PA 30
POSITIVELY AWARE

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SEP+OCT 2020

THE FIGHT FOR WHAT MATTERS

ABOLITION AND HIV DECRIMINALIZATION

AIDS 2020: VIRTUAL CONFERENCE UPDATE
WHEN PANDEMICS COLLIDE

POSITIVELY AGING
'THE COMMUNITY NEEDS MORE'

COVID-19 PREPAREDNESS FOR PLHIV

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LIVE LIFE POSITIVELY AWARE.

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

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FRONT COVER BACKSTORY

Making the connection

BY **RICK GUASCO**

“The better you can tell your story, the more you can connect to someone,” says **Morris A. Singletary**, who appears on the cover of this issue. To help others, he draws from his own life story as a gay Black man who grew up in Atlanta.

Singletary, 43, was already seriously ill when he was diagnosed with HIV in June 2006, and had to be hospitalized twice. He turned to substance use, losing his job. Eventually he became an HIV peer educator for public health organizations, but life changed in 2016 when he discovered Thrive SS, an organization for Black gay men living with HIV that provides advocacy, peer support, and community building. He saw how storytelling could overcome stigma, and make a connection to people, helping get them connected to care and the services they need.

He soon took to Facebook and began live streaming, sharing his personal experiences. The effort evolved into The Pozitive2Positive Initiative, a Facebook page and a nonprofit HIV education and prevention organization he is slowly building.

Through social media, people are reaching out to him. Many have their own stories to share, but also ask him questions about HIV and where to find services. He'll get calls or messages at all hours, he says, and energetically helps find the resources they need. With his outgoing personality, he's constantly building a network of contacts throughout Atlanta and across the country to connect people. “I network like crazy,” he says.

The COVID-19 pandemic has revealed the deep disparities in services—particularly access to medical care, he says.

“In public health I've learned that **there is COVID, and then there's Black COVID; there is HIV, and there is Black HIV**,” he says. “You can see the difference in access to care, resources, and education by ZIP code.”

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EVERY ISSUE

PA30 THIRTY YEARS OF POSITIVELY AWARE

THIS ISSUE

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>> CONTINUED FROM PAGE 2

That disparity is especially obvious in telehealth, which many doctors' offices, clinics, and service organizations now widely use in this pandemic-driven era of social distancing and self-quarantining.

"For people who don't have smartphones or internet access, telehealth doesn't work," he says. "For people who've lost jobs and can't keep their phone on, this puts worry on them. And if that worry becomes stress, it's going to affect their T cell counts and their health."

Singletary is doing what he can to help people overcome the same hurdles he's faced, whether it's inequality or stigma. Storytelling can be an antidote to stigma, he says, particularly self-stigma.

"Self-stigma is the sum of family stigma, community stigma, and church stigma. After a while, you believe what you've heard about other people like you. You need to believe in and tell your own story."

PHOTOGRAPHER **Habeeb Mukasa** (@habeebmukasa) shot the cover at Jack Guynn Plaza at the Federal Reserve Gardens in Atlanta.

"Taking Morris' portrait was a unique experience for me," he says. "When I learned about the hard work that he tirelessly does for the community, I thought to myself that this would be quick—this man has no time. I was wrong. I was moved by his efforts and particularly the time he took to share his story about how he became an activist. Listening to him gave me the perfect opportunity to capture him in his own element, in his own words. I have been a photographer for just over a decade and taking portraits of everyday people, especially those who make an impact on all our lives, is priceless."

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JOHN GRESS

EDITOR'S NOTE

JEFF BERRY
@PAeditor

The stories of our lives

OUR STORIES are incredibly important, not only to remember and honor our history, but also as a map to help guide us forward, lest we repeat the mistakes of our past.

In this issue you'll hear from Ross Slotten, MD, who chronicles his life as a gay physician in Chicago from the 1980s to current day in his new memoir, "Plague Years: A Doctor's Journey through the AIDS Crisis." Slotten's unflinching look at his own life during a pandemic help shed light on our current crisis with COVID-19, and offer hope in a time of uncertainty and change.

S. Mandisa Moore-O'Neal in her first article for POSITIVELY AWARE poses the question, "What does abolition have to do with HIV decriminalization and modernization?" and offers up some thought-provoking answers.

Lambda Legal's Scott Schoettes debuts his new regular column in POSITIVELY AWARE which focuses on legal issues for people living with HIV. First up? COVID-19 preparedness for PLHIV.

These and other stories remind us of our failings and our successes, and sometimes tug at the heart. The following originally appeared in the December 1989 issue of *TPA News*, the forerunner to POSITIVELY AWARE. My husband came across some old issues of PA the other day while cleaning out a closet. I read this and wept. In honor of 30 years of publishing POSITIVELY AWARE, I've decided to rerun an edited portion in this column, just as I did in the March+April 2008 issue. Some stories are worth repeating.

Take care of yourself, and each other.

'It Was Your Love That Got Me By'

TPA News, December 1989

THOM HUDSON HELPED *begin TPA [TPAN] in the summer of 1987 and served on our first Board of Directors. In September of [1989], he spoke at TPA during our program on "HIV and AIDS Anniversaries." That was four years after he learned he was HIV positive and 16 months after his first bout of pneumonia. After an autumn of mixed health, Thom died on October 19th [1989], surrounded by those he loved and who loved him. Here is a transcript of portions of his comments just five weeks earlier.*

I was hospitalized this year...with Cryptococcal pneumonia...When I was in the hospital the drug that got me by was those of you here at TPA. You know who you are. The cards and the letters and the visitations. It was your love that got me by; it wasn't any drug that they could give me; it wasn't any shot, any IV. It was love that got me by. And I sincerely meant that from the bottom of my heart.

It was the beginning of '85 when my lover Dale was diagnosed with AIDS. I knew, then and there, that I was positive also.

These and other stories remind us of our failings and our successes, and sometimes tug at the heart.

Lots of people have asked "is it like sitting around, waiting for something to happen?" Well, yes, but I never really dwell on it. And I didn't. I just kept going and doing everything I wanted to do. I travelled more. That's why so many folks don't see me and think I'm a millionaire because I'm always out of town. Don't talk about it, DO it. Just get up, get on a plane, train, bus and GO; you won't regret it. Any of you can do it.

Many times I didn't attend meetings because I just didn't have the energy. You come home after trying to do different errands during the day and you're huffin' and puffin' after trying to get up the stairs. But these things you have to expect; you can't let them hold you back. Don't use them as excuses. There's no such thing as a good excuse.

When I was HIV+, I did not live in dread. I figured "whenever it happens, it will happen." I think it helped me, it encouraged me. I still remember the day we knew Dale was diagnosed with AIDS, I turned to him and said "for some reason I'm gonna be a better person by the time this is all through."

Dale only lived 18 months after his diagnosis. But I still believe that, because I know that's the way it is in my life. I mean, look at this! Look at all of us sitting here tonight. That's bad? No, that's good. Think of all the good, all the love here.

'Numbers aren't everything'

I ALWAYS LIKE to mention this because deep down I'm really proud of it. There's quite a few of you here, in fact, whose mouths used to drop wide open when we talked about this: A couple years ago when I did orientation my T cells were about 150. And some of you would come with your T cells at 450 or 500 and you'd be frantic: "I'm gonna die next week!"

Get over it. Numbers aren't everything. I've had three T cells for the last six months. I've named them after the Three Stooges: Mo, Larry and Shemp. (I always like Shemp better than Curley.) It's what's up here in your head, and here in your heart, that really counts.

MARCH+APRIL 2008 ISSUE

ENID VÁZQUEZ @ENIDVAZQUEZPA

BRIEFLY

A new option

FDA approves new HIV drug for people with limited treatment options: Rukobia

The U.S. Food and Drug Administration (FDA) has approved a medication for multi-drug resistant HIV that is the first of its kind on the market, Rukobia (fostemsavir). Rukobia is very different from other HIV medications in several ways.

First, Rukobia was approved for people who are:

- heavily treatment-experienced
- with multidrug-resistant virus
- on a failing regimen due to resistance, intolerance, or safety considerations

Rukobia is also the first HIV drug of its type on the market. It is a gp120 attachment inhibitor. As such, it is part of the HIV entry inhibitor group of drugs, all of which are used for heavily treatment-experienced people.

“This approval marks a new class of antiretroviral medications that may benefit patients who have run out of HIV treatment options. The availability of new classes of antiretroviral drugs is critical for heavily treatment-experienced patients living with multidrug resistant HIV infection—helping people living with hard-to-treat HIV who are at greater risk for HIV-related complications, to potentially live longer, healthier lives,” said Jeff Murray, MD, in a press release. Dr. Murray is deputy director of the Division of Antivirals of the Center for Drug Evaluation and Research at the FDA.

The FDA approval of Rukobia on July 2 was expedited under the agency’s Fast Track, Priority Review, and Breakthrough Therapy Designation for new drugs to address unmet medical need of treatment in serious or life-threatening conditions.

As noted in the Positively Aware annual HIV Drug Guide, “Fostemsavir works on the gp120 protein that lies on the surface of human immune cells. It’s a necessary part of getting the virus to enter the cell. Fostemsavir prevents attachment to the CD4 immune cell by binding to the CD4 receptor binding sites on gp120 on the virus. This causes the virus to accumulate in extracellular space and is subsequently removed by the body’s immune system. Very cool.”

Inside the body, fostemsavir first converts into the drug temsavir, which then attaches to the glycoprotein 120 (gp120). This makes fostemsavir a prodrug of temsavir, basically, a drug that converts into another drug in the body. Because fostemsavir is the first drug to target this step of the HIV life cycle, no resistance to other classes of antiretrovirals is expected.

WATCH a video of Rukobia’s mechanism of action at youtu.be/WnreXE-TVi8.

Rukobia is dosed as a 600 mg tablet taken twice daily with or without food. It must be taken in combination with other HIV antiretrovirals (ARVs).

The FDA’s approval was based on Phase 3 data from the BRIGHTE study. A group of 272 participants received fostemsavir plus one or two other active new drugs on top of their failing regimen. For this group, 60% had undetectable viral load (less than 400) at 96 weeks, with an average T cell increase of 205. For the group of 99 participants who only added fostemsavir plus—in some cases—an active investigational drug, 37% had viral load less than 40 at 96 weeks, with an average T cell increase of 119.

The most common side effect seen in clinical trial was nausea (10%). About 7% of participants stopped treatment because of adverse reactions; the most common were nausea, fatigue, and diarrhea. Serious drug reactions were experienced in 3% of fostemsavir recipients, which included three cases of severe immune reconstitution inflammatory syndrome (IRIS), and elevations in liver enzymes in participants in who also had hepatitis B or C virus. IRIS, a sign of returning immune system strength, is not uncommon in people with advanced HIV disease who begin taking powerful antivirals. Symptoms of disease should be discussed with your doctor.

Among the BRIGHTE participants, about 75% were men, 60% were over age 50, nearly 30% had a viral load above 100,000, 71% had been treated for HIV for more than 15 years, and 85% had been on at least five different drug regimens.

Rukobia is contraindicated with (cannot be used together) strong cytochrome P450 (CYP)3A inducers, which are drugs that include enzalutamide (an androgen receptor inhibitor); carbamazepine and phenytoin (anticonvulsants); rifampin (an antimycobacterial, used for tuberculosis); mitotane (an antineoplastic, used for cancer); or the herbal St. John’s wort.

—WITH **RICK GUASCO**

FOR MORE INFORMATION GO TO positivelyaware.com/fostemsavir

FDA NEWS RELEASE: fda.gov/news-events/press-announcements/fda-approves-new-hiv-treatment-patients-limited-treatment-options

ANNOUNCEMENT: bit.ly/FDAannouncementRukobia.

PRESCRIBING INFORMATION: bit.ly/RukobiaPrescribingInfo

JOHN GRESS

DRUG AND TREATMENT UPDATES

Dovato receives switch indication

The HIV medication **Dovato can now be taken by people switching over from another HIV regimen**. Previously, individuals had to be new to HIV therapy (treatment-naïve) in order to take it.

Dovato is a complete HIV regimen in one pill (a single-tablet regimen, or STR). Switching to Dovato, an individual must have undetectable viral load (less than 50) on their current HIV regimen, with no history of treatment failure or drug resistance to the medications in Dovato. Dovato contains dolutegravir, an integrase inhibitor, and lamivudine (3TC), a nucleoside reverse transcriptase inhibitor (NRTI).

Lamivudine, used as a background drug for more powerful HIV medications, has practically no side effects. The powerhouse dolutegravir, however, has been associated with distressing weight gain. HIV treatment-related weight gain is becoming more recognized and is being researched.

Dovato's drug label was also updated with 96-week safety data. The percentage of individuals who discontinued Dovato due to adverse events had increased from 2% to 3%. At 96 weeks, anxiety was added to the potential side effects that may occur with Dovato. It was observed in 2% of study participants taking the STR.

READ the August 8 FDA announcement at bit.ly/DovatoSwitchAnnouncement; **GO TO** positivelyaware.com/dovato.

New pediatric approval for Evotaz and Prezcobix

For the third time this year, the U.S. Food and Drug Administration (FDA) has expanded the availability of HIV medication for pediatric use.

Children can now use these two-in-one combo pills:

- **Evotaz** (atazanavir/cobicistat) or
- **Prezcobix** (darunavir/cobicistat)

Children must weigh at least 77 pounds (35 kg) to use Evotaz and at least 88 pounds (40 kg) to use Prezcobix.

The **approval basically formalizes the use**, since children could already use the drugs in Evotaz or Prezcobix separately (Reyataz plus Tybost or Prezista plus Tybost). The FDA's July approval means kids can officially be given one of the combo pills instead.

Evotaz and Prezcobix are each taken as one tablet once daily with food and must be taken with at least one other HIV drug. They can be taken by people using HIV therapy for the first time or those who are already HIV treatment-experienced. The side effect profile for each medicine is similar to that seen in adults.

As with adults, children taking Prezcobix cannot have darunavir-associated drug resistance.

READ the FDA announcement, which includes pediatric clinical trial data, at bit.ly/pediatricEvotazandPrezcobix. **READ MORE** at positivelyaware/evotaz and positivelyaware/prezcobix.

Long-acting injectable cabotegravir submitted to FDA

The treatment activist group HIV i-Base, in London, reported the re-submission of long-acting injectable cabotegravir (CAB-LA) to the FDA for approval. The filing was not reported by the drug maker in the U.S. Indeed, the long financial report from pharmaceutical giant GSK, headquartered in England, said simply: "Cabenuva resubmitted in the U.S. as HIV treatment; regulatory decision anticipated Q1 2021." That is to say, **the new medication may be approved in the first quarter of next year**.

The company also noted in its July update that, "Positive data from the CUSTOMIZE trial, the first ever implementation research study on how best to integrate an investigational once-monthly injectable HIV treatment in U.S. healthcare practices, were presented at AIDS 2020."

Cabenuva is the name for the CAB-LA injectable plus long-acting rilpivirine (RPV-LA) injectable for HIV treatment. The complete HIV regimen is to be given as two shots every four weeks.

HIV i-Base writer Simon Collins notes that, "It is good that a regulatory decision is closer given the high expectation among HIV positive people for an alternative to daily tablets. Access though in many countries will be dependent on price."

In the U.S., GSK long ago put all of its HIV drug development into a new subsidiary company, ViiV Healthcare. ViiV received FDA approval of a new HIV medication, Rukobia, in July, which was also noted in the GSK report. **GO TO** i-base.info/htb/38707 and positivelyaware.com/la-cab-rpv.

……

CDC expands hep A vaccine recommendation

The Centers for Disease Control and Prevention (CDC) now recommends the **hepatitis A vaccine for everyone over the age of 12 months**. Read the updated recommendations published July 3 in the *Morbidity and Mortality Weekly Report* at http://cdc.gov/mmwr/volumes/69/rr/rr6905a1.htm.

BRIEFLY

HIV prevention drugs now available without first-time prescription in California

California has become the first state in the U.S. allowing pharmacies to sell HIV prevention drugs without a prescription under a new state law that took effect July 1.

Pharmacies in California can now sell up to a 60-day supply of PrEP for pre-exposure prophylaxis or a 28-day course of PEP for post-exposure prophylaxis treatment without a prescription from a medical care provider.

After that, a doctor's prescription will be required, but the new law also prevents insurance companies from requiring prior authorization to pay for the drugs. Medi-Cal, the state's version of Medicaid, is also now required to cover PrEP and PEP.

Before receiving PrEP or PEP, under the law, a person must show proof that they have tested negative for HIV in the previous seven days. It is necessary to test for HIV before starting PrEP because if a person with HIV takes PrEP, their virus could develop resistance to the drugs that are also used in some HIV medications, potentially limiting a person's future treatment options. It's also important to have regular check-ups while taking PrEP to test kidney function and to test for sexually transmitted infections.

PEP is used to prevent an HIV infection that may already be in progress, so no HIV test is needed.

The law also requires pharmacists to educate patients about PrEP—including side effects, the importance of adherence, additional testing, and about other infections such as HIV, hepatitis B, and hepatitis C. Pharmacists must also discuss additional safety information about PrEP use during pregnancy and breast feeding.

The new law's restrictions are the result of a compromise. The California Medical Association and other medical groups had originally opposed the bill's passage, concerned about the long-term use of PrEP and PEP without follow-up testing and medical supervision.

Signed into law last October by Gov. Gavin Newsom, Senate Bill 159 was authored by state senator Scott Wiener and co-sponsored by assemblyman Todd Gloria. In 2014, as a member of the San Francisco Board of Supervisors, Weiner disclosed that he was taking Truvada as PrEP. Weiner chairs the LGBTQ caucus of the California state legislature.

—RICK GUASCO

Methadone take-homes during COVID shutdowns

For decades, advocates have fought the hardships faced by patients forced to travel to a clinic on a daily basis to take their methadone treatment. The thought of a natural disaster struck terror into patients who would get sick from withdrawal if they were unable to go to the clinic. **Opioid treatment programs (OTPs) reported good results with giving patients multiple doses to take home** in the face of COVID-19 shutdowns, AT Forum reports.

READ the article at atforum.com/2020/07/extended-methadone-take-homes-during-covid-nothing-but-success.

A free newsletter, *Addiction Treatment Forum* is available only online; it's a must-read for anyone interested in issues of treatment and justice surrounding drug use. **GO TO** atforum.com.

Supreme Court upholds anti-prostitution pledge

"When it comes to sex workers in the U.S. and around the globe, many of whom are Black, Brown, and transgender, discrimination and criminalization of sex work have put them at a high risk of violence, contracting preventable diseases like COVID-19 and HIV, and have exposed them to police brutality. Yet the U.S. continues to weaponize life-saving global AIDS assistance programs against sex workers by demanding recipients of PEPFAR funding to officially adopt a position opposing prostitution and acquiesce to the U.S. conflation of sex work and trafficking. The Supreme Court has just ruled in favor of the Anti-Prostitution Loyalty Oath (APLO), a provision in the 2003 United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act, that required all recipients of funding through the President's Emergency Plan for AIDS Relief (PEPFAR) to "have a policy explicitly opposing prostitution,'" writes Serra Sippel Bergen Cooper in the Washington *Blade*. Sippel is president of the Center for Health and Gender Equity (CHANGE), and Cooper is director of policy research at the organization. CHANGE is a human rights organization advocating for sexual and reproductive health and rights. **The pledge has been a thorn in advocates' side since the creation of PEPFAR in 2003.** Or as Sippel and Cooper note, "The APLO is and always has been a bad policy." The court ruling was made in July.

READ the opinion piece at washingtonblade.com/2020/07/17/anti-prostitution-loyalty-oath-undermines-hiv-fight. Learn more at srhrforall.org.

Long-time HIV advocates join U=U campaign

Three long-time HIV advocates have joined Prevention Access Campaign (PAC) to help promote PAC's Undetectable Equals Untransmittable (U=U) campaign.

Davina ("Dee") Conner has signed on as PAC's U.S. creative engagements and outreach specialist; Deondre B. Moore as U.S. partnerships and community engagement manager; and Esther Dixon-Williams, as coordinator of global affairs.

"Dee, Deondre, and Esther bring decades of collective experience and an understanding of communities that will strengthen our social and racial justice work," said Bruce Richman, PAC's founding executive director.

Cameron Kinker, who has been PAC's community engagement coordinator, will become the U.S. program and communications manager. Murray Penner remains as U.S. executive director, with Richman continuing to oversee the growing international campaign.

The full announcement is at bit.ly/pacstaff820.

Provider=Prevention for U=U

No matter the advances in HIV, stigma always remains a problem. Ironically, this applies to the medical profession as well.

But the medical profession confronts the issue. Researcher Sarah K. Calabrese, PhD, an assistant professor at George Washington University, in Washington, DC, and HIV specialist Kenneth H. Mayer, MD, of Fenway Health, in Boston, recently published a paper outlining stigma surrounding U=U in provider communications with patients. More importantly, **they created strategies to help health care systems fight stigma around HIV prevention**.

"U=U" is a community-driven campaign message spreading the word that "undetectable equals untransmittable." A person living with HIV is unable to transmit the virus to sex partners when their viral load is undetectable (under 200 copies) on stable therapy for at least six months and in the absence of any other STI. In medical terminology, this fortuitous by-product of successful HIV therapy is called "treatment as prevention" (TasP).

"There has been a notable challenge around consistently communicating the discovery that sustained viral suppression eliminates risk of sexual transmission (undetectable = untransmittable, U = U) to patients," Calabrese and Mayer wrote. "Failure to routinely incorporate U = U patient education into clinical practice is peculiar because the U = U message aligns with treatment goals. Moreover, it is providers' professional responsibility to inform patients of treatment risks and benefits. So why aren't these conversations happening? Although there are multiple contributing factors, including structural challenges that vary by setting (e.g., time limits on patient visits), we contend that stigma—that is, social devaluation based on one or more distinguishing characteristics—could be a key reason underlying the lack of consistent U = U patient education."

Some other considerations mentioned include lack of knowledge; fear of being blamed if transmission occurs; and concerns about risk compensation, the idea that people may take greater risks than they normally would.

ISTOCK

Calabrese and Mayer created four overarching categories for fighting stigma against U=U discussion:

1. **"Establish universal U=U patient education in normative guidelines dictating clinical practice**
2. **"Incorporate U=U into clinical education for all HIV service providers**
3. **"Facilitate patient-provider conversations about U=U with concrete tools**
4. **"Broaden public awareness through public health messaging"**

There are steps to take under each item along with informative messages. For example, establishing professional standards could indicate substandard care if the U=U message is not provided.

Public education is important because it can reach people who are not receiving medical care as well as those who have difficulty accessing it. It can also encourage some people to go see a doctor.

The authors also note that HIV treatment guidelines from the Department of Health and Human Services now expressly state that, "All persons with HIV should be informed that maintaining a plasma HIV RNA (viral load) [less than] 200 copies/mL … prevents sexual transmission of HIV to their partners."

It's a message that may not be heard above the stigma.

"It is not only the discretionary nature of U = U education as a clinical activity that renders it vulnerable to stigma; it is also the patient populations impacted and behaviors associated with HIV transmission that may be stigmatized in and of themselves," wrote Calabrese and Mayer. "Worldwide, people living with HIV have been mistreated in healthcare, facing providers who refuse to treat or provide substandard treatment. This is consistent with stigmatizing attitudes towards patients with HIV that providers have endorsed, including stereotypes related to sexual irresponsibility. Given the concerns related to risk compensation that providers have reported as reasons for not discussing U = U, these preconceived notions about patients living with HIV may reinforce existing concerns and potentiate stigma. People living with HIV who have other, intersectional marginalized statuses (e.g., men who have sex with men or people who inject drugs) may be more likely to be stereotyped as irresponsible or at risk, further exacerbating providers' concerns about the consequences of U = U discussions and fueling disparities."

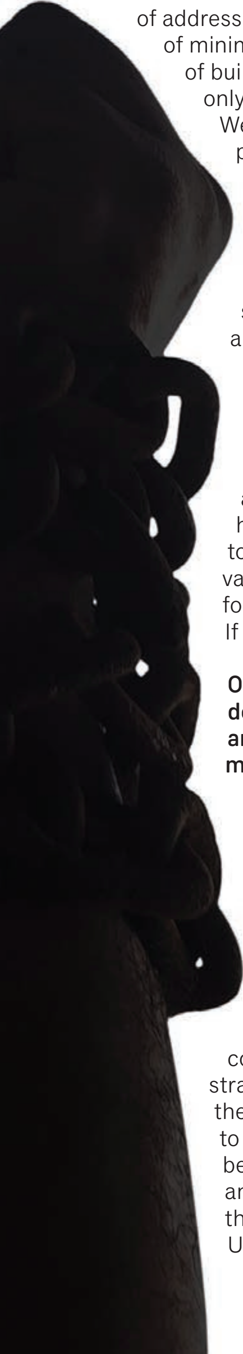
READ the article, including footnotes, published online July 19 in the *Journal of the International AIDS Society* at bit.ly/UequalsUstigmaJAIDSarticle.

What does Abolition have to do with HIV decriminalization and modernization?

Working to free us all

BY S. MANDISA MOORE-O'NEAL

For the HIV Decriminalization and Modernization Movement to win our demands, some of which we have been moving towards for over 30 years, every aspect of our work must be grounded in and relevant to our communities directly targeted by the Prison-Industrial Complex*. It is imperative that we be abolitionist in our analysis of our work and abolitionist in how we do and assess our work. We are in a particularly critical moment—where power and harmful systems for so many of us (from those of us just coming into justice work, to those of us who have been involved for some time, to those of us who have been involved in one sector and are now involved in other sectors) are much clearer and sharper than ever before.



While this may seem like a moment of immense despair and hopelessness, this is also a moment to center the radical imagination as we demand and dream that another world, another way of addressing violence, another way of minimizing harm, another way of building community is not only possible but necessary. We must learn to name in precise detail what needs to shift in our local, state and federal governments and private institutions and actualize what needs to exist instead. It may seem impossible or just a waste of time to move towards a world that does not punish people with cages and where all our communities have what they need, but we have to ask ourselves: what do we have to lose? Are we ready to align ourselves and our values with the movement for freedom and justice? If so, at what cost?

Our current HIV decriminalization and modernization movement

We know there is so much to highlight in our HIV decriminalization and modernization movement. From a necessary increase in Black and Latinx trans femme leadership, to many statewide coalitions working to strategically modernize their HIV criminal statutes, to necessary connections between HIV surveillance and COVID-19 surveillance, the "Undetectable Equals Untransmittable" (U=U) campaign is particularly insightful. Some state coalitions have been successful in using "U=U" data to modernize criminal statutes and public health codes. Others have used the data to grow bigger, more effective coalitions and community partners, as well as to educate People Living with HIV (PLWH) and service providers on HIV criminalization.

Are we prepared to abolish the police inside of us—
that voice, that socialization that screams at us to regulate, control what other people are doing—that threatens force when someone is perceived to fall out of alignment with the "norm?"

While the U=U campaign is necessary to the ongoing health and political education we all must engage in, as advocates who believe in justice, we should be wary of this and similar campaigns as the basis for broad-brush public policy for our decriminalization and modernization efforts. If we are advocating that people who are virally suppressed cannot transmit HIV and therefore should not be criminalized under existing statutes, we are implying that people who are not suppressed should be criminalized or should have to go through further scrutiny to avoid incarceration. Focusing on viral load as the dividing line for who can be criminalized deeply undermines our efforts. Not only does it highlight a viral divide, but it will ensure that division happens in alignment with the white supremacist cisheteropatriachal value of targeting those already with the least access to resources and systemic power, which is often the basis for the increased viral load in the first place.

Not only are there so many racial and class-based implications of who can achieve viral suppression—and is therefore worthy of praise and not punishment—it reinforces the HIV stigma and discrimination so many fight so hard against. It also reinforces the belief that some PLWH are "deserving" and others are "undeserving"—based on something like viral suppression that is often out of their control.

There are systemic barriers that are often the underlying reason for non-viral suppression. We cannot have a movement that blames the individual for not being able to "overcome" systemic and institutional barriers meant to see them fail. This is not to say U Equals U or other data-driven initiatives cannot be effective when PLWH are actually charged under these antiquated statutes or even that these campaigns don't have some place in our decriminalization and modernization efforts, but they cannot be at the center. What may be effective as an individual criminal defense strategy is not effective for policymaking that will impact thousands.

Oftentimes, our response is: we have to start somewhere. And that when we get this "win," we will come back for the people and experiences we left behind. History shows otherwise.

A close examination of state and municipal LGBTQ non-discrimination campaign efforts reveals that when short-sighted advocates pushed to expand rights of only gays and lesbians because that would be "easier" or "less-controversial" than including our transgender and gender-nonconforming siblings, it took decades, if it happened at all, to expand the laws and policies to include our siblings who should have been included all along. There were conscious decisions to leave out tens of thousands of our community, and our movements are still paying the cost.

Likewise, we cannot use what seems "winnable" in the moment to craft policies that continue to harm our communities. We actually have the skill and the fortitude to include all of our people—and if we believe we do not, then let's step aside for those who can do this vital work. We must create, push for, and build the necessary coalitions to create policy containers that take everyone at the same time. An abolitionist framework gives us the lens and shows us how to build the strategy to do so. >>

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* **The Prison Industrial Complex** (PIC) is a term used by abolitionist organizers, activists, academics, etc. to describe the overlapping interests of government and industry that use surveillance, policing, and imprisonment as solutions to economic, social and political problems. For more information on the PIC, please check out Critical Resistance, one of a few organizations doing critical work on this topic. The national office can be reached at 1904 Franklin Street, Suite 504, Oakland, CA 94612.

We cannot have a movement that blames the individual for not being able to 'overcome' systemic and institutional barriers meant to see them fail.

The necessity of an abolitionist framework

While much exists on abolition, Black feminist organizer, writer, and scholar Mariame Kaba defines it most effectively: "What is, so to speak, the object of abolition? ***Not so much the abolition of prisons but the abolition of a society that could have prisons**, that could have slavery, that could have the wage, and therefore not abolition as the elimination of anything but abolition as the founding of a new society.*"

Asserting that abolition is not only a political framework but an organizing strategy, Kaba makes it clear that abolitionist work cannot solely focus on prisons or the police, but must address the systemic causes that have created the carceral state. To be abolitionist in our work, we must commit to bringing our full selves to the work, including all our contradictions and the ways we perpetuate harm and wrongdoing, even when not our intention. An abolitionist framework requires that as we honestly assess ourselves, we take responsibility when we are in error and do the continual repairing work to prevent it from happening again. Abolition mandates that we look at all of society and move beyond the binaries—not just those in prisons or those who directly put people in prisons, not only at the victims and the perpetrators, but all of us because we are all participants in these systems. Rooted in the Black radical tradition and Black feminism, a contemporary abolitionist framework is necessary to HIV decriminalization and modernization work. This is because so much of our decriminalization work to date has focused on these absolute dichotomies (that we inherit from the dominant culture) that don't actually move us closer to actualizing our demands.

When we focus on transmission versus exposure, or contact from sex versus contact from needles, even those who are virally suppressed versus those who are not virally suppressed, we validate the idea that there are some People Living with HIV who deserve to be "punished" for their life circumstances and choices. We affirm that the complex lives that we live deserve to be reduced to the categories of "guilt" or "innocence," which is another way of determining who is "good" or "bad" and who is "disposable" or who is "worth saving."

We cannot ignore the reality that we live in a white supremacist society and in a white supremacist society, the notion of criminality, disposability and guilt will always maintain Blackness and those in the closest proximity to Blackness as culpable. Who is criminalized and policed via HIV exposure statutes is similar to who is criminalized and policed in other areas of our criminal legal system. We have to ensure that our efforts are not setting up those already targeted by this oppressive system to be further targeted by the criminal legal system overall. We did not "win" if PLWH are still targeted by the system, even if that system did not use an HIV-specific statute to do so.

An abolitionist lens to our decriminalization and modernization work means we must examine the ways we as advocates, providers, and community members participate in criminalization. We are not bystanders, helpless as police arrest our people and charge them under statutes that we know are unfair.

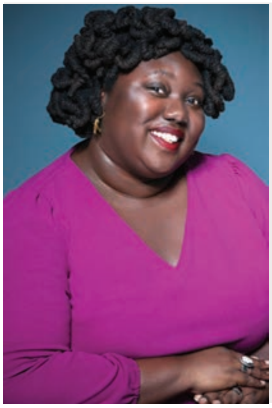
First, we have to take responsibility for the reality that HIV criminalization occurs not only when our community members are arrested. HIV criminalization occurs in the way we treat Black trans women in the waiting room, the way we partner with law enforcement even though we advertise a walk-up syringe access program or the way so many case managers are quick to get law enforcement involved in the lives of their clients instead of looking at other solutions to solve a problem. HIV criminalization occurs in the ways we criminalize poverty.

Since we all can participate in perpetuating this unjust society, we all must participate in the deconstruction of the injustice. In many ways, this demands a reckoning.

How many times have service providers been invested in getting law enforcement involved with their clients? Do our conversations around HIV criminalization include the ways that we criminalize our Black, Brown, trans, GNC, and working class clients just for existing? Are we prepared to have a deep conversation about the ways we uphold white supremacy by regulating and policing our Black clients, all in the name of "service provision?" Are we prepared to abolish the police inside of us—that voice, that socialization that screams at us to regulate, control what other people are doing—that threatens force when someone is perceived to fall out of alignment with the "norm?"

To honestly ask these questions and to honestly sit with our answers and most importantly to honestly shift our behaviors, policies, and procedures is a vital part of decriminalization and modernization work. It reminds us that change can happen and that we have the power to do it. It also builds the power we need to sustain the coalitions to modernize because we are no longer tokenizing people but engaging the fullness and complexities of who they are. Last, it deeply strengthens our strategies because we not only have a clearer sense of what we don't want, but a clearer sense of what we need in its place.

In summation, there is so much more to say about the necessity of an abolitionist framework for our HIV decriminalization and modernization efforts. May this be a small piece of the ongoing conversations and ongoing work necessary to stop the criminalizing of our communities and building the world we deserve to live in.



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Our Ending the Epidemic plan needs to invest in PrEP—and not just the cost of the pill

BY **GIFFIN DAUGHTRIDGE, M.D.** AND **JIM PICKETT**

BOWONPAT SAKAEW/ISTOCK

Ending the HIV Epidemic: A Plan for America (EHE) aims to end the HIV epidemic in the United States by 2030. Doing so requires a massive investment in HIV prevention efforts, largely focused on pre-exposure prophylaxis (PrEP), but this public health investment must support removing all the financial barriers to a patient being on PrEP, not just access to the medication.

Effective PrEP can be thought of as a three-legged stool. If any one of the three legs are missing, the stool falls over, and PrEP doesn't prevent HIV. The three legs are:

1. Uptake: getting people on the medication through affordable access, education efforts, and building awareness.

2. Adherence: ensuring the medication is taken consistently and correctly.

3. Persistence: ensuring the individual continues taking the medication consistently and correctly through their season(s) of risk.

To date, PrEP investments have largely focused on the Uptake leg, and this has limited PrEP's impact. The recent data on the Ready, Set, PrEP program reported at June's Presidential Advisory Council on HIV and AIDS (PACHA) meeting perfectly demonstrates this. Ready, Set, PrEP is a program set up by the pharmaceutical company Gilead Sciences and EHE to provide 200,000 free PrEP prescriptions to those who cannot afford it. At June's meeting, it was reported that only 891 people had received PrEP through the program in its first six months. A major reason why is that Ready, Set, PrEP only supports the Uptake leg of the stool, without addressing barriers to people staying on the medication, like the cost of required lab testing and clinical visits.

The slow uptake of Ready, Set, PrEP underscores the larger trend in PrEP adoption in the U.S. Since Truvada (FTC/tenofovir disoproxil fumarate) as PrEP got its Food and Drug Administration (FDA) approval in 2012, Gilead has provided access to PrEP free of charge for uninsured and underinsured patients through its Patient Assistance Program. However, only covering Uptake has led to fewer than 20% of the 1.2 million people in the country who the Centers for Disease Control and Prevention (CDC) says should be on PrEP actually taking it.

Though the PrEP drug itself (Truvada and Descovy [emtricitabine/tenofovir alafenamide] both have FDA approval for use as PrEP) is by far the most expensive element of being on PrEP (at over $20,000 per year), it is not the only cost. Being on PrEP requires a series of lab tests for HIV, sexually transmitted infections, and kidney function, which the CDC recommends be done every three months. For uninsured patients, those with a deductible or copay, or those whose lab is not in network with their insurer, these lab tests can cost the patient hundreds of dollars a year out of pocket, depending on the specifics of their plan. As a result, even though Ready, Set, PrEP, and Gilead's Patient Assistance Program are covering the Uptake leg, the PrEP stool is falling over, because patients aren't able to Persist on the medication due to these costs.

In other words, we have a drug that can prevent HIV, and we already have the political will to pay its substantial cost. **But we are failing to prevent HIV for the majority of people in this country who need it**, because we won't pay less than 5% of the drug's cost per year for lab testing.

The following three solutions could dramatically increase access to PrEP lab testing:

1. Guideline adoption and payer coverage: The United States Preventive Services Task Force (USPSTF) and CDC PrEP guidelines inform insurance coverage of lab testing. The USPSTF has given a comprehensive PrEP package—which includes the medication, clinical visits, and lab tests—an A grade, its highest recommendation. Typically, this means that insurers would then cover the medication and lab testing without copays. The advocacy work to ensure payers cover this comprehensive PrEP package is currently underway. UnitedHealthcare, one of the largest payer plans in the country, just announced they would be doing so, and it is critical that other payers follow their lead.

2. EHE and public health payments for lab testing: EHE and the CDC have extensive public health budgets for HIV prevention. This funding is often used for safety-net care for the uninsured. Allocating some of this funding specifically for PrEP lab testing could help ensure every patient has access to the tests needed to be on PrEP.

3. Expansion of payer networks with labs offering PrEP testing: Currently, LabCorp and Quest Diagnostics have a stranglehold on payer networks. Payers force patients to go to LabCorp or Quest Diagnostics, despite other labs offering a more convenient option to the patient. For example, Molecular Testing Labs (MTL) offers the entire PrEP panel in a self-collection format, which makes it easier for the patient and the provider, but MTL is blocked from getting in-network with many payers.

To truly end the epidemic, we must invest in paying for PrEP lab testing alongside our investments in the PrEP medications. Otherwise, our stool will never stand on its own, and PrEP will never live up to its potential to eradicate new HIV infections.

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Seeking protections for sex workers

Proposed legislation will address the harms of current laws

BY **ANNA FORBES**

In 1991, Ashunte Coleman was forced to leave her hometown of Canton, Mississippi. It meant leaving friends, quitting her gospel choir, no more playing tuba in the band—all because her mother was ashamed of her. Her family enrolled her in a Job Corps program in Kentucky to "get her life together." There, she got a GED and took courses in welding and culinary arts. Most importantly, she said, "I was finally able to live out my truth."

She met and bonded with two other transgender women, close friends who helped her get through her transition. Of course, they also experienced transphobia at Job Corps but, for the first time, Coleman didn't have to face it alone.

Job Corps ended after graduation, so Coleman went back home. Growing up, she was closest to her grandfather, her defender, and she frequently helped with loading her grandfather's truck every morning to ease him into his workday as a roofer. But, when she went back home after her transition, he no longer wanted her help, "looking like that." He gave her $100 and drove her to the bus station so she could get to the state capitol, in Jackson, where a friend had offered to take her in. The friend promised work for her there.

When she arrived, her friend told her to put on her sexiest clothes because they were going out. Coleman put on her "Daisy Dukes," sandals, jewelry and a blond wig and they went to a designated spot. Her first guy offered her $20 for oral sex. After she provided it, the man tried to grab her breast and realized she was transgender. Enraged, he grabbed a machete from the back seat and tried to kill her. Coleman fought her way out of the car, terrified and sobbing. Her girlfriend told her it's part of the game. "It's all about survival," she said.

After about six months in Jackson, Coleman moved to Florida, where she was arrested several times and ultimately sentenced to two and a half years in prison. In 1999, she experienced an epiphany, deciding that she would never again go through the abuses of prison, no matter what. Arriving home after her release, she found it empty, her former partner having taken all of Coleman's clothes, furniture and photographs, leaving her with nothing.

Sex work is one of the very few jobs available to someone with felony conviction. But this time Coleman chose to diversify. She found shelter in a halfway house and worked for Goodwill. Then, with her culinary training, she got some restaurant jobs. She trained as a Certified Nurse's Assistant—the first job, she said, that ever allowed her some weekends off.

Those Saturdays and Sundays were when she supplemented her income with sex work. Getting dates became easier and safer thanks to the internet. Online communication also introduced her to other people who were fighting for their rights as transgender women and as sex workers.

They helped her develop public speaking skills, to advocate for herself and bring her peers together to demand their rights. Today, Coleman works with SWOP/Tampa (Sex Workers Outreach Project/Tampa) and she founded LIPS-Tampa (Ladies Intervention Project for Success), to provide food, condoms, information and mutual support to Black transgender women and street-based sex workers.

Then, in April 2018, the U.S. Congress passed the Fight Online Sex Trafficking Act (FOSTA) and the Stop Enabling Sex Traffickers Act (SESTA). Both made sex work more dangerous by making it difficult or impossible for sex workers to screen clients online. While named to sound like a noble effort to protect people from sex trafficking, the acts haven't alleviated sex trafficking—they may have worsened the problem—and they put those who choose of their own agency to engage in sex work at much greater risk of harm.

Some HIV and human rights activists pitched in on sex workers' efforts to block FOSTA-SESTA, but it was not enough. The twin bills passed, making it very risky for sex workers to go online to screen potential clients, require photo IDs, confirm safe meeting places, and negotiate their terms (cost, condom use, etc.) before meeting—all steps that make sex work safer.

ASHUNTE COLEMAN

Driving sex workers offline and onto the streets —and then arresting them for carrying condoms there—has made sex work riskier and harmed HIV preventions efforts.

COURTESY OF ASHUNTE COLEMAN

Data from Seattle, Washington, DC, Phoenix and San Antonio show that, since FOSTA-SESTA, the number of street-based sex workers has at least tripled. With sex workers unable to negotiate online to require condom use and take other protective steps in advance of meeting clients, HIV transmission rates started to rise. In some jurisdictions, police arrest “suspicious” people carrying more than a few condoms, citing possession or more than a couple of condoms as proof of an intention to sell sex.

Driving sex workers offline and onto the streets—and then arresting them for carrying condoms there—has made sex worker riskier and harmed HIV preventions efforts.

SINCE 2018, the numbers have been climbing of sex workers doing business on the street, earning less money and facing higher risks from both police and violent clients. The women visiting LIPS-Tampa, Coleman said, are desperate for food, condoms, clean clothes and bus fare—anything to protect themselves and support their families. And when COVID-19 showed up, things got much worse.

Massage parlors and strip clubs closed. Sex workers, even those legally employed, are not eligible for unemployment compensation. Those with the resources and skills to earn a living via cam work have over-saturated that market. For others, getting work is a desperate catch as catch can. Sex workers rights organizations are now holding fundraisers all over the country. Along with harm reduction organizations, they are fighting an uphill battle just for sex workers’ survival.

For those old enough to remember it, this feels a lot like the early years of HIV in the United States when HIV was invisible to most people. The president didn’t mention AIDS publicly until 1987 and the Ryan White CARE Act didn’t pass until 1990, by which time 1 million people nationwide had been diagnosed with HIV.

A few years from now, COVID-19 may be a memory for most people. But sex workers will still be fighting an uphill struggle to overturn FOSTA-SESTA and get sex work decriminalized. But it has to be done and the trend is favorable: New Zealand has decriminalized sex work nationally, several other countries are heading in that direction and the move for decriminalization has grown in the United States in recent years.

After getting kicked in the teeth by FOSTA-SESTA in 2018, late in 2019 sex worker activists and their allies got Rep. Ro Khanna (D–California) and Rep. Barbara Lee (D–California) to introduce HR 5448, the SAFE SEX Work Study Act (an acronym for the SESTA/FOSTA Examination of Secondary Effects of Sex Workers Study, or SSWSA). The same bill was introduced in the Senate, (S 3165) by co-sponsors Elizabeth Warren (D–Massachusetts), Ron Wyden (D–Oregon) and Bernie Saunders (I–Vermont).

The SSWSA will help policy makers and legislators understand the effect that FOSTA-SESTA has had on the health and safety of persons involved in the domestic sex trade. When passed, it will fund research to document what happens when sex workers are deprived of the ability to use online harm reduction strategies, such as client screening, negotiation and information sharing. It will assess outcomes across populations and locations of barring the internet from sex workers as a legitimate tool of their work. Finally, the SSWSA will take a deep look at different sex worker subpopulations and the disproportionally high rates of violence and discrimination they experience.

We need to get SSWSA passed for the same reason we needed to get the Ryan White CARE Act (and lots of other HIV legislation) passed: because people are dying without it.

FOSTA-SESTA is our government telling us that sex workers’ lives are not worth protecting. Whatever stigma and loathing that we have been able to lift from the backs of people with HIV since the ’80s has now been shifted onto the back of sex workers—the pariahs du jour.

The HIV world, of all people, should not tolerate this. As Coleman puts it, “My life has already been hard...trying to survive in this world. We need [SSWSA] just to be safe. We’re human, too.”

ANNA FORBES has been working in HIV since 1985. A writer and consultant, her primary focus now is on integrating sex workers’ rights into our current HIV response.

This commentary originally appeared on poz.com.


LIVE LIFE
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NEW HORIZONS
HIV DRUG GUIDE

When pandemics collide

International AIDS conference looks at the intersection of HIV and COVID-19

BY **ENID VÁZQUEZ**

A WOMAN WALKS PAST GRAFFITI PAINTED BY THE WACHATA ARTISTS GROUP TO RAISE AWARENESS ABOUT WEARING MASKS TO AVOID COVID-19 IN THE TANZANIAN CITY OF DAR ES SALAAM.

PHOTO: ERICKY BONIPHACE/AFP

Like other important HIV conferences this year, the international AIDS meeting took place remotely via internet due to the world's COVID-19 shutdowns. Appropriately, **AIDS 2020: Virtual** opened with global health leaders presenting information on how the new COVID world order was affecting HIV prevention and care.

"These are remarkable times—and defining times—for the global HIV movement and for the world. Every conversation we have now sits at the confluence of the COVID-19 pandemic and a new global reckoning with systemic racism," said Anton Pozniak, president of the International AIDS Society President (IAS) and International Scientific Chair for the conference.

HIV in a COVID world

According to a survey from the World Health Organization (WHO), 73 countries reported that they were at risk of running out of HIV drugs due to the COVID pandemic; 24 of them were critically short. UNAIDS estimates that a six-month disruption of access to HIV antiretrovirals could lead to a doubling of AIDS-related deaths in sub-Saharan Africa this year alone.

WHO reported that the 24 countries running critically short represent one-third of all people on the planet living with HIV, and 8.3 million individuals taking antiviral medications.

UNAIDS issues a global report on the HIV epidemic at every international conference, titling this year's release, "Seizing the Moment: Tackling entrenched inequalities to end epidemics."

"**The report shows remarkable but highly unequal progress around the world**, most of the progress being in expanded access to antiretroviral therapy," said UNAIDS Executive Director Winnie Byanyima. "But because the tremendous achievements that have been made have not been shared equally within countries and between countries, our targets for 2020 will not be reached. We have work to do."

She was referring to

the UNAIDS goal for 2020, known as “90-90-90”—90% of all people living with HIV would know their status; 90% of those would be on HIV medications; and 90% of those would have undetectable viral load.

WINNIE BYANYIMA

“We were already off-track to achieving our HIV goals, but now coronavirus is really blowing us completely off-track,” Byanyima said.

The 1.7 million new HIV infections last year was three times higher than the hoped for lower number of 500,000, and was driven by human rights violations, she said.

“This is about men who have sex with men. This is about sex workers, gay men, prisoners, people who inject drugs—these are people whose rights are denied, basically,” Byanyima said. “And it is about lifting the human rights violations and restrictions on them. ... We need political will, to remove those barriers. In at least 73 countries we have laws that criminalize same sex relationships. In 160 countries we have laws that criminalize personal drug use. So we need to see progress there.”

The comprehensive 400-page report covers statistics, strategies to address the epidemic (such as ensuring gender and sexual rights), and goals for ending HIV.

This year’s report includes a section about COVID-19, and ways to help people living with HIV in light of the pandemic.

The organizer of the conference, the International AIDS Society (IAS), issued its own report, “COVID-19 and HIV: A Tale of Two Pandemics.” According to the report, “COVID-19 is impacting the HIV response in three key ways. First, the shift of health system resources to focus on COVID-19 and national lockdowns has severely affected HIV treatment and prevention services, including interrupting care and increasing obstacles to accessing treatment, clinical services, and psychosocial support. Second, COVID-19 has exacerbated challenges for people living with HIV and key populations who are experiencing renewed stigma, with evidence of increasing vulnerability to HIV in the lesbian, gay, bisexual, transgender, and intersex (LGBTI) community. Third, the COVID-19 pandemic is highlighting existing system-level weaknesses in healthcare and supply chains, adversely affecting people living with HIV.”

The report outlined 10 recommendations for adapting HIV care to a COVID world, such as alternative ways to refill medications. There were also 10 recommendations for implementing COVID-19 care based on the HIV experience, such as addressing stigma, social justice issues and stigma in health care, and securing political commitment to evidence-based knowledge.

LGBTI vulnerability

“We know that the COVID-19 crisis is amplifying and exploiting [areas] where there are fragilities,” said UNAIDS Senior Economist Erik Lamontagne, “so we aimed to give a voice to, and understand the impact of, COVID-19 on one of the communities most stigmatized and disproportionately affected by HIV—lesbian, gay, bisexual, and transgender people.”

UNAIDS brought together a group of scientists and community activists to create an online survey in 10 languages, conducted from mid-April to mid-May. At the time of IAS, more than 20,000 LGBTQ people from over 130 countries had responded. Seventy-five percent of respondents reported being partially or totally confined to their homes due to COVID-19 lockdowns.

“About 12% of the respondents were living with HIV,” said Lamontagne. “The good news is that 72% of people living with HIV retained access to their lifesaving HIV treatment. However, 21%—a fifth—reported that because of the lockdown and the restrictions on movement, they had limited access to ART, and furthermore, 7% are at risk of running out of HIV treatment because they cannot access or refill it. And we also found that LGBTI people who were from racial or ethnic minorities face systematically lower access to HIV services.”

The survey showed that 13% of respondents had lost their job due to the pandemic, and 20% were at greater risk of losing employment.

YOUNG GAY MEN AND OTHER MSM AGED 15–24

are at particular risk in high-income countries of western and central Europe and North America, accounting for

36%

of new diagnoses in those regions

“A quarter of the respondents also say that they had started to cut meal sizes or skipping meals because there’s not enough money for buying food due to the COVID crisis,” said Lamontagne. “We also found that sudden change in income has induced behaviors that increase susceptibility to HIV infection. For example, 1% reported they had started sex work due to COVID-19 crisis. And for those engaged in sex work, the economic instability lowered their negotiating power with clients. As a result, 4% have been engaging in riskier sex and 1% engaging more in condomless sex.

“The take-home message here is that COVID increases the vulnerability of groups that are already disproportionately affected by HIV,” Lamontagne said in

BYANYIMA: UNAIDS/R. JUILLIART • COUPLE: UNAIDS

DEMONSTRATION LAST MARCH ORGANIZED BY HOLLABACK! JAKARTA. SEXUAL HARASSMENT AND OTHER FORMS OF GENDER-BASED VIOLENCE REMAIN A SERIOUS ISSUE FOR WOMEN IN INDONESIA.

UNAIDS PHOTOS

conclusion. “It exacerbates the inequality, so targeted interventions are required from community networks as well from the governments to help the LGBTI community not only to survive but emerge from the crisis.”

Asked about a potential lull in HIV transmissions due to social distancing required with COVID-19, Lamontagne said that social distancing may lead to less contact, but at the same time, there is another risk. The inability to access medication may move people from HIV to AIDS.

He then used the question to address stigma. “One of the challenges, I think, as health care providers and health care organizations, is that **it’s important that we don’t stigmatize people, people who might be engaging in sexual behaviors during COVID-19**, so that they won’t feel ashamed to come forward and request PrEP and STI testing, for example, HIV testing. This is an issue in general in terms of stigma with HIV and PrEP care, but I think it can be exacerbated if the message is that you should be ashamed for engaging in sexual contact at a time when people are experiencing tremendous social isolation. And of course, sexuality is an intrinsic human quality and people have the need to connect with other people. So, I hope that the messaging can be open and non-judgmental to people, that to the best of our abilities we’re creating a safe environment among providers and facilities for people to come in for preventive sexual health care.”

PrEP disruption during COVID

As the new coronavirus has hurt HIV treatment, it also hurts HIV prevention. Boston researchers looked at the effect of the COVID-19 outbreak on HIV pre-exposure prophylaxis (PrEP).

“As we know, COVID-19 has disrupted health care globally, which could create important barriers to PrEP-related health care efforts to control the HIV epidemic,” said Douglas Krakower, MD, of the Division of Infectious Disease Faculty, Beth Israel Deaconess Medical Center and an adjunct faculty member at The Fenway Institute, Boston.

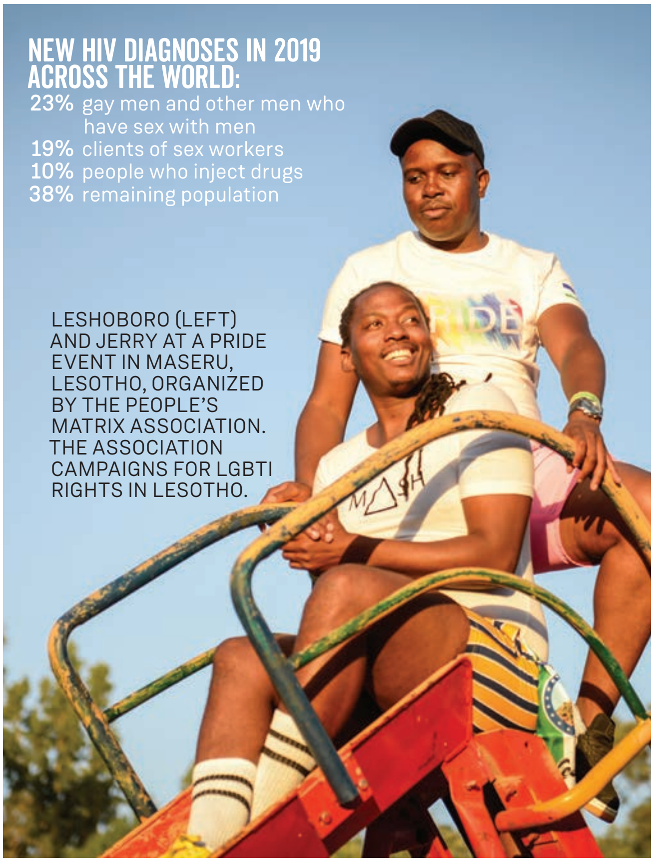
COVID-19 first emerged in Boston in March, followed by a large surge of new cases in April.

“The setting for our work was Fenway Health, which is a community health center that specializes in LGBTQIA+ health care research and education, and is the largest provider of PrEP in all of New England,” said Dr. Krakower. “What we did is extract electronic health records data of Fenway patients from January through April 2020 to characterize a number of aspects of PrEP-related health care, including PrEP refill lapses, which we define as not having a PrEP prescription refill before the end of a prior prescription; new PrEP starts; testing for HIV and sexually transmitted infections; and use of telehealth medicine.”

The study cohort included 3,520 PrEP patients. The average age was 37. Most, 73%, were White, with 14% identifying as Hispanic, 6% as Black or African American, 6% as Asian, and 4% as multiracial. The vast majority, 92%, identified as cisgender men. The majority, 86%, also had private insurance; the remainder had public insurance.

“In terms of our main findings, we found that PrEP refill lapses increased by 191% from January to April 2020, with 140 such refill lapses in January and 407 as of April. New PrEP starts decreased significantly, by 72% from 122 new starts in January to only 34 in April at the peak of the surge,” Dr. Krakower reported. “HIV testing also decreased substantially, by 85% with 1,014 tests conducted in January and only 151 in April. There was a single positive HIV test in this four-month period and that occurred in January prior to COVID. Gonorrhea and chlamydia testing also decreased by the same degree of 85% and positive tests decreased by 81% from 130 positive tests for gonorrhea and chlamydia in January and 25 in April.”

The study found important discrepancies



NEW HIV DIAGNOSES IN 2019 ACROSS THE WORLD:

- **23%** gay men and other men who have sex with men
- **19%** clients of sex workers
- **10%** people who inject drugs
- **38%** remaining population

LESHOBORO (LEFT) AND JERRY AT A PRIDE EVENT IN MASERU, LESOTHO, ORGANIZED BY THE PEOPLE’S MATRIX ASSOCIATION. THE ASSOCIATION CAMPAIGNS FOR LGBTI RIGHTS IN LESOTHO.

by demographics. As Dr. Krakower reported, “We found that PrEP refill lapses were more common among patients that were under the age of 26 vs. over the age of 26; more common among those identified as racial minorities vs. White; more common among those identified as Hispanic vs. non-Hispanic; and more common among those with public vs. private health insurance.”

Similar to other IAS reports regarding clinical care, Fenway responded quickly in the face of coronavirus. “We observed a near complete shift to telehealth quite rapidly, with none of the visits at Fenway being conducted by telehealth in January or February and 98% as of April.”

“Our major conclusion based on these data is that COVID-19 was associated with major disruptions in PrEP health care at our health center despite a very successful pivot towards telehealth quite rapidly,” Dr. Krakower said. “A really important limitation of this study is that we could not ascertain sexual behaviors or pill-taking behaviors using the structured electronic health data we had.”

Additional study is needed to assess changes in adherence to prevention, with particular attention paid to the most vulnerable populations, said Dr. Krakower.

“In terms of the ethnic disparities, I think we need to learn more about the individual level, why people might be having PrEP refill lapses,” Dr. Krakower responded when asked about the discrepancies by race and ethnicity. “Are they facing economic vulnerabilities that make it challenging to continue with things like copays or other financial characteristics? Were they too scared to come into the health center for fear of exposure to COVID-19? Were there changes in sexual behaviors? We really need to dig in deeper, which are our plans for our future studies.”

EASTERN AND SOUTHERN

AFRICA

is the region of the world that’s seen the most rapid decline of AIDS-related deaths between 2010 and 2019:

-49%

TWALIB ABDUL
IS A PEER EDUCATOR
LIVING WITH HIV IN
DAR ES SALAAM, TANZANIA

UNAIDS/D.MSIRIKALE

Clinical advances

LEAVING BEHIND struggles with COVID-19, there was a lot of great news for HIV treatment and prevention presented at AIDS 2020: Virtual.

PrEP injectable CAB-LA

An injectable drug in development for HIV prevention was reported to be 66% more effective than a prevention pill already on the market.

That may not be saying much, however, since the other drug is already highly effective at preventing HIV. But as a new drug that’s both highly effective and taken very differently, it could make a huge difference in fighting HIV.

“The context of this study is that despite remarkable efficacy of daily oral TDF/FTC [Truvada] to prevent HIV infections in diverse transmission contexts and populations, its public health impact has not delivered uniform benefits to all populations,” said Raphael Landowitz, co-director of the UCLA Center for Clinical AIDS Research and Education (CARE). “Those disproportionately affected by HIV are the same populations that have not found equal access, uptake, adherence, and persistence to oral tablets for pre-exposure prophylaxis [PrEP].”

The HPTN 083 study compares long-acting injectable cabotegravir (CAB-LA) to Truvada for PrEP. The injectable is given as one shot every eight weeks. Truvada for PrEP, which was FDA approved in 2012, is taken as one tablet daily.

Dr. Landowitz said the trial efficacy statistics are “definitively establishing superiority of cabotegravir compared to TDF/FTC.

“Unfortunately, due to delays in complexity and sample shipping and laboratory activities in the setting of global SARS-CoV-2 pandemic, I do not have drug concentrations nor resistance testing results from any of the incident or prevalent infections found in HPTN 083 here to present to you today," Dr. Landowitz reported.

There were 52 HIV infections—13 in the CAB-LA group and 39 in the group taking Truvada. This represented an HIV incidence rate of 0.41% for CAB-LA, and 1.22% for Truvada.

"That's 66% fewer HIV infections in the participants receiving cabotegravir compared to those receiving TDF/FTC," said Dr. Landowitz.

More than 4,570 participants are in the study, from 14 trial sites around the world.

"Of the 13 HIV infections diagnosed in participants in the cabotegravir arm, five were diagnosed after a prolonged hiatus from cabotegravir treatment, three were diagnosed during the oral lead-in period, and five acquired HIV despite—as far as we're able to ascertain—good oral lead-in adherence and on-time cabotegravir injections," said Dr. Landowitz. "The cabotegravir concentrations that were associated with these specific infections are particularly critical to understand."

The clinical trial enrolled a diverse population of cisgender men and transgender women who have sex with men. Two-thirds of participants were under the age of 30. Nearly 13% were transgender women. Half of the participants from the United States identify as Black or African American. Study sites were in North and South America, Asia, and Africa—Argentina, Brazil, Peru, South Africa, Thailand, the U.S., and Vietnam.

HPTN 083 protocol co-chair Beatriz Grinsztejn, MD, PhD, said, "A long-acting injectable for PrEP that does not require adherence to an oral daily pill is a great addition to the HIV prevention toolbox. Prevention strategies have never been one-size-fits-all."

Responding to the study's report, Mitchell Warren, executive director of the HIV prevention advocacy group AVAC, said in a press release, "We need options that will work in people's lives, we need existing daily PrEP delivered at scale now, and we need multiple additional PrEP options to address diverse needs. CAB-LA, the dapivirine vaginal ring, and future products that show efficacy must be brought to market as quickly as possible."

A sister study, HPTN 084, is looking at CAB-LA vs. Truvada in women and adolescent girls. Long-acting injectable cabotegravir is also being studied for HIV treatment with long-acting injectable rilpivirine (see *Briefly*, page 7).

Another cure?

A Brazilian man appears to be the first adult to achieve long-term remission of HIV without first having received a bone marrow transplant. The case raised the possibility of a cure.

At the time of the IAS report, the man had been in remission for 64.7 weeks. He was off treatment for that time and HIV could not be found.

The man was diagnosed with HIV in October of 2012. Two months later he went on HIV treatment with TDF/FTC/EFV. The triple-drug combination available in one pill taken once a day is available under various brand names in other countries. (There are similar drugs available in the U.S., of which Atripla comes the closest.) He achieved and has maintained an undetectable viral load since then.

At the time of his diagnosis, he had a CD4 T cell count of 372 and a viral load of 20,221, indicating that he had a chronic (not recent) infection.

In this cure clinical trial he was one of five individuals whose HIV therapy was "intensified." Participants were also given 500 mg nicotinamide (NAM), a form of vitamin B3, twice a day. He continued taking his antiviral treatment, but with the NAM and the HIV medications dolutegravir and maraviroc added to his regimen.

In brief, NAM is a compound with anti-latency properties for HIV—it helps flush HIV out of hiding places (latent sites) in the body, where medications can't "see" it and thus destroy it. It also boosts the immune system. It can, however, be toxic, so don't try this on your own.

Maraviroc was used because of its potential anti-latency properties as well.

The Brazilian patient stopped all therapy on March 28, 2019 as part of an analytic treatment interruption (ATI). He had tested undetectable for HIV DNA in his peripheral blood mononuclear cells (PBMCs) before his ATI. HIV DNA had tested low positivity at baseline and at 48 weeks for his PBMCs and rectal biopsies.

As of February 3, 2020, results of his EIA test (also known as an ELISA test) remain negative. The test looks for HIV antibodies, the body's immune response to the virus. Basically, he's testing HIV-negative. Other measures also indicate that he's in remission for HIV.

His last viral load as of the time of the conference was on June 22.

Information on other participants in the study was not provided, but they did not achieve the same results.

Dr. Ricardo Diaz of the Federal University of São Paulo presented the report.

Press conference moderator Monica Gandhi, MD, MPH, of the University of California, San Francisco, noted that data are needed for more than one patient in remission, that this patient needs to be followed longer, and that it would be good to know how long he had been infected with HIV.

Dolutegravir for pregnancy

There was relief at the latest news about birth defects previously observed with the HIV medication dolutegravir (DTG). In the latest analysis, dolutegravir was not associated with an increased risk of neural tube defects (NTDs), which are birth defects of the brain, spine, or spinal cord.

Two earlier reports had shown an increased risk of neural tube defects when using dolutegravir around the time of conception compared to other antiretrovirals. Now, more data after a longer period of time were able to demonstrate that the risk was not greater.

Furthermore, the risk was stabilizing to a rate equal to that of the other antiretrovirals.

Dolutegravir is a first-line HIV treatment for pregnant women in guidelines from WHO and the U.S. Department of Health and Human Services (HHS).

The data came from the observational Tsepamo study in Botswana, a large birth outcomes study that began in 2014, funded by the U.S. National Institute of Child Health and Human Development (NICHD).

"In May 2018, Tsempamo first reported a preliminary safety signal associating neural tube defects with exposure to dolutegravir at conception," reported Rebecca Zash, MD, of Beth Israel Deaconess Medical Center in Boston. "At that time, we had found four neural tube defects among 426 women taking DTG at conception, a prevalence of almost one neural tube defect per 100 births, which was way higher than the expected prevalence of one neural tube defect per 1,000 births, and also significantly higher than all the other comparator groups, which included women on other non-dolutegravir ARTs at conception, women specifically on efavirenz at conception, women who started their dolutegravir during pregnancy, and women without HIV.

"These preliminary findings led to warnings from FDA [U.S. Food and Drug Administration] and EMA [European Medicines Agency], and stalled the plan for a roll-out of DTG and really adversely impacted treatment options for women living with HIV around the world," said Dr. Nash.

"At IAS in Mexico City last year," she continued, "Tsempamo reported out updated analysis using data from the beginning of the study through March of 2019 with a total of 5 neural tube defects in 1,683 exposures to DTG at conception a prevalence of .3%, or about 3 neural tube defects per 1,000 births. And although this was much lower than the initial report it still remained higher than the comparator groups. The Tsempamo study continued, so now we're able to report on 13 additional months of data with a total now of more than 158,000 births up through April of 2020.

"Since March 2019 we had two more neural tube defects among 1,908 additional exposures to dolutegravir at conception, for a total prevalence of 7 neural tube defects in 3,591 DTG conception exposures, a prevalence of 0.19%. And if you look at how the prevalence of DTG changed over time, after a period of decline since the original safety signal in May 2018, the prevalence of neural tube defects among infants born to women on dolutegravir conception appears to be stabilizing, right around two NTDs per 1,000 births. And it's really only about 0.1% higher than women on efavirenz at conception and women without HIV," Dr. Nash said. "This small absolute increased risk of NTDs is usually far outweighed by the potential benefits of DTG and our continued reassuring data should allow for broader use of DTG in women."

In response to a question about supplementation with folate, Dr. Nash said, "I think folate supplementation is a no-brainer. If we care about preventing neural tube defects, we know that supplementing with folate, especially putting it into food, so that everybody gets it preconception, will reduce neural tube defects by at least 50%. So that needs to happen everywhere. We've been a huge advocate for that. It's been really slow to develop in a lot of countries."

She also noted the problem of excluding pregnant women from studies. "I think if there's really one thing that Tsempamo and the DTG story has taught us is that women aren't a niche population in HIV. They make up half of the people living with HIV and maintaining gender equity in HIV treatment outcomes really requires pregnancy safety data. This is an important lesson not just for future HIV treatments like two-drug therapy and long-acting injectables and bNABs, but also for coronavirus, which also impacts women of reproductive age, and if we don't include pregnant women in therapeutic and vaccine trials for COVID-19 we really aren't protecting women. We're failing them."

Making PrEP delivery easier

"Oral PrEP is highly effective for HIV prevention, but we need better lower-barrier approaches for delivery in sub-Saharan Africa," said Catherine Koss, MD, of the University of California, San Francisco.

Rather than wait for people to come to a clinic for PrEP, the SEARCH study research team used community-based HIV testing fairs to offer the prevention pill to those they considered at greatest risk for acquiring the virus.

"HIV testing is the entry point for PrEP and community-based HIV testing is an alternative to testing in health facilities that is more accessible for groups like young adults," said Dr. Koss. "Community testing can also provide an opportunity to offer and engage people in taking PrEP. We offered a low-barrier model for PrEP delivery during community-wide HIV testing in 16 communities in the SEARCH study in rural Kenya and Uganda.

"To do this we offered universal access to PrEP. We have **an inclusive approach to PrEP eligibility** for individuals in sero-different partnerships, those identified by an HIV prediction tool, and those who self-identify as being at risk for HIV. We provided same-day PrEP start on site during the community-wide testing at health fairs and then we provided a flexible care delivery model with follow-up visits at clinics or community-based sites where people could receive repeated HIV testing and PrEP refills."

Of 74,541 people who tested negative, a little over 15,000 were estimated to be at elevated risk for HIV.

Of these, 5,447 (35%) started PrEP.

This group experienced a 74% reduction in new HIV infections compared to a matched control group not taking PrEP. There was, however, a 76% reduction in incidence among women vs. a 40% reduction in incidence among men.

"We think that these results show that in generalized epidemic settings, offering universal access to PrEP can reduce HIV incidence," said Koss. "And moving forward, having comprehensive HIV testing with linkage to treatment and prevention, including PrEP, with flexible service delivery, is a promising approach to accelerate reductions in new infections."

Koss was asked about the incidence difference between men and women.

"In terms of the reductions in incidence that we saw among women," she replied, "we think that this really adds to the accumulating evidence from open label studies that PrEP is effective, that it works for women, and that women want to take it. So, this adds to the data that says PrEP works. We found that among men there were only eight seroconversions, so we saw a reduction in incidence that was not statistically significant, potentially due to limited [statistical] power to detect a difference there. We may have actually seen less of a difference in incidence in men because of a slightly lower PrEP coverage in that group, when we look at how people followed up for refills and reported adherence over time. We think, finally, that having a flexible model for PrEP delivery in this case may have also helped, and allowed women to match periods of PrEP use with periods of risk. We found that many individuals—far more than half—in this study stopped PrEP use at some point during the study, and half of them restarted PrEP. So that flexibility may have been important as well in the incidence results we saw."

GO TO positivelyaware.com/aids2020topnews for more conference coverage.

IN 2019, MSM MADE UP

40%

of new HIV cases in Asia, the Pacific, and Latin America

64%

in western and central Europe, and North America

Highlights from the HIV cure pre-conference

BY **KARINE DUBÉ**

The International AIDS Society (IAS) held a virtual pre-conference meeting titled **Pathways to an HIV Cure: Tools for Community and Clinicians**, held July 1–3. The meeting focused on research developments, challenges of HIV cure clinical trials, and strategies for low and middle-income countries. Following are a few highlights.

Michael Louella from the defeatHIV Collaboratory Community Advisory Board in Seattle, Washington, discussed the need to **better understand community attitudes and values to achieve an HIV cure**. Louella recommended moving from a deficit approach to an asset approach that starts with meaningfully engaging the community. Louella added that it will be critical to understand the perspectives of HIV care teams in the search towards an HIV cure.

Dr. Jillian Lau from the Alfred Health and Monash University in Australia discussed **community and clinician perspectives around HIV treatment interruptions**. Dr. Lau recently completed a global survey on attitudes towards HIV treatment interruptions in people living with HIV and HIV care providers. Dr. Lau emphasized the need for targeted educational and community engagement materials. Barriers to HIV cure research participation—such as risk of transmission, and PrEP provision and counseling for sexual partners—will also need to be addressed.

Dr. Sarah Fidler from the Imperial College London reviewed challenges in HIV cure clinical studies. An important challenge will be **determining when will it be considered safe to resume clinical studies given the ongoing COVID-19 pandemic**. Dr. Fidler's recommendations were to exclude participants who have a potentially increased risk of severe COVID-19 disease (e.g. diabetes, high BMI and older age). Dr. Fidler also emphasized the important role of community consultation in defining acceptable clinical trial parameters during the COVID-19 pandemic to reduce unnecessary risks and burdens.

Professor Sharon Lewin, director of the Peter Doherty Institute for Infection and Immunity in Australia, and **Dr. John Frater** [from Oxford University, England, squared off in a debate titled, *Gene Therapy versus Immunotherapy—Which is More Likely to Work?* Dr. Lewin presented **five arguments for gene therapy**: 1) studies should be aimed at complete elimination of HIV in the body—not remission; 2) there is proof of concept for the elimination of the CCR5 towards an HIV cure—with the Berlin Patient, Timothy Ray Brown and the London Patient, Adam Castillejo; 3) there are multiple gene therapy candidates in the pipeline; 4) the potential for ease of delivery; and 5) improvements in reducing complexity, toxicity, and cost of gene therapy approaches. Dr. Frater presented the argument towards immunotherapy, or drugs that could enhance the immune system. Examples include broadly neutralizing antibodies (bNABs) and chimeric antigen receptor (CAR) T cells. Immunotherapy could be used in thousands (or even millions of people), is relatively safe, and could eventually allow people living with HIV to stop their antiretroviral therapy and stay well.

Dr. Thumbi Ndung'u from the Africa Health Research Institute (AHRI) in South Africa provided an overview of **HIV cure research relevant to resource-limited settings**. HIV cure research will need to include high-burden settings in the future. Further, the need for a cure is justified by the high incidence of HIV and presence of significant HIV-associated multi-morbidities, such as cardiovascular disease, metabolic disorders, neurocognitive abnormality, and malignancies. Promising HIV cure strategies in development include early treatment, immune modulation, gene editing, and combination approaches. Dr. Ndung'u and **Dr. Steve Deeks**, professor of medicine at the University of California San Francisco (UCSF), announced a new initiative with the Bill and Melinda Gates Foundation aimed at developing a target product profile (TPP) to guide the development of HIV cure strategies relevant to low- and middle-income countries and align stakeholders in defining acceptable HIV cure research regimens. An ideal HIV cure product should be safe and effective (comparable to, if not better than, antiretroviral treatment), scalable and affordable, able to prevent re-infection, and work in all populations.

KARINE DUBÉ is an assistant professor at the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. She is a socio-behavioral scientist focused on integrating a patient/participant perspective to HIV cure-related research.

PLAGUE YEARS

A doctor's journey

INTERVIEW BY **JEFF BERRY**

Ross Slotten, MD, is a family practitioner specializing in the care of people with HIV and AIDS. Dr. Slotten has been a frequent contributor to POSITIVELY AWARE, most recently in the 2020 HIV Drug Guide. He's also been my physician for the last 25 years. I talked with him about his new book, *Plague Years: A Doctor's Journey through the AIDS Crisis*.

JB: How did this book come about?

RS: Well, this book has been forming for 40 years, believe it or not. Not that I really intended to write a book, but I kept journals early on. And then many years after dealing with HIV, I thought maybe I would write something, but I really couldn't do it because I was too emotionally close to this. Especially in the '80s and '90s when people were dying. I can keep a journal, but I couldn't actually write a coherent book. A number of years passed before I felt that I could be more objective, because it was really in the last 15 years or so that I've had no one die of HIV. I feel like I had more distance. I thought it was important timed right now, because I thought that the younger generation didn't really know what it was like to go through this. And like the holocaust, it's something that has to be memorialized.

You mentioned your journal. I think all of us who have read the book and hopefully will be reading the book, are very grateful that you did that. Was that a conscious decision?

I like to write, that's one thing. I like to channel anxieties, stress, frustrations, to sort of record. I didn't really have something primary in mind when I kept them. I didn't keep them all the time—it was intermittent. But they turned out to be immensely useful to me today, because so many years have passed since I've had those experiences, that I can't remember them, it's very difficult. But the journals brought them back to life.

They sure do. Some of the passages are so descriptive and detailed, I felt like I was taken back to that time. I remember back in those days going to the 11th floor at St. Joseph's [Hospital] when you were a physician there, and visiting friends, particularly one friend, who may even have been your patient,

through the AIDS crisis

ERIC HERZOG

who was very sick. We probably crossed paths at that time, before you became my physician. What was the writing process like, and how did it feel to write that way?

It was painful. It was painful to go back and remember that, so immense sadness. But I thought it was still an important story to tell. I can't say that I was depressed as I wrote this, but I would say as I reflected on the stories that I was relating, it was very sad. I wrote about people I knew very well, some friends, who went through this. It was very cathartic in a way, to work through that. My friend Neal, who was my roommate in college, we never really had closure with this. I mean he died. I found out through his mother that he died, so we never really got to say goodbye. I didn't know he was even ill, until that very end. He hid everything from me. So it was a way, in my own mind, to close that part of my life, but it was hard, it was very challenging. There were so many stories I didn't tell and things that I took out. But again, it's a creative process.

And it's interesting too, because it chronicles a lot of the history of AIDS in Chicago during that time. There are a lot of people in the book with only first names, but I know who you're talking about, so it's a fascinating look at the history. And I got a personal side of you that I've never really known. We've been friends, and I've been your patient, you've been my doctor—I hate that word patient...

So do I [laughs], I hate that.

After all these years, I was like—you forget sometimes when you're in that kind of relationship, that there's a person behind that. You were a gay man coming to terms with your sexuality prior to and during the AIDS crisis, and this was all happening for a lot of other people too.

Well, it was a hard time because being gay was not looked at in a very good way. So dealing with that and on top of it all a horrible disease comes along, and people who are very private are suddenly outed, in a way that they didn't plan. My journey was a lot like that journey too. It was hard to write about that aspect of myself because I'm a pretty private person, but I thought it was important to use myself as a vehicle to help people understand what this crisis was—or is—still. Who I am as a person doesn't really matter to the greater world, but I think in terms of a story about AIDS it was important to show that side of me, even though it was very difficult, and embarrassing to some degree, in some ways.

Yes, you're very candid, refreshingly so I would say, but you're also very straightforward. It's very personal but also educational, and heart-wrenching at times. I would point out to folks that this book was written and came about before COVID. How do you feel about that?

I'll tell you, first of all, the book had an unintended message to it, which COVID has brought to the forefront, and the message is that we will get through this. We found a way—I mean obviously we haven't solved HIV, but we found a way for people to live normal lives. We didn't see that as it was happening and going on; it took a long time to get there, but we got there. And we'll get through COVID in some way. So the book ends with a positive message, but I think the COVID pandemic deepens the meaning of the book.

Definitely, and I think you kind of have that way with people, you have a positive outlook. I will just say, a good bedside manner.

Thank you, I appreciate you saying that—I try my best!

I wrote about people I knew very well, some friends, who went through this. **It was very cathartic in a way, to work through that.**

You say in the book that you actually took a writing course. Can you talk a little bit about that, because I think it changed how you approached the book.

I didn't mean for it to be a memoir initially. I just started writing a book—I wouldn't say academic, but more medical. A friend of mine is a friend of an editor at the *Journal of the American Medical Association*, so I showed it to her. She read through it and said, "You know, I think this needs to be more of a memoir, but I think you have to take a course." [Laughs.] So she found a course for me. It's at this place called StoryStudio in [Chicago's Ravenswood neighborhood]. It's a wonderful place, so I took this course called "Memoir in a Year." Basically, there were 10 people in the class, and they were all working on a memoir. We brought our writings in, and the instructor, who was very good, she read 100 pages of it and she made very insightful comments and remarks, which really helped me write the book. In a sense, I totally refashioned it as a result of the course. Originally I had not intended for it to be a memoir, but as I was writing it there were stories and I was in those stories, and that needed to be brought out, but I wasn't sure how to do it. So that's kind of how it evolved.

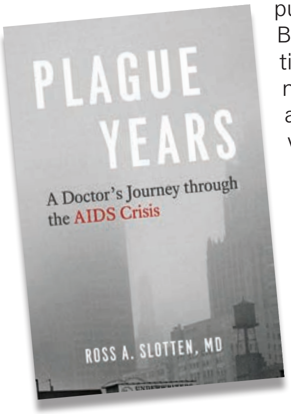
And I think at that point you were probably really glad you had those journals.

Oh absolutely. There was no way I would have even attempted this otherwise. It's not that I have no memory, but the memories are dim. You know how it is if you try to remember back 20, 30 years. The details are gone. The journals were detailed enough that it brought things back, and of course I embellished things, and sharpened the writing and that kind of thing—the journals are pretty raw. But there's enough in there that I could really bring all that back to life. I read a lot of memoirs, too, that I thought were really good that helped me shape my memoir. How does someone write a memoir that's successful, that's readable, that's good. So I read other people's memoirs, and it was very helpful.

It is very readable, and very good. I can vouch for that. There are a lot of people that you have come in contact with over the course of your career and your life who are still around. Do you run this stuff by them, or just say, "you're in a book?"

The book had an unintended message to it, which COVID has brought to the forefront, and the message is that **we will get through this**.

I was very careful. First of all, most all of the people in the book are gone. Toward the end there is someone who is sort of an amalgamation of a couple of patients. I want to be very careful, because I don't want to offend people. When you write something medical, you have to be really careful. Especially when putting living people in them, you could get sued. Because the bulk of the book is at the hardest time in the AIDS crisis, the people, as I said, are not here anymore. So it was not an issue. It was an issue early on. Initially, I had some people read versions of it—I had Dr. David Blatt [one of the leading HIV physicians in Chicago at the height of the epidemic] read it, who said, "Maybe you should be careful about who you put in here." [Laughs.] Or he'd say, "Are you concerned about this?" I don't know if you know David, but he approaches things cautiously. So he looked through it and made some comments, and I had to pull some things out. I don't think the book would be offensive to anyone with HIV.



Oh no, not at all. Actually, you talk very candidly about—I don't want to give too much of the book away—your own struggle and your own fears. You're a gay man, you're in relationships, and you talk about going to some of the bars back then. I moved to Chicago to work at the bars as a DJ, and I remember those same bars. So it was interesting how your personal life paralleled many of the people who were coming to you for medical care.

Well, that's why I wrote it, too, because no one's written it from that perspective. There have obviously been a lot of books written about AIDS, but I think my perspective is unique in that way. Being gay, being a primary care physician, being there at the beginning of the epidemic—my whole career has paralleled this epidemic. It was all serendipity. So the book works on multiple levels, and serves multiple purposes.

You were able to get a publisher—anything you would like to tell us about that?

It's very hard to get published! I first tried to find an agent. I had an agent once in the past, but that was not very successful. I found out that university presses don't require agents. You can make a proposal yourself. I got this in a circuitous way. I looked for another agent, couldn't get an agent. Then I just looked through the catalogues of various university presses. A patient of mine had a book published by Northwestern University Press, and he had gotten an "in" for me and they were going to publish it. But then at the last minute they decided they weren't going to publish a memoir, and they sort of dropped me. So then, strangely, out of the blue I got a query from University of Chicago Press, because I had written another book, on Alfred Russel Wallace, published in 2004, a biography. The University of Chicago Press was publishing some essays about Wallace, and they wanted me to look at the book, and asked me would I make some comments on it, which was very flattering. I read the book, and I made some comments. And then I wrote back and I said, "Oh, by the way, I don't know if you know this other part of me, but I'm a physician. I've taken care of people with AIDS. Would the Press be interested in an AIDS memoir?" The marketing person went to—it turned out—the editor-in-chief, then contacted me and said, "Why don't you send a proposal and four chapters?" So I sent a proposal and four chapters, and a few days later he said send the whole book. Then a week later he said, "I want to talk."

Wow! That's great.

It was so lucky. The editor-in-chief, he got it. He understood what I was doing. He really liked it. They sent it off for peer review. The two peer reviewers were favorable, so they offered me a contract. It was kind of an accident, because I was almost ready to give up. I didn't want to self-publish, although I might have done it, just to get it out there. The University of Chicago Press is an excellent press, so I feel very honored and very lucky to be able to get them. And they did a beautiful job. The cover is beautiful, they did all the design. So that's my journey with publishing. It's a daunting process. You have to be dogged, and be set for disappointment, which I was many times [laughs].

And your husband Ted said the first version was "nitty," I think was the word. What is nitty?

It was his term [laughs], it's not in the dictionary. He just said it was too clinical—it needs to be more emotional. And I said, "Well, how do I do *that*?" That was the real trick. When one's writing, I'm sure it's like doing anything creative; it's hard sometimes to know the kind of effect it's going to have on someone who's looking at it. Because I can't be objective, and when you work on it over and over again, sometimes the emotion seems drained from it. So I couldn't tell … I can't tell. But people have read it and said they cried at some point, they found themselves very moved. That's what I was trying to do but I didn't know if I did it, or could do it. I want people to be able to feel, even though it's painful. It's something that people can't forget.

We can't, and we won't forget. Your book is part of that legacy, so thank you for helping us to remember a very dark but important time.

THIS INTERVIEW has been edited for length and clarity.

Fighting for our shot

How HIV activists won their fight for inclusion in a major COVID-19 vaccine study

BY RICK GUASCO

VICTORY CAME in the form of a tweet posted in the middle of the afternoon on August 5: Pharmaceutical company Moderna was dropping its exclusion of people living with HIV (PLHIV) allowing those whose immune system was stable while on antiretroviral treatment to take part in the drug maker's Phase 3 study of a leading COVID-19 vaccine candidate.

The reversal was a huge win for a group of HIV advocates scattered across the country who had pulled together to urge the National Institutes of Health (NIH) and the National Institute of Allergy and Infectious Diseases (NIAID) to convince Moderna to change its protocol.

The Cambridge, Massachusetts-based company had already started recruiting 30,000 U.S. volunteers for a Phase 3 clinical trial of mRNA-1273, one of the more promising COVID-19 vaccine candidates. Jeff Taylor, of the HIV+Aging Research Project who lives in Palm Springs, discovered that people with HIV were excluded from the study.

"I didn't realize they were starting to recruit already, so I checked out the clinicaltrials.gov listing," Taylor said. "I alerted my activist colleagues, who swung into action. Lynda Dee led the charge in contacting officials at NIAID and at the company itself. We rapidly put together a sign-on letter that we distributed widely."

A quick sequence of events followed. Dee emailed Richard Jefferys, of the Treatment Action Group (TAG), a community-based research and policy think tank devoted to better medical research on HIV, HCV, and tuberculosis. Together, Dee and Jefferys drafted a letter to Francis Collins, MD, PhD, director of the NIH. To ensure diverse representation in the sign-on letter, they reached out to Daniel Campbell, of the AIDS Treatment Activists Coalition; Guillermo Chacón, president of the Latino Commission on AIDS; and NMAC's Moises Agosto, among others. Nelson Vergel helped with the Change.org petition, which drew more than 1,100 signatures.

"It was extremely important for people living with HIV to be included in the Phase 3 trial because we need safety and efficacy data on PLHIV," said Lynda Dee, a long-time advocate at AIDS Action Baltimore. "Without this essential data, how would we know if the Moderna vaccine is safe and if it works in PLHIV?"

The Infectious Diseases Society of America/HIV Medicine Association sent a letter of its own to NIH director Collins and to officials at Operation Warp Speed, the White House's effort to speed up COVID-19 vaccine development.

Dee credits Carl Dieffenbach, director of NIAIDS's Division of AIDS (DAIDS) for working "diligently" to "persuade" Moderna. The federal government has committed up to $955 million for the drug maker to develop mRNA-1273. Moderna's study makes use of the federal government's existing network of DAIDS clinical trial sites across the country.

"Moderna got a small fortune from the government and is using DAIDS clinical trial networks to conduct their studies on the taxpayers' dime," Dee remarked.

AN ESTIMATED 1.2 million people in the U.S. are living with HIV, according to the Centers for Disease Control and Prevention (CDC). While it is unclear whether HIV by itself makes a person more vulnerable to COVID-19, the majority of people with HIV are now over age 50 and many live with co-existing conditions (or comorbidities) such as diabetes or cardiovascular disease, which can put them at greater risk.

The study's original exclusions disqualified anyone who is in an "Immunosuppressive or immunodeficient state, including human immunodeficiency virus (HIV) infection." However, the study's inclusion criteria include, "Healthy adults or adults with pre-existing medical conditions who are in stable condition."

"From what's known about people with HIV on stable treatment with CD4 counts in the normal range (which is quite wide), there's no issue with mounting protective responses to routine immunizations," Jefferys said. "So, there's no obvious reason why people with HIV shouldn't have the option to participate in a COVID-19 vaccine efficacy trial if they choose."

Dee compared Moderna's exclusion of PLHIV to Gilead's study of tenofovir alafenamide (TAF, Descovy) for HIV prevention (PrEP), which did not include cisgender women. Men who have sex with men (MSM) and transgender women took part in the study, leading to last year's FDA approval of TAF for PrEP, but not for use in receptive vaginal sex. "No data in women, no FDA approval [for women]," Dee said.

Taylor raised another consideration. "If there's no data about PLHIV, insurance companies and other payers might refuse to cover the cost of any vaccines approved, in an effort to save money until there's data proving efficacy in this population."

Communications among pharmaceutical companies, federal agencies, and the HIV community need to be improved, the activists said. Their battle underscores the need for community involvement in designing and developing clinical trials.

"HIV activists have a 35-year history of responding to inequities and bad science in research, and have a lot to offer researchers and biotech to ensure they do research right," said Taylor.

Other companies developing COVID-19 vaccines such as Sanofi, NovaVax, and Johnson & Johnson are all including PLHIV in their studies, according to Dee, as will another Phase 3 study of a vaccine from the University of Oxford and AstraZeneca. Soon after the Moderna announcement, Pfizer responded to a separate letter it had received from the activists.

"Pfizer has already been in the process of amending the protocol to clarify that people with stable HIV, HBV and HCV infections can enroll in the study," said the letter, signed by the company's senior vice president of vaccine clinical research and development. "This will require discussions with regulators, who will ultimately make the decision whether this clarification can be included."

"I very much hope it encourages other COVID-19 vaccine developers to review exclusions for their large-scale efficacy trials—not just for HIV, but other infections such as hepatitis B [HBV] and C [HCV], and populations often studied as an afterthought, such as pregnant women and children," said Jefferys.

TO VOLUNTEER for a COVID-19 prevention study, **GO TO** coronaviruspreventionnetwork.org. For more information on ongoing and upcoming clinical trials for treatment and prevention of COVID-19, **GO TO** clinicaltrials.gov and enter COVID in the search term.

ISTOCK

POZ ADVOCATE

SCOTT SCHOETTES
@PozAdvocate

COVID preparedness for people living with HIV

Hello, POSITIVELY AWARE readers! I am excited to be launching this column exploring legal issues of importance to people living with HIV. Over more than a decade as the HIV Project Director at Lambda Legal, I have learned about the specific legal problems that people living with HIV face.

While there has been tremendous progress in protecting and advancing our rights as people living with HIV, there are always new challenges. This inaugural column is going to focus on the latest challenge: COVID-19. Here are a couple of important things to keep in mind as we continue to stare down this life-threatening pandemic:

It is more important than ever to be adherent to your HIV medications—or to get on HIV medications if you are not already. There are no studies indicating that people with HIV who have a non-suppressed viral load or who have a reduced CD4 count are at a greater risk for COVID-19 or more severe consequences from it, but it is *possible* that they are. And as far as researchers can tell so far, those with a suppressed viral load and normal CD4 count are not at any increased risk with respect to COVID-19. We should be doing all we can to put ourselves in that second category right now. Do all you can to keep yourself otherwise healthy. Better safe than sorry!

Some of us are going to get COVID-19. While researchers have not documented an increased risk for people living with HIV, they also have not established any immunity conferred by being HIV-positive or from taking antiretroviral medications. There were some theories toward the beginning of the pandemic that some HIV medications might be useful as a treatment for COVID-19, but none of those theories have yet panned out. More studies are underway and recommendations are constantly evolving as scientists learn more; but until you hear definitively otherwise, you should not assume that your HIV medications are going to protect you from COVID.

In fact, I can attest to this myself: I was diagnosed with COVID-19 in late July. Fortunately, I had a very mild case (which nonetheless included the loss of my sense of taste and smell) and bounced back quickly. Part of what prevented me from freaking out after my diagnosis was knowing I am in overall good health and that my well-controlled HIV did not put me at a greater risk of severe disease (see first point above). Knowledge is power!

Know your rights. Even people with good insurance and solid access to healthcare have experienced obstacles to timely COVID-19 testing and results. Personally, I ended up going to a COVID testing site when I learned it was going to take *a week* to get even a telehealth appointment with my regular doctor. You may not be able to control the length of time it takes to get results, but you should be able to get a COVID test relatively quickly if you have symptoms. Even if you don't have a way of paying for it right now, call your local health department and ask about free COVID testing. Be insistent about your right to learn this important information.

If diagnosed with COVID-19, especially if experiencing more severe disease and potentially entering a hospital for treatment, you may want to review this guide, "Know Your Rights: HIV & COVID-19" put out by Lambda Legal and The AIDS Institute (lambdalegal.org/publications/kyr_covid19-hiv). Many people—even doctors—have the misperception that all people living with HIV are at greater risk with respect to COVID-19. The "Know Your Rights" factsheet recommends asking questions about potential rationing of care, designating a friend or family member to look out for your best interests, and reaching out to Lambda Legal if you think the care you receive may be negatively impacted by your HIV status. People with HIV are not second-class health care consumers and should not be deprioritized based on the erroneous perception that we are not as likely to benefit from care.

One thing people living with HIV learned many years ago—and taught the world—is that we have power as health care consumers. This new pandemic, involving yet another potentially fatal disease, is an opportunity to put those important lessons to use. Together we will get through this latest pandemic, just as we are (incrementally) winning the battle against HIV.

SCOTT SCHOETTES lives openly with HIV and is the HIV Project Director at Lambda Legal, where he engages in impact litigation, public policy work, and education to protect, enhance, and advance the rights of everyone living with HIV.

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‘The community needs more’

The HIV community should not marginalize long-term survivors the way the broader community often marginalizes seniors, says **Jax Kelly**

Several years ago, when I was in my first decade of living with HIV, I felt a need to create something to benefit people aging with HIV. Perhaps it was too soon for me (I was in my forties) or the community (we hadn’t become half of all people living with HIV yet). What started with support groups morphed into research, and now you can attend conferences on HIV and aging.

But the community needs more.

As president of Let’s Kick ASS (AIDS Survivor Syndrome) Palm Springs, I joined a local network of agencies and non-profits engaged in the health and well-being of seniors. People joke about Palm Springs, calling it “God’s waiting room,” but I sensed there was a lot to learn from seniors in this desert community.

Seniors and my LKAPS colleagues have in common the problems of isolation, co-morbidities, poly-pharmacy, and stigma. Some have suggested the HIV community should not marginalize long-term survivors like the broader community often marginalizes seniors. During election season we are often reminded of the power of seniors as a voting bloc. Aren’t our elders aging with HIV similarly empowered to make change?

The differences reveal themselves through our experiences of surviving a plague, HIV criminalization, and an illness that is passed on by stigmatized sexual behavior and sometimes illegal substance use. Our stories—our wisdom—is validated by our willingness to stand up and use our voices to share what makes us unique. It is no accident that a lot has been written about long-term survivors of HIV during the COVID-19 pandemic. We may have lost heroes since the plague years, but people like Dr. Anthony Fauci, Peter Staley, Phill Wilson, Ann Northrup, and many others are witnesses still with us. We have a history of existing beyond the margins.

In my observation, I find that the differences are significant enough to advocate for services for people aging with HIV. I look to our elected officials to be inclusive of HIV-positive people in writing legislation that addresses services for seniors. I ask that our safety net programs like Ryan White and HOPWA develop Standards of Care for people aging with HIV and programs that finance senior housing for HIV-positive people. Researchers looking for a cure or improved therapies must continue to include people aging with HIV in their clinical trials and community advisory boards.

Because of the COVID-19 pandemic, LKAPS social activities went online. No longer could we meet at coffee houses, movie theatres, bowling alleys, or each others’ homes. We taught each other “Zoom 101” and how to make it fun by passing private notes to each other via “chat” during a slow point in a presentation. Others have used the green screen to create elaborate backgrounds or backdrops of exotic places we can only dream to visit.


JAX KELLY

These online experiences enable us to connect with folks we haven’t seen in ages because we couldn’t afford the airfare or because we couldn’t find time to travel. This sense of connection permits a semblance of community, an opportunity to forget our isolation, and a way to add order or routine to our recently untethered lives.

In a recent article in this space, Gabriel Maldonado, CEO of TruEvolution Inc., asked if there is “a role for community-based organizations who do not choose to fully medicalize their operations?” I hope so. LKAPS does not provide medical services but dreams of being part of a brick and mortar operation where community members can meet socially, learn about services and opportunities, and consider advocating on behalf of people aging with HIV. Our members need social workers and therapists to assist with access to housing and legal services and individual or group therapy. Our volunteers are invaluable, but we need paid staff dedicated to navigating a system that people aging with HIV often find too stressful and bureaucratic to access.

In California, there is government funding for independent living centers and aging and disability resource centers. Senior nutrition programs and caregiver resource centers also receive public support. LKAPS has recently taken up providing information about these programs to people aging with HIV. We have collaborated with local groups helping with wills, health directives, and other legal issues. There is a need for a compassionate voice from our community to educate and serve people aging with HIV.

Senior centers and senior living spaces are at the frontlines of the battle with coronavirus. Through advocacy for inclusion of people aging with HIV in the future plans of these facilities, perhaps we can extend our outreach and use our expertise to assist the broader aging community, gain a seat at the table, and find that brick and mortar building to sustain us.

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JAX KELLY, president of Let’s Kick ASS (AIDS Survivor Syndrome) Palm Springs (LKAPS.org), serves on the California Planning Group, the Community Scientific Subcommittee of the ACTG, the steering committee of The Reunion Project, and NMAC’s HIV 50+ Strong and Healthy program.

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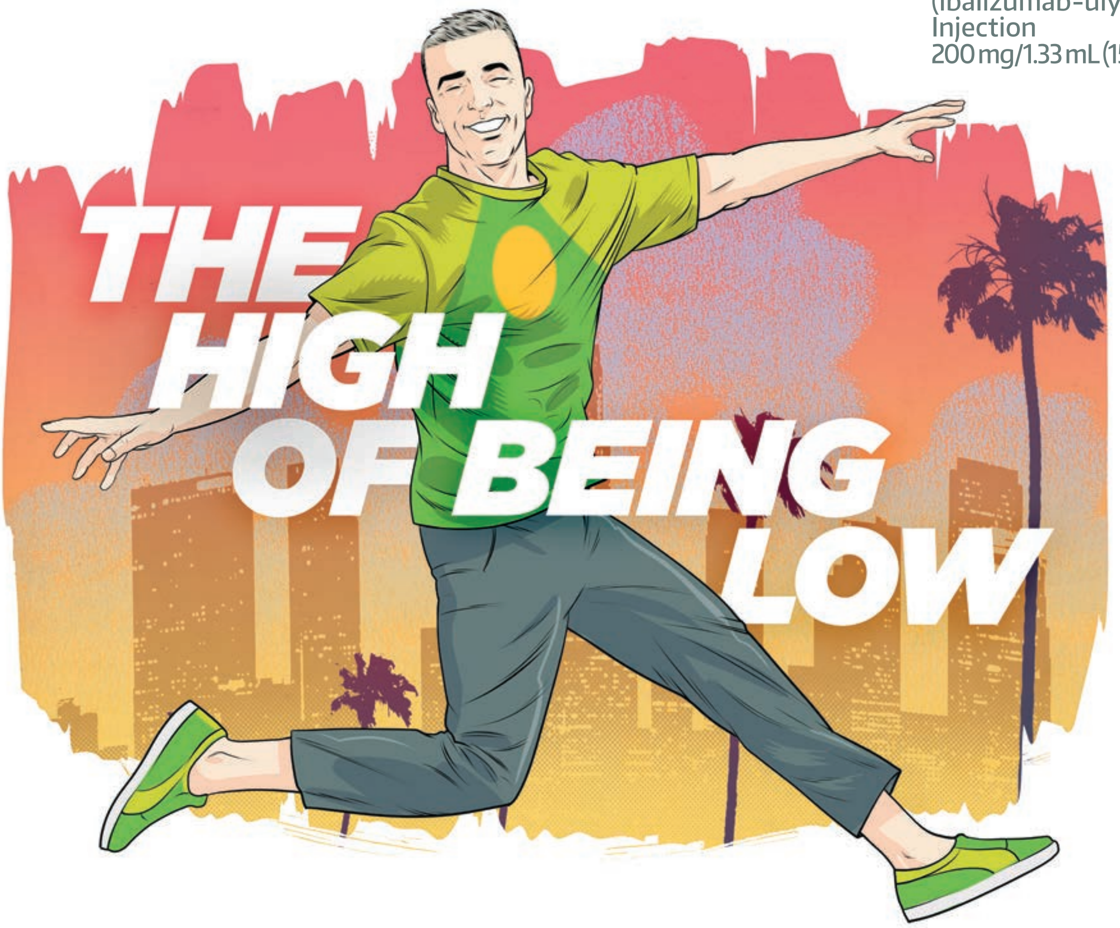

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You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

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THE CATEGORY IS...

REALNESS OF THE MOMENT

What does living with HIV today look like for you?

That's the question we asked our followers on Facebook, Instagram, and Twitter. They served up some honest feelings and experiences

"It's been 10 years since I've been diagnosed. For the most part that one pill a day takes care of everything. Between my day job and photography, I try to keep myself busy, overwhelm myself with too many projects, try to bike more, work on keeping healthy, listen to music. Anxiety is what's keeping me on my toes, not the virus. I'm getting older and seeing changes that I question if they would be the same if I didn't have this thing hiding in my body. What gives me peace is photography, this is truly the only thing that lets me forget about the reality, a way to escape. Unfortunately, with the pandemic I've been mostly stuck at home, and the live local performances that I was shooting have all been cancelled and the venues shut down. So far, I've not been able to find new activity to help me find peace."

—**PETER SEROCKI**

"In a perfect world as a heterosexual couple honoring our vows, for better or worse, in sickness and health, we would be accepted and acknowledged for weathering the storm of 36 years of marriage and still standing together. Sadly, we are not!

We are the exception and only marginally accepted. The unwritten rule is that after diagnosis, the split up is the obvious next step with a couple.

It takes its toll. Choosing not to always explain why we are still together and knowing it's falling on already made up minds seems pointless after a while.

We seem to be the proverbial third wheel when out with our circle of friends, the only couple in a sea of single men and women.

Not many couples are actually active together in the HIV community. We feel like we are on the outside looking in for that connection. Life as a married couple living with HIV is a challenge. We do the best we can do."

—**EUNICE AND KALVIN MARSHALL**

JAY GRANDIS (ABOVE, LEFT, WITH PARTNER JOE SHRINER): "I'm still living a combination of fearless living mixed with muddling through on some days. This is a picture of me and my partner at one of our many BLM events in our area. I've become heavily involved with regional organizing and facilitating in our region of largely rural northcentral Pennsylvania, helping diverse groups network, communicate, collaborate, and share skills. I can't sit still."

"As a 30-year survivor and having spent more than 25 of those years living openly with my positive status, I've settled into a 'quieter period.' Gone are the requests for educational presentations that I once did for various groups and organizations, in and around the rural area in which I live. Luckily, for me, I have reaped the benefits of improved treatments for HIV. Lucky, in that I'm still here in 2020, when in 1991, when I tested positive, I was given about five years to live. The trade-off has been chronic kidney disease (stage III), fat redistribution, facial wasting, and such. Thank goodness for Sculptra, that not only works as a filler, but as a self-esteem builder. So, thriving? Maybe. 'Maintaining' would be a better description, as the mental aspect of it plays a huge part now as a long-term survivor."

—**HAROLD R. SCOTTIE SCOTT**

You Don't Refuse to Breathe

I'm looking at this new plague and I'm thinking
about David Wojnarowicz and how in the last plague
it mattered so much to be queer and the pathos

of your family hating you and the pathos
that the government was always be happy to let you die
but how in this plague though the marginalized

will surely suffer the most it won't be
a gay thing and it won't be about my identity
and whoever dies might not be your secret lover but

your grandpa or great-grandmother or that snotty kid
who always looked at you funny when you walked
down the street yeah it got him too though

it wasn't supposed to but it did and it wasn't
supposed to bring people together but people
are trying so hard on video conference crappy Zoom

or whatever but that's not being together that's a more
exquisite sense of your own isolation and how you can't
kiss boys on the street like you did thirty years ago

and didn't that feel good although people
were still dying and yeah they're going to die again and
soon and I think about the Black Death and how the one

who was singing in the morning would manifest
foul pustules in the afternoon and be dead by nightfall
but no novel coronavirus doesn't work that way

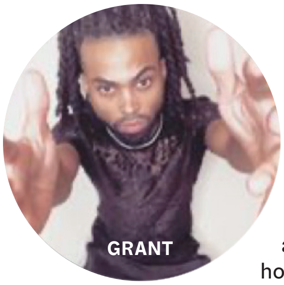
you could kill twenty people before you have a clue
that something might be wrong and yeah
in that way it's like HIV but there's no part of this

quarantine this holding back that could in any way
be related to fun it's like Frank O'Hara said
you don't refuse to breathe do you

—**MERRILL COLE** @merrillcole

"Living with HIV for 35-plus years and now living with my 90-year-old mother as her caregiver at her assisted care is the most fear and stress I've ever had. My meds are delivered. I am now 66 years old, receiving my retirement which is helpful but not much. I'm at high risk living in a high-risk zone, the assisted care home with 80–90 year olds who often forget their masks and won't stay in their rooms. Normally, they would be out in the community, having art classes and outings and entertainment. Now I am all that for my mom—giving her medication, exercise, and going for walks outside. She is in a wheelchair, so I'm pushing it. But I am grateful. She has three meals a day and help with her bathroom needs. This is an opportunity to be of maximum service to my mom for however long she's got. Keeping her safe and lighthearted helps me, too."

—SHERRI LEWIS



"I am thriving with HIV because I chose to take a positive diagnosis and live a positive life. I have a partner who is HIV-negative who has stood by me for the last five years. We thrive by telling our story openly to help others see that living with HIV is not the end. Be the love you want to see."

—ERIC GRANT
@speakup_eric

"I stay home, watch Netflix. I didn't survive this far to be taken out by another virus."

—DEREK CANAS

"I'm about to lose my insurance and nobody has real answers as to how to get your HIV medication, and insurance has been a hassle too—prior authorizations for meds and harassment from insurers, pharmacies. HIV organizations who have no clear answer or a system to help with medications—it's stressful. It should not be this way. There is no cure, and we need the medication. I feel so lost sometimes because of this uncertainty. It never stops."

—LUIS COLLADO

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