POSITIVELY AWARE
WINTER 2023+2024

40 YEARS ON, WARD 86 STILL LEADS THE WAY

The oldest HIV clinic in the U.S. is 'an exciting place to be because it's so cutting edge,' says medical director **Monica Gandhi, MD, MPH**

CLINICIANS MUST BE THE LIGHT

WHAT'S NEW WITH HIV

IAS 2023 CONFERENCE UPDATE

PARTNERS IN RESEARCH, PART 4

PREPARING FOR SUCCESS

WINTER 2023+2024

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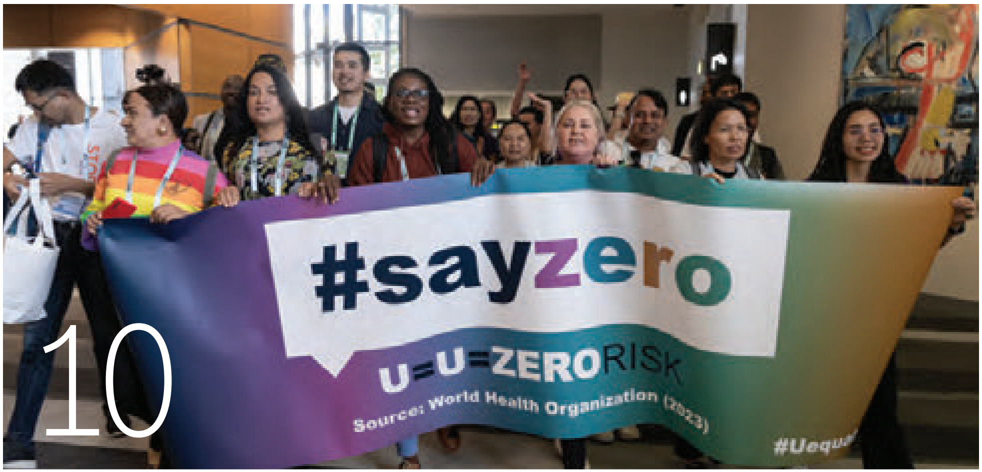

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TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals living with HIV gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission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

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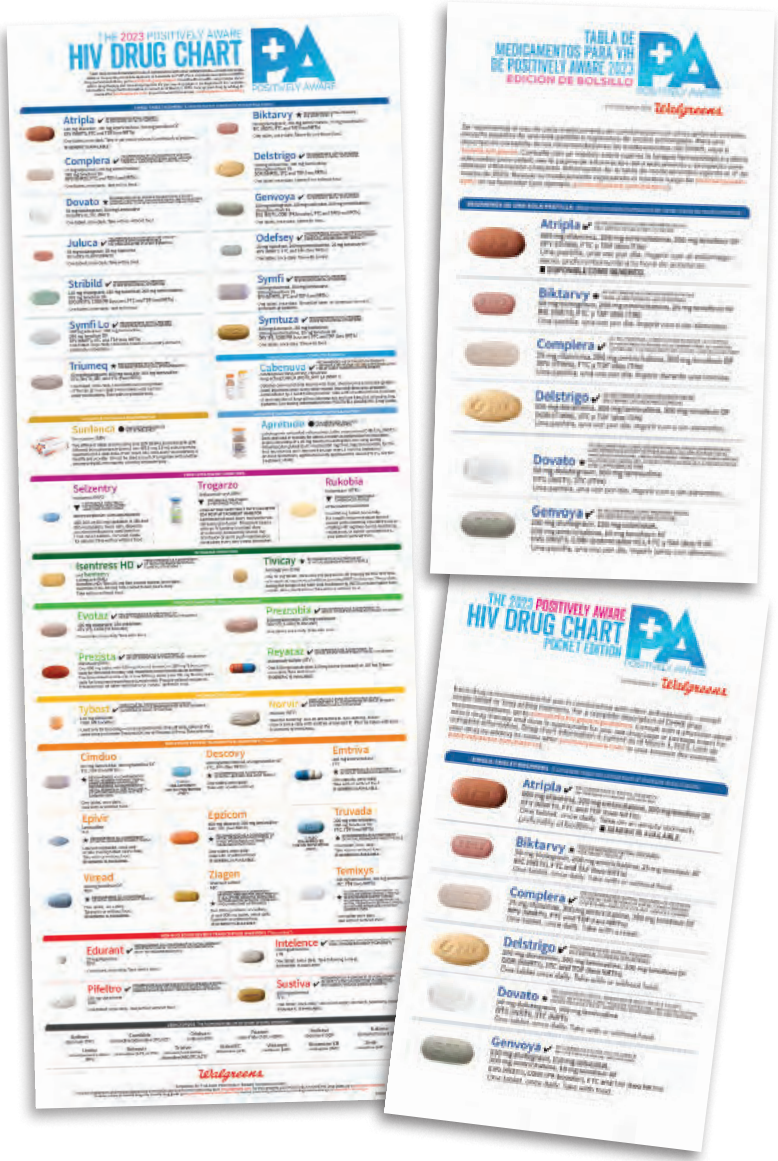

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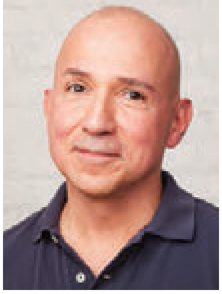

EDITOR'S NOTE

Rick Guasco
@rickguasco

Change and continuity

Forty years is a long time. That's how long San Francisco General Hospital's Ward 86, the first and longest continuously operating HIV medical clinic in the country, has been open. Four decades into the epidemic, Ward 86 is still a pioneer and leader in HIV care, research and education. How do you manage change while still maintaining a standard of excellence?

As Mathew Rodriguez's cover story explains (page 22), one key to Ward 86's success is that "as providers identify a need, they establish a program to address it." In 2008, they established a clinic for women living with HIV. In 2013, they created a program to get people newly diagnosed onto antiretroviral treatment the same day. And when it became clear that a significant majority of people living with HIV in San Francisco were over age 50, they launched the Golden Compass program in 2017 to address some of the health complications associated with aging with HIV.

People often think that *change* and *continuity* are two opposing ideas. But if the purpose of *change* is to adapt and *continuity* is to ensure intentionality, then I believe that one can help inform the other. If life has a motto, it could be summed up in one word: *adapt*.

One of my favorite lines in the animated TV series *Futurama* is when Philip J. Fry says, "People hate change. It makes them angry and confused." As Homer J. Simpson would say, "That's so funny because it's true!"

But it doesn't have to be. Change challenges us to adapt. That often means going outside of our comfort zone, what we're familiar with and instead trying new things when old ways of thinking no longer work. The worst reason for continuing to do something is, "because we've always done it this way." If we are to win the fight against HIV, we're going to have to fight it on its terms. The virus mutates; we have to adapt.

Ward 86 has not only been around for so long but has been a leader in part because of that concept. "Another essential ingredient to the clinic's success is the unique relationship between patients and providers," Mathew writes. "These advances in treatment are only possible because staff are attuned to the needs of the people who come through the clinic's doors."

That speaks to intentionality. *Why do you do what you do?* And if you're in the HIV sphere—as a care provider, case manager, researcher, policymaker or advocate—why do you do what you do, if not for the most vulnerable and the most in need?

That's in stark contrast to the experience of Bridgette Picou, who encountered stigma at the office of her care provider, of all places. Stigma is the one form of thinking that has refused to change in over 40 years. It can be hurtful when care providers (or their staff) have biased or outmoded attitudes toward the people they're supposed to care for. As Bridgette says in her column, *Being Bridgette* (page 44), "Clinicians must be the light."

"HIV is stigmatized, criminalized and misunderstood for both what it was and what it is now," she writes. "What it has always been is a *human condition*. Clinicians must learn to connect to humans and not the virus. My favorite affirmation is 'when you cannot find the light, be the light.'" Amen to that!

Elsewhere in this issue, our coverage of the International AIDS Society's conference in Australia, known as AIDS 2023, looks at how research and innovation are addressing disparities in public health and in the face of uncertainty around the world.

Writing about how lifestyle changes could lower cardiovascular risk for women with HIV, innovative tech solutions to prevent HIV in vulnerable populations or how New York City's queer community helped shape the local response to mpox, Larry Buhl's AIDS 2023 reporting shows how innovative thinking can help lead in the fight against HIV.

Taking a cue from Bridgette, it's up to all of us to be the light when the need arises. Be an agent of change.

You are not alone.

Rick

> If we are to win the fight against HIV, we're going to have to fight it on its terms. **The virus mutates; we have to adapt.**

GUASCO: JOHN GRESS • FOTOVOYAGER-ISTOCK

Briefly

ENID VÁZQUEZ @enidvazquezpa

Zero HIV Stigma Day

The theme of the first Zero HIV Stigma Day was *Human First*

Commemorated on July 21, the day was created by the London-based sexual health organization NAZ and IAPAC in collaboration with the Global HIV Collaborative and other organizations to raise awareness around HIV and act against the stigma that surrounds it.

“Our 2023 theme of *Human First* is meant to emphasize the human dimension of people living with and affected by HIV, because we are all Human First,” the organizers wrote. “It means… **we see the person before the virus, that a person living with HIV is first a human, they need to be recognized and acknowledged and they deserve every human right** just like everyone. Any discrimination against people living with HIV should be seen as a human right violation.”

July 21 was chosen because it is the date that Prudence Nobantu Mabele became the first South African woman to go public with her HIV-positive status, in 1992. She addressed issues of gender-based violence in addition to her HIV work and helped found the Positive Women’s Network in 1996.

“The only thing preventing us from ending all new HIV transmissions by 2030 is stigma,” said NAZ CEO Parminder Sekhon.

To watch the *Human First* documentary on YouTube, GO TO bit.ly/human-first-doc. GO TO zerohivstigmaday.org.

Mpox chapter added to OI guidelines

A comprehensive chapter on mpox has been added to the *Guidelines for the Prevention and Treatment of Opportunistic Infections in Adults and Adolescents with HIV*. The guidelines are produced by an expert panel brought together by the U.S. Department of Health and Human Services (DHHS).

According to the new chapter, “Strategies to prevent mpox exposure are similar for people with and without HIV. Regardless of vaccination, **people with HIV at risk for mpox should avoid skin-to-skin or other close intimate contact (including sex) with people who may have constitutional symptoms or a rash suspicious for mpox, avoid contact with contaminated surfaces or objects** (including linens) used by a person with mpox, and perform frequent hand hygiene after touching rash material or surfaces that may have had contact with rash material.”

The new section includes recommendations for vaccination and for treatment. GO TO clinicalinfo.hiv.gov.

Profile of people living with HIV

The Medical Monitoring Project (MMP), a national survey of clinical and behavioral aspects of people living with HIV, released its latest report in August. Organized by the Centers for Disease Control and Prevention (CDC), **MMP asks people about such aspects of life as smoking, mental health concerns, food insecurity, sexual behaviors and pregnancy**.

The latest survey, covering June 2021–May 2022, reports that

- At year-end 2022, an estimated 1,072,051 persons in the United States and 6 dependent areas were living with diagnosed HIV
- In 2020, the number of new HIV diagnoses was 30,692.

Among medical findings for the 3,995 individuals responding to the survey:

- 66% were virally suppressed (had less than 200 copies HIV per mL on a viral load test, also called undetectable)
- 95% had received outpatient HIV care during the past 12 months
- 81% did not miss any HIV care appointments
- 80% were prescribed antiretroviral therapy (ART, or HIV medication)

Nearly all (99%) had health insurance or coverage for care or medications: 47% through the Ryan White HIV/AIDS Program, 43% through Medicaid and 42% through private insurance.

Other findings include:

- 37% had one or more visit to the emergency room
- 17% had one or more hospitalization
- 33% of cisgender female adults had experienced pregnancy since their HIV diagnosis

Reasons for missing an ART dose:

- Forgot to take HIV medicine, 65%

VÁZQUEZ: JOHN GRESS

TOP OF THE NEWS
➤ Zero HIV Stigma Day ➤ For people with detectable, but low-level viral load, an ‘almost zero’ chance of sexual transmission ➤ Mpox chapter added to OI guidelines ➤ USPSTF adds injectable PrEP to its recommendations ➤ From the USPSTF PrEP recommendations ➤ Statement from HIV+Hepatitis Policy Institute ➤ Good results with children’s STR: IMPAACT 2019 ➤ HIV criminalization handbook

- Change in daily routine or were out of town, 42%
- Fell asleep early or overslept, 40%
- Felt depressed or overwhelmed, 17%
- Had a problem getting a prescription or a refill for HIV medicines, 16%

GO TO bit.ly/MMP-survey.

USPSTF adds injectable PrEP to its recommendations

The United States Preventative Services Task Force (USPSTF) in August added injectable PrEP, Apretude, to its list of recommendations for the prevention of HIV. **The “A” rating for pre-exposure prophylaxis (PrEP) drugs to prevent HIV is important for allowing these medications to be provided for free, including lab tests.** Legal challenges and congressional opposition continue to threaten access to PrEP.

USPSTF noted that, “PrEP is underutilized, particularly for Black and Hispanic/Latino persons with indications [evidence of need] for PrEP.”

In an interview with Ayesha Rascoe of National Public Radio following the USPSTF update, Carlos del Rio, MD, noted that while various funding sources help in accessing PrEP, “The reality is that, at the end of the day, it’s not enough. There’s a group of academic researchers, of lawyers, of community advocates that have proposed a national PrEP program—really optimize PrEP access equitably because if we were to use PrEP appropriately, we would be able to really prevent many new HIV infections.”

Listen to the interview, “People with insurance will now have easier access to HIV-prevention medication,” at bit.ly/NPR-del-Rio-PrEP.

GO TO uspreventiveservicestaskforce.org. The guidance was published in the August 22 issue of *JAMA*.

From the USPSTF PrEP recommendations

The USPSTF recommends that the following individuals be considered for HIV PrEP:

1. Sexually active adults and adolescents weighing at least 77 lbs. (35 kg) who have engaged in anal or vaginal sex in the past 6 months and have any of the following:
    - A sexual partner who has HIV (especially if the partner has an unknown or detectable viral load).
    - A bacterial sexually transmitted infection (syphilis, gonorrhea or chlamydia for men who have sex with men and transgender women; gonorrhea and syphilis for heterosexual women and men) in the past 6 months.
    - A history of inconsistent or no condom use with sex partner(s) whose HIV status is not known; assessing risk in conversation with the patient and considering factors such as number of partners, the specific sexual activities a person engages in, and whether their sex partner or partners are in a group with a higher prevalence of HIV (e.g., men who have sex with men or with men and women, transgender women, persons who inject drugs, and persons who engage in transactional sex).
2. Persons who inject drugs and have a drug injecting partner who has HIV or who shares injection equipment.

Transgender women are at especially high risk of HIV acquisition and should be considered for PrEP based on the criteria outlined above.

Persons who engage in transactional sex, such as sex for money, drugs, or housing, including commercial sex workers or persons trafficked for sex work, constitute a group at increased risk of HIV acquisition and should be considered for PrEP based on the criteria outlined above.

Statement from HIV+Hepatitis Policy Institute

Executive director Carl Schmid issued this statement following the PrEP announcement: “Including a long-acting drug as part of **the USPSTF PrEP recommendation is an important step in improving HIV prevention efforts** in the United States. While daily oral PrEP is highly effective, adherence can be an issue. That is why the FDA called long-acting PrEP superior to daily oral PrEP. With PrEP uptake deeply lagging in Black and Latino communities compared to Whites, long-acting PrEP can be a game-changer. Now we urge the federal government to immediately issue guidance to direct insurers to cover all forms of PrEP without cost-sharing. It took two years after the initial 2019 USPSTF PrEP recommendation for the Center for Consumer Information and Insurance Oversight (CCIIO) to issue coverage guidance to insurers. That delay helped lead to many PrEP users being charged cost-sharing by insurers, a situation that still continues today. People seeking PrEP must not face any additional barriers as they seek to access the form of PrEP that best meets their individual needs.”

Briefly

Good results with children's STR: IMPAACT 2019

Development of medications for children lags behind that for adults. In HIV, this means that **single-tablet regimens (STRs) which began revolutionizing antiviral therapy two decades ago are still largely unavailable to many children around the world**.

Noting that "child-friendly, fixed-dose combination (FDC) antiretroviral therapy (ART) options are limited," the international IMPAACT 2019 pediatric study published early Phase 1/2 results using both a dispersible formulation and the regular STR formulation containing dolutegravir (DTG) that is sold under the brand name Triumeq.

"Both FDC formulations were overall safe and well tolerated in our study population through 24 weeks of treatment," the study team reported.

IMPAACT 2019 enrolled 57 children weighing at least 13.7 pounds (6 kg). In addition to determining safety, the study achieved its goal of meeting pharmacokinetic targets (including drug levels) at all weight levels of the study. (Dosing for children is often determined by weight.)

The vast majority of the children (54, or 95%) had undetectable viral load (less than 200 copies of HIV per mL of blood) at the six-month mark.

The IMPAACT 2019 study team made the following points by way of a background statement:

- The combination of dolutegravir, abacavir and lamivudine [brand name Triumeq] is recommended globally [by the World Health Organization, or WHO] but is not widely available for children in a fixed-dose combination formulation.
- FDC tablets only recently became available within the U.S. in immediate-release form for children weighing at least 55 pounds [25 kg] and dispersible form for children weighing at least 22 pounds [10 kg].
- However, no child-friendly dolutegravir-containing FDC formulations are available outside the U.S. or for children weighing less than 22 pounds within the U.S., thus requiring the use of several tablets and formulations to provide a complete ART regimen for more children with HIV globally.
- High pill burden can present adherence and administration challenges in children, often resulting in poor treatment outcomes for this vulnerable population.

In a comment piece in the issue, "A step closer to optimal ART for all children," Intira Jeannie Collins and Anna Turkova of University College London explain that, "Dolutegravir-based antiretroviral therapy (ART) is the WHO-recommended first-line and second-line treatment for children and adults with HIV. Tenofovir disoproxil fumarate, lamivudine and dolutegravir (TLD) is a once-a-day, highly efficacious and safe fixed-dose combination, widely available as a low-cost generic formulation in low- and middle-income countries (LMICs) for adults and adolescents. However, there is currently no equivalent fixed-dose combination specifically designed for children.

"The publication is timely and commendable," they continued further into the comment. "This treatment will be the only fixed-dose combination providing a complete and WHO-recommended regimen for children in LMICs weighing 6 kg [13.7 pounds] or more, given that TLD is not recommended until children reach 30 kg [66 pounds] because of tenofovir-related renal and bone toxicity concerns, and pediatric fixed-dose combinations of tenofovir alafenamide are not yet available in many LMICs.

"The study provides important supportive data on a long-awaited pediatric fixed-dose combination of abacavir, dolutegravir and lamivudine, which has been on the Pediatric ARV Drug Optimization priority list for LMICs and will simplify ART treatment for children across several weight bands," note Collins and Turkova, adding that, "Affordable generic versions of this formulation are expected to be available this year."

According to the commentary, half of the world's children living with HIV are on antiviral treatment compared to three-quarters of adults, and a child dies of AIDS-related causes every five minutes. In other statistics, the study article says that children make up 5% of the global population living with HIV, but account for 15% of individuals who died from AIDS-related causes.

The IMPAACT clinical trials group conducts research to improve the health of parents living with HIV and their children. It is funded by the U.S. National Institute of Allergy and Infectious Diseases (NIAID) and others. The IMPAACT 2019 study results were published in the August 2023 issue of *The Lancet HIV* medical journal.

Children's HIV treatment

Here in the United States, most of the HIV single-tablet regimens (STRs) are available to children, with limitations related to their size and age. Also available in pediatrics is the only complete HIV treatment via long-acting injection, Cabenuva, which can be given once every two months.

The latest advance came in March 2022, when a new formulation of the STR Triumeq was approved by the U.S. Food and Drug Administration (FDA). The new pediatric formulation, Triumeq PD, is dispersible in liquid. The number of pellets are taken based on the weight of the child.

This new formulation allowed an STR to be given to children as small as 22 pounds (10 kg). Previously, only two of the STRs could be used by children weighing as little as 55 pounds. Only one of those, Biktarvy, is commonly used.

At the same time, the original larger Triumeq tablet was approved for pediatric use at a lower weight, from 88 pounds (40 kg) down to 55 pounds (25 kg).

The backbone medication in Triumeq, dolutegravir (brand name Tivicay), has had a PD formulation since 2021, for children as young as four weeks old and weighing at least 6.6 pounds (3 kg). Again, this would require multiple medications instead of an easier-to-take STR, since HIV drug regimens are made up of at least two medications and usually three (such as Triumeq). Two other STRs contain dolutegravir—Dovato and Juluca. Both of them contain only two medications. Neither has an FDA approval for pediatric use.

Globally, dolutegravir is considered a "preferred" drug for HIV treatment in WHO guidelines. According to those guidelines, "**By September 2021, 78% of the people receiving ART were receiving TLD** (50% in September 2020)." This STR is not sold in the United States, but made available at generic prices in other countries, often provided through PEPFAR (the United States President's Emergency Plan for AIDS Relief).

HIV criminalization handbook

Released in August, *All Pain, No Gain: HIV Criminalization in Pennsylvania* is a new handbook from the AIDS Law Project of Pennsylvania in collaboration with several other organizations and legal writers. The book is useful to everyone everywhere because it **details the history of HIV criminalization laws in the United States and what can be done about them**. It covers the dated science behind the laws—how often negligible risks of transmission are treated as an actual risk. There's no reason for HIV to be specifically singled out for criminal law involvement. It details the meanings behind certain legal terms (such as *reckless endangerment*, *simple assault* and even *terroristic threats*). It discusses "sentence enhancements" for people in jails and prisons or for sex workers. (Note: *sex work* is different from *sex trafficking*, a point that continues to evade some people.)

Under "The Alternatives," the authors write, "No one benefits from prosecuting and incarcerating people with HIV for consensual sexual activity. Prosecution may result in the disclosure of private medical information, creating a potential risk of partner violence and a negative and irreversible impact on all parties. Incarceration increases stigma, impedes access to healthcare, and upon release causes instability in housing and employment, for the individual, their families and their community. Instead, alternatives to criminalization should be considered for any person who engages in consensual activity and feels harmed because they think they may have been exposed to or infected by HIV."

In the conclusion, they note that, "HIV criminalization undercuts important public health initiatives by ignoring actual transmission risk, exacerbating stigma, and devaluing the importance of personal responsibility in HIV prevention. Criminalization makes it more difficult for those who have been diagnosed with HIV to disclose their HIV status to partners or to access and stay in care. In short, it's all pain and no gain. Pennsylvania can and must do its part to reduce HIV transmission by ending HIV criminalization."

All Pain, No Gain was produced in collaboration with the Center for HIV Law and Policy, the Sero Project and the Philadelphia Regional Chapter of Positive Women's Network-USA, with the review or support of many other organizations and individuals. To download it, GO TO bit.ly/all-pain-no-gain-handbook.

ISTOCK

ACTG updates its name

It was previously short for "AIDS Clinical Trials Group," but now ACTG stands for *Advancing Clinical Therapeutics Globally for HIV/AIDS and Other Infections*. In a brief announcement, the longstanding research group stated that the updated name better reflects what it does today. With its global work, **ACTG helps with the prevention and treatment of other conditions, such as tuberculosis. Its focus, however, remains heavily HIV-related**.

'All children can be born free of HIV, syphilis and hepatitis B'

That's the message from the Clinton Health Access Initiative (CHAI), which discussed the extent of these conditions in pediatric and **promoted a "triple elimination" strategy** in an announcement issued in August. There are missed opportunities to protect children despite the availability of safe, effective and affordable interventions, the group said.

"Over 1.5 million babies are infected by human immunodeficiency virus (HIV), syphilis, and hepatitis B virus (HBV) each year globally. About 80 percent of these infections occur in low- and middle-income countries (LMICs)," the announcement reported.

"Pregnant women living with HIV, syphilis or HBV can pass these infections on to their infants during pregnancy, delivery or post-partum. This is known as vertical transmission. Without access to preventive measures, infants at risk of these infections can progress to chronic disease and early death.

"Safe, effective, and affordable tools exist to prevent transmission of these deadly infections from mothers to babies," CHAI continued. "Expanding access to prevention measures, including stopping new infections among people of reproductive age, timely screening, treatment and HBV vaccination, all delivered through a common reproductive, maternal and child health (RMCH) platform can increase the survival of babies significantly. However, implementation of these measures in LMICs differs dramatically across the three diseases, reflects uneven investment levels, and political will."

GO TO clintonhealthaccess.org.

Briefly

For people with a detectable, but low-level viral load, an ‘almost zero’ chance of sexual transmission

Much has been said about undetectable equals untransmittable—known as U=U— the science-based principle that people living with HIV (PLWH) have a “zero chance” of transmitting the virus if they are adherent to their antiretroviral therapy (ART) regimen and, as a result, have a viral load that is undetectable, that is, fewer than 200 copies per milliliter of blood. But what about people who, while not undetectable, have low level viremia, whose virus is “suppressed but not undetectable”

A systemic review of HIV studies has found that PLWH who are adherent to their antiretroviral treatment regimen and whose detectable is viral load is 1,000/mL or less have an “almost zero risk of sexual transmission of HIV.” The report’s deliberate wording was intended to fit next to the context of U=U science.

“Although an undetectable viral load is the goal for all people living with HIV on ART, these data demonstrate that the risk of sexual transmission of HIV at low-level viremia is almost zero,” the review said.

From 244 HIV studies published between 2010 and 2022, the review analyzed findings from eight studies on sexual transmission of HIV, representing 25 countries and comprising a total of 7,762 couples—mostly heterosexual and who were serodifferent, where one partner was living with HIV and the other was HIV-negative. Only studies that provided viral load data were reviewed.

Three studies showed no HIV transmission in which the partner living with HIV had a viral load less than 200 copies/mL. The other studies totaled 323 cases of HIV transmission, none from people who were considered “stably suppressed [undetectable] on ART.” Among all studies, there were two cases of transmission in which the positive partner’s most recent viral load was greater than 1,000 copies/mL, however, this was complicated in both cases by the amount of time between the last viral load test and transmission date—50 and 53 days.

None of the studies assessed transmissibility of HIV through the sharing of injection drug use equipment when a person’s viral load was less than 1,000 copies/mL. The findings do not apply to vertical transmission, from pregnant parent to child, the report added, stating that transmission can occur during pregnancy, at childbirth or through breastfeeding/chestfeeding feeding.

Published in *The Lancet* in July, release of the review was timed to coincide with the 12th International AIDS Society Conference on HIV Science in Brisbane, Australia (coverage of IAS 2023 begins on page 28).

At the same time, the World Health Organization issued a policy brief describing the role of HIV viral suppression. It outlined three categories of HIV viral load measurements: **unsuppressed** (greater than 1,000 copies/mL), **suppressed** (detectable, but less than 1,000 copies/mL) and **undetectable** (less than 200 copies/mL, or too low to be measured by the test being used).

#sayzero: ACTIVISTS AT IAS 2023 DEMONSTRATE IN SUPPORT OF THE WORLD HEALTH ORGANIZATION’S DECLARATION THAT U=U MEANS ZERO CHANCE OF HIV TRANSMISSION.

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At the IAS conference, one of the study’s authors, Lara Vojnov, PhD, explained what the “suppressed” category could indicate. “There is some virus replicating and present, but too little to be quantified. It could be due to missing doses, recent treatment initiation or drug resistance.” But she stressed that “people living with HIV who have a suppressed viral load have almost zero or negligible risk of transmission to their sexual partners.”

In addition to Dr. Vojnov, the review was authored by Laura N Broyles, MD; Robert Luo MD, MPH; and Debi Boeras, PhD.

“By demonstrating that the risk of sexual transmission of HIV is almost zero when the index partner has a viral load less than 1,000 copies per mL, **our findings underscore the importance of prevention campaigns, while also suggesting that the U=U message applies to people living with HIV experiencing low-level viremia**,” the review said. “This message is crucial for low-income and middle-income countries where the disease and infrastructure burdens are high and national programs are often reliant on alternative sample types and technologies to fully expand access of viral load testing to all people living with HIV. Further, it might encourage more positive and clear messaging on the role of ART in preventing transmission to sexual partners.”

The report concluded, “The benefits of treatment as prevention are clearer than ever before, which should encourage [PLWH] to seek and adhere to treatment and support efforts to destigmatize and decriminalize HIV.”

READ the review in *The Lancet*: bit.ly/Lancet-low-level-viremia-review. The WHO policy brief is at bit.ly/WHO-HIV-suppression-policy-brief. —RICK GUASCO

Long lasting

ISTOCK

Long-acting injectables are a game changer for HIV prevention and treatment; so, we asked our social media followers:

Have you thought about long-acting injectable medication, either for HIV treatment or for PrEP? What are your questions or thoughts?

COMPILED BY **RICK GUASCO**

“**I am a nurse** and have a few patients on Cabenuva, and I wonder if market-based insurance is covering more Cabenuva? I have yet to have a convo with my own doc about it.”

—**JOSEPH EDWARD**

“**I think injectables** are great for some people and I am glad that that option is available to those who want it. I take 16 pills a day and only one of those is for my HIV. So, eliminating one pill a day out of my usual regimen and having to go to the doctor’s office every three or four months instead of twice a year like I do now doesn’t really make me want to switch to an injectable. This is just my opinion.”

—**RANDY BOWLING**

“**I don’t find it** difficult to adhere to one pill per day that is currently very easy to get, so there’s little attraction here but under other circumstances, maybe.”

—**LILLIAN THIEMANN**

“**I discussed this** with an infectious disease doc in August amid blippy viral load (44, 48, 28, likely due to inability to digest lactose-based Odefsey tablets fully), and he erroneously indicated one’s viral load must be below 20—ViiV says under 50! Still, after thinking through the need to try oral cabotegravir first [no longer required] and that I take other pills daily anyway, the novelty has worn off. Further, the ViiV ad with the line implying a need to hide one’s meds when having people over rubs me the wrong way in reinforcing self-stigmatization.”

—**DAVIDMICHAEL PHILLIPS**

“**I’m on** Trogarzo infusion therapy that works for me.”

—**ALBERTO PEREZ BERMUDEZ**

“**People I know** who are on Cabenuva like it, but they admit that the shots can be uncomfortable, if not painful for some. I myself don’t want to do it because I don’t want painful shots. I am okay with taking a tablet every day. I miss a dose once in a blue moon.”

—**TOM HUNTER**

“**At 57,** I take multiple one pill per day medications to manage other health issues. Do not wish to spend more time in the doctor’s office than I currently do.”

—**XIO MORA-LOPEZ**

“**Maybe pain,** labs and visits every six months might be worth it. I am hoping that implants are next.”

—**ANDREW ESPINOSA**

“**I’m on** Sunlenca, but still need to take oral meds with it.”

—**TIM HOEFFGEN**

“**I already do** an injectable for high cholesterol every 14 days. I think getting such for HIV would be great. I would hope the benefits would outweigh any negatives that might be associated with the injection. As a now 34-year survivor of HIV, and dealing with ESRD [end-stage renal disease] and dialysis, anything that makes life easier is a plus.”

—**HAROLD SCOTT**

“**Wow!** We hope that this will be available in South East Asia soon.”

—**@STEPHXCHRISTIG**

“**I’m an** HIV long-term survivor from the ’80s and have been involved in HIV research all my adult life… For people dealing with polypharmacy, it’s so much easier to think about HIV treatment just six times a year. Medication adherence used to be a daily burden for them, as well as worrying about how to get refills every month. Now, not having to think about HIV every single day is almost miraculous! All medications can have serious side effects that your doctor should be checking for; one side effect most people complain about with HIV LAIs is soreness at the injection site for a few days. That’s not that hard to deal with in the context of a couple of days, six times a year, with better results, if you ask me.”

—**FERNANDO DE HOYOS**

“**I’ve been on** Cabenuva for 15 months and love it. I still take daily medication for other conditions, but I don’t have that anti-HIV pill staring me in the face. It’s kind of changed my outlook on some things. In June, at a conference, I realized that for the first time in 28 years, I had gone a day and a half without thinking about me being HIV-positive.”

—**ERIC MOORE**

“**Very interested,** but how do the costs compare with pills?”

—**BEN COLE**

“**I’d definitely** love to have injections so that I won’t have to think about missing a single dose.

“I want to get on one so bad. After I moved from Illinois, they made it available there through ADAP but Colorado doesn’t have it as an option yet. For people like me with ADHD, I often forget my daily pill, so it’d be extremely freeing to have one less thing to worry about.”

—**@SLEDDOGMARS**

“**As a long-term survivor** living with AIDS and having been heavily pretreated with other highly active antiretrovirals, I am out of the running of any of these medications.”

—**ROB TOTH**

“**I have considered** it and actually talked with my provider about getting started!”

—**MARISSA GONZALEZ**

Preparing for success

Drawing from their experience, long-term survivors offer their insight for researchers

CONTRIBUTING EDITORS **TOM VILLA** AND **KARINE DUBÉ**

This marks the fourth and final installment of the series sharing our perspectives and experiences as HIV cure-related research participants. Our aim has been to help support HIV cure clinical trials and ensure the safety and well-being of future analytical treatment interruption (ATI) trial participants, their partners and affected communities.

In Part 1, we focused on community response to the HIV epidemic and why some of us have gotten involved with HIV cure research.

Part 2 featured a participant readiness and resilience framework, published together with POSITIVELY AWARE's annual HIV Drug Guide. This framework aims to better support the mental and psychosocial well-being of HIV cure research participants and their partners before, during and after ATI trials.

Part 3 highlighted the growing family of people who have achieved *cure* or *long-term suppression off ART*, as well as various psychosocial aspects of HIV cure. This fourth and last issue examines variable outcomes of HIV cure research, and the need to prepare now for continued research success.

Our calls to action, informed by lived experiences

We are part of the community of people living with HIV (PLWH) who have volunteered to participate in early-stage clinical trials of HIV cure strategies that included an ATI. In this series, we have invited people from diverse backgrounds to share their lived experiences and to highlight our community response to the HIV epidemic through HIV cure-related research.

Together, we have advocated for a comprehensive support program around ATI participants to preserve the long-term community trust around HIV cure trials. We have called to increase diversity of participants to ensure research findings benefit all communities, to minimize physical and psychosocial risks, and help ensure an adequate number of participants for future trials.

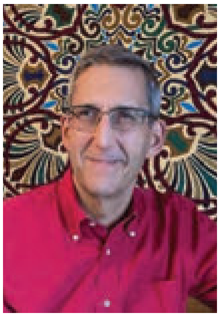
How to get involved in HIV cure-related research

As it comes to a conclusion, we hope you have enjoyed reading this community-driven series and that you will remain engaged in research efforts to end HIV. Here's how you can get involved in HIV-related research:

- Read previous articles from POSITIVELY AWARE: positivelyaware.com/hiv-cure-research
- Consult the Treatment Action Group (TAG) research towards a cure trial page for a list of ongoing and past trials: treatmentactiongroup.org/cure/trials
- Help accelerate research to end HIV by joining the Red Ribbon Registry: helpendhiv.org/red-ribbon-registry

GARY STEINKOHL

'Boston Patient B'



March 11, 2013 was like most other days for me, with one significant exception. As I was reaching for my daily HIV meds, I remembered, no HIV meds today, and hopefully never again.

Months earlier, I agreed to participate in a study to see whether a stem cell transplant, which I had undergone to treat cancer, would eliminate HIV. To test this premise, I agreed to stop taking HIV meds. March 11th was the day I stopped.

I was diagnosed with HIV in 1985. My viral load was manageable for years without HIV meds (one of the strategies at that time). In 2003 I was diagnosed with lymphoma, likely caused by HIV. Before undergoing chemotherapy, my HIV had to be brought under better control, so I started taking HIV antiretroviral therapy. The chemotherapy treatment worked, though the lymphoma returned in 2006. I began another round of chemotherapy, followed by a stem cell transplant that used cells from my own body, a more challenging experience and recovery than from chemotherapy.

All went well until 2009 when tests revealed myelodysplastic syndrome—my bone marrow was slowly failing, a consequence of many chemotherapies. With

THE CONTRIBUTING EDITORS

Thomas J. Villa works to help end the HIV epidemic as a writer and serial participant in HIV clinical research. He serves on the ACTG Partner Protections Working Group and is a Community Advisor to both the HOPE and RID HIV Martin Delaney Collaboratories for HIV Cure Research.

Karine Dubé works at the intersection of biomedical research, socio-behavioral sciences, ethics, and patient/community engagement in HIV cure research in the United States and South Africa. Karine is passionate about centering the voices of patients/participants in HIV cure-related research across the lifespan.

donor cells from my sister, I had a second transplant, and it was successful.

In 2012 my doctor asked if I would talk with a researcher who was conducting an HIV cure study to assess whether the stem cell transplant I had might have also eliminated HIV. I remember having two thoughts as we talked: *if what this study is testing proves true, I will no longer have HIV*, and, *if this is true this could be amazing for others with HIV.*

The risks of participating in the study included damage to my long-term health, including the possibility that I might die. My emotions ranged from being elated and hopeful to fears of what could happen. Tim Henrich, the lead researcher, was honest and forthright in answering my questions, never trying to sway my decision. The only promise he gave was that I would help advance cure research.

The study protocol required I stop HIV medications, the only way to test whether any HIV remained in my body. Having experienced HIV-related complications—two bouts of lymphoma—the risk of giving any suppressed HIV the chance to rebound was scary. Big time scary. Research at that time showed the virus usually returned in 8–12 weeks, and treatment interruption had an overall, and sometimes strongly negative, impact on health.

I asked myself what participating in this study could mean for me and for others who have HIV. I talked a lot with my sister and with my closest friends. In late 2012 I agreed to participate. The first step was a thorough investigation of my body to ensure no HIV could be found. I was poked, prodded, stuck with needles, had a spinal tap; no virus was found. When I passed all the study pre-research tests the next step was stopping my HIV meds.

Weekly tests found no detectable virus. As time passed, I started to hope that I might have been cured of HIV. I felt hopeful, and then I felt alone. There was only one person, Timothy Ray Brown, who had been cured. Even with the support of my sister and close friends, this was a surreal time for me. When someone asked, as we all casually do when seeing a friend, *how are you feeling?* I thought, *what do I say?*

Test results through the 24th week were the same, no virus. I was now beyond the timeframe of anyone who stopped meds and whose virus hadn't returned. I tempered my growing hopes of being cured with the reality of *this isn't a done deal yet*. Having HIV was enmeshed in who I was, including feeling different from others, and self-doubts and fears of living with a deadly virus.

My hopes of being cured vanished in October 2013. After an emergency room visit because I was felt fluish, I was informed I had tested positive for HIV. I felt sad; very, very sad. I immediately restarted HIV meds, which I continue to this day.

I was deeply disappointed not being cured—disappointed for myself and for others. I also felt I had let Tim Henrich down. He told me I hadn't, that my participation advanced knowledge about the virus and was already shaping new directions for cure research. No cure... at least not yet.

It's been ten years since this happened. I still admire and respect those dedicated and wonderful people working valiantly on cure research, and my choice to participate in helping find a cure. To my fellow research participants—*thank you.*

* * *

ANDREA LAMOUR-HARRINGTON

Investing in community so community can invest in your research

***I am a 56-year-old ordained minister, mother, activist and health department employee who happens to have been living with HIV since December 12, 1988. Over those years, I have been witness to advances in medical research that have kept me alive. If I could safely participate in a clinical trial that would help find answers to scientific questions about my health, and help the people coming behind me, then my life will have fulfilled its purpose.* I want to help others to heal.**

My clinical trial involved an analytical treatment interruption that lasted for about six months. It was all smooth sailing, and I had nothing to worry about. Toward the end of the study, my numbers went down a bit, and the researchers put me back on my HIV meds. It was nothing that made me fearful; it was nothing that put my health in jeopardy. They kept an eye on everything, telling me what was going on the whole time. Except for a headache once, I really had no issues, nothing that put me in danger, made me fearful or made me regret anything about the study.

The researchers thoroughly explained everything to me, I did not feel like I was at these appointments alone.

The study doctors and nurses came in and explained to me what was happening. The staff was on point. It was a wonderful experience because I felt like I had family taking care of me.

When I went back on my HIV medications, everything returned to normal, and my body was fine. The clinicians cared about me and my health beyond the research.

During the treatment interruption, we took steps to protect my partner, who is also living with HIV. We still had sex as we did, until my viral load became detectable. We just laid off, to make sure everything was okay. The clinicians suggested that we abstain, which we did. Before long, I was undetectable again and everything was back to normal.

Overall, everything went well for me. I haven't been too fearful of HIV. But there are people who may not be as informed or educated. I would have liked, though, to have seen during the trial that there was a therapist or counselor who could stay in contact with participants. Someone who could explain what a slight drop in T cells meant, and that it was not the beginning of something serious. Even when a doctor explains something, sometimes you need someone who can repeat that information in a more comforting way to help you stay calm. For someone who might not be as informed or who hasn't been living with HIV that long, they may need that extra crutch, just to reassure them.

I also think researchers need to do a better job sharing information with participants after the study. They need to break down the science, so it is better understood by the community. If they do that, they'll be investing in the community so that community can invest in them again.

LUIS CANALES

Moving beyond uncertainty

I'm a choreographer, performance artist and community activist. I manage a kitchen in North Beach, California, an acrobatic circus and dinner theater. I'm chunky, funky, thick, phat and all that. I also volunteer for nonprofit organizations. I've been a participant in clinical trials for HIV cure research since 2014.

I lived as a person with HIV from 2013 until I moved to Los Angeles, where I had to get tested to verify that I'm positive to access care. I tested negative. I had no idea why. Eventually, I moved back to San Francisco and linked up with my old doctors here. That's the beginning of my journey. Through the SCOPE study at the University of California-San Francisco General Hospital, I've been part of a plethora of clinical trials. It all seems like the same trial, the same journey, the same goal of finding a cure for HIV.

My analytical treatment interruption (ATI) took place from July 2021 until January 2023. The study enrolled participants who started medication very early into their HIV seroconversion, to observe when the virus rebounded. The ideal situation was that HIV would rebound, the numbers would climb and then plateau, maybe even peter off into "suppressed remission." That was the term. A few months at the most, not past a year. I never rebounded. They never anticipated participants in the trial to get cured of HIV.

Treatment interruption was the scariest part of my journey, really scary. I don't understand all the science. Even worse was how it affected me interacting sexually with others, trying to make sure they were safe, because I was a person with HIV who was not on medication. I can't recall the last time I've met someone in that situation. I tried to explain to guys I met online. Most everyone was confused, so they just decided *no*. Even when all the barriers were broken down, there was this fear in the back of my mind: *What if in the past few days my virus has rebounded?* No one wants to have protected sex these days. That's what made it really scary, the thought of potentially harming someone else.

I would overload people with information, trying to be forthright and super honest. But who on Grindr wants to have to read a PDF document before hooking up? *Not that sexy*. People got overwhelmed. Not just confused, but *overwhelmed*. My doctors and nurses helped me simplify. I broke it down to, "Hey, I have HIV, but there's a caveat. I'm off my meds for a clinical trial for an HIV vaccine."

I never considered that I could also get super-infected with multiple strains of HIV. Not only was it hard to protect my partners, but protecting myself as well. This was further complicated psychologically by my personal journey as a gay man recovering from meth addiction directly linked to sex. I was trying to have a renaissance with the way I engaged in romance and sex, and treatment interruption was yet another roadblock. That's why this part of the study was the most terrifying, even beyond getting electroporated for the vaccines. I'd rather do that every week. *I'm a pain pig, so bring it on!*

If I have a suggestion to the study clinicians, it's make the participants aware of psychological things they might experience, how it may change their romantic and sexual interaction with partners. Be repetitive. Researchers go over all the physical risks, be very thorough with that. The mental health component has to be considered, too. Someone can describe a situation, and you think you're prepared for it, and then you enter into it. I was feeling alone and isolated. What could have alleviated that feeling is a support group comprised of other study participants going through the same thing. I experienced similar isolation when I first started clinical trials. I was lucky enough to have been connected to Timothy Ray Brown, the Berlin Patient, by mutual friends. He agreed to meet and gave me much needed support.

I was in the study longer than anticipated. In lots of ways, I was putting my life on hold. I couldn't be spontaneous. I don't understand the science, so I thought the longer I'm off meds, the better. *The vaccine's working! Maybe this is the cure that we've been searching for!* Going back on medication felt like ending the journey, and I'm not a quitter. My doctors said that they'd learned 99% of what they wanted to learn. They just had to keep explaining to me over and over again that they learned almost everything they needed, that I wasn't giving up or failing by starting HIV meds again. When I heard that I felt like I was released.

As soon as I took that first pill again I felt safe, *protected*. I do not want to go on another treatment interruption. I might feel differently in the future, but I'm not in a rush to jump back in. I have no idea what's next. For now, I'm just trying to enjoy being a regular, middle-aged gay man on meds and not really having to think about things. Just enjoy my life.

Shout out to everyone at UCSF on the SCOPE study team. They've been there for me, super forthright, honest and caring. I really appreciate that!

Elements of Comprehensive Participant Readiness and Resilience Framework – A journey approach to HIV cure research

Creating a framework that supports study participants throughout their experience—and beyond

Before ATIs

Reframe the approach to informed consent to a person-centered framework (e.g., decision support around ATI trial participation, availability of peer navigators for decision support).

Enhance the informed consent process (e.g., multi-media/multi-modal informed consent process to accommodate disparate learning styles, literacy levels and cultural, linguistic and socioeconomic backgrounds of prospective participants).

Provide clear information about known and potential risks of ATIs (based on previous trials), risks of experimental interventions and risks of monitoring procedures.

Explain to prospective participants the legal liabilities that may result from not disclosing their HIV status to sex partners during an ATI.

Discuss the potential long-term adverse events that can result from an ATI.

Ensure that treatment costs for adverse events due to the ATI are not borne by the participant.

Conduct pre-ATI assessments to determine a prospective participant's understanding and psychosocial readiness.

Plan and provide support around partner protection measures (for HIV-serodifferent relationships).

Multi-center trials must have a single lead institutional review board; there should be only one informed consent for the participant to sign.

During ATIs

Conduct close monitoring without overburdening trial participants.

Build support around partner protection measures.

Understand and consider the relationship dynamics and potential risks, including the risk for intimate partner violence.

Conduct psychosocial and mental health assessments and support—particularly addressing anxiety around being off HIV treatment.

Assess the impact of ATI participation on other people in participants' immediate social circles.

Develop and provide home-based viral load testing to self-assess transmissibility potential.

In case of unexpected intercurrent events (e.g., COVID-19, mpox pandemics), establish a mechanism for consultation with ATI participants, participant-centered communications, mental health safety screening and guidance to reduce risks to trial participants.

After ATIs

Conduct a mental health follow-up after the ATI period and study have ended.

Establish regular check-ins with participants following an ATI or the study's completion every six months.

Monitor for potential long-term effects of ATIs.

Provide ART resistance testing and assistance with ART regimen change if needed.

Disseminate research outcomes to participants in a way that is accessible to them.

Provide medical journals and other publications in which the study's findings appear free of charge to study participants.

Continue to check in with participants who have resumed ART after an ATI period has ended.

For participants who are post-intervention controllers, provide continued psychosocial support around being off ART and provide partner protection support.

For participants who are cured, provide psychosocial support around the anxiety of potentially having to relive the experience of an HIV diagnosis if they are no longer cured; offer support systems to maintain the social benefits they had received during the time they were living with HIV (e.g., housing benefits) and offer guidance around PrEP uptake if needed.

ATI support program goals

Provide high-quality research and patient/participant involvement in ATI trial designs.

Study designs should take into account other circulating endemic viruses such as new COVID-19 variants and/or seasonal flu, and how they may impact HIV viral load during an ATI.

Establish mechanisms to better understand research attitudes and perceptions around ATI trials.

Develop greater support services for ATI trial participants and partners—mental health services, access to pre-exposure prophylaxis (PrEP), referral to a support hotline.

Create an ATI participant experience database and research hub.

Offer professional development opportunities for community advisory board (CAB) members or former trial participants (e.g., certified peer navigators).

View behavioral and social sciences research as a gateway to ATI research participation.

Examine how the arts can be used to inform, engage and build trust among members of community groups underrepresented in HIV cure research (with approaches to measure effectiveness of community engagement).

Create and expand programs that encourage support of and participation in HIV cure research (e.g., HIV cure research ambassadors).

Use person-centered language—e.g., *participants* instead of *subjects*.

Develop community-centered education materials around ATI trials.

Provide adequate compensation to trial participants and CAB members for their participation expenses.

It is essential to involve primary care physicians during the entire research participation; this includes referrals to independent counselling and other support mechanisms during and after ATI periods.

What's new with HIV

BY **LARRY BUHL**

Since the last issue of HIV Basics in 2021, several changes have impacted HIV treatment, research and health risks. Some developments (HIV disparities, weight gain with INSTIs and anal cancer awareness) are a continuation of trends, with a renewed focus but no clear answers. Others (such as doxy-PEP) are potential game changers for health care providers and people living with HIV.

Moving to a language of care

In July, the 12th International AIDS Society Conference on HIV Science (IAS 2023) for the first time had no presentations referring to people living with HIV (PLHIV) as "HIV infected." It was a victory for advocates of using UNAIDS terminology guidelines, which were published in 2015. Proponents of "people first" language have long decried the word "infected" as not only stigmatizing but dehumanizing. The People First Charter was launched in 2021 to push for the removal of stigmatizing language in HIV research, including "mother-to-child-transmission."

Language evolves. In the 1980s, people living with HIV were called victims of the virus. The research community is slower to change, however. Researchers in a study published in 2022 looked at person-centered language in HIV-related research published between 2017 and 2021 and found that 57% of the HIV-related articles used terms "HIV-infected" and even "AIDS-infected," and 30% of the publications used the rather antique language of "HIV patient" or "AIDS patient." Using the term "AIDS-infected" is especially troubling because it doesn't follow science: AIDS is an advanced stage of HIV and not something one can catch.

Despite the slower evolution of some research publications, outlets that report on HIV, including *Living Positively*, are committed to a language of care, rather than dismissal.

A push for more inclusive clinical trials

People from racial and ethnic minority groups have perennially been underrepresented in clinical research. The U.S. Food and Drug Administration (FDA) has been aware of this and plans to require researchers to actively ensure greater diversity among trial participants.

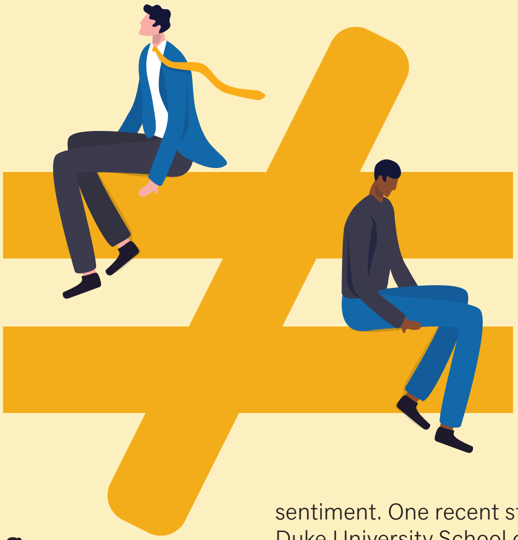
Ensuring diversity in clinical trials is especially important in HIV research, where more than half of all people living with HIV globally are female, but less than 20% of those participating in HIV cure-related clinical trials. In the U.S., where African Americans are 13% of the population, they account for 42% of new HIV diagnoses.

Some researchers are offering suggestions for how to increase diversity in HIV treatment and cure trials. Karine Dubé at the University of North Carolina has been urging researchers to consider obstacles—such as jobs, transportation and family demands—that could prevent more diverse populations from participating. Some recommendations include asking the community how to best conduct the trials, and for publications to require demographic information. Lauren Cirrincione and her team at the University of Washington came up with suggestions for increasing participation of transgender and gender diverse (TGD) in randomized clinical trials:

- establishing or leveraging existing community and global advisory boards comprised of TGD community members
- enriching enrollment for transgender women
- modifying protocol language and recruitment efforts to include transgender men and nonbinary people in the study priority population.

HIV activists, including the Treatment Action Group, are also pushing for inclusion of PLWH in non-HIV related trials. TAG scored a big victory in 2020 with the addition of PLWH as part of Moderna's phase 3 COVID-19 vaccine trials.

ISTOCK



A greater urgency to fix HIV disparities

This is another good news/bad news trend: According to latest figures by the CDC, while the U.S. is making progress in prevention of HIV transmission, the gains are uneven, and these disparities will make it difficult for the U.S. to reach its goal of reducing new cases of HIV by 90% by the end of the decade.

PrEP is a key prevention tool that could make the difference. But although nearly 80% of white people who would benefit from PrEP are being prescribed it, only 21% of Hispanic/Latinx people who could benefit are getting a prescription. That prescription percentage drops to 11% among Black people who could benefit from PrEP.

There are no easy answers to the increasing disparities in who accesses PrEP. Raising awareness helps, but it doesn't automatically translate into use, especially in communities with higher HIV stigma and anti-LGBTQ+ sentiment. One recent study out of the Duke University School of Medicine uncovered some specific reasons why PrEP uptake is so low among African Americans, including sociocultural (community/social network influences, stigma, medical mistrust) and structural factors (PrEP availability, accessibility, and PrEP engagement strategies). Researchers included some suggestions: "...future research should consider working directly with African American communities (leveraging social networks) to co-develop strategies for decreasing stigma, medical mistrust, and conspiracy beliefs among young African Americans. Additionally, to intervene at the organizational (institutional) level, PrEP should be integrated into routine primary care practice (especially those who serve cisgender women) to improve awareness and access, which can boost uptake." Researchers also encouraged AIDS services organizations to hire more African Americans from local communities "who can draw upon insider community knowledge to assist ASOs to establish their presence within the community and scale up PrEP outreach efforts."

'Practice changing' doxy-PEP for bacterial STIs

The use of doxycycline taken as post-exposure prophylaxis (PEP) is gaining interest among people who work in sexual health, based on a study that was stopped early, in 2022, due to its high efficacy. The trial found that doxy-PEP as a "morning-after" pill was highly effective in preventing syphilis, chlamydia and gonorrhea after unprotected sex, cutting the risk of these common STIs by up to two thirds. Though it does not prevent HIV, mpox or other viral infections, this treatment regimen has been found to be highly effective in substantially reducing bacterial STIs in MSM and transgender women (TGW), regardless of their HIV status.

Although the CDC issued a response to the clinical trial, it hasn't yet offered clinical guidance on doxy-PEP. However, clinics and jurisdictions, including Chicago's Howard Brown Health, the San Francisco Department of Public Health and others, see the study results as "practice changing" and have moved forward in developing guidelines and protocols for the use of doxy-PEP.

In the era of Treatment as Prevention and PrEP, bacterial STIs among MSM and TGW have risen dramatically. Look for increasing recommendations of doxy-PEP among doctors who care for sexually active people, especially those who care for patients with HIV, in the future.

Anal cancer awareness for PLWH

In the general population, anal cancer is relatively rare, but among people living with HIV it's the fourth most common cancer. The likely reason is the human papillomavirus (HPV), which, as with HIV, can be transmitted more easily through anal intercourse. More than 90% of anal cancers are caused by HPV, specifically the HPV-16 strain, which can also cause anal and genital warts. Many people are able to clear HPV from the body without problems, but for some, especially those with suppressed immune systems—such as people living with untreated HIV—HPV may later develop into pre-cancerous lesions and eventually cancer.

Anal cancer screening through anal cytology (also known as a PAP smear) is not yet part of routine care for people living with HIV. But experts like Alan Nyitray, an associate professor of psychology and behavioral medicine at the Medical College of Wisconsin, say it should be. Nyitray said one reason it isn't yet routine is the current lack of a national consensus recommending anal cancer screenings.

"Awareness of anal cancer is poor among gay and bi men," Nyitray said. "Right now, there are too many barriers to anal cancer screening."

While the U.S. Preventative Services Task Force (USPSTF) has stalled on recommending anal cancer screening for people at higher risk of anal cancer, Nyitray believes the USPSTF will move forward again, so that anal cancer will be on the radar of every practitioner who cares for PLWH. And he hopes the USPSTF will investigate biomarkers like HPV genotyping to find people who are at higher risk of anal cancer, regardless of their HIV status.

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Caution over COVID-19 and mpox

According to the World Health Organization, PLWH have a 38% greater risk of developing severe or fatal COVID-19 compared to people without HIV. However, studies have shown that people with well-suppressed HIV face far fewer risks of serious complications from COVID. But considering the percentage of people in the U.S. who have HIV but don't know it—an estimated one in five—and the continued unabated spread of COVID-19, PLWH would do well to be COVID cautious.

Although many people in the U.S. have caught COVID at least once, there is no "herd immunity." Each infection is more likely to produce T cell exhaustion, which is disconcertingly problematic for people with already exhausted T cells. The CDC notes that re-infection can occur in as little as 90 days after initial infection, and that re-infections can sometimes be more severe. Vaccines and boosters have been effective in preventing death and serious illness for most, but they are not effective in preventing transmission of the virus. That's a problem because even mild COVID can lead to debilitating long COVID in addition to higher risks of vascular and organ damage, and that's true for people with or without HIV.

PLWH who have a low CD4 count are also at greater risk of serious complications from mpox, according to the CDC, and they are over-represented in current mpox cases. According to CDC data, of 38 deaths from mpox in the U.S. between May 10, 2022 and March 7, 2023, 94% were PLWH and most had advanced HIV. There are no data, however, suggesting that having HIV increases the likelihood of getting mpox when exposed to it.

One thing is clear: the health risks from COVID-19 and mpox—not to mention the myriad health risks from advanced HIV—underscore the importance of testing for and treating HIV.

More questions, but few answers, about weight gain with HIV meds

A top story in HIV medicine was excess weight gain experienced by some PLWH who take integrase inhibitors. These antiretrovirals are potent and have a high resistance barrier. And they're very well tolerated, if you discount the weight gain. Recent studies have shown that one in six people gain at least 10% in body weight over one to two years after starting treatment.

Follow-up from the ADVANCE trial on antiretroviral therapies hasn't concluded exactly why the start of integrase inhibitors—especially dolutegravir and bictegravir—appears to bring dramatic increases in weight, especially for Black women. That presents a thorny problem for people on treatment and the providers caring for them. If a person is underweight at the start of treatment, weight gain can be seen as a "return to health" effect. But for people with normal body weight at the start of treatment, weight gain could bring an increased risk of cardiovascular disease and diabetes. And people living with HIV are already at a higher risk of cardiovascular disease than the general public.

Shifting to long acting injectables… slowly

Possibly the biggest change since our last update on HIV basics is the wider availability of long-acting injectables for HIV treatment and for PrEP. With the promise to reduce the issue of adherence to pills, injectables have been billed as a game changer for treatment and prevention. Comprehensive data on how many people have ditched the pills and embraced injectables are hard to come by. But based on one study, uptake of LA-ART might be slower than anticipated. In an analysis of patients in one California HIV primary care clinic from 2021–2022, researchers found a little more than half of patients who expressed interest in LA-ART actually switched. The most common reasons for not changing were fear of injection site pain and the inability to receive follow-up injections in a timely manner. The results of this study suggest that clinics and practitioners should consider possible limitations in uptake of injectables and if possible, make accommodations for patients who could benefit from them but for good reasons might be hesitant.

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Advice for future HIV pharmacists

BY **DAN SCALES, PharmD, AAHIVP**

The number of new pharmacists entering the field has been growing at a remarkable rate since the mid-1980s, and even more pronounced since the mid-2000s. In 2020 alone, over 14,500 graduates received their first professional pharmacy degree.[1] That said, the Bureau of Labor Statistics estimates only a 2% growth in jobs between 2021 and 2031, equating to about 13,600 new positions each year.[2] As might be expected, the variance between new pharmacists applying for positions and the shortage of positions available leads to an extremely competitive market, requiring the development of skills attained outside the classroom.

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The purveyors of HIV health, in all its parts, tend to be drawn to this work by some intrinsic driver, like shared experience or passion for advocacy, more so than by the science of disease. While passion is an excellent foundation to build a career, it is not all that's needed for long-term career success, and rarely is it enough to make that optimal first impression. I have been practicing across the pharmacy space for just shy of 20 years now, with over 10 of those years rooted in the field of HIV care and prevention. Following is a smattering of the advice I have for pharmacists entering, or considering, the HIV field for the first time.

Knowledge of the medications is obvious. Learn the drugs. Read the studies. Be a pharmacist. The truth is, the medications we have in our toolbox now are amazingly effective, and with appropriate selection and quality adherence the vast majority of patients will be virally suppressed, with no risk of transmission and without notable side effects. Appropriate selection is the space where pharmacists can play a huge role, and the reason isn't particularly HIV specific. According to data published by the National Institutes of Health, by 2030 over 70% of all people living with HIV and 18% of people newly diagnosed will be over the age of 50. This reinforces the approach to HIV management that has pivoted from a position of infectious disease to one more akin to a chronic geriatric condition.[3]

The effectiveness of today's HIV medications make viral suppression the icing on the cake, as more and more patients seek medical care for their uncontrolled comorbidities, like diabetes, hypertension, depression, etc. As the population of people living with HIV continues to get older, pharmacists must place a stronger emphasis on understanding the comorbidities associated with aging, and the intersectionality of antiretroviral selection. Polypharmacy, especially in the occurrence of age or disease-related declining cognitive function, places individuals at higher risk for drug-drug interactions. Renal and hepatic disease, along with endocrine and metabolic changes, can cause significant alterations in drug metabolism. Malignancy, frailty and fall risk and cardiovascular incidence are all more likely to be experienced by senior individuals living with HIV than those without.

The other major piece of advice I have for new pharmacists entering the HIV care space is also associated with approach mindset, as opposed to clinical prowess. HIV was one of the first disease states to be evaluated under the lens of syndemic theory, which was developed by medical anthropologist Merrill Singer in the early 1990s, and essentially describes two or more concurrent, but seemingly unrelated, epidemics that actually have synergistic effects.[4] In layman's terms, it is impossible to separate the medical impact of HIV from other medical comorbidities or the social, racial, political and economic disparities affecting people living with HIV.

The concept of syndemics has been given a considerable increase in attention as we grapple with understanding the *whys* and *hows* of the COVID epidemic. The modeling that has developed in recent years has begun to be applied to other disease states, diabetes in particular, but the conceptualization began in the study of the HIV epidemic over 30 years ago. New pharmacists, or those entering the HIV space for the first time, should understand that not only do disparities in health exist, but that these disparities are not isolated points of data. They are symbiotic contributors, applying pressure to clinical and social outcomes, and must be addressed concurrently at the system and patient levels if we truly hope to end the HIV epidemic.

DAN SCALES is director of Pharmacy Collaborative Care at Vivent Health.

FOR CITATIONS, go to the online version of this article: positivelyaware.com/adviceforfutureHIVpharmacists.

40 years later, Ward 86 still leads in research and treatment

BY **MATHEW RODRIGUEZ**

ROBERT SILVER FOR POSITIVELY AWARE

Big ships turn slowly, according to the adage. The metaphor usually serves as an aphorism that warns against the slow nature of bureaucracy; whether it's a university or the federal government, you can't expect new ideas to take root or new policies to supplant old ones without a generation's worth of debate, back and forth and compromise until the fateful day of implementation. That's not the case with Ward 86.

> 'It's an exciting place to be because it's so cutting edge'
>
> —Monica Ghandi

The San Francisco-based HIV inpatient clinic, the first of its kind in the nation, which is celebrating its 40th anniversary this year, has made innovation with alacrity its hallmark, constantly pivoting to meet the changing needs and demands of the AIDS epidemic as it exists in the city outside its doors. "It's an exciting place to be because it's so cutting edge," Monica Gandhi, MD, MPH, the current medical director, who has been in the role for a decade, said. "It doesn't stop. It's kind of exhausting, but it doesn't stop."

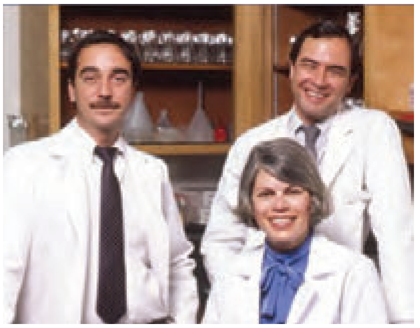
A recurring theme is that, as providers identify a need, they establish a program to address it. In 2008, they established a clinic for women with HIV. In 2013, they started a program to get people onto antiretroviral therapy the day they are diagnosed, something that, 10 years later, is now a standard of care in cities nationwide. When, in 2017, it became clear that the majority of people living with HIV in San Francisco were over the age of 50, it launched Golden Compass, a program to help address several of the complications that can accompany aging with HIV.

Another innovation came in 2019 with the opening of its POP-UP program, meant to address health care among people with unstable housing, who are much less likely to be virally suppressed than the average (and housed) San Franciscan living with the virus. In the past year, the program began administering long-acting antiretroviral medication to people who were previously detectable, including people who couldn't adhere to daily ART because they experience homelessness, despite the treatment not being indicated for this particular group. They did this because they knew that the people seeing them for care needed it; because it was right. "It's really exciting to be at a place like Ward 86, and to

A sure sign of a landmark contribution to HIV care is **when an entire treatment model is named after the city where it was born.**

help lead it, because we aren't treating an affluent population," Monica Gandhi said. "We're trying to benefit a patient population that in other fields sometimes gets advances last."

One reason for such advances is Ward 86's unique set of affiliations and partnerships: it is well-funded and enjoys support from the city's Department of Public Health and is attached to a single academic institution, UCSF. The clinic's success is not only a testament to those inside it, but to the good that can be done when innovation and public health are supported monetarily by those in power.



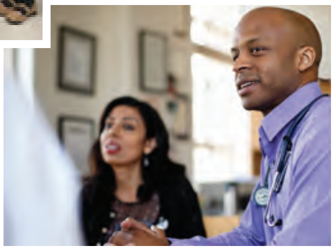
People who know the clinic's reputation might wonder if it gets difficult to keep up a reputation of innovation, but their propensity to pioneer is not driven by a need to be first, it is driven completely by their person-centered approach. Because they keep close relationships with their clients, 96% of whom are on either Medicaid or Medicare, they are able to identify client needs and respond quickly with appropriate programs and initiatives. Gandhi has said that, in the past, she's heard commentary saying the clinic is "so Wild West" in their approach, but she wears that as a badge of pride. "You have to be willing to take risks and think outside the box. It can backfire, but it's worked out so far."

A sure recognition of a landmark contribution is when an entire treatment model is named after the city where it was born. In the world of HIV care, the concept of a holistic approach to treating HIV is called the "San Francisco Model," and it began at Ward 86, which early on recognized that treating HIV was about more than dispensing pills, but required a robust response from an entire care team. Today, this model has been deployed across the world, changing the way that people with HIV and care providers relate. Gandhi says part of her mission as the clinic's medical director is to ensure that it disseminates, through channels such as conferences, journals, and community events, the successes they've encountered so that others can emulate it in a way that works for them.

Another essential ingredient to the clinic's success is its unique relationship between patients and providers. These advances in treatment are the result of a staff that is attuned to the needs of the people who come through the clinic's doors. For Steven Deeks, a professor of medicine at the University of California in San Francisco and a primary care provider at Ward 86 since 1993, it's this deep symbiosis that has kept him working in the same place for three decades. He was supposed to stay there for only one year, but his interactions with patients, especially one named Joe, led him into activist communities such as Golden Gate ACT UP. He began to attend meetings and to know, intimately, the struggles of people living with HIV at the time. "I enjoyed the fierce advocacy and engagement," he said. "I unexpectedly became more of an activist, as much an activist as a physician."

That ability to know what patients want is what keeps them coming back, and even leads some people to seek out care there specifically, after years of living with HIV. Paul Aguilar, a long-term survivor who has been living with HIV since 1988, just came to Ward 86 last year because of its reputation. Aside from describing it as a "cutting edge place to get care for HIV," Aguilar also emphasized that, when walking into the clinic, he automatically feels welcome. "Everyone knows my name. It's like coming home." Aguilar also credits the Golden Compass program for landing him with this care team. He says that few doctors are focused on treating the aging HIV population in a way that looks beyond CD4 count and viral load.

Being a part of this machine, a place that continues to care for people with HIV in ways that are old and new, continues to inspire Deeks. "I have never once considered leaving Ward 86," he says. "I don't think there's any place like this in the world. That magic that occurred in the '90s exists to this day. That same special sauce." That special sauce is they key ingredient to its novel efforts. This past year, Ward 86 launched the Revival of Care program, which seeks to practice preventative care for potential complications, including cardiovascular disease, in people living with HIV.



As the clinic celebrates 40 years and looks ahead, Gandhi shared what she thought is the ward's surprising future: obsolescence. "We are hoping in the next 40 years that we're out of business because there is an HIV cure and an HIV vaccine," she said. She acknowledges that, if—or when—such a breakthrough happens, Ward 86 wants to be poised to make it accessible to all, just as they have worked to make care available to anyone who needs it. In a way, her answer underlies just how willing to embrace the new the clinic really can be, that its dedication goes far beyond its name and its reputation. It's all about the patients. Their job will be done when it comes to an end. "We don't want to be here in 40 years. That's our goal." PA

> 'I have never once considered leaving Ward 86, I don't think there's any place like this in the world.'

ROBERT SILVER FOR POSITIVELY AWARE

A ‘human rights-based approach to health’

IAS 2023 balances research and innovation with the ongoing need to address disparities

BY **RICK GUASCO**

“TODAY, ON THIS BEAUTIFUL DAY, I HUMBLY REPRESENT BOTH SIDES OF THE TABLE. I COME TO YOU AS A PROFESSIONAL AND ALSO AS PART OF A COMMUNITY HEAVILY IMPACTED BY HIV.” **—DR. ALEGRA WOLTER**

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“HIV is not just a virus, it’s a reflection of the unfairness that continues to persist in all our societies,” said James Chau, president of the China-United States Exchange Foundation, as he made his introductory remarks at the opening plenary of IAS 2023, the International AIDS Society conference being held in Brisbane, the third largest city in Australia.

While speakers addressed a number of themes, they focused on worldwide uncertainty, disparities in global health and the need to include community as partners.

Sharon Lewin, president of the International AIDS Society and director of the Peter Doherty Institute for Infection and Immunity in Melbourne, outlined some of the news expected to be announced at the conference.

“New findings from a trial in Africa found that cisgender women overwhelmingly prefer long-acting injectable PrEP to taking a daily oral pill, providing proof of the high need for equitable global access to this critical prevention tool,” she said. “The REPRIEVE trial has definitively demonstrated how we can prevent adverse cardiovascular outcomes that still occur more commonly in people with HIV. And a sixth person [already making headlines as the Geneva patient] may be cured of HIV after a stem cell transplant, but in his case, the donor was not genetically resistant to the virus. COVID-19 has taught us that with significant investment and global commitment, transformational advances in science can and really must move faster.”

Lewin also pressed for the continuing need to invest in research and innovation in HIV research, for better prevention tools and treatment options and improved efforts to include marginalized communities and address health disparities. She also addressed stigma and anti-queer sentiment.

“The rise in increasingly hostile and discriminatory laws against LGBTQI+ communities, sex workers and people who inject drugs is a major concern,” she said. “We must actively oppose these attacks on human rights through our influence and our advocacy as individuals and as the IAS. The goal of the IAS is to unite the HIV response to overcome HIV

in the face of uncertainty

as a threat to public health and individual well-being. In a world of increasingly conservative and populist governments, this is more important than ever."

The point was driven home in a stirring address by Dr. Alegra Wolter, the first openly trans physician in Indonesia.

"With the rising polarization of good versus evil, us versus them, sensitive issues are being politicized with malicious intentions impacting the lives of many, including persons living with HIV and other vulnerable groups who are left behind," she said. "Today, on this beautiful day, I humbly represent both sides of the table. I come to you as a professional and also as part of a community heavily impacted by HIV.

"I honor my friend who stopped her ART treatment and chose not to continue because she felt that life was not worth it," she added. "May her soul rest in peace. What saddens me the most is that her reality is not far different for many."

She described the work ahead. "Our challenges now rely on the integration of care into health systems along with the streamlining of universal health coverage and a person-centered approach free from stigma and discrimination across all life dimensions," she said. "What is the human rights-based approach to health?

"A wise friend once told me not everyone is given the privilege to help others," she added, "and now, more than ever, we need to challenge our charity point of view and tokenistic approach, turning it into true compassion. What can we do to help? What can we do to make things *better*?"

In his welcoming remarks, Mark Butler, a Labor Party member of Australia's parliament, noted that the government had worked with organizers, especially at the community level, to bring in as many delegates from overseas as possible. In a veiled reference to what has happened at previous conferences in the U.S. and elsewhere, he remarked, "I'm very pleased to say that not a single visa has been refused on the basis of a person's HIV status."

Butler touted the news that Australia is on track to become the first country in the world to eliminate new acquisitions of HIV. He credited "three pillars" for this accomplishment. Australia's federal government has been consistent and united in its efforts despite political changes over the decades since the start of the epidemic in the 1980s, he said. In addition, affected communities—including people living with HIV, sex workers and injection drug users—along with clinicians and researchers worked in partnership. "And thirdly, **we're proud that it's been comprehensive from the earliest days—condom programs, needle and syringe programs and more recently, public subsidy programs for treatments for PrEP** and for testing," he said.

"I also want to say that the U=U call to action is strongly endorsed by the Australian Government. It's a straightforward reflection of the science and it's already incorporated into the country's eighth National HIV Strategy," a plan that was launched in 2018.

SOMBER TRIBUTE BY A STRING QUARTET FROM THE MELBOURNE CONSERVATORIUM OF MUSIC

As the opening plenary drew to a close, its tone changed to honor the HIV clinicians and researchers who were on their way to Australia for another international conference, but were lost in a tragedy.

"The last time I stood in front of many of you was hosting the opening of AIDS 2014 down the road in Melbourne," Chau recalled. "It was a moment marked by resilience and grief and profound loss when our friends and colleagues were killed when traveling to Australia to join us—298 people died that day when [Malaysian Airlines] flight MH17 was shot down over Ukraine, among them six champions in the fight to end AIDS."

Pim de Kuijer, Lucie van Mens, Maria Adriana de Schutter, Glenn Thomas, Joep Lange and his partner Jacqueline van Tongeren were aboard the ill-fated flight.

Chau introduced a string quartet from the Melbourne Conservatorium of Music, who somberly performed on stage.

"Let us recommit ourselves to carrying on their legacy," he said.

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Could lifestyle interventions lower cardiovascular risk for women with HIV?

BY **LARRY BUHL**

Lifesaving antiretrovirals do come with some downsides for people living with HIV: in some cases, they're faced with comorbidities. For example, although highly effective in suppressing HIV, integrase inhibitor-based antiretrovirals (INSTIs), now the preferred first and second line antiretroviral therapy, have been associated with an increased risk of diabetes as well as weight gain and increased body mass index (BMI) compared to other therapies.

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One session at IAS 2023 explored several comorbidities and what kind of interventions might make a difference. Presenter Sherika Hanley, a family physician and lecturer at the University of KwaZulu-Natal in South Africa, shared data on a study exploring whether lifestyle changes could lower cardiovascular (CVD) risks for women with HIV. Hanley explained that **women with HIV (WHIV) face an added burden of obesity and hypertension, particularly in under-resourced settings**. "WHIV have higher odds of developing metabolic syndrome comprised of central obesity, elevated blood pressure, lipids and blood glucose, thereby doubling the risk of CVD compared to men," she said. "As a result, CVD has surpassed HIV as a leading cause of death in women."

Hanley shared findings from the ISCHeMiA study, which looks at integration of cardiovascular disease screening and prevention in the HIV management plan for women of reproductive age, and assessed the effectiveness of regular screening and lifestyle modification interventions in modifying CVD risk factors in South African WHIV. South Africa has one of the highest rates of HIV in the world.

All women in the study were 18–50 years old (with a mean age of 36 years) and had been in HIV care for one year. Women in the intervention arm received a lifestyle modification advice sheet, which was emphasized at subsequent visits. Women with a high BMI, hypertension, diabetes and high cholesterol levels were referred to a dietitian. Women in the control arm continued their management per standard of care with no intervention at a primary healthcare clinic. Of the 372 women enrolled, there were 149 in the intervention arm and 120 in the control arm, all of African descent, and all in the township of Umlazi in the South African province of KwaZulu-Natal, which has the second highest prevalence of HIV in the world. Follow-up was 32 months.

The intervention arm advised women on dietary modifications, which included reduction of salt, carbohydrates, and high fatty kind of foods, alcohol reduction, smoking cessation, and exercise. "They were advised to exercise at least 30 minutes a day, such as including brisk walking into their work activities."

The intervention was a modest success. Women in the intervention arm increased physical activity slightly, Hanley said, and they had a modest benefit in HDL cholesterol and blood glucose levels. HDL levels in the intervention arm improved significantly from abnormal to normal levels. However, there was no effect on obesity. In fact, BMI increased significantly—not just in the intervention arm, but in the control arm as well. Women in the control arm saw declining health—more required immediate intervention for elevated LDL cholesterol levels and many were newly diagnosed with diabetes and hypertension.

"Fifty-two percent of women referred to the dietician actually attended qualitative analysis at one-year post enrollment, and they identified several barriers to lifestyle change, including financial limitations, work commitments, lack of social support, poor body image perception and lack of insight into CVD risk."

Hanley noted that women in this environment faced high barriers to lifestyle changes, including poverty, limited access to health food and lack of safe spaces for exercising.

While the study showed missed opportunities, "the findings encourage the continued efforts towards lifestyle interventions in the prevention of CVD in women with HIV, who are characterized by higher levels of inflammation," Hanley said. She added that HIV services still could be the locus of CVD risk prevention, even in under-resourced settings. What's needed, she emphasized, is a person-centered multidisciplinary approach that empowers clients. Such an approach would offer clients "the opportunity to select their own targets, profiling households and communities and creating champions and strengthening healthcare provider and user relationships. Interventions needed to be sustainable, adaptive, and culturally sensitive, with robust long-term monitoring of CVD risk."

HIV prevention: Novel approaches, promising findings

Oral PrEP has been a key HIV prevention tool since its rollout more than a decade ago. Now, with uptake less than HIV advocates had hoped, plus new options (long-acting injectables), researchers have been looking into how to encourage more people to use this greater variety of options. One panel at IAS 2023 explored different ways **how PrEP use could be affected, including the accuracy of HIV testing, the role of race in PrEP adherence and the likelihood that PrEP could lull users into a false sense of security regarding bacterial STIs**.

Positive predictive value of HIV serological tests in HPTN 084 trial

Two speakers presented data from the HPTN 084 trial, a safety and efficacy study of Long-Acting Injectable Cabotegravir (CAB-LA) Compared to Daily Oral TDF/FTC for Pre-Exposure Prophylaxis (PrEP) in HIV-Uninfected Women. First, Mina Hosseinipour, an infectious diseases physician and professor of medicine at UNC-Chapel Hill, shared data evaluating the positive predictive value of the HIV serological testing.

As CAB-LA is rolled out, interpreting HIV status will require strategies for confirmatory testing, counseling and transition planning to either ART or resumption of PrEP, but while HIV serology tests have a high positive predictive value, antigen/antibody tests have shown a very high number of false positive results, and had low positive predictive value, particularly for those on cabotegravir (CAB).

HPTN 084, a phase three randomized control trial, showed that injections of CAB every eight weeks are effective for PrEP in women and superior to daily oral TDF/FTC. But HIV diagnosis in the context of PrEP use may be complicated by both false positives and false negative tests, Hosseinipour said. "False negative results... could result in delayed ART initiation or emergence of resistance. However, false positives could result in incorrect initiation of lifelong ART, implications for interruption of effective PrEP and the complex counseling that our sites will be faced with when seeing such clients with discordant results."

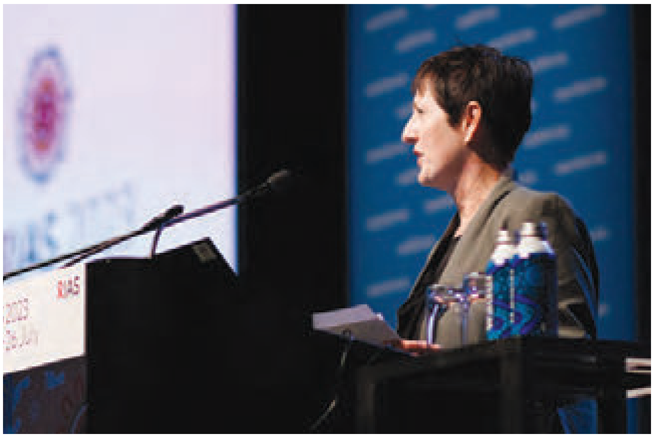
Most of the study's sites were in low-income settings where PrEP will be rolled out and use a WHO-recommended algorithm for testing: serial testing of three tests, the first having high sensitivity, and the second two would have high specificity, with a goal of 99% positive predictive value or higher. Hosseinipour and her team evaluated the positive predictive value of HPTN 084 site-based testing to guide HIV treatment initiation. Out of 20 websites, 14 elected to do two rapid point-of-care tests and six used a point-of-care test. All 20 sites did a lab-instrumented antigen/antibody test, which was available some days later. Any reactive tests prompted confirmatory testing at both the site and the full battery of tests done by the HPTN central lab.

Evaluating more than 30,000 tests over 67,000 visits, the team focused on 159 participants who had 162 reactive test results: of the 159, 88 were false reactive, essentially equal in the CAB and Truvada arms. But the positive predictive value of these results was consistently lower in the CAB arm—as low as 15 percent for any reactive test. "With a single reactive HIV test and the high frequency of false positive testing, programs should anticipate the need for further testing, counseling about false positivity and plans to resume PrEP after excluding HIV," Hosseinipour said.

"Two reactive tests of different types [were] still highly predictive of having seroconverted, so we can have confidence that if you have two tests that are reactive that you should convert to ART," she added.

What factors determine choice of PrEP?

In another presentation using HPTN 084 data, Sinead Delany-Moretlwe, research professor and research director at Wits RHI at the University of the Witwatersrand, Johannesburg, spoke on the same trial, but with a focus on PrEP choice. Delany-Moretlwe and colleagues assessed reasons for the initial PrEP choice and factors associated with that choice.



SINEAD DELANY-MORETLWE, MBBCH, PHD, DTM&H

The majority of participants—78 percent—chose CAB-LA for PrEP, and that choice was influenced by product attributes, personal risk factors and the social context, Delany-Moretlwe said. The overwhelming reason participants chose CAB-LA was a dislike of pills and preference for injections, followed by the convenience. People who chose TDF/FTC did so primarily because of a dislike for injections and concern about injection site pain. "We think these data are important particularly for product introduction programs and the region, and serve as a reminder to ensure that health care providers support product choice aligned with user values and preferences," Delany-Moretlwe said

Delany-Moretlwe said future PrEP programs must include approaches to support shared decision making for PrEP clients, and support PrEP choices that align with user values and preferences in order to ensure high PrEP continuation during periods of risks.

"The more that people are able to make product preferences, that product choices align with their values and preferences, the more likely they are to stick with that product," she said. "Providers are very influential, but also what's happening in your community may be determining people's choices."

How race impacts PrEP non-adherence for MSM and trans women in Latin America

Lucilene Freitas from the Evandro Chagas National Institute of Infectious Diseases presented a study exploring the racial disparities in HIV incidence and PrEP non-adherence among gay and other men who have sex with men and transgender women in Brazil. Highlighting the disparities in health care in Brazil, Freitas noted that Black Brazilians "face severe health inequalities due to the country's historical legacy of slavery," and that health disparities rooted in structural racism have persisted since the colonial era. Her study revealed, not surprisingly, that because of this structural racism and racial disparities in Brazil, HIV rates and PrEP non-adherence were higher for Black and Pardo (in Brazil, defined as "brown" or mixed African, European and Indian ancestry).

Freitas shared results from the ImPrEP study conducted from February 2018 through June 2021, in which 3,928 participants were enrolled at 14 sites in 11 cities across Brazil, Mexico and Peru. Over 94% were men who have sex with men (MSM) and just under 6% were transgender women (TGW). What researchers found was not surprising: rates of PrEP non-adherence varied significantly by race. Non-adherence for Blacks was 26.2%, 24.2% for Pardo and 18.7% for Whites. Transgender women and younger participants, aged 18–24 years, had higher rates of PrEP non-adherence across all racial groups. She said the results show the need for studying health outcomes disaggregated by race, and public policies to mitigate racial and social inequalities in Brazil.

Freitas's recommendations: "Public policies to increase healthcare equity and accessibility, and tailored interventions to improve PrEP adherence among vulnerable populations," in addition to fostering social justice though collective efforts. >>

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How does PrEP affect bacterial STIs among MSM and trans women?

Bacterial STIs are increasing globally and disproportionately affect MSM and transgender women, in part, it has been theorized, due to use of PrEP to prevent HIV. Jorge Gallardo-Cartagena, a researcher at Universidad Nacional Mayor de San Marcos, Peru, and his team set out to determine if there was an increase in bacterial STIs (bSTI) among PrEP users and whether any increase could be explained at least partly by risk compensation. Risk compensation means an increase in risky behaviors when an intervention—PrEP, for one—reduces a person's, or even a population's, perception of risk.

In a post-hoc analysis of data from HTVN 704 and 085 trials of participants receiving at least one infusion and had bSTI results, researchers categorized bSTI prevalence by subgroups and categorized bSTI incidence rates according to PrEP use. Determining the effect of PrEP use on bSTI incidence, they found that, first, bSTIs were very high in Latin America compared to the U.S., which could be partly explained by reduced access to bSTI diagnostic testing throughout Latin America. Regarding the effect of PrEP, the team found that PrEP users had, not surprisingly, a lower incidence of HIV, but higher rates of bSTI while on PrEP, "which may suggest risk compensation," Cartegena said. His recommendations: advance STI prevention in HIV vaccine research—for example using DoxyPEP—and use of "tailored strategies to increase PrEP uptake among those with higher vulnerability."

"We know that behavioral risk for HIV is not the same thing as behavioral risk for STI acquisition," he said. "So, one of our next steps will be to evaluate individual behavioral risk factors, and see if this influences the effect of abuse on incidence or maturity."

AT THE SESSION, PROTESTERS TAKE THE STAGE.

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How innovative tech solutions can prevent HIV in vulnerable populations

Using tech to meet people where they are to provide sexual health information

BY **LARRY BUHL**

As he introduced a session at IAS 2023, Elwin Wu, co-director of the Social Intervention Group and the HIV Intervention Science Training Program for Underrepresented New Investigators at Columbia University, urged colleagues to "elevate voices without imposing a white Eurocentric POV [point-of-view]," and to "decolonize scientific methods," when developing interventions for vulnerable populations.

Populations include adolescents, racial/ethnic minorities, immigrants, people impacted by the justice system, people who use substances, and sexual and gender minorities. Several presenters showed **how tech-based interventions could help vulnerable populations prevent HIV and other sexually transmitted acquisitions**. What can bridge the gaps with those populations, provided people have access to it, is technology, and presenters shared different ways tech can meet people where they're at to provide sexual health information.

Chatbots for survivors of gender-based violence

Peter Memiah, DrPH, MSc, program director of Implementation and Dissemination Science at the University of Maryland, described how a chatbot could help leverage technology to give people access to information on gender-based violence (GBV). It is estimated that one out of three women, one out of four men, and 1 in 10 youth will experience GBV in their lifetimes and they, Memiah noted, are vulnerable to both HIV and unwanted pregnancy.

"Most don't get any help for GBV and they need to get connected to services quickly," he said. His proposal, AGILE—Accelerating Access to GBV Information and Services Leveraging a Technology Enhanced Chatbot—is an artificial intelligence (AI)-powered chatbot that can quiz users on the risks that they may be experiencing, and immediately offer service recommendations. The AGILE pilot is aimed at youth in Kenya. He explained a possible scenario: "A young woman, call her Lisa, who is beaten by her boyfriend, can use this app to get immediate help, whether she needs health services or police."

There is enthusiasm for tech in Kenya, he said, "but we just scratched the surface." Memiah said the AGILE platform should be available to the public before the end of the year.

Relationship and dating role-play through an interactive app

Interactive technology can also improve HIV education, said Caroline Kingori, associate dean for Research and Faculty Affairs at Ohio University, who shared early results of Dating Forward, a dating simulation app intended to help immigrant and refugee youth, a vulnerable population for HIV. Dating Forward is a collaboration between Ohio's GRID Lab and Ethiopian Tewahedo Social Services (ETSS), an Ohio organization that supports immigrant and refugee youth with a goal of helping them make more informed decisions about sexual health. “We want the app to increase knowledge and decrease unsafe behavior and reduce stigma,” Kingori said.

Kingori and colleagues focused on Somali youth 18–25 years old. **To test youths’ knowledge of HIV, they built an interactive app** in which users can see how a couple—for the first iteration it’s a male-female couple—navigates dating. Users of this app can help the characters make various choices—to get tested for HIV and STIs or not, for example—and change the characters’ outcomes. Kingori’s team is utilizing user feedback to refine the app. “Users said they were impressed with the testing scene and that they learned something new, but they were still not comfortable discussing HIV in person,” Kingori said. Dating Forward can be found at New American Youth Health Resource (nayhr.org).

Using social media for culturally-tailored sexual health promotion

In presenting a pilot social media app, to “meet users where they are,” with their understanding of sexual health, Jaih Craddock, assistant professor at the University of California-Irvine School of Medicine, set the stage with statistics for young Black men.

“HIV rates for young Black men ages 25–34 are stable, even though rates of HIV for other groups are going down,” Craddock said.

Craddock and colleagues surveyed 19 young adults 18–24 years old in Baltimore to learn what they wanted from a tech-based social media app to provide sexual health information.

“They told us they want: culturally tailored sexual health interventions,” Craddock said. Specifically, respondents said they related to “people like us” better, “someone who looks like us and talks like us.” **Respondents also wanted in-depth information on a range of sexual health and relationship topics—including hygiene and mental health—in addition to HIV**. They also wanted guidance on tough conversations on sex. “Even one straight man wanted general information about same sex relationships,” he added.

Will they use such an app? “Yes, if you make it easy to use, make it engaging and entertaining and constantly update it with new information,” Craddock said. “Don’t assume because they have social media literacy that they have digital health literacy.” Also, make the intended users of the app part of building and implementing it. “Keep them involved,” he said. “For example, one respondent asked us if he could host a podcast episode on a topic.”

Telemed for sexual and reproductive health services

Telemedicine was on the rise before the COVID-19 pandemic put health care in a tailspin, but the convenience of it, for people who could access it, really took off at the start of the pandemic, and continues to be popular.

Megan Threats, an assistant professor at the University of Michigan School of Information and a health informaticist, shared **results of a study to understand how well women would accept telemed apps and chatbots to access sexual and reproductive health services**, including HPV vaccination, cervical cancer screening and HIV testing.

In a nationwide survey based in the U.S., Threats and colleagues recruited both cis and trans women from a variety of races—Black, Native American, Asian and Pacific Islander among others—from ads on social media and aps for queer women and community services. Out of a total of 135 participants with an average age of 25, 65 were Black and 55 percent identified as bisexual.

Three out of four said they favored video calls and an even greater number, 82 percent, said video calls were more convenient than in-person visits. Chatbots regarding HPV risk were favored by 72 percent.

“Our survey also showed they have low knowledge of HIV and STIs, as well as cancer risks,” Threats said. “More than 60 percent had past discrimination that deter them from using in-person healthcare. We also found that the higher the education level, the more likely they were to use chatbots.”

Beyond PrEP: Innovative solutions for HIV prevention

Although pre-exposure prophylaxis, or PrEP, remains a key HIV prevention method, **there are barriers to uptake, including lack of awareness, stigma, lack of healthcare options and structural inequalities, including racism**, that prevent more people from protecting themselves. Two sessions at IAS 2023 focused on studies that explored some of those barriers and solutions for breaking them down.

What prevents people who inject drugs from accessing methadone?

Central Asia remains one of the few regions in the world where HIV incidence and mortality continue to increase, and people who inject drugs (PWID) are more likely to have acquired HIV than any other population. Throughout the world, harm reduction experts have found that opioid agonist therapies (OAT) like methadone or buprenorphine used for opioid use disorder (OUD) are important HIV prevention tools. Although methadone has been provided for free in Kazakhstan since 2008, less than one percent of people are on OAT among the estimated 90,000 PWID in the nation.

Amanda Liberman, a student researcher at the Yale School of Medicine, presented a study looking at barriers and facilitators to methadone uptake for HIV prevention and found a very good way to learn what kept PWID from accessing methadone: just ask them.

In addition to asking focus groups of PWIDs, Liberman’s team met with other groups: those who are not on methadone; people who are enrolled in a methadone program; and physicians and community health care workers. They also conducted in-depth interviews with methadone clinic directors and with political figures. The interviews took place in four cities representing different regions of Kazakhstan.

The top three answers for why PWID have not joined a methadone program were: fear of methadone, lack of program sites, and extensive and demanding requirements for program entry.

PREP1519 STUDY REPRESENTED AT IAS 2023. AMANDA LIBERMAN (THIRD FROM LEFT).

PREP1519

Participants told the team that an inability to travel to different methadone sites was also a problem, and some were incarcerated or in hospitals and were not able to access treatment centers. Doctors said that a lack of information, or misinformation, about methadone was a barrier (although a few program directors showed bias against drug users).

What would make it easier for PWIDs to get on methadone? People already in a program said take-home dosing would make it easier for others to start (generally people are required to take their daily doses in the clinic). Community health care workers emphasized the need for multidisciplinary collaboration among different specialties, and doctors said better information for PWIDs was needed. PWIDs recommended changing clinic hours, providing 24/7 access, as well as increasing the number of sites and adding sites, specifically in hospitals and in the criminal justice system.

"Several highlighted the need to access different types of medications for opioid use disorder such as buprenorphine," Liberman said.

However, methadone program directors appeared resistant to some proposed changes, saying it was "not right" to let patients take home doses, and, paradoxically, that a narrow window of daily distribution was necessary because "drug addicts are lazy."

"Barriers were at all levels: state, program, clinician, and patients [and potential patients]," Liberman said, and solutions could begin at any level. "While fear of methadone is high only among people who are not on methadone, it's low among all other groups. This suggests the possibility for 'diffusion of innovation,' which is an implementation science concept that suggests that if more people were on methadone, it would encourage others to enroll." She also recommended provider-based stigma interventions, which have shown promise for methadone programs.

Would women and girls use the dapivirine vaginal ring?

Zimbabwe has a very high HIV burden, with nearly 13% of the population having HIV. Adolescent girls and young women (AGYW) are disproportionately affected compared to their male counterparts. As in other countries, oral PrEP is a key HIV prevention tool, but there are barriers to uptake, including pill burden and concern over privacy. Malvern Munjoma, a research statistician with Population Solutions for Health in Zimbabwe, shared results from a pilot study conducted through the Zimbabwe Ministry of Health showing **monthly DPV-R as an alternative to daily oral PrEP, and might even sidestep some of the structural and behavioral challenges** to PrEP uptake.

The aim was simple: compare acceptability of DPV-R against daily oral PrEP. Conducted across eight districts in the country, AGYW ages 18–25 years old screened as highly vulnerable to HIV were enrolled in two arms of the study and followed up monthly between June and November 2022, to compare uptake and continuation rates. Interviews were conducted with clinicians involved in PrEP service.

Of 1,466 AGYW deemed eligible for PrEP, more than two-thirds (1,128) chose DPV-R. Uptake was similar by age but differed significantly by residence: those in rural districts preferred DPV-R at a rate of more than 97 percent. Clients were slightly more likely to continue DPV-R compared to oral PrEP although continuation rates were high for both arms. Only five participants seroconverted after starting on DPV-R, compared to one seroconversion while on oral PrEP over the same period. Service providers said AGYW liked the DPV-R for its convenience and discretion.

"In most districts most girls come from a very conservative culture, and sex before marriage is a taboo," Munjoma said. "Also, our rural population has limited options [for prevention] and condoms are not as readily available as in the urban areas, and if friends and peers and family find out that you are taking some form of medication, it always raises curiosity. So, the ring is offering that very discreet option. One provider said, 'the ring is their most prized secret their parents or friends will never know.'"

PrEP4U: Helping youth in Vietnam access HIV prevention and sexual health care

Vietnam has reported a growing number of new HIV cases among people 15–29 years old, and sexually transmitted infection (STI) rates are high in this population. "Knowledge and awareness of young people and students are very limited about HIV and PrEP and also STIs," said Tham Tran from the PATH STEPS Project. She shared one "edutainment-based intervention," PrEP4U, co-created by the USAID, STEPS and the Vietnam Ministry of Health to promote HIV and sexual health care engagement and practices among students and other youth.

In March 2022, STEPS and partners embarked on a "PrEP4U tour" across three cities—Ho Chi Minh City, Hanoi and Dong Nai—to reach out to youth about HIV risks and prevention tools, with an emphasis on reducing stigma and gaps in care. The tour included talk shows with clinical experts, interactive edutainment games—even a PrEP song—focused on safer sex and sexual health, and booth exhibitions where students interact with staff from community-based primary care clinics and receive HIV testing and PrEP counseling.

The key to PrEP4U was a collaboration with student associations and school clubs as well as key influencers, often the president of the student association, to build and leverage "PrEP4U ambassadors." There is also a PrEP4U Facebook fan page that serves as a hub of information on sexual and reproductive health, and it's had over a million views since its launch in May 2022. "Between March and September 2022, 32 in-person PrEP4U events reached more than 8,500 students, distributed 1,096 HIV self-test kits and enrolled 317 individuals on PrEP," Tran said. "Targeted edutainment activities centered around principles of choice and equity to ensure that PrEP4U messaging and imaging resonated with different youth segments, including [LGBTQ+] youth."

Tran said PrEP4U increased health care access and convenience by offering HIV and sexual reproductive health (SRH) services directly within schools and engaging campaign ambassadors and influencers. Youth-focused PrEP/SRH campaigns can be scaled and adapted for other settings to bring PrEP and sex education closer to populations in need. "We are continuing (PrEP4U) with a network of students and we are collaborating with a private sector partner to amplify that campaign on a larger scale," Tran said.

Racial inequalities in HIV testing

PrEP and other HIV prevention tools go hand-in-hand with testing. The HIV test comes before the prescription, meaning **if people don't get tested, they're not likely to get PrEP**.

Marcus Vinicus Franca, a researcher from the Universidade do Estado da Bahia in Brazil, shared results of testing inequalities among adolescent MSMs and transgender women. He started with the assumption that race was a major factor. "We all know that HIV testing is an important method for early diagnosis, treatment and prevention,” he said. “Unfortunately, in Brazil, we have a difficult situation with men who have sex with men and transgender women being deeply affected by the epidemic. Additionally, we have racial disparities with a reduction of 51% in the proportion of AIDS cases among whites, versus a reduction of just 36% for Blacks. And we can see another worrisome situation—it’s an upward trend in HIV incidence among men aged 15–24.”

In the PrEP1519 cohort study, Franca and colleagues set out to investigate the association between HIV testing in a lifetime and race among adolescent males who have sex with men (MSM) and transgender women in three Brazilian state capitals: Salvador, São Paulo and Belo Horizonte. The outcome variable was having been tested for HIV in a lifetime. Race was self-reported in three categories: White, Black and mixed race (or *brown*, which is called “pardo” in Portuguese). White adolescents had far more HIV tests than Black and mixed-race Brazilians combined, and testing rates decreased with the darkness of skin tone: just under 57% testing rate for Blacks, 58% for exclusive mixed-race (or brown), and nearly 79% for Whites.

“In the multivariate analysis, when we adjusted for age, education, employment, living with family, mother’s lack of knowledge about their sexual orientation, sex work and unprotected anal sex,” he said, “Black and mixed-race combined people were 33% less likely to have been tested for HIV in a lifetime than were Whites, and Black people had less access to higher education and to private health insurance, which reflects the Brazilian reality.” These results, he said, stem from structural barriers to accessing HIV testing and prevention services as well as structural racism in society and health institutions in Brazil.

Finding the right message

How NYC’s queer community helped shape the city’s response to mpox

BY **LARRY BUHL**

A little over a year ago, cases of mpox (previously called monkeypox) were showing up in queer communities in North America and Europe with many questions and few answers. No one knew exactly how severe the outbreaks—soon to be called a public health emergency of international concern—could get, nor how communities should respond to reduce harm. Panelists at a session at IAS 2023 shared their experiences of responding to the crisis in New York City and possible lessons for future outbreaks of sexually-transmitted diseases.

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Keletso Makofane, MPH, PhD, a public health researcher at Harvard University’s T.H. Chan School of Public Health, told the audience he was watching Twitter in the spring of 2022 and becoming alarmed about a growing number of outbreaks of mpox in Europe. “We were on the verge of Pride in New York, and I was worried it would arrive soon in the U.S., with ineffective systems for testing and not enough vaccines.” Makofane co-wrote an op-ed in the *New York Times*, saying key populations should act quickly with care and without spreading fear; but he also understood that **community activists needed to respond quickly and strategically**, and not wait for public health to lead the effort (though public health did play a crucial role in disseminating vaccinations).

“We set out to know the need for vaccines, when there was a limited stock,” Makofane said. “If you can only provide it for a fixed number of people, who would those be?”

The growing group of mpox “first responders” needed a name and a non-stigmatizing message aimed at the most vulnerable as well as at the general public. “There had to be a public conversation about group sex without hysteria.” The name MPX NYC was chosen and a marketing agency was identified to create visually coherent messaging. But this growing group of mpox responders also needed money, recruitment and community consultation to get data on who needed outreach.

The nascent campaign also emphasized harm reduction—without stigma—because it was initially uncertain whether everyone who needed a shot would be able to get it—even if data could quickly be compiled to determine which neighborhoods were most likely to be impacted.

“There was talk about breaking up one [mpox] vaccine dose into fifths,” recalled Jenifer Barnes-Balenciaga, a member of the NYC Commission on Gender Equity, who came on board early in the summer of 2022. Barnes-Balenciaga helped the group reach everyone who was vulnerable, including queer New Yorkers of color and people who identified as trans, with inclusive messaging.

Within a few weeks an MPX NYC website was built, in English and Spanish, with the goal of gathering information about who was being impacted by mpox, where they lived and where they gathered for sex. There was a series of community-led weekly meetings on Zoom and a shared Google doc to capture what was discussed. Dr. Demetre Daskalakis, deputy coordinator of the White House National Monkeypox Response Team, was also involved. “We wanted everyone on the same page regarding empowerment and harm reduction so that we could move forward,” Barnes-Balenciaga said.

One result of the weekly conversations was getting useful criticism about the lack of clear messaging and information that was not stigmatizing to gay men and trans women, Makofane said.

To reduce stigma and make the website more accessible, emojis were used. They were seen as a humorous way to talk about sex without triggering negative reactions or giving the impression that sex itself—and who is having what kind of sex—was the problem.

"Sex positivity was a huge factor in the work we were doing," Barnes-Balenciaga said.

Meeting (and finding) people where they live and gather

Out of approximately 1,500 respondents to an online survey, 40 percent said they had group sex in the past four weeks and, importantly, they shared where they had sex. "We measured geographically where people were gathering, all anonymously, and got a total of 700 places," Makofane said. Their insights proved valuable in targeting where to focus efforts. What they learned:

- Most group sex, 60 percent, took place in private residences, meaning that interventions couldn't focus only on public places like sex clubs.
- Queer and trans people's homes were in certain parts of the city, but subgroups (e.g., Black, Latinx) did not cluster in the same places.
- Some communities were popular destinations across subgroups.

With this understanding, interventions could be set up in the most frequented communities, two or three neighborhoods at most. "If you use the venues as well as the places where people live, you can reach the same proportion of people in fewer communities," Makofane said. "It's a more effective way to work with limited resources."

MPX NYC has implications for public health broadly, said panelist Ken Mayer, medical research director of the Fenway Institute, in Boston. "It was a nimble response," he said. It was especially important that MPX NYC used anonymous spatial and network measurements to understand the physical locations, he said. "Using census track data, by neighborhood, is effective in learning the hot spots where people hang out, party and play."

Makofane said that because the team was able to share data and provide policy recommendations to public health quickly and on a tiny budget, "there's no excuse for bigger agencies not to do this quickly too."

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

THE MANY FACES OF IAS 2023

MORE THAN 5,000 CAME TOGETHER IN BRISBANE, AUSTRALIA FOR IAS 2023 —VOLUNTEERS, PRESENTERS, INDIGENOUS PERFORMERS AND ADVOCATES AMONG THEM.

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Remaining COVID aware

What people living with HIV should know about COVID-19 today

BY **LARRY BUHL**

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With the conspicuous lack of masks, even in hospitals, as well as people speaking of the COVID pandemic in the past tense if they speak of it at all, you might be lulled into believing that an infection with SARS CoV-2 is no longer a concern. But that's not the case, and people living with HIV (PLWH), especially if HIV is not well controlled, should remain COVID aware and stay up-to-date on vaccine boosters, according to recent studies.

Presenting data from a World Health Organization (WHO) study at IAS 2023, Nathan Ford of the WHO said that while COVID deaths declined during the omicron wave starting in late 2021 (when vaccines were beginning to roll out), death rates declined less for PLWH with low CD4 counts. Using the WHO Global Clinical Platform, Ford and colleagues identified 821,331 patients hospitalized with COVID during the pre-delta, delta and omicron waves, and of these patients 5.3% were living with HIV.

Researchers evaluated the association of HIV with in-hospital mortality across three SARS CoV-2 waves: pre-delta, delta and omicron. The variant periods were defined as timeframes when greater than 90% of cases were from these variants. Across all waves, the death rate from COVID for PLWH was 23% for PLWH compared to 19% for people without HIV (PWOH). But the differences became more stark during the omicron wave: PLWH with COVID-19 had a 54% higher risk of death pre-delta, a 56% higher risk during delta and a 114% higher risk during omicron, as compared to PWOH. Risk factors for mortality for all were a severe COVID-19 infection requiring hospitalization and a CD4 count of less than 200 c/ML. Other risk factors included chronic kidney disease, older age and diabetes.

The findings emphasize "the need to implement WHO recommendations for giving booster vaccine doses for all PLWH," Ford said, as well as "the need to offer HIV testing services for possible prioritization for possible therapeutic interventions and COVID-19 booster vaccines."

Both Pfizer and Moderna have requested that the U.S. Food and Drug Administration approve their updated COVID boosters designed to target a newer subvariant and if approved the boosters could be available sometime in the fall of 2023. The protein-based Novavax COVID vaccine is just as effective as the mRNA vaccines in minimizing the seriousness of initial COVID infections, though Novavax can be harder to find. The Centers for Disease Control and Prevention (CDC) notes that all the approved COVID vaccines are safe for people living with HIV.

Long COVID is a concern for everyone

Vaccines, so long as they're up-to-date, have been proven effective in reducing the seriousness of acute COVID infections and reducing the possibility of death from an infection, but with rapidly mutating and increasingly infectious variants, they're less effective in preventing transmission of the virus. And while most people get through an acute infection with symptoms no worse than a cold, some—an estimated 1 in 10—have severe symptoms that can last months or years, according to an analysis of the most recent data from the CDC.

Long COVID, defined by the CDC as symptoms that can include neurological conditions, kidney failure, musculoskeletal conditions, blood clots and vascular issues, respiratory conditions and cardiovascular issues, and crippling fatigue. These symptoms may linger weeks, months or longer, leaving some COVID "long haulers" unable to perform daily activities, or even get out of bed. It's not clear why one person will end up as a long hauler and another one won't. The antiviral Paxlovid can minimize the severity of the initial infection and reduce the risk of long COVID, but there is still no cure for long COVID.

Even if someone doesn't suffer long COVID, people of any age who get COVID—whether they have HIV or any comorbidity—increase their chance of having multiple health problems, including chronic kidney disease, type 2 diabetes and a 72% greater risk of heart disease. The SARS CoV-2 virus is not unlike a trojan horse, doing long-term damage to multiple organs, including the brain. The reasons are not yet clear, but researchers are looking at something familiar to people living with HIV: viral persistence.

More bad news: each infection is more likely to produce T-cell exhaustion, according to several studies. And due to the rapid mutation of SARS CoV-2, there is no upper limit to the number of times a person can get COVID. The CDC recently acknowledged this point, changing its guidelines to state that reinfection can occur in as little as 90 days after initial infection, and that reinfections can sometimes be more severe. While the COVID-19 death rate—at least from an initial infection—is low, the very real possibility of being sidelined with long COVID puts every public interaction into question, especially with transmission rates (via wastewater surveillance) spiking in most places since early July 2023.

The scourge of conspiracy theories

It's not always easy to know the difference between misinformation and disinformation—or the facts

BY **ENID VÁZQUEZ**

Everywhere around the world, death and destruction are fueled by misinformation (that which is incorrect) and disinformation (the deliberate spread of misinformation). It stops many people from getting appropriate medical care. Worse, it spreads faster on social media than does factual information, according to at least one study.

> 'It took the truth about six times as long as falsehood to reach 1,500 people.'

CROI 2023, the largest HIV medical conference in the United States, took on bad actors in the information world in a special presentation.

One surprising fact: the term "fake news" isn't new. It's more than a hundred years old.

GO TO croiconference.org for a webcast of *Science Communication in the Age of Misinformation* for these presentations along with a talk by Scott Ratzan of the City University of New York (CUNY). The school has established an online master's program that takes on misinformation, Health Communication for Social Change.

Taking on health lies

Looking specifically at vaccine misinformation, "the first thing to notice is that there's just a lot of it," said Emily Vraga, an associate professor at the University of Minneapolis' Hubbard School of Journalism and Mass Communication. A meta-analysis examining several studies published in 2021 in the *Journal of Medical Internet Research* (who knew?) reported that 37% of vaccine information on YouTube was misinformation, as was 26% on Twitter and 33% on social media overall.

"Part of this problem, though, is that there are places where it's increasingly hard to know how much misinformation there is," Vraga said. "It's not a mistake that we know a lot more about misinformation on Twitter [now known as "X"] and YouTube. Those are the most public social media platforms. As more and more of this conversation moves into spaces that researchers cannot access, more and more of this problem becomes something we just don't know about... something we cannot even begin to address because we don't know it exists."

She said misinformation matters because people believe it. Another study reported that nearly 8 out of 10 individuals surveyed either believed or were unsure about common falsehoods about COVID-19 or its vaccines, such as the incorrect notion that pregnant women shouldn't get vaccinated.

She also cited a study that found that 65% of all vaccine misinformation came from 12 online accounts.

"On social media, it's not always easy to know the difference between misinformation and disinformation because we don't know someone's intent. But what we do know is a lot of vaccine misinformation is coming from a very few bad actors," Vraga said. "Now they're not the only one sharing it. They spread it and then my aunt

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picks it up and believes it and shares it with me."

She pointed to a 2018 report in *Science* by Dartmouth assistant professor of computer science Soroush Vosoughi and colleagues which declared that, "Falsehood diffused significantly farther, faster, deeper and more broadly than the truth in all categories of information, and the effects were more pronounced for false political news than for false news about terrorism, natural disasters, science, urban legends or financial information."

The researchers also reported that "it took the truth about six times as long as falsehood to reach 1,500 people."

Moreover, information is politicized. The non-partisan Pew Research Center found a general decline in trust of medical scientists and scientists among both Republicans and Democrats, but more so among Republicans. This matched a greater death rate from COVID-19 in red states than blue states.

"It's hardly surprising that a lot of Republicans are increasingly distrustful of our medical organizations, the people who are encouraging vaccination. If you don't trust them, you're not going to get vaccinated," Vraga noted. Moreover, "On social media, we've learned time and time again that misinformation is much more engaging than accurate information."

The same is true of mpox, Vraga said.

Part of the reason people believe falsehoods, she said, is due to information overload. There is so much information available online that people may struggle to find what they need to know. Vraga herself looked a long time to figure out when her child's vaccine booster could be given. Others might give up and be willing to accept whatever information pops up first—or easiest.

Then there's the question of gatekeepers, the people through whom information flows.

"There are fewer gatekeepers that we can depend upon to make sure they're vetting [checking] information. So, for example, one study found that a lot [33%] of Generation Z trust TikTok more than their doctors for medical information, something that should be really concerning if you've spent any time on TikTok," Vraga said.

> ...one study found that a lot [33%] of Generation Z trust TikTok more than their doctors for medical information, something that should be really concerning if you've spent any time on TikTok.

Knowing that information can help, however. The White House, for example, reported last year that it will turn to TikTok more in order to reach younger audiences.

"But at the same time," Vraga pointed out, "this is a space where we can't just allow whoever's on TikTok—and there are a lot of people there—to determine what is true and what is false, to determine what people are believing about information."

Given the facts, people can protect themselves.

The title of a study from the Czech Republic addresses this point well: "Communicating doctors' consensus persistently increases COVID-19 vaccinations."

Vraga said that while 9 out of 10 Czech doctors surveyed supported vaccination, many individuals in the country thought the number was much lower, about 50 or 60%. When they learned that the consensus was actually 90%, they became more likely to seek out vaccination.

"That was a huge gap," said Vraga. "The good news is that correcting that gap—giving people accurate information—increased their intentions to get vaccinated, and these are long-term effects. So if they didn't just increase intentions as vaccine rollout continued, people who saw that correction, who learned that 90% of doctors in their country supported vaccination, were more likely to actually go out and get the vaccine when they're eligible.

"This is known as a gateway belief model. When we know the scientific consensus on a topic, that's incredibly convincing. It doesn't just switch our attitudes. It changes our actual behaviors," Vraga said.

Global visions

Around the world, different groups of people react in similar ways to health care. Many groups share medical mistrust and reject government mandates or recommendations.

In her book *Stuck: How Vaccine Rumors Start and Why They Won't Go Away*, Heidi J. Larson of the London School of Hygiene and Tropical Medicine, in Brussels, Belgium, includes a chapter on "Emotional Contagion." As she told the CROI audience, misinformation is one thing, but "where's the appetite for misinformation and disinformation coming from?"

"Infodemics [in general, false or misleading information around disease] are not only about misinformation," she said. "They reflect deeper emotions, beliefs and the polarization of publics [groups] that amplify the speed."

Larson pointed to a medical reference book that used to sit on shelves and was used "for God knows how long." Today, information spreads quickly and widely—but this includes misinformation.

"So there's volatility [rapid change]. That is partly because of the information environment. Wildfires [of information], the viral spread, emotional contagion—how viral emotions are becoming and that's partly mediated by YouTube videos and the increasingly emotive nature of spread and the power of belief," said Larson, an anthropologist who's originally from the U.S.

Some people latch on to the title of the last chapter in her 2018 book: *Pandemics and Publics*.

"I wrote the last chapter, and the book came out just before COVID. Some people say, 'you knew it—you should have told us.' I think we all knew it. We just didn't know when [a pandemic would strike]," said Larson.

Larson and colleagues travel the world surveying people about their responses to health care information. They have since 2015 measured confidence in vaccines. Among the issues raised by many individuals was the fear of dying after a COVID vaccination or of being microchipped without their permission via the vaccination, as one rumor has it.

"I have a cartoon from the 1800s that uses the term 'fake news.' It wasn't [then-president] Trump inventing it for the very first time. What is different now is the rapid speed and scale," said Larson. "What is giving that traction? There is the issue of the algorithms that are the business plan of the social media companies. But the bigger viral spread of misinformation is about emotions. It's about beliefs. It's about the polarization of publics, who are hungry for another story, because they're not happy with the story they're getting."

‘It constantly amazes me how little scrutiny there is on anything that’s natural’

In a protest in California against vaccinations, a banner was waved that declared, “This is the new civil rights movement,” which some people found offensive. Larson noted a quote from the head of the U.S. Food and Drug Administration (FDA) from last year (2022).

“I actually believe that misinformation is the leading cause of death right now in the U.S. because whether we’re looking at COVID or chronic disease, people are making bad choices driven by the information that they get,” said FDA commissioner Robert Califf.

Larson added that, “It’s about ideology, notions of freedom. But it’s way beyond that. These kinds of emotive, organized movements couldn’t care less about the facts. You can spend all your time debunking and it just angers them, because that’s not their point. They’ve got something else going on.”

Misinformation still needs to be countered, she said. “But there is another sector—and unfortunately, it’s growing at a fast speed—of these ideological, belief-driven publics.”

She showed a newspaper report of COVID vaccination protesters in Brussels, a city not given to protests around health issues, she said. Their signs included the word, “Liberty.” In South Africa, there were 511 protests around the COVID-19 lockdown in one five-month period.

These were just two examples of protest movements around the globe. More concerning, said Larson, was the pushback on childhood vaccinations.

“When you see the significant drops in confidence in childhood vaccine, in routine immunization, that’s a worry,” she said.

Sometimes it seems possible that rumors might be true. There was, for example, an incorrect report of two cases of the Marburg virus from Equatorial Guinea found in neighboring Cameroon.

“It is perfectly plausible that it could have come across the border. These were a couple of border towns,” said Larson. “So, we do have to understand there are certain situations that have a plausibility, when they’re not getting a different story.

“And one of the oldest persisting rumors is about sterilization—anxiety about sterilization and vaccines,” Larson noted.

One anthropologist colleague who looked at sterilization rumors across Africa found they extended beyond vaccines and into concerns about micronutrients and quinine.

“Again, it’s about people feeling like they can’t trust the government,” Larson said. “Now, we’ve got another problem when the U.S. government and the CIA fake a vaccine campaign in Pakistan. That doesn’t help me in my job. I was out there with UNICEF telling people, *Don’t worry. The CIA is not trying to spy on you with this polio campaign.* I’m glad I hadn’t seen this before in my 10 years of work in that program, because it would have been much harder to do my job. As one of my colleagues said, *Why couldn’t they pick the milkman instead of faking a vaccine campaign to find Osama bin Laden?*”

Despite all the analyses of the vaccines, she said, “It’s about civil liberties. It’s about morality, etiology, religious beliefs, natural [substances], Mother Nature. It constantly amazes me how little scrutiny there is on anything that’s natural. If you put *nature* on it, people are not going to ask about it. But the level of questioning we get around scientific, evidence-based things—they get much more scrutiny.”

The struggles that broke out over the use of science to control death and disease in the face of the COVID-19 pandemic ended up taking many people by surprise.

“A lot of people in the world had *no clue* there were these alternative, negative, anti-vaccine sentiments going around a vaccine. They were totally shocked to find it when they started to look for information. Who would have expected a group of truck drivers to organize and block a border because of having an opinion about vaccines? And this was lining up with the right-wing extremists,” Larson said.

She quoted another national leader.

“The president of Tanzania, who died of COVID, said, ‘Pray to God.’ In Tanzania, we had people selling COVID organics [to control the virus] to different countries, saying that would cure them. We also saw polio workers and Ebola workers *killed*. They were killed by people because of fear and anxiety and [questions of] *where are you coming from and what do you really want here?* So this was not about misinformation. This was about anger, fear, not having enough information, not having had the kind of preparedness to understand, *What are these people coming for? What’s going on?*”

That’s where partnerships need to be made, said Larson: “Histories matter. Community histories matter. Distrust may be justified. That’s a challenge to me. You can’t go in there and say, *let’s build trust* when you know that communities in some countries … *I* wouldn’t trust some of the governments. So we need to find things that they can build trust in. We need to embed facts when we are there with empathy. We need to make it relatable to their lives.” And, trusted local individuals need to be engaged.

One more thing: Larson said that science and research need to build in funding for communication work. It doesn’t happen by itself.


The Debunking Handbook 2020

Resources

GO TO skepticalscience.com for *The Debunking Handbook 2020* by Vraga and colleagues, available in 18 translations with more to come.

For more about the IRIS Academic Research Group, founded by Larson and other researchers to take on infodemics, **GO TO** irisacademic.org.

For the Centers for Disease Control and Prevention (CDC) manual on health communication, **GO TO** cdc.gov/eis/field-epi-manual/chapters/Communicating-Investigation.html.

Getting into bed with healthcare: A sexy partnership?

A sexual health outreach worker offers his take on a recent HIV-STI conference

BY **CHARLIE PETERSON**

After a four-year absence, the STI/HIV 2023 World Congress was held in Chicago last July, offering a glimpse into some of the emerging changes in sexual health.

ISTOCK-JEFF BERGEN

One way to quickly incorporate change is to listen to the community. Sometimes we know best. Also, healthcare providers and researchers must approach communities of interest—often the LGBTQ+ community—with respect, intentionality and purpose. They must also provide inclusive healthcare, where services are accessible to all, and where people feel seen and understood. **People want their intersectionalities, social inequities of health and traumas (those lived and intergenerational—historic) acknowledged.** While none of this may be new, the fact that it's being discussed at medical conferences means that healthcare is listening and that we are becoming more than a checkbox, a fingerprick or a number.

Community, not a fingerprick, is key to improved healthcare. A pay-it-forward model in Asia was highlighted by Joseph Tucker, MD, PhD, from University of North Carolina at Chapel Hill, which is increasing community connectedness while addressing healthcare needs. People receive a free healthcare service like a sexually transmitted infection (STI) screening, and then either give money or write a message on a postcard to motivate others to get tested. Donations help cover 20–60% of STI testing costs and give good feelings as kindness begets kindness.

ANOTHER CHANGE discussed by Jagadīśa-Devaśrī Dācus, PhD, MSSW, from Northwestern University's Institute for Sexual and Gender Minority Health and Wellbeing (ISGMH), is that **community engagement must shift to community leadership**. In his presentation, he mentions Rena Janamnuaysook, a transgender woman advocate from Thailand who simply states, "key populations cannot only be service recipients," the healthcare system must empower community members and advocates by providing education on the importance of testing, different prevention and treatment options, and the drug pipeline. Communities must further share these learnings. They must then take community-determined needs and work with public health agencies to create appropriate healthcare services. With community members as stakeholders in healthcare conversations, healthcare becomes more targeted and inclusive, helping to reduce stigma and deliver messaging that resonates.

BECAUSE OF the heavy burden currently placed on the clinical system, another tactic being explored in healthcare is to **decentralize STI testing by using self-testing and artificial intelligence** (AI) approaches. Self-testing or point-of-care kits became popular during COVID-19 and STI testing is ingeniously following suit. These tests can be available anywhere, from pharmacies and supermarkets to vending machines or websites. More locations and increased availability can only mean more testing. As Joseph Cherabie, MD, from Washington University in Saint Louis mentioned, home tests offer many benefits—convenience, quick results, decreased person-to-person interaction (potentially reducing stigma) and increased availability of tests (especially important in regions where same-sex relations are criminalized or heavy stigma is experienced and in rural settings where healthcare providers are distant).

- At Washington University in St. Louis, over half of patients preferred home kits, irrespective of insurance status.
- A Preventx presentation showed that in the UK, home testing led to the diagnosis of a similar number of STIs (chlamydia, gonorrhea, hepatitis B and C and HIV) to what clinic diagnoses would have been, demonstrating quality and reliability.

AI diagnostic screening tools and chatbots are other soon-to-be widely available options for people to turn to. They are confidential, accessible from mobile devices and can provide personalized answers for users.

- Screening apps require the user to submit a picture of a potential STI, which is then identified with an accuracy of 71% or higher. As more data are collected, the AIs learn and improve recognition and diagnosis.
- Tom Nadarzynski, PhD, from the University of Westminster mentioned that chatbots are great for initial conversations with clients. They can better help reach marginalized communities without judgment or stigma, offer safe spaces to discuss private, vulnerable topics and provide relevant, personalized answers.

While these apps are in their infancy, they may be potentially invaluable tools in the future as predicted by Lei Zhang, PhD, from the Melbourne Sexual Health Centre, and Yudara Kularathne, MD, from HeHealth. That being said, professor Claudia Estcourt from Glasgow Caledonian University reminds us to be mindful of systemic barriers such as no or limited access to the internet, computers and smartphones, and that action to minimize these inequalities must be taken to improve healthcare for all.

WE MUST end on the fact that people are sexual beings. Teodora Wi, MD, from the World Health Organization (WHO), called for **integrating STI services with primary care, sexual/reproductive health and HIV services**. She also recommended creating environments where people feel comfortable discussing STIs. Her final major point was that we must facilitate point-of-care diagnostics and other affordable technologies. People must have access to many testing options. Like in the bedroom, this should not be a one-size-fits-all situation. Options are good, and they must be affordable. Lastly, the Participatory Designathon Committee, community members from around the globe, stated that a reframing or gain-framing of STI messaging is needed. Essentially, move away from risk messaging and move towards dialogue on sexual pleasure, sexual health, sex normalization and positivity.

‘I feel an impulse to **create** again.’
WALDIE MURRAY

Waldie’s new adventure

A once and future influencer rediscovers his power

BY **RICK GUASCO**

It’s been nearly nine years since the last time we spoke. For the September+October 2015 issue, Waldie Murray talked with me about how he had turned to social media the year before as a way of processing the news that he had tested positive for HIV—he had gone on Facebook almost as soon as he had gotten home from the clinic where he’d been tested. But little more than a year after the story was published in POSITIVELY AWARE, he disappeared. Now, we reconnected, finding each other on social media, and catching up over Zoom.

At the time of the 2015 story, Waldie had been out and open about his HIV status to his employer. When he left and started a new job in April 2017, however, he was concerned about how his new company might discover his status if they saw his social media and how it might affect his insurance.

“Part of it was also not being able to manage all of the people reaching out to me,” he says. “I was grateful that I could help a lot of people. But social media can be very anxiety inducing, even if you’re a person who wants to be a personality online. So, I kind of went away.”

He deleted his Facebook page, YouTube channel and all his other social media accounts. He had virtually vanished.

Fast forward to early 2019. Waldie was still living in Baltimore, where he had grown up, and met someone—a guy in the Navy who was stationed in Hawai’i and visiting the area—through a dating app. From their first encounter, they began a long-distance relationship.

They got together every few months. Skiing in Colorado. Spending Waldie’s birthday and Christmas in the Baltimore area. Not long afterward, his boyfriend retired and eventually moved to Maryland to be with Waldie. His boyfriend couldn’t take the mid-Atlantic winters, so in July 2022 the two moved to Honolulu.

Waldie’s HIV status was never an issue for his boyfriend. He had told his boyfriend very early on, and his boyfriend had already been taking PrEP.

“It’s very empowering that he understands that the onus is not just on me,” he says.

“The fact that he’s taking his health in his own hands and respects our relationship to do his part—as I do my part, that’s really valuable.”

He was able to get a referral through his care provider back in Baltimore, Chase Brexton Health Care, who knew of a local provider.

He’s been taking the HIV medication Genvoya for so long, “I can’t remember when I started.” His provider recently recommended he switch to a long-acting injectable treatment regimen. “But my concern with the shot is I’m not certain if it’s covered by my insurance yet,” he says. “If it is covered by my insurance, I think I would be okay with that.”

Waldie first ventured onto social media in August 2013, with his own YouTube channel. So, in 2014 when he found out his HIV status, he posted a video about it. “That’s because I wanted to be transparent with the people who were already watching me. I felt like I’d be a hypocrite if I didn’t share that.”

Now that years have passed since he left social media, he no longer feels pressure or anxiety, but he’s getting that old feeling.

“I feel an impulse to create again,” he says. “I feel the urge to do something very similar to what I used to do. Talking to folks on camera comes easily for me. I think I want to create more of a conversation, maybe interviewing. I’m not really sure how that’s gonna look.

“I had a little bit of a love-hate relationship with the idea of being an activist,” he adds. “I felt pressure. When I started my YouTube channel, I really wanted to express things that I was learning along the way, as me. And then at some point it became solely focused on HIV. In my mind, I think I was losing track of what I was doing because as an HIV activist, there were so many people who reached out to me. I was conflicted. Now, I think I can more easily manage the interaction between myself and social media. I’m more sure of myself. Now that I’ve done it once, I’m like, if I embark on this again, I’m well equipped, mentally and emotionally.”

That increased visibility also applies to the real world. “When I moved here, no one knew my status. After establishing a core group of friends over a few months, I disclosed it to them,” he says. “Some responded with a bit of shock. I didn’t ask why. Maybe they just weren’t prepared when I said, *I want to share something with you. It might come as a surprise, but I want to share it because we’re close friends.*

“One of my close friends here is also living with HIV,” he adds. “I had a heart to heart with him. It was really nice to be able to have someone who understands mentally and emotionally what it’s like. He’s very open about his status, too. It’s super empowering for me to be around people who are putting themselves out there that way.

“Back when I first found out my status,” he continues, “in the first few years, and probably up until meeting my partner, there was anxiety about meeting someone.”

Having lived there now for over a year, as he makes new friends, Waldie is building his own community and finding a place for himself.

ON THE COVER OF THE SEP+OCT 2015 ISSUE

“I want to add my voice to make sure that people are informed,” he says.

Waldie was 27 when he was first interviewed for POSITIVELY AWARE. He turned 36 in November, so I asked him the question he had recently posted on social media—*Where are you in your arc?*

“I love this question so much because it really gets you thinking,” he says, smiling. “I feel like I have very recently discovered my own power after being dormant for a while. And by very recently, I mean just the other day. The conversation with you ignited this impulse to look at old videos and pictures of me. And I was like, *Wow, I really put myself out there, no fear at all.*

“I saw this spark that I’m inclined to revive again,” he adds. “As far as this arc, it’s like [in *The Wizard of Oz*] when Glenda tells Dorothy that she’s had the power the whole time. Dorothy’s like, and I’m paraphrasing. *I could’ve clicked my heels this whole time and gone home? Why didn’t you tell me?* And Glenda says, *Oh, you wouldn’t have believed me.* So it’s like, okay, I went through that entire journey, and we’re back at Oz. Where am I going now? It’s a brand new adventure. I’ve discovered that I’ve had this power the whole time. Now what? I think I’m going to be creating again. I think I’m going to be putting myself out there again with the power I’ve found as a result of that time away.”

Since the time of this interview, there were significant new changes in his life, so we spoke again, this time over the phone, in late January. Waldie and his partner ended their relationship in December 2023. “We don’t have any bad feelings towards each other,” he says. “We’re very amicable. As for the arc of my journey, it’s very focused on my wellbeing.”

He has started seeing a therapist for the first time in his life. And after a DJ friend invited him to try it, he’s now DJ’ing once a month at an LGBTQ+ bar in Honolulu.

“A few months after I moved to Hawai’i, I started to feel really grounded here, like I belong here at this point in my journey,” he says. “I started to create my own community, having my own group of people that I am connected to. I lived in Baltimore for so long that when I moved to Hawai’i, you would think that this would’ve been a fish out of water story, but I actually feel like this is a *fish who found water* story. I have never felt more myself.”

READ the 2015 interview with Waldie Murray: positivelyaware.com/articles/shared-experience

BEING BRIDGETTE

Bridgette Picou

Clinicians must be the light

Certain types of doctor appointments can be more stressful by nature. Maybe it's because you don't seek care regularly or there is family history or mistrust involved. Going to the OB-GYN stresses me. There are a number of reasons, but at its base, the idea of exposing my hoo-ha to a stranger brings anxiety. Your specific type of appointment unease may vary, but many of us have had that trigger, if not often, at least once. Sometimes anxiety is the unknown, such as not knowing what the outcome of tests may be. All too often, it is the *knowing*. Knowing you won't be respected, frustration about the way they will talk to you (or won't talk to you), the lack of answers. Feeling unseen or other microaggressions that at times may make you decide to just not go. Consequently, missing appointments may cause you more stress.

Whether you call them clinicians or providers, practitioners, researchers, scientists and the other staff that do the work of medicine—whatever the designation—health care providers need to do better by the people they serve. This is not limited to HIV providers. Appointments to non-HIV clinicians can also offer a unique kind of stress to people. They, *we*—I'll include nurses, because I am one and therefore part of "the profession"—are stumbling if not outright falling in simple but critical ways to really serve and impact the lives of people living with HIV. That is not to say that there are not amazing care providers. There are! I've met them, listened to them and learned from them. Yet, I listen to peoples' experiences, I hear their stories and know there is a disconnect. I have firsthand experience—the casual disregard and the impatient behavior that comes from being entrenched in the burnout of having "seen it" too many times, or the painful ignorance of not knowing about HIV and not caring enough to learn.

One of the worst experiences I had at a clinician's office came very early on in my HIV diagnosis, at a GYN office, which further imprinted the trauma in my head. I had to course correct this physician four times away from insisting on using the word *AIDS*, his asking me personal questions about the why and how I acquired HIV that had nothing to do with my visit and him telling me that I was his "first AIDS patient." He then went overboard taking precautions for my exam by wearing two gowns, goggles, booties and a head cap. For a simple Pap smear. This was 2013, and I wish I was making this up. His use of language, his casual indifference toward my feelings, the line of questions, the ignorance, and not recognizing the difference medically and emotionally between AIDS and HIV are what I am talking about. I have another example of an instructor in nursing school; I'll spare you the details, but it is one of the reasons I am the nurse I am today. I know a hundred stories, but most are not mine to tell.

Medical professionals are supposed to be the bridge between illness and health. The problem we face starts when clinicians refuse to see us as more than a disease. It continues when their academic knowledge of viruses causes them to forget there is a person living with the virus. The doctor I'm talking about didn't use *acquired*. That's my word. He said *infected*. "How did I get infected?" Imagine yourself *infected* with something, and see how the word feels in your brain and tastes on your tongue. Now imagine it attached to you every time you visit the doctor. Not just in doctor offices, but in articles you read and advertisements you see. By scientists who also refer to you as an "HIV-infected study subject." Envision yourself being referred to as a "risk population." Now, replace these things with your name and see it in those same spaces. Year after year as part of your daily life. It's not just the words, it's the casual disregard from clinicians who don't practice in HIV, who therefore don't bother to learn about it. They may sit on their phone or computer and look up the HIV basics they haven't seen since med school, *right in front you*. How does that inspire confidence in the bridge? Not to mention the nonchalant discussion of your diagnosis by front office staff in front of the whole waiting room when they are tasked to respect confidentiality but don't.

HIV is stigmatized, criminalized and misunderstood for both what it was and what it is now. What it has always been is a *human condition*. Clinicians must learn to connect to humans and not the virus. My favorite affirmation is "when you cannot find the light, be the light." We need them to be the light.

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.

PICOU: CHAD SAIN • ILLUSTRATION: ISTOCK