IV immunoglobulin infusion. Besides living with HIV, I have another immune deficiency and this treatment has saved my life. This takes about four hours, so I work while I'm here. I am a medical peer navigator, a most rewarding position that I *love*!

1:45 PM: THE GULF OF MEXICO, TEXAS > **Bob Bowers and Nita Costello:** Kismet! Love and miracles in the age of HIV and U=U.

1:48 PM: FORT LAUDERDALE, FLORIDA >> **Carlos Ernesto Masis:** I choose myself. I choose my inner peace. I chose my mental health, so I walked to the beach and relaxed, and chose communion with the universe, with nature, being in harmony with everything and with myself. Choose yourself, your inner peace; mental health is the foundation for a balanced healthy life.

1:57 PM: SAN JOSE, CALIFORNIA > **Jamie Nguyen:** Living with HIV since June 2020. Working as both a clinician and a patient advocate in sexual health, harm reduction in the LGBTQ community.

3:00 PM: PANAMA CITY, FLORIDA >> **Derrick Robinson:** Prevention Works, because All Lives Matter.

3:38 PM: LAS VEGAS, NEVADA > **Davina (Dee) Conner:** Outside in front of my house, enjoying the fresh air. It's amazing how being in the sun can change the day.

3:50 PM: SAN FELIPE, CHILE >> **Rodrigo Acuña Cofré:** ¿Sabías que tratar a alguien diferente porque tiene el VIH es un ejemplo de estigma? Aprendamos a crear un mundo sin estigmas del VIH comprometiéndonos a hacer cambios positivos en nuestras vidas y familia. Escuchar y conversar, sin juzgar, a quien te ha confiado que tiene HIV es una forma de apoyarlo.

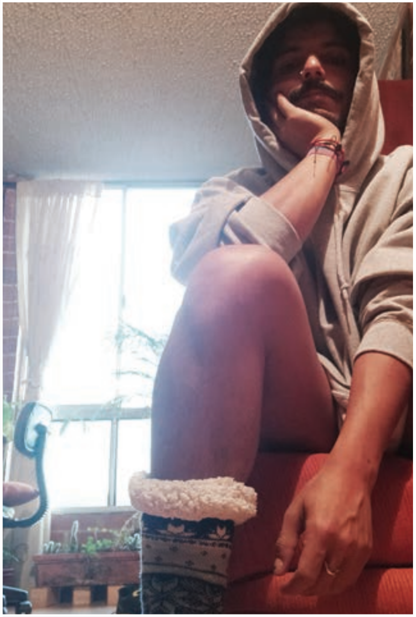
Did you know that treating someone differently because they have HIV is an example of stigma? Let's learn to create a world without HIV stigma by committing ourselves to making positive changes in our lives and family. Listening and talking, without judging, to someone who has confided in you that they have HIV is a way of supporting them.

<< 4:01 PM: LUSAKA, ZAMBIA

Precious Kaniki: This year, I am adding my baby as a proud HIV-positive mother. It's a constant reminder to adhere to my medication so one day when my baby is older, I will tell her I didn't transmit HIV to her.

< 5:00 PM: LONDON, ENGLAND

Ant Babajee: I've been living with HIV for 15 years, and this afternoon I went for a walk in the park next to my home after a meeting of the Fast-Track Cities London Community Advisory Group.



< 5:01 PM: BOGOTÁ, COLOMBIA

Juan De La Mar: Un día en el que reflexiono, que uno de los mayores aprendizajes de estos cinco años viviendo con el VIH, es que los días pueden ser grises. Y yo estoy conmigo, me acompaño, me cuido. VIH, estamos juntxs en esto.

A day in which I reflect that one of the greatest lessons of these five years living with HIV is that days can be gray. And I am with me; I accompany myself, I take care of myself. HIV, we are in this together.

<< 5:20 PM: LOS ANGELES, CALIFORNIA

José Magaña: Getting my second COVID booster at our monkeypox/COVID-19 vaccine pop-up at The Wall/Las Memorias office in Boyle Heights.

< 5:26 PM: LONDON, UNITED KINGDOM

Susan Cole-Haley FRSA: Joyous day, co-chairing with Catarina Santos and David Alain Wohl a fantastic HIV conference, Life Beyond HIV, bringing together incredible activists, nurses and doctors from around the world.

5:30 PM: MELBOURNE, AUSTRALIA >
Brent Allan and Paul Kidd: Date Night. Living together positively for 23 years and celebrating our future together.

7:20 PM: LOS ANGELES, CALIFORNIA >>
Andrea de Lange: Nancy and I have been friends for 22 years. As long-term HIV survivors, we appreciate each other a great deal and spend a lot of quality time together. Here, we're at the Hollywood Bowl, looking forward to seeing Loggins & Messina perform, having just finished a delicious picnic. We both love live music and cultural events, but we could be sitting in a park watching the grass grow, and still have a great time.

8:07 PM: LAS VEGAS, NEVADA >>>
Deral Takushi: I've been channeling my inner joy by playing with makeup lately, and tonight I was feeling my favorite color of joy and amaze-ness. I stoned my crown in the form of a tiara and put on my signature bow-tie, and I am feeling amazing. Thank you to my friend who took this picture.

8:44 PM: DETROIT, MICHIGAN >
Claire Gasamagera: Resilience is bringing back to our awareness good memories of foods, people and places to get through tough times.

8:50 PM: CHICAGO, ILLINOIS >>
Evany Turk: Doing one of the things I love—traveling! Living in Gratitude, Love and Peace. It's been amazing seeing all the photos today. Love y'all!

9:15 PM: GREATER MANCHESTER, UNITED KINGDOM >>
Ana Oliveira: This is how I end my day, by taking my Biktarvy tablet. I hope this picture reaches those who are afraid to start or continue ARV treatment.

Reasons for love

HARLEY & CO.

A conversation that centers Black women

BY **ENID VÁZQUEZ**

Think of your reasons for living and living well. Of your reasons for being healthy. Your reasons for being there for your loved ones. A group of powerful Black women from the HIV community is asking us to consider our reasons for taking care of ourselves. They say that when it comes to HIV prevention and care, the use of the word “risk” promotes stigma to the detriment of health.

“For Black women, the greatest ‘risk’ for HIV may be poverty, homelessness, where you live, intimate partner violence or other social determinants—which are rarely captured in the campaign messages, questionnaires or intake materials used to identify who should be counseled on or connected to preventive HIV care,” the women wrote in their guidebook, “From Risk to Reasons.” They gathered together to change the conversation, creating the concept of reasons for taking care of ourselves. Not “risk” for HIV or for HIV progression but “reasons” to protect our health, whether we are living with HIV or not. “You’re at risk” sounds too much like “you’re to blame.” “We know that language matters when stigma is a primary issue in ending the epidemic,” said Amelia Korangy, director of external affairs strategy and programs for ViiV Healthcare, which convened the working group. “It’s not about ‘high-risk’ behaviors that drive women’s vulnerability. It’s about the context and the circumstances around women that give them real reasons for HIV prevention.” The Black Women’s Working Group to Reframe Risk also asks us to address the realities that make it more likely for many people—whether Black or white, male or female, or anyone else—to acquire HIV and to experience HIV progression, but more so Black women. Kimberly Smith, MD, head of ViiV’s research and development, summarized it best: “Providers can be educated too and need to be armed with the language that we’re talking about here, so that when a woman asks for an HIV test, the response is not *Why do you want it?* but *Yes, we can give you an HIV test, and let’s talk about how you’re going to live your best life if you’re positive and about how we’re going to keep you negative if you’re negative.*” Remembering our reasons for taking good care of ourselves—that’s love. And that’s the power of love. The conversation continues.

Heart and soul

Lighting the way

COMPILED BY **ENID VÁZQUEZ**

ViiV Healthcare's Risk to Reasons initiative is designed to reframe and refocus HIV prevention and care for Black women. Guided by advocates across the country, Risk to Reasons sets out to develop new messages, new messengers and new methods to increase awareness and action around HIV prevention and care to Black women of cis and trans experience. The initiative creates content, funds community action and connects advocates across the country to change the impact of HIV in Black communities and connect more Black women to prevention and care, with an investment of nearly $8 million in grants to activate Black women-led programs across the U.S. that disrupt disparities.

The following excerpt is taken from the global virtual launch of the Risk to Reasons *initiative in April 2022. It has been edited for length and clarity.*

LEISHA McKINLEY-BEACH (moderator)**:** For over 20 years, my email signature has been, *History will record my commitment to stop the spread of HIV.* And today is one of those history-making moments. We definitely recognized in our group that the word *risk* is stigmatizing and demoralizing for all women, but specifically for Black women. We are about to embark on a conversation that will dismantle the system of negative framing of HIV services for Black women. Getting us to a new way of delivering sexual health services for Black women in our culture and all of our diversity, of trans experience or cisgender.

ONI BLACKSTOCK, MD: *Risk* versus *reasons* makes me think about the difference between *what's the matter with you* versus *what matters to you. What's the matter with you?* makes the person the problem, while *what matters to you?* is really about centering the person and understanding their motivations, their needs and their reasons for taking care of themselves.

From *Risk to Reasons: A Guide for Communicating and Connecting with Black Women about HIV*

Our call to action

We must reframe risk to end the stigma and find solace in knowing there are sisters advocating for you, for me, for all of us. So that none of us fall through the cracks. To normalize health as wealth.

We must reframe risk to leave a legacy of change, make a difference, bridge the gap. To learn, to grow and to share. To be part of a bigger impact.

We must reframe risk to work collectively. To commit to Black women. To shift the narrative.

We must reframe risk to show there's life after HIV. To take control. To delight in the beauty of our shapes and sizes. To enjoy happy, healthy and fun sex lives.

We must reframe risk to affirm that we are creators, that we are powerful, that we are brilliant, that we are bold, that we are enough, that we matter.

The Black Women's Working Group to Reframe Risk, 2021–2022

Gina Brown
Southern AIDS Coalition

Jamanii Brown
Former patient navigator, CrescentCare

Tori Cooper
Director of Community Engagement for the Transgender Justice Initiative, Human Rights Campaign

Olivia G. Ford
Editorial director, The Well Project

Justine Ingram
Capacity-building assistance specialist, Southern AIDS Coalition

Deirdre Johnson
Founder, Deirdre Speaks; co-founder, ECHO VA

Leisha McKinley-Beach
National HIV/AIDS consultant

Kneeshe Parkinson
Co-chair, ICW-NA

Jay Reed
Former HIV peer navigator, Christie's Place

Beverly Ross
Former prevention specialist, AIDS Foundation of Chicago

Kimberly Sanders
Vice president of Education and Training, Planned Parenthood of Greater New York

Ashlee Wimberly
Senior program manager, Washington AIDS Partnership, Washington, D.C.

The Black Women's Working Group to Reframe Risk was formed as part of Positive Action for Women (PAFW), an initiative of ViiV Healthcare.

‘...reframing the term *risk*, I thought, *Wow, we’re talking about empowering women.*’

TORI COOPER: Let’s be honest, the word *risk* is scary. We say, *risk your life*. That’s frightening. *Risk your money.* This implies that you could lose just as well as you can win. In church, we say, *risking your salvation*. That’s certainly not something we want to do. *Risk your heart*, when you’re talking about love—that’s frightening. We don’t want people to think about HIV care and prevention as something in which you could possibly lose.

DR. BLACKSTOCK: Providers are often uncomfortable talking about sexual health and a lot of it has to do with the training that they receive. It involves more of a risk-based framing.

So we need providers to be more comfortable and more capable in terms of having these discussions, and to really approach them without judgment. Using open-ended questions like, *Tell me more about what’s important to you? Tell me more about what you are doing when it comes to your sexual health?* When it comes to power and control and choice, saying something like, *Prevention can give you choices to take care of yourself on your own terms*, *take that control back and keep you healthy*. We just need to do much more in terms of training and resources for providers so that they can engage in these conversations without stigma, without judgment, without shaming. For Black women in particular who are already marginalized by sexism and transphobia and anti-Black racism, using risk-based language further stigmatizes Black women. In terms of the relationship with the healthcare provider, this disconnects patients and providers from one another.

McKINLEY-BEACH: Let’s talk about *social determinants of health*. That is a nice public health phrase to say that there are some things that are happening beyond HIV that’s preventing us from getting to the health outcomes that we desire.

ASHLEE WIMBERLY: What we refer to as the social determinants of health—things like housing, employment, income, mental health, education—are really big things that are foundational to the ‘Risk to Reasons’ framework because they directly impact our vulnerability to, and experience of living with, HIV... *period*.

OLIVIA FORD: All of the reasons that we ultimately landed on over many months of conversation that ended up in the guide represent expansive and just pretty desperately necessary shifts in thinking about Black women and health—Black women across the gender spectrum. Talking about intimacy and desire and pleasure and joy and normalizing taking care of ourselves in the context of sexual health should not be as radical or as rare as it is.

One aspect of our process that I’m especially thrilled to see lifted up in this initiative is the circumstances—issues around power and control—that women didn’t choose for themselves that are part of their reasons for HIV prevention.

Those approaches that reinforce over and over and over that a person’s likelihood of acquiring HIV is their fault are really deeply entrenched. And it’s not exclusive to HIV. It’s a pretty insidious habit in our society in general to address systemic concerns solely with individual solutions.

But if we’re to acknowledge that it’s those social

Four core values for communicating and connecting with Black women about HIV prevention

- Respect and recognition of the whole person
- Bodily empowerment and autonomy
- Freedom from fear and shame
- HIV stigma-free communications and treatment

Three motivating reasons for prevention

- Power, circumstances and control
- Intimacy and desire
- Normalizing self-care

***Because Black women’s sexuality** has been policed and pathologized throughout history, it is especially important to find language and approaches that support their desires, address their unique circumstances, enhance intimacy and avoid stigma, shame and re-traumatization.*

DOWNLOAD *From Risk to Reasons—A Guide for Communicating and Connecting with Black Women about HIV* here: bit.ly/from-risk-to-reasons-guidebook

PHOTOGRAPHY BY HARLEY & CO.

determinants of health that are driving the HIV epidemic, then we need to actually address those conditions and not just individual actions and choices in order to make HIV prevention and care possible for so many Black women.

McKINLEY-BEACH: When I first saw this, reframing the term *risk*, I thought, *Wow, we're talking about empowering women*. Coming from a rural community, we're talking about communities of Black women who have had messaging passed down from generation to generation like *women were made to be seen and not heard*. And *what happens in this house stays in this house*. And so if I am staying where the trauma is happening, I don't have anyone to speak to and this is a very uncomfortable conversation. How do we bring into this conversation, then, the word *values*, which for some of us can have a negative connotation as well. We're talking about valuing women's lives. What is important about these values? (See "Four core values for communicating and connecting with Black women about HIV prevention," page 34.)

WIMBERLY: I think that this guide represents a fundamental shift in how we talk about HIV and Black women. I think that the list of values in the guide really reflect better ways of communicating about HIV with community members and in particular, those who may not see a connection to HIV or feel that it's relevant to their life. And the value that really stuck out to me that's in the guide is respect and recognition for the whole person.

COOPER: As Black women, regardless as to how you got to your Black womanhood, we navigate the world differently than everybody else. And I wrote down a few words to describe what I think we're all talking about in different ways. As Black women we went from being homeless to being homeowners. We went from millions of copies to undetectable. We went from being tested to now testing other individuals, and we went from being stigmatized to being peers. We went from living in shame to becoming Sheroes. We went from living in shame to being liberated. Alright, we went from being in bondage to being free. And once you free you, you ain't *never* going back. And also, we went from *risk* to *reasons* because it's so important. We don't talk the way that other people talk. So we have to speak in a way that we get it.

DR. KIMBERLY SMITH: I want us to be having this conversation at the dinner table at Thanksgiving. I want us to be able to talk about normalizing self-care more and normalizing health. HIV is a part of the reality that we all live in. And so if we're not able to talk about it, then we're not going to be dealing with it. So having that conversation with everybody from Grandma to young teenagers becomes important, so that we can actually talk about the reasons we have to take care of ourselves. Taking care of ourselves means being able to be in care if we're living with HIV or being tested if we haven't been tested, and to be able to access prevention options, if we so choose to.

When we see those statistics in the brochure, they strike us every time, and we say, *What are we doing?* We have to do something different. Something different includes having this conversation. We *all* should be having the conversation because we *all* have those vulnerabilities because of the world that we're living in. I want a conversation where it becomes normal to talk about HIV, the world we live in, how we can protect ourselves, and be empowered to get that self-care that we need.

Speak

Messages from
Risk to Reasons

I know *you can't tell a person's HIV status by looking at them, and that's plenty of reason for HIV prevention.*

Prevention makes *sex more pleasurable, because it gives me peace of mind and helps me enjoy the moment.*

Sex should *feel good to you, too. Prevention can help you enjoy the moment without fear or stress.*

You are *your own best reason for HIV prevention or for HIV care. You're worth it, and you deserve to keep yourself healthy now and in the future.*

Your kids, *your family, your community—they all want and need you to be around for them. HIV prevention, or HIV care, is how you can show love for yourself and for them.*

Prevention can *mean you don't have to stress about your partner's HIV status or talk about your own status until you're ready.**

* In 12 states, laws require people with HIV who are aware of their status to disclose their status to sex partners.

BEING BRIDGETTE

BRIDGETTE PICOU

Something new under the sun

Looking at your well-being

I'm going to directly quote someone, but I'm not going to give them any credit. They don't deserve it. I remember exactly what they said. It was one of those moments when I was offended and pissed, so it stuck with me. It was a doctor. He said, "You know Ms. Picou, even though you are Black, fat and forty, I'd take your blood pressure any day. It's always good." There was a moment of uncomfortable silence while I looked around to see if anyone else heard him, and then I asked him to repeat what he said. Mind you, I didn't want him to repeat it, I just wanted to see if he would. He did. *Sigh*.

ISTOCK

Every time I get a new twinge in my joints, or an unexpected symptom of illness I've never had before, I have to think, is it age or the HIV?

I wasn't 40 yet. But close enough for him to be comfortable saying it. That was my first experience with the term "comorbidity," a disease or medical condition that is simultaneously present with another or others in a patient. He gave me some *blah-blah-blah* I was only half-listening to about my chances for high blood pressure (inevitable), the risk of diabetes (likely) and cardiovascular risk (also likely). Here we are more than 10 years later, and I am free of high blood pressure, no diabetes and don't have heart disease. Still "fat" though. Go figure.

Comorbidities weren't a topic of conversation again until I started nursing school, which was soon after being diagnosed with HIV, so I learned more about them and how they related to HIV about the same time. I don't want to turn this into a medical lesson or lecture. Let's just say the potential for comorbidities lie within us all, and HIV has the capacity to exacerbate them. There are some things that certain groups are just more prone to. According to the Department of Health and Human Services, Black folks are 60% more likely than non-Hispanic Whites to be diagnosed with diabetes. Black women are nearly 60 percent more likely to have high blood pressure than their White counterparts. In an article on Heart.org, they postulate that people living with HIV are more likely to suffer from high blood pressure and heart disease related to both HIV medication (ART) and the effects of the inflammatory process of the disease itself.

Having said that, the idea of living with a plethora of medical problems shows up more often than I like. Every time I get a new twinge in my joints, or an unexpected symptom of illness I've never had before, I have to think, is it age or the HIV? Could it be symptoms of long COVID?

The truth is somewhere in the middle. I am getting older, so my body will have natural changes. I do have HIV and even though well controlled, it's inflammatory and will have its effects as well. I think in theory everyone with HIV should pay attention to their health and do the best they can for their well-being. Yet I also know in reality that isn't always possible. Life is going through life. There are going to be bad habits that are hard to kick once started and emotions we won't always be able to control. You know the lecture. *Don't smoke or drink, eat right and exercise every day.* That's not always feasible. Maintaining your personal balance is what matters. I call it *mitigating the morbidities*. It doesn't have to be to extremes. Mine looks like this: I might have a couple of extra tacos, but I don't smoke. I might have a drink or two here or there, but I'm going to try to swim or walk for exercise. Depression and anxiety may hit, but there is sunlight and water to smooth out those edges. If going to the gym every day and a strictly regulated diet works for you, do that. Yoga, meditation or just being with friends—do it! The point is managing these things is how you live your best life. Like I always say: *It's your life, not HIV's*.

Be well. You matter.

……

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

ISTOCK

POZ ADVOCATE

SCOTT SCHOETTES
@PozAdvocate

STIGMA: A POX ON ALL OUR HOUSES

The message continues to be difficult

It has been a rough couple of years. In the fourth decade of the HIV epidemic, another deadly and much more easily transmitted disease came along to put the whole world into quarantine—making it more difficult for people living with HIV to access care and for people at higher risk to access prevention and testing. Then just when things were getting back to some semblance of normal, the very same communities at the highest risk for HIV were hit with MPX, an extremely painful and temporarily disfiguring disease most often transmitted through sexual contact.

One commonality between these three epidemics is the stigma that arises for those who acquire a virus or acknowledge they may be at higher risk. Public health experts have long agreed that stigma drives the HIV epidemic by making it harder to get people to test for HIV, to consistently engage in care, and to use certain prevention tools, like condoms or PrEP. From the beginning, AIDS was associated with gay men, injection drug users, sex workers and Haitians—all marginalized groups. In the eyes of many, the first three of these groups engaged in activities that made this modern-day plague appropriate "punishment" or consequences for their conduct.

Even as the epidemic grew in other populations, it never really lost its identity as a disease of the marginalized. For many, people with HIV had engaged in morally objectionable activities or had sexual contact with people who engaged in those activities. Either way, many considered people living with HIV not just responsible but blameworthy for their medical condition; the label of "innocent victim" was reserved for those who acquired HIV neonatally or through blood transfusion.

Our culture has come a long way since then, but we still have a long way to go. By the time I tested positive in 1999, the blaming and shaming was not quite so pointed, but I distinctly remember people asking, "How could someone so smart be so dumb as to acquire HIV?" This question, with its implicit assumption that "all" one needed to do is wear a condom, was pretty devastating to my fragile post-diagnosis self-esteem. I finally pushed back with one straight female friend by asking if she had used a condom every time she had sex in the previous 10 years; she sheepishly backed off.

We did a version of this type of blame game in the early days of COVID. Because it was easily transmitted, not through sex (or worse yet—anal sex!) but simply through the air, COVID was never going to carry the kind of stigma that HIV does. But once people were aware of the seriousness of COVID and were being encouraged to take precautions to prevent it, there was a sense of failure—and perhaps some judgment—if one got COVID in 2020.

At least that is how I felt when I came down with it in July 2020. Not only did it seem like proper precautions should have prevented acquisition ("how could someone so smart be so dumb?"), but I also felt I had let the team down and was perpetuating the epidemic. Even though I'd been doing this work for many years—and took all the appropriate steps to ensure I did not pass COVID to anyone else—I still managed to internalize that bit of blame and the stigma that comes with it.

Perhaps some amount of stigma is inevitable with preventable illnesses—and maybe some is even useful. In my opinion, people who were medically cleared for the COVID vaccination did have a moral obligation to get it, because getting that vaccination not only preserved personal health but also shut down a line of potential transmission. If it is effective to shame people into getting the vaccine for the sake of their loved ones or society in general, perhaps that type of shaming is appropriate.

And I must confess I had little sympathy for people who refused the adequately tested and extremely safe vaccine and subsequently acquired COVID. I may not have been affirmatively stigmatizing those people, but my sentiments seem just a few hops down the spectrum from those who had little sympathy for my HIV diagnosis given that I could have taken precautions to avoid it.

A certain amount of scaring and shaming people into acting to advance the common good has always been a part of the public health playbook. Those were certainly the tactics used to encourage people to engage in safer sex, and it was the tremendous fear of HIV instilled in people by those campaigns that helped foster the intense stigma that still surrounds HIV today. Do we really think public health campaigns should not use such scare tactics or promote a moral obligation to protect others? Those campaigns undoubtedly saved lives over the course of the HIV epidemic. Instead of disavowing such tactics altogether, maybe public health has an obligation to weigh the benefits and harms of such messaging—and when it is used, to do all it can to mitigate the ancillary harms.

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Public health officials, it seems, have been doing some of this balancing when it comes to MPX. MPX presented many of the challenges as HIV, because it is transmitted primarily through prolonged intimate contact and initially grew most rapidly within GBT communities. First, it must be acknowledged that public health officials were on top of this epidemic relatively quickly as compared to HIV. Second, they seem to have taken appropriate steps to address the stigmatizing original name. Third, they targeted the limited vaccines to those most affected, despite the fact they were particularly sexually active GBT people. (There were even some mobile vaccination units set up outside of bathhouses. Terrific!)

And fourth, they got the public message out to the most affected communities. One friend of mine criticized this messaging campaign because it seemed to imply MPX was a "gay disease." But this is one of those instances in which the benefits must be weighed against the harms. Sexually active GBT people needed to know they were at a significant risk and that they could take steps to protect themselves; if that meant some people would think MPX was a "gay disease," that seems an acceptable harm (which could be mitigated over time) to ensure the urgent health messages and prevention tools got to those most at risk.

Don't get me wrong—the MPX response was not uniformly effective in avoiding stigma. One misstep I witnessed involved an expert on television saying public health's job was simply to "call balls and strikes" in sharing data about the groups most affected (no it's not!) and explaining the whole gay community should not feel stigmatized because it was just the most promiscuous part of the community that was at higher risk. Oh good, we will just stigmatize very sexually active gay men. Ugh! Another misstep involved the lasting red mark left on people's forearms (including mine) by intracutaneous vaccinations, visibly identifying those who are at higher risk for MPX—though I understand those vaccinations are now being offered in less conspicuous places.

And there may have been other missteps not directly related to stigma (for instance, it is not yet clear what role the public health response played in creating or exacerbating racial disparities surrounding MPX); but overall, it seems public health officials have learned some of the lessons from previous epidemics. Here's hoping they continue to evolve and learn from past mistakes, not just to address stigma in the context of HIV, COVID and MPX but also to better prepare us for the next epidemic. And if the next epidemic could hold off for at least a decade or so, that would be appreciated—we've got enough on our plates right now!

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