



POSITIVELY AWARE

HIV TREATMENT, PREVENTION AND HEALTH FROM TPAN
MAY+JUNE 2022

**SEX, LOVE,
DATING, AND
HIV AFTER 60**

**WHEN
HIV THERAPY
FAILS**

**HUMANIZING
SCIENCE**

CONFERENCE UPDATE
**VIRTUAL
CROI 2022**

This time for Alexandra

Transgender actor, activist, and teacher **ALEXANDRA BILLINGS**
talks about her new memoir, and how there are gifts in chaos



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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.



ON THE COVER AND ON THIS PAGE
ALEXANDRA BILLINGS, PHOTOGRAPHED BY MARK HARVEY

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*'We're not listening to the humans in front of us,
we're not paying attention to the events at hand,
we're not taking into account that there are gifts in chaos.'*

—ALEXANDRA BILLINGS, PAGE 14

A lesson in community

ALEXANDRA BILLINGS IS INTENSE.

A consummate professional, she changed poses and expressions from one moment to the next as photographer Mark Harvey clicked away furiously to keep up.

The photo shoot went by so quickly, there was little time or opportunity for small talk, but when she mentioned Joey Luft, she chided me for not knowing who he is.

Billings is an actor, a fierce LGBTQ+ activist, and a dedicated teacher, and as the shoot ended, she suddenly schooled me.

Luft is the son of Judy Garland, and brother of Lorna Luft and, arguably their more famous sibling, Liza Minelli. Children of one of the most iconic of gay icons, each with varying degrees of fame, talent, and charisma.

Billings is a great admirer of Garland and the legendary performer's children. They are Billings' inspiration and foundation. They represent a continuity that helps build and connect this community of LGBTQ+ people. A bridge from past to the present, and from present to future generations.

How could I have a sense of place in my own community, she said, if I didn't know about the people who came before me? And how could I pass that legacy on to younger generations if I didn't know it myself?

Knowing who we are, as individuals, and where we come from as a community are vital. Billings is passionate about community and identity, because she sees LGBTQ+ people under attack by society and by political forces.

"Because what they're trying to do is eradicate us," taking time after the shoot to make her point. "Because we're not an actual community, to those



MARK HARVEY PHOTOGRAPHING ALEXANDRA BILLINGS IN BIXBY PARK IN LONG BEACH, CALIFORNIA.

people. [To them,] we don't exist. We're just a group of humans who are either making choices about who we want to fall in love with, or making choices about what we want to wear. We're either one of those two categories. And if they annihilate us, if they eradicate us, they can feel better about who they are, about what they know and understand."

"...And how they're doing that is by making the choices about us," I interjected.

"That's right," she continued. "So, if we implant, especially in the younger generation—who we used to be—we allow this younger generation to grow up with pride, with honor, with grace, compassion, and knowledge—knowledge about

where they come from, that they come from a people, a group of humans that traversed across the planet Earth to get to this point. We're not an idea. We're not a philosophy. We're not a fad. We're not a fetish. We belong in the United States of America, we are American citizens. And we deserve not just inclusion, but respect. And the only way we're going to get that is to teach the younger generation that they matter, and they come from somewhere." —RICK GUASCO

WATCH Alexandra Billings give a lesson on community: positivelyaware.com/alexandra-photo-shoot

READ Jeff Berry's interview with Alexandra Billings, on page 14.

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EDITOR'S NOTE

JEFF BERRY
@PAeditor

The state of HIV and aging

By now we've all heard the statistics: 50% of people living with HIV (PLWH) are over the age of 50, and by 2030 it will be 70%. When we talk about HIV and aging it always tends to sound like a laundry list of everything that can possibly go wrong as we get older.

But please indulge this old-timer as I ponder a few things for us to consider.

Today, thanks to advances in treatment, older adults with HIV are faring better, but we tend to have an average of three or more comorbidities than our peers without HIV, and these occur more frequently and at an earlier age.

Things like frailty, bone and neurocognitive issues, cardiovascular disease, cancers, kidney and liver disease—and inflammaging, the idea that chronic inflammation is the driver of many of these co-occurring conditions.

But what about invisibility as a co-morbidity? Stigma is still a huge issue for PLWH, and for those of us who are aging, we face the dual stigma of aging and HIV. Our society does not value our elders, and the wisdom that can come with aging. How do we tap into that wisdom and begin to turn the tide of this impending silver tsunami?

We hear about trauma, too. Many long-term survivors (LTS) have experienced multiple traumas—trauma from our childhood, the trauma of racism, sexism, homophobia, transphobia, and the trauma of losing entire support networks of lovers, friends, and family members to AIDS early on in the epidemic. People who acquired HIV around birth or at an early age and have been living with HIV 10, 20, 30 years now are also long-term survivors. We need to include them in the conversation and pull up a chair for them at the table.

Along with these co-occurring conditions we see increased rates of isolation, depression, substance misuse, post-traumatic stress disorder (PTSD) and other psychosocial issues.

We know that HIV disproportionately affects Black, Indigenous and other People of Color (BIPOC). And then issues such as unstable housing, justice system involvement, poverty, food insecurity and other social determinants of health all affect the quality of life (QoL) of people aging with HIV, and often can change the trajectory of the lives of PLWH, for better or for worse.

As advocate Jules Levin likes to point out, our healthcare system is broken, and ill-equipped to deal with an aging society, let alone people who are aging with HIV.

We've heard stories of older LGBTQ+ people and PLWH having to go back into the closet when entering into long-term care facilities, for fear of being outed, ostracized, and stigmatized—and still being stigmatized and receiving suboptimal care.

Not only is our healthcare system broken, the entire system is broken.

But, I promise, there is some good news.

The updated national HIV/AIDS strategy includes people aging with HIV and long-term survivors for the very first time. Clear goals for improving the quality of LTS are articulated in the strategy—let's hold our leaders accountable, and work together so that we may achieve them. Organizations and programs around the country and globally are already starting to address some of these issues.

We know that many LTS have developed resilience in the face of all these odds, so how do we help support and build models of resilience? Just as PLWH created a system of care and support where none existed early in the epidemic, we are the ones who will need to create new systems and models of care, from the ground up, because no one else is going to do it for us.

We need to advocate for policies and reforms that will improve the quality of life and deliver culturally appropriate services and care for people aging with HIV.

We need increased research on HIV and aging, but we also need implementation science that will help translate that research into improved outcomes and quality of life.

And lastly, it's imperative that we strengthen and harness the collective voice and power of networks of individuals living and aging with HIV to achieve all of these goals, and provide people living and aging with HIV the support and dignity we all so richly deserve.

We've earned it.

Take care of yourself, and each other.

We need to advocate for policies and reforms that will improve the quality of life and deliver culturally appropriate services and care for people aging with HIV.



Briefly

ENID VÁZQUEZ @ENIDVAZQUEZPA

Cabenuva long-acting injectable no longer requires a month of oral lead-in medication

It's official. Cabenuva, a long-acting regimen given as two injections once every two months, was approved by the U.S. Food and Drug Administration (FDA) in January of last year for maintenance therapy (switching from another regimen, with undetectable viral load). This year, in March, the FDA updated Cabenuva's drug label, making the recommended oral lead-in optional before starting injections.

"Oral cabotegravir and rilpivirine [the medications comprising the long-acting regimen] can be taken for a month to assess tolerability to the medicines contained in Cabenuva," said manufacturer ViiV Healthcare in a press release. "However, **this oral lead-in is now optional after clinical trial data demonstrated similar safety and efficacy profiles for both initiation methods** (with or without the oral lead-in)."

Because the two drugs that make up Cabenuva are administered as long-acting injections, an oral lead-in consisting of the two medications in pill form was recommended in order to first check for side effects before going on the injections. The pills are also used to keep

people on their treatment if they are unable to go to the clinic for the injections.

The label change is based on Phase 3 data at 124 weeks from the FLAIR (First Long-Acting Injectable Regimen) study, which showed that whether people went immediately on Cabenuva injections or began with a month of oral lead-in pills, the results were similar for virologic suppression (achieving undetectable viral load), safety, tolerability, and pharmacokinetics (how substances move through the body, including absorption, metabolism, and elimination).

Cabenuva can also be taken once monthly, still with the two injections. Cabotegravir injections by themselves were approved for HIV prevention in December 2021, under the brand name Apretude, given as one injection every other month (go to [positivelyaware.com/cabenuva](https://www.positivelyaware.com/cabenuva) and [positivelyaware.com/apretude](https://www.positivelyaware.com/apretude)).

Cabenuva now for adolescents

More good news on Cabenuva: in March, the FDA approved its **use for adolescents ages 12 and**

older who weigh at least 77 pounds (35 kg). As with adults, adolescents must first be on stable HIV therapy with no history of treatment failure and no known or suspected drug resistance to the medications that make up Cabenuva (cabotegravir and rilpivirine).

The approval came based on data in adults and from

16 weeks of analysis in the ongoing MOCHA (More Options for Children and Adolescents) study. MOCHA is conducted in collaboration with the International Maternal Pediatric Adolescent AIDS Clinical Trials Network (IMPACT).

There were 23 adolescents in the MOCHA analysis. They received either

FDA approves first condom for anal sex

The first condom recommended specifically for use in anal sex has been approved by the U.S. Food and Drug Administration (FDA). Manufactured by Global Protection Corp., the ONE Male Condoms has also been approved as a contraceptive and for reducing sexually transmitted infections during vaginal intercourse.

"[T]his authorization helps us accomplish our priority to advance health equity through the development of safe and effective products that meet the needs of diverse populations," said Dr. Courtney Lias, Ph.D., director of the FDA's Office of Gastrorenal, ObGyn, General Hospital, and Urology Services, in a press statement. She added that **the FDA's go-ahead for the anal condom establishes a regulatory system for other condom brands to seek market approval** and increase condom use.

Condoms have long been recommended for use during anal sex, but prior to approval of the One Condom, none had been marketed for anal sex in the U.S. This is due in part to a lack of sufficient data to prove the safety of condoms used for this purpose. Anal sex poses the highest risk of HIV transmission when performed without protection; PrEP and condoms are both forms of protection against HIV.

In the largest study of its kind by Global Protection Corp. and Emory University, ONE Male Condoms had a failure rate of less than 1%, significantly lower than the 5% failure rate set by the FDA. Conducted between May 2016 and May 2017, the study involved 504 men engaging in 2,351 anal and 2,533 vaginal acts of intercourse. The study defined failure as any slippage or breakage of the condom occurring during intercourse.

ONE Male Condoms are available in three versions: thin, standard, and fitted; the fitted version offers 54 different sizes. According to the trial study, the condom version has no effect on its efficacy. — JACK REDING



► TOP OF THE NEWS

- Cabenuva long-acting injectable no longer requires month of oral lead-in medication
- Cabenuva now for adolescents
- HIV vaccine trial begins enrollment—and dosing
- Cancer and HIV in men
- Advocates meet with lawmakers virtually for AIDSWatch 2022
- Latino web series updates the narrative of HIV
- Empowering youth living with HIV through storytelling
- Magic Johnson docuseries available on AppleTV+

cabotegravir or rilpivirine in addition to the HIV therapy they were already taking. Thirteen experienced injection site pain (all Grade 1 or 2, meaning mild or moderate). Two experienced insomnia (one of which was Grade 3, “severe”). One experienced Grade 3 hypersensitivity (allergic reaction) to rilpivirine that led to discontinuation of the drug during the oral lead-in.

Cancer and HIV in men

Men living with HIV had nearly twice the rate of cancer as did men who were HIV-negative, according to a research team analyzing Medicaid data.

“Cancer is one of the most common comorbidities in men living with HIV (MLWH),” reported Siran M. Koroukian, PhD, and colleagues in the March 14 issue of *Cancer*, a journal of the American Cancer Society. “However, little is known about the MLWH subgroups with the highest cancer burden to which cancer prevention efforts should be targeted.

HIV Long-Term Survivors Awareness Day is June 5

Sunday, June 5 is HIV Long-Term Survivors Awareness Day (#HLTSAD). This year’s theme is “Mobilize to Thrive.”

“Today, HIV Long-Term Survivors (HLTS) represent a diverse group of people diagnosed with HIV before the advent of Highly Active Antiretroviral Therapy or HAART in 1996,” says the community-based group Let’s Kick ASS (AIDS Survival Syndrome), which first organized the awareness day. “Often **overlooked HLTS include people born with HIV or who acquired the virus as babies and are now in their 30s and 40s. HLTS are also those living with HIV and AIDS for over 25 years.** We are developing a working social media campaign and tangible calls to action to improve the quality of our lives.”

Among the priorities of Let’s Kick ASS:

- improving the quality of life for people aging with HIV/AIDS
- demanding universal treatment access

to help end the HIV epidemic

- prioritizing culturally aware mental health care
- overcoming the challenges of poverty and economic insecurity
- fighting against “discrimination and invisibility facing older adults with HIV and AIDS” (the group declared that “ageism is a virus”)

Let’s Kick ASS (LKA) calls universal treatment access “the message of Undetectable = Untransmittable” (U=U). The group invites long-term survivors to share their stories, wisdom, and lessons. This in turn can help set an agenda for needed changes. Photos and videos are welcome.

Watch a poignant short video of LKA members speaking to their issues at hltasad.org, where people can also sign up for the group’s HIV Long-Term Survivors League newsletter.

Because Medicaid is the most important source of insurance for MLWH, we evaluated the excess cancer prevalence in MLWH on Medicaid relative to their non-HIV counterparts.”

Among the MLWH, **cancer was found much more**

often in those who had symptomatic HIV than those who did not have symptoms of HIV disease.

The cancers most often found in MLWH, whether the men had symptomatic HIV or not, were anal cancer and lymphoma.

The greatest difference found was a higher prevalence of anal cancer in younger men with HIV, whether symptomatic or not. In terms of race/ethnicity, the highest incidence of anal cancer was in Hispanic men.

“Given the Medicaid program’s role in insuring MLWH, the current findings highlight the importance of the program’s efforts to promote healthy behaviors and vaccination against human papillomavirus [HPV] in all children and adolescents and to provide individualized cancer

screening for MLWH,” the team said in its conclusion.

According to an accompanying editorial, “People living with HIV have a great incidence of some cancers, and many of these people can [be] expected to live long-term and will require treatment for cancer. Because many of them are also insured by Medicaid, new approaches to public health practice and policy are needed.”

There were 82,495 MLWH in the analysis, compared with more than seven million men who did not have HIV, all between the ages of 18 and 64.

The study was presented in part at the 44th Annual Meeting of the American Society of Preventive Oncology held virtually in March.

Cancers most often found among men living with HIV, whether they had symptomatic HIV or not, were anal cancer and lymphoma.



HIV vaccine trial begins enrollment—and dosing

The Fred Hutchinson Cancer Research Center announced that, “The first 12 study participants have been enrolled in a new Phase 1 clinical trial using the messenger ribonucleic acid (mRNA) vaccine technology developed by Moderna. The study **evaluates the safety of and immune responses to three different experimental vaccines against HIV.** This randomized, open-label trial represents one of the first clinical studies of the use of mRNA vaccine technology against HIV.”

Fred Hutch, as the center is also known, is the international headquarters for the HIV Vaccine Trials Network (HVTN). HVTN is a publicly-funded international collaboration.

“The investigational vaccines are not expected to provide protection from HIV infection, yet the knowledge gained from this study will aid in the future development of an HIV vaccine regimen,” the institute continued in its March 14 press release. “Researchers hope to learn whether the immune system will respond to the experimental vaccines by making antibodies and T cells that

could fight HIV if a person is ever exposed to the virus in the future. The trial will also build knowledge about how the immune responses to an mRNA vaccine compared to the responses to protein-based vaccines, while helping define the potentials of using mRNA to increase the pace of developing an HIV vaccine.”

Moderna gained fame for its mRNA technology that was successfully used for developing a vaccine against COVID-19.

“The experimental vaccines carry mRNA, a piece of genetic code, delivering instructions to cells for making proteins, in the same way that the mRNA vaccines against COVID-19 instruct the body’s cells to make the SARS-CoV-2 spike protein,” Fred Hutch explained. “These instructions show human muscle cells how to make small portions of proteins that resemble parts of HIV, but are not the actual virus. People cannot get HIV from the vaccines. Once human immune cells have used the instructions, the mRNA is quickly broken down, and does not stay in the body.”

“Developing a vaccine regimen that induces sustained protective levels of

Empowering young adults through storytelling

Howard University has launched a new program for young adults (18–29) in the mid-Atlantic region who are living with HIV. StoryTIME: Telling Is My Empowerment uses photography as a starting point to share experiences and break down HIV stigma. **The program provides mentorship, leadership, and advocacy skills** to help their participants become leaders in their communities.

The program takes place mostly online, consisting of 8–10 virtual sessions over a 12-week period. Two in-person sessions per year take place at Howard University’s Washington, D.C. campus. The program offers transportation assistance for the in-person sessions, and participants are compensated for their time in gift cards. There are two groups in staggered succession. The first group mentors the second in weekly meetings.

StoryTIME is open to young adults living in states from Virginia to New Jersey. **TO APPLY**, email Patty Houston: phouston@howard.edu.

—JACK REDING



HIV neutralizing antibodies in humans has been difficult to achieve. At Moderna, we believe that mRNA offers an opportunity to take a fresh approach to this challenge,” said Stephen Hoge, M.D., president of Moderna, in a company press release.

The company announced that it had dosed its first study participant in the trial.

The HVTN 302 trial is sponsored by the Division of AIDS (DAIDS) of the National Institute of Allergy and

Infectious Diseases (NIAID) within the National Institutes of Health (NIH). Up to 108 HIV-negative adults will be enrolled.

GO TO the statements of Project ACHIEVE and Columbia University, in New York City, which are also participating in the study: harlemworldmagazine.com/new-york-blood-center-and-columbia-university-in-harlem-conduct-groundbreaking-hiv-vaccine-research-study, and of the NIH



Magic Johnson docuseries— ‘They Call Me Magic’—now available on AppleTV+

A new four-part documentary series about one of the world’s most iconic figures, Earvin “Magic” Johnson, premiered on AppleTV+ on April 22. “They Call Me Magic” follows his life during the early days as a basketball sensation from Lansing, Michigan, his turbulent championship years with the Los Angeles Lakers, an “earth-shattering” HIV diagnosis, and his comeback as a business mogul and family man.

Magic Johnson “changed the conversation around HIV and transcended into a community activist and successful entrepreneur,” says a press release announcing the documentary. “Featuring never-before-seen footage and interviews with Magic, his family, powerhouses from business and politics, and those in his inner circle, the series will offer an unprecedented look at one of the biggest cultural icons of our era.”

Directed by Rick Famuyiwa (“Dope”) with editor Dirk Westervelt (“Ford v Ferrari”) and cinematographer Rachel Morrison (“Black Panther”), the docuseries is produced for Apple by XTR and New Slate Ventures, and produced in association with h.wood Media and Delirio Films.

—JEFF BERRY

at hiv.gov/blog/nih-launches-clinical-trial-three-mrna-hiv-vaccines.

AIDSWatch 2022

Each year during the advocacy event AIDSWatch, people from around the country go to Washington, D.C. to talk with members of Congress and staff about urgent issues related to HIV/AIDS.

Advocates from 34 states held meetings with more than 135 offices on Capitol

Hill during this year’s virtual AIDSWatch, according to the organizer of the event, AIDS United. This year’s event focused on:

- supporting the health of people living with and vulnerable to HIV
- addressing structural and institutional racism and other inequities, and
- increasing funding for programs that address the HIV, STD, and overdose epidemics

Martha Cameron, from the US PLHIV Caucus, urged participants to “make sure you talk about quality and gender-affirming care from providers that are well-versed on their patients’ options and rights. Make sure you talk about expanding HIV prevention and coverage of PrEP. Make sure you talk about protecting our rights to vote. Make sure you talk about reforming and repealing HIV criminalization laws. Make sure you talk about

sexual and reproductive health.”

Assistant Health Secretary Rachel Levine delivered the keynote address during the annual advocacy event, held in April. She noted President Joe Biden’s update to the National HIV/AIDS Strategy (NHAS), released on World AIDS Day, December 1. Not just federal, but also non-federal, groups are called to “accelerate efforts to end the HIV epidemic in the United States by 2030,” because

federal action alone is not enough. “We need all of you, and the organizations, individuals, and programs you represent to also innovate and collaborate in ways aligned with the strategy,” she said. She also promoted the president’s request for a new program to promote HIV prevention via PrEP (pre-exposure prophylaxis), medication that stops infection in its tracks, providing the treatment of uninsured and underinsured individuals.

Said AIDS United’s vice president, Carl Baloney Jr., “We absolutely have the tools necessary to end the HIV epidemic. We have overcome odds that have seemed insurmountable before. Together we can show the world what an HIV advocate can do, and more, what we can do together. Together, we can end the HIV epidemic.”

Go to AIDS United’s YouTube channel for more.

Latino web series updates the narrative of HIV

Once again, the pioneering bilingual media company Latino Alternative TV (LATV) takes aim at stigma and discrimination through the stories of community members living with HIV. The series of online video shorts was birthed by the company’s creative team which focuses on LGBTQ+ advocacy. *Living y Ready* explores personal issues such as disclosure experiences, self-harm, substance use, and depression, but teams them up with facts, resources, and science.



Call for reader submissions from the justice-involved

For an **upcoming issue focusing on HIV criminalization and people who are justice-involved**, POSITIVELY AWARE invites reader submissions, especially from currently or formerly incarcerated people. SEND letters, notes, stories, photos, drawings, and poems to POSITIVELY AWARE, 5537 N. Broadway, Chicago, IL 60640-1405; email to inbox@tpan.com. If currently incarcerated, please state whether or not your name and contact information may be used. **The deadline is Friday, July 22.** There is no guarantee of publication or that items will be returned, especially within correctional facilities.



“We created *Living y Ready* to update the narrative around HIV in the media because the conversation today needs to be about living with HIV, not just tragedy and loss,” says the creator and director of the series, Andres Palencia. “The people living with HIV featured on the series are talented, ambitious about their future, and making a difference in the world. I have a deep admiration and respect for them and I know a lot of our audience will see hope for themselves by getting to know the cast of *Living y Ready*.”

The show premiered April 13 and continues through Pride Month, scheduling its last episode on June 22. “*Living y Ready* was created to have **genuine conversations that reframe the narrative around the stigma of HIV through informative segments, candid round table conversations, and queer expression** with the same goal as [the company’s video series] *My Health Agenda*, to continue creating safe spaces for the LGBTQ+

community to be open, honest, and real without the fear of judgement and rejection,” says an LATV press release.

The panelists living with HIV who join the series include Alfredo Trejo, a scholar and artist currently working on his PhD; Erick Velasco, host of “The Homo Homie Podcast;” Mallery Robinson, an Afro-Caribbean transwoman who works as an advocate for transgender and HIV healthcare (and who was among the people featured on the cover of the POSITIVELY AWARE 2022 HIV Drug Guide); Jennifer Rodriguez, a Latinx transgender woman who is a trans recovery advocate; Melody Torres, National Director of Health and Wellness for FLUX; and Miranda Ramirez, a PrEP navigator helping people gain access to HIV prevention medication.

The experts joining in the conversation are Natalie Sanchez, MPH, Director of UCLA Family AIDS Network; Hilda Sandoval, PhD, LMFT, Director of Behavioral Health Programs at JWCH Institute, Inc.; and Ray Fernandez, AMFT, Patient Care Manager for AltaMed Healthcare. José Ramos, National Director of Sales at the AIDS Healthcare Foundation, will host the informational episodes.

Sanchez and Sandoval previously collaborated on a bilingual telenovela (similar to a soap opera) exploring HIV stigma, *Sin Verguenza* (see May+June 2018 POSITIVELY AWARE).

GO TO latv.com.

Prison Journalism Project appoints its first board

The Prison Journalism Project, a national initiative that trains incarcerated writers to be journalists and gets their stories published, appointed its first board of directors in March. **The seven board members represent several professional disciplines in media and law.**

“Each of PJP’s newly appointed directors shares our vision of building a strong network of prison journalists and brings a unique array of ideas and experiences to help us continue to grow,” said board co-chair and PJP co-founder Yukari Kane in a press release.

PJP was recently awarded a major grant from the FWD.us Education Fund to expand its newsroom operations and its journalism school program.

GO TO prisonjournalismproject.org. WRITE TO Prison Journalism Project, 2093 Philadelphia Pike #1054, Claymont, DE 19703.



YUKARI KANE



Sex, love, and dating over 60 with HIV

New treats and challenges
BY MICHAEL BRODER

tested positive for HIV in 1990. I was 29 then; I'm 61 now. For the past 15 years or so, health professionals have been paying a lot of attention to the aging of the HIV population. They often discuss the so-called "graying of HIV" in terms of people over 50. We seem to like slicing history up into quarter-century segments. We get excited about 25th anniversaries, 50th anniversaries, 100th anniversaries. But as I slide into my sixties, I realize that 50 and 60 are at least as different as horses and zebras, if not zebras and giraffes. How does this apply to the impact of HIV on the sex, love, and dating lives of people over 60? I'm learning by doing, asking other people what their experience is, and sharing what I learn with you.

I'm finding that HIV holds new treats in store for us as we exit our 50s. For example, in recent months I had cataract surgery on both eyes. The doctor says I'm a bit young for cataracts, but a bunch of studies have observed a greater risk of cataract surgery among people with HIV. Some of these studies suggest that the increased risk may be related

to long-term antiretroviral therapy (ART). Even if that's the case, you'll get no complaints from me—ART saved my life, and cataract surgery has rendered me glasses-free for the first time in 50 years, so it's kind of a win-win. Not sure the vision issue is really related to sex, love, and dating, although some may think I look more handsome

without glasses, and it's a sterling example of how HIV may affect us in surprising ways as we transition into retirement savings, Medicare, and Social Security territory.

But while health and medical issues are certainly relevant, what grabs my attention the most are issues of sex, love, dating, and other forms of intimate relationships with HIV over 60. I will fess up to the fact that this topic interests me right now because I'm in the process of divorcing from my husband, to whom I got married in 2004, and with whom I've been in a relationship since 2000. Now the divorce plunges me back into the deep end of the dating pool for the first time in over 20 years.

Because our relationship was always open, I've been, if not dating with HIV, at least hooking up with HIV without interruption (more or less, with the exception of one jealous boyfriend and one outright monogamous boyfriend in the 1990s) for some 30 years now. Right

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off the bat, I'll say things are much easier for me now, HIV-wise, than they were in 1990. I don't need to go into a lot of tedious details here about what those early days were like. Suffice it to say that living with HIV back then sharply curtailed your sex and dating options (unless you were comfortable with lying, whether by commission or omission, about your HIV status). Those were the days of dates getting up from the table and walking out on you in the middle of dinner when you disclosed your HIV status. And by "you," I mean me, but I know I was not alone in having that rather devastating experience.

The great equalizers, so to speak, have been ART and PrEP (pre-exposure prophylaxis, or medication an HIV-negative person takes to prevent acquiring HIV through sex). In 2016, a group of activists started a campaign to spread the word that a person with HIV who is on ART, and whose virus has been undetectable for at least six months, cannot transmit HIV sexually. They sloganized this concept as "Undetectable Equals Untransmittable" (U=U). I suspect the first population to feel the impact of U=U was people in serodiscordant relationships; that is, where one person is HIV-positive and the other is not (in a sense, both partners in such a relationship are "living with HIV"). Understanding U=U provided a sound scientific and medical basis for serodiscordant couples to stop using condoms with each other if that was their mutual preference. In my case, my HIV-negative husband and I were able to begin having unprotected sex safely. When he and I first met, in 2000, he had friends who urged him to dump me because of my HIV status. His parents were particularly concerned, and not unreasonably. He assured me I was not "getting rid of him" that easily—but in fact, we continued to use condoms for many years.

Beyond the context of couples in committed relationships, however, I don't think HIV-negative people—for the most part—were banging down the doors to have condomless sex with HIV-positive partners. In my experience, however, PrEP did in fact change that reality, and dramatically so. While the first PrEP medication was approved in

the United States in 2012, it took a number of years for PrEP to really catch on. You may remember the years of Truvada shaming, when some gay men referred to PrEP takers as "Truvada whores," equating the prevention strategy with sexual indiscretion, aka being a slut. Once U=U took off, however, there was an interesting synergy between U=U and PrEP. A whole new population emerged, particularly among gay men and people who are trans (women and men alike), comprised of those who were living with HIV and undetectable on ART, and those who were HIV-negative and on PrEP, who were interested in interacting sexually with each other.

This advent of U=U and PrEP has created a context in which sex, love, and dating with HIV over 60 today has a much greater range of possibilities, and even probabilities, than it had even 10 years ago. And this is where I get into potentially salacious territory about my own experience as an older—perhaps I may be so bold as to say "much older"—sexually and emotionally available gay man living with HIV over 60. To put it bluntly, and with no scientific or medical data to back me up (well, not that I've looked for any, frankly), I have found that older gay men—particularly older gay bottoms—who are living with HIV and are undetectable on ART, are veritable magnets for younger gay men—particularly younger gay tops and vers tops—who are HIV-negative and on PrEP. Many of the latter appear to believe that many of the former "make better bottoms," and I am certainly not going to argue with them on that score. (I told you this might get salacious.)

But enough of my own personal cotton candy factory. I want to turn now to some stories I've uncovered, on social media and via email, of people with HIV over 60 who are in various kinds of sex, love, and dating situations. This is the "community perspectives" part of our program, you might say. Communications have been lightly edited.

A friend of mine in New England, age 62, tells me she has been monogamous and married for some 25 years. *I probably acquired HIV around 1984. I was diagnosed somewhere around 1986 or 1987. It took a decade to become an AIDS*

patient (my lowest CD4 count was 7). I struggled with notions of love and sex way back then, thinking I would never have them in my life again. Turns out I did find a love and sexual relationship, with someone nine years my junior, and HIV-negative. And then later, love and sex and pregnancy, a baby, marriage, and another baby, all in the relationship with my husband (seven years older than me), also HIV-negative. So now we are an old married couple with an almost empty nest (younger son has another year of college to go), and to be extremely honest, we have practically no sex life anymore. Just cuddling. And I am happy with that—in the real world. Of course, in fantasy land, I would be wildly sexual with someone and enjoying that...but I am very rooted in what is actually happening, rather than pining for something else.

I love that story. And this from a longtime HIV/AIDS activist in Brookfield, Illinois, Roy Ferguson, who wrote to me about his life with his partner, Michael Winkfield, also an activist. *I am 70 and my partner is 63. Both U.S. military veterans. I did two and a half years before I was discharged in 1972. He was 21 years in the Air Force, 14 years in NATO, and was discharged in 1997. We have been together four and a half years. Both of us are HIV-positive.* Roy is on the board of directors of AIDS Foundation Chicago.

I posted a call for comments in a number of HIV/AIDS-related Facebook groups. A woman in the United Kingdom commented: *Well, I have no experience about dating over 60 with HIV, but lots about love and sex, as I am 69 and still with the person who passed HIV to me (he is 70). We have been together since 1985, long before HIV came into the picture. So, no experience with dating at all, but certainly about love and the challenges and sex, now and then.*

Not everyone has such a rosy story to share. A man in Mendocino, California, commented: *I'm 60. I've been positive for 25 or more years. I find dating to be extremely difficult at 60. It's difficult to meet anybody, and when you do, in today's world they're often a long way away. You start off with some long-distance relationship that generally ends up going nowhere. I find it difficult to relate to people that I am positive, as they tend to shy away after that. And loneliness is such a drag.*

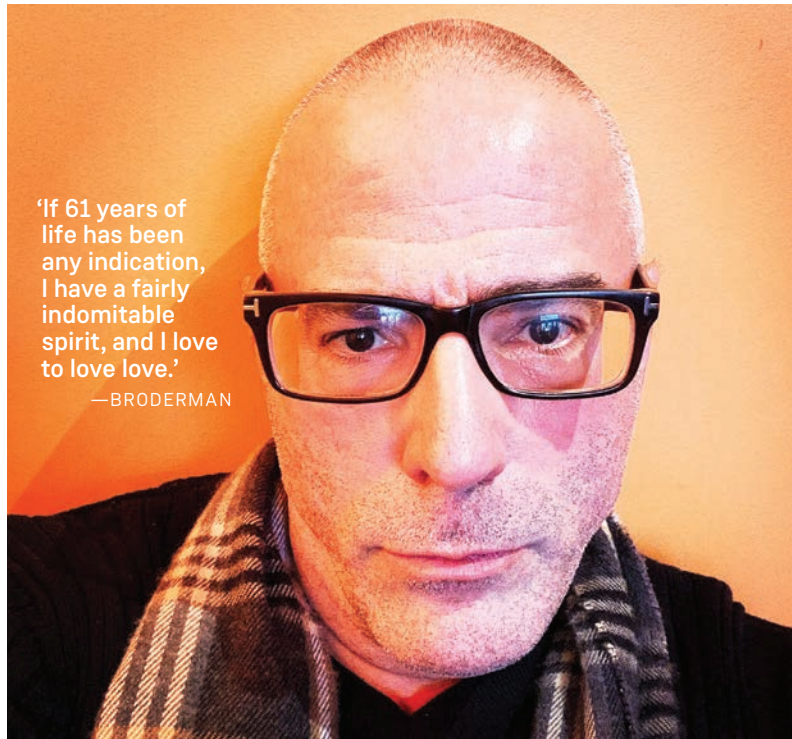
The comment by the Facebook group member in Mendocino reminds us of the dark places where we may find ourselves more frequently as we get older. A 2017 study by researchers at the University of California San Francisco (UCSF) participating in the HIV Over 60 Cohort Study found a significantly greater burden of psychiatric symptoms among people with HIV over 60 compared to their HIV-negative peers in the same age group. These symptoms included more frequent agitation, depression, anxiety, apathy, irritability, and nighttime behavior disturbances.

As we wrap up here, I can bring this part of the story back to my own experience. Yes, I like to focus on what a boy magnet I am, and on my gratitude for all the young gay men who are HIV-negative on PrEP and think that my status as a gay man over 60 with undetectable HIV makes me a “better bottom.” But if the truth be told, facing my divorce as who and what I am is freaking me out. I make my living as a freelance writer. I sing for my supper, as it were. No biweekly paycheck. No employer paying for my health insurance or contributing to my retirement savings. None of that is HIV-specific, of course; but add HIV to the mix, and the whole thing becomes that much scarier.

I've spent 30 years telling people I was fine. In the early '90s, the founding chairman of amfAR (The Foundation for AIDS Research) Mathilde Krim herself told me that if people like me could hang on just a few years more, there would be lifesaving medications for us. And of course, she was true to her word. Even during COVID, when friends urged me to go to the front of the line for vaccinations or boosters, I would patiently explain that I don't get to go to the front of the line, because I am not immunocompromised. I have lots and lots of very healthy, happy, functional T cells. And yet....

I wrote a poem once about getting blood drawn for my labs. It starts:

On command I make a fist, hold it like a little boy facing off against the schoolyard bully (holding back hot tears—ain't affeared o' nuthin').



That poem refers to the “before times”—before effective ART. The speaker in the poem, who is of course an “autofictional” me, is in fact afraid. And now, I'm afraid again. I can't quite believe this run of amazing luck and incredible good fortune is going to continue indefinitely. I mean, HIV or no HIV, I'm going to be 70 (if I'm lucky), and then (if I'm lucky) 80, and then... who knows?

I guess what I'm saying is that, thanks to the miracles of modern science and medicine, people living with HIV over 60 face the same basic dilemma as everyone else over 60—impending mortality, time's winged chariot hurrying near. But again, those pesky cataracts: concrete evidence that maybe my friends who tell me to get to the front of the line because I'm immune compromised—maybe they have a point. I hate to admit it, I hate to acknowledge it, I hate to accept it—but that doesn't make it any less true.

Have I strayed too far from the topic of sex, love, and dating? Wasn't this supposed to be a fun, funny, lighthearted piece about how aging with HIV these days is barely any different from aging without HIV? Well, if so, maybe I've

failed. Wouldn't be the first time. Perhaps I'm just breaking through my denial. I'm pretty sure there is sex, love, and dating in my future. Well, there's already sex; I mean, a leopard can't change its spots that easily, right? As for dating...do people actually date anymore? I have Netflix; let's just get some takeout and chill. As for love, well, I'm going through a rough patch, but if 61 years of life has been any indication, I have a fairly indomitable spirit, and I love to love love. Maybe this time it will be somebody my own age for a change. Maybe somebody with HIV for a change. Although younger is fine, and older is fine, and HIV-negative is fine. It's all fine. Maybe that's the real bottom line. As I like to say, as long as you're alive, everything's going to be fine, one way or another...isn't it? [PA](#)

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This time for Alexandra

Transgender actor, activist, and teacher **Alexandra Billings** talks with editor-in-chief **Jeff Berry** about her new memoir, and how there are gifts in chaos

PHOTOGRAPHY BY MARK HARVEY

I feel a kindred spirit in Alexandra Billings. We both were bullied in elementary school, came of age in Chicago in the early '80s, danced on some of the same dancefloors, probably hooked up in some of the same alleyways, yet somehow survived the AIDS epidemic.

In her new book with co-author Joanne Gordon, *This Time for Me: A Memoir*, Alex's story of survival and her unique journey from sex worker to performer to actor to teacher will resonate with many of us. We overcame seemingly insurmountable obstacles, toyed with death, and endured endless trauma and pain. Yet here we are. Alex exemplifies to me the qualities it takes to be a survivor: grace, humor, empathy, and truth-telling. Her unflinching look at her own struggles teaches us that, yes, we are made of stardust, and indeed anything is possible.

Just coming off of playing the role of Madame Morrible on Broadway for the acclaimed show *Wicked*, Alex is probably best known for her role as Davina on the Emmy award-winning TV show *Transparent*. I sat down with her recently to discuss art, AIDS, and the teachers in her life.

JEFF BERRY I want to acknowledge the very difficult time we're in in this country and the world right now. I saw your heartfelt post the other day talking about how there's no safe space for you. It really made me think about and acknowledge my own privilege. I also want to thank you for your videos and posts on social media [during the pandemic shutdown in 2020]; how wonderful they were for me, and I'm sure a lot of other people. You're on your balcony clapping for people who had masks, shaming those who didn't. It was a scary time, and you helped lighten it up. So, thank you.

ALEXANDRA BILLINGS: I'm so glad. It saved my sanity. I really don't know what I would have done without

social media; I really think I would have lost my mind, because I still love it. It's such an outlet for creativity for me. And this whole live thing where you can converse with people is just extraordinary to me. I mean, when you and I were little, we didn't have any communication [with] any other LGBT people on the planet, let alone you'd be able to see them. I know that this new generation is like, 'What are you talking about?' But for us? It's extraordinary. Social media just opened up a portal I never dreamed possible. And this was our second plague. This was the second viral plague this queer generation has been through so I was already triggered.

JB Thank you for sharing your life with us in this incredible journey

you take us on in your book. I know it'll be instantly relatable for many in the queer community, especially the Chicago theater and queer community. And me personally. There are so many familiar places and faces. I came to Chicago to DJ at the Bistro and you have the scene where you're on the Bistro dancefloor. You mention TPAN [publisher of POSITIVELY AWARE] in the book, and Ross Slotten [who] has been my doctor for over 25 years.

Oh my God, that's incredible!

JB And I was bullied growing up, like many gay men and trans people. So, reading about all of this trauma in your life, it resonated with me. But then thinking about collective trauma and trauma in our community, and your post the other day got me thinking. I'm a white cis man, and I quickly learned that if I assimilated, there was a place for me. But you didn't have that option, right?

Well, it's an interesting question for the trans community, because some of us can assimilate and some of us cannot. And the only reason that that's true is because... remember, gender identity is the construct, meaning it's an idea. It's a collective decision. I always talk about gender the way I talk about my recovery meetings, because when I go into my recovery meetings, we're all sitting in a room, a bunch of drunks

and drug addicts and prostitutes, and we're all talking about recovery, and I remind everybody, this isn't a thing. It doesn't exist. What I mean is, there's no head of this organization. Nobody's the president, nobody's keeping this together. Nobody's organizing it. It's just a bunch of people who got together in a room and said, *You have a similar experience. How are you dealing with it?* And so we all make up our own rules.

The same is true with gender. All of us as a country got together in one room—say the United States of America is one room—and we all said, *Okay. So how do we do this thing, this mating thing and love thing?* And we all made up the rules. It's not true—it's just what we've decided. Because we've decided now in the 21st century what gender is supposed to look like. Remember, in the 17th century, it looked very different than it does now. In different countries, it looks very different than it does in America. But since we're talking about this country, because we have made a collective decision as to what it looks like, what it sounds like...there's a whole bunch of people that [got] left out. Because the people that actually did the organizing [were] a white cisgender patriarchy. They did it in the way that they felt safest, they felt most seen, and they could keep their power. So, when you're talking about assimilation, what you're actually asking me is, how best can you fit into the idea that the cis white male has of you? And when you ask me that question, I go, *I have no idea*. Because I'm not that person. So, I don't know. That's really all assimilation is, like your ability to assimilate is easier. It's not easy, but it's easier for you, more familiar to you, because you're closer to that icon than I am. I'm much farther away. So, for you, it just makes more sense. So that's true. Anybody in the trans community, anybody who's Brown,

anybody who's not that icon, the farther away they get, the harder it is to assimilate.

JB Yeah. Well, it makes perfect sense when you explain it. You describe being horribly bullied at school, and your girlfriend at the time, Cin, helps you and takes care of you, and she says, *"You don't have to use your fists, Scott. That never solves anything,"* she comforted in her easy tone. *"Peaceful resisting doesn't make you a coward. It makes you kind."* I never forgot her advice.

You know, it's funny you should bring her up. I just spoke to her, strangely, about a week ago. And we were talking about the book—she's a poet now, and very well known in her poetry circle—a very, very well-known poet, actually, and has written several books. And we were talking about writing a book and I said, 'This was a nightmare for me. This is a nightmare. This was not fun. It wasn't joyous. I did not ... I did not enjoy this. It was very difficult for me to do. I'm glad it's done. And now I'm enjoying it. But the process was very difficult, because I'm not a writer.' And she said, 'No, no, no, no, no, Alex. All of us write, everybody writes, and I don't know anyone who writes something personal that enjoys doing that, unless they're talking about how fabulous they are, and that's not really descriptive writing. So that's true of everybody on the planet. Don't take away the gift of you being a writer simply because you've had a hard time writing.' I thought that was really interesting. Hemingway, I think, said basically the same thing—Tennessee Williams too—that they were these prolific writers, and yet they were like, *'Blech! God, I'd rather be a beggar!'*

JB You start out the book with, "I lie." Why was that important to you?

I know. I did that purposefully. Because I have to be honest with myself. If I don't speak out loud about the elephant in the room for me, it all becomes about the elephant in the room and I can't concentrate. I do it in class all the time. One of the first things I remind my students is, nobody can teach you acting. It's bullshit. And it's a sham. Listen to nobody. If anybody tells you





they're an acting teacher, run screaming from the room. It's a ridiculous thing to say. Because you can't teach art. You either do the thing with relish, or you don't want to do the thing. That's it. I can teach you technique. I can teach you how to specify. I can remind you when you're full of shit, because I'm a liar. So, I understand other liars. But that's the only thing I can do. So, I wanted to start the book off—and that was really hard, starting the book off—but I wanted to talk to people the way I talk. And one of the first things I always preface any story with is *Alex, tell the truth*. If you're gonna tell this story, tell the truth, because you're a liar. So, I wanted to warn everybody before I started. And you know, it's funny because I wrote stuff, and because Chrisanne has been in my life since I was, you know, 14 years old, I would write it and then hand it to her and go, 'Did this happen, or is this a Bette Davis movie? Like, which is a Bette Davis movie?' And she would read it sometimes and go, 'Mmm, no, that's a movie, honey. You didn't... that didn't happen to you.'

JB We all have angels who come into our lives. You're an angel in my life. But I'd like to talk about your dear friend, Joanne Gordon, about whom you write, 'She

had the courage to tell me the truth. And I really hated it.' So, how did it come about that she became your co-author? Did you have the material and think, *Oh, I need someone to help me get it down?* Or did she approach you and offer her help? You don't really talk about it in the book, but maybe that's the way you want to leave it.

Oh, no, please. She and I met at California State University in Long Beach when I went to go get my master's degree. I actually never went to college, and I didn't know in order to get a master's degree, you had to have an undergrad degree. I met Joanne, who was the chair of the Theatre Department, and I told her what I wanted to do and she said, 'Well, let me see you teach.' So she hired me as just a teacher, and she watched me teach and she loved it, and she said, 'Yeah, you should go do the program, you should absolutely do that.' So, she went into the office of the big cheese. And they had a contract that was a minority hire for one year. And she said, 'I'm going to get you this contract. And if I can get you this contract, and you teach for one year, I can possibly get you into the MFA program.' And I said, 'Great.' So, she goes into the office and says to the old white

cis dude, 'Listen, I have this Brown transgender lady,' and she lists my credits. And he laughed at her, literally laughed her out of the office.

Not to be deterred, she waited another year for the contract to come up again. And she walked back into his office and said, 'Okay, look, I have the same person here, she really wants to study here, and if you don't give her this contract, I'm going to the press.' And he went, 'Oh, okay, never mind.' And then she came to me, and she said, *I need your undergrad degree.* And I said, 'I've never been to college, what are you talking about? I'm just an ex-hooker from Inglewood. What are you talking about?'

JB She didn't know.

No! And she said, 'Oh, god, Alex, I don't know what we can do.' So she took—because remember, I've been working since I was seven, literally—and she said, 'I'm going to take all of your work. And I'm gonna put it like it's college and put it towards an undergrad degree and see if they'll swallow it.' And they did, and so that went towards my undergraduate degree. I went for three years to get my master's degree and studied under Joanne, and what Joanne taught me was invaluable. One of the great things she taught me was that I was a good student. And that changed everything for me. It shifted everything for me, because I realized I wasn't stupid, I wasn't an idiot, and that I could learn. She said, 'Stupid people are not curious. They don't want to learn any more. They don't want any more information. They have everything they need right in front of them.' As I started to write this book, I thought—and she's written several books before, she's quite prolific in the Sondheim circles—I need somebody that's gonna keep me honest, that's going to direct the story, like, tell it linearly, because that's not the way my brain works—I work in the abstract—and also who I trust implicitly. And that was Joanne. There was no second guessing, it was her.

JB I love the journey from your childhood, your life experiences, and performing cabaret and acting in theater and film and television. But it sounds like your real passion, and what you eventually realized, is that you are a teacher first. You have this beautiful passage about art. You're talking to your students, and you write,

'Hello, Angels.'

And feeling my confidence kick in, I continued.

'I have no idea what we're going to do. But I know whatever it is, we're going to move through it with kindness, grace, and compassion for each other. I'm not going to treat you as if you don't know how to act. I couldn't care less if you know how to act or even if you want to. It's not really what I teach, anyway. I'm going to treat you the way I'd like you to treat me, and hopefully, before we leave the room, we can all do a little better job out there in the universe. So, we can take everything we've learned in here and give it away to the stranger we've yet to meet. And that's art, I think.'

And then you go on to write, *'I began to understand that art isn't about winning awards. I explored the notion that art is a gift we all have and realized that everyone's story is worth telling. Art is not just for the shiny people in the front row.'*

I think that's so important for people to know, that their story is important. And we all have different stories. A lot of the work I do is about helping long-term survivors of HIV share their stories. Because I feel like

even though our stories can be very different, there's a common thread of humanity that's woven throughout each of them that binds us together.

Well, I think you're absolutely right. And you know, the book, before the actual life journey begins, there's an anecdote in the very beginning of the book, which is me at the Golden Globe Awards. And I did that purposefully, too, because I wanted the very first thing to be this sort of image of shiny Hollywood, and the end to be something else. The last page of the book is a complete turnaround from the first page. And for me, the book is about the teachers in my life—those moments when, even as low as I got, where I had to stop and go, *I think I'm supposed to learn something.* I mean, most of the time, even if that were true, I would just skip off into the distance and pretend it wasn't happening. But the older I got, the more sober I got, the more grounded I became, I started to really listen for those moments. There's a Buddhist philosophy that says, when the student is ready, the teacher appears. So, you have to really be open, and you have to be ready for your teachers and your guides to come forward. We spend a lot of our time sort of cursing, you know. 'What? Why isn't this working out?' And, 'My life is crap!' There may be a lot of reasons for that. But one of the reasons that that may be true is that we're not *listening*. We're not listening to the humans in front of us, we're not paying attention to the events at hand, we're not taking into account that there are gifts in chaos. So, this idea that I became a teacher was sort of true for a while for me. And now what I realize was that I've always been a teacher. And now I'm living in it and revealing it—that really is the only action I'm taking.

JB Yeah, that's true, because we can teach the wrong thing sometimes by our behavior and our choices. And we're always learning, hopefully. So, then there's Chrisanne, who you met in 1976 and married twice. I would be remiss not to mention her. You've both been there for each other—that's true love. There're so many things... you're just so candid in this book. I was really surprised to learn and read about your whole relationship with Larry [Kramer]. And I shouldn't be surprised, but it's just something I didn't know about you. There're a lot of things I didn't know about you, but you put it all out there. And you're probably thinking, *Well, actually, no, I didn't put it all out there. There are a couple things I left out of the book.* But I think that's very courageous. But maybe it's the only way you could have done it?

Yes, it is the only way I could have done it. And that's why I started the journey off with, 'I'm a liar. So, now I need to tell the truth.' I spent so many years—I don't... I'm done, I don't care anymore. Lying takes an enormous amount of energy, and I just don't have it. I'd rather expend my energy on my wife, or going to the beach, or teaching, so I just don't do it anymore. And, interestingly, I told Chrisanne, who's an extremely private person, which is hilarious being married to me, because I'm like Bozo the Clown. So, I said to her, I'm gonna write this book. I'm not going to censor anything. I'm going to write absolutely everything down. And if there's anything you don't want, I don't care what it is, you tell me and out it goes, no questions asked. She took out two lines from the whole book, just two lines. And so, for me, when you're talking about courage, *that* for me is courage. Because I have a big spotlight on me. That's something I've chosen to do. She did not. She just fell in



love with me. And all of a sudden, all this shit started to happen, and she's like, 'Really? Really? You're kidding. *Can't we just read?*'

When we were living in Chicago, I was on the second story of our house looking out and it was dead of winter. We had a truck, a flatbed truck that we used to drive, and she's got those little scrapers that scrape ice off your window, but they're the little ones, we couldn't

'That's why I started the journey off with, "I'm a liar. So, now I need to tell the truth."'

afford the big ones. It was a little one, and she's scraping ice off, and you know [makes a blowing wind sound] she's about four feet tall. She's a tiny person scraping ice, and weeping, with her sad hat, and her big Alaskan coat. And just this, you know, a little bit of face, pie face, but just tears turning into ice cubes, rolling down. And I said to myself as I'm staring out the window—*we're moving*. That's it. *Piss off, Chicago weather!* So, I went in the next day and I said, *Honey, we got to get the hell out of here. This is crazy. Besides my career's going nowhere, let's go to California.* So that's been our marriage. I just like to come up with ideas and go, 'Hey, I've got an idea! Let's ride a camel.' She's like, alright. So, when you talk about bravery, you're talking about courage, and I always think of her, what she's done.

JB A different type of courage for sure.

Oh! The other thing I want to tell you is, speaking of my wife, when I was first diagnosed with AIDS, 30-something years ago, I had seven T cells, which means nothing to the children now but [it did] back in the day. When I was diagnosed, [my doctor] Ross Sloten literally said to me, 'I don't know how you're alive. I don't know why you're alive.' I had hepatitis A, hepatitis B, I had AIDS. I had thrush. I had neuropathy. I had the beginnings of lesions. It was crazy. It made no sense, how I was still walking. And so we went through the usual, you know—I *can't believe this is happening and what are we going to do and*

what happens next. And one day—because this is how [Chrisanne's] brain works—she's like *solution, solution, solution.* One day, I'm crawling up inside myself, ready to die, and she said, 'Look, if you're going to sit here in this house and curl up into a little ball and blow away, I'm not going to watch it. I'm going to go. So, you've got to figure out what you want.' And I said, 'Well, I don't want to do that. But what is there to do?' And she said—I'll never forget this—I found an organization called TPAN. They're like 15 minutes away, and they have meetings. And at the meetings, there are doctors that you can apparently talk to. And you can be around other people that were just diagnosed, that are just as frightened and scared as you.' And I said, 'I can't go to one of those things, are you nuts? I'm not gonna do that.' Then I said, 'And come with me!' She said, 'No, no, no. This is something you should do. And something you should do by yourself.' And walking into that first meeting, I don't remember who the doctor was, he was sitting in the center. And there was this huge circle of all of these people. And all of us looked exactly the same. It looked like we belonged to one family. All of us were just as sick. Just as scared. And we were all the same age. And it changed my life. TPAN changed...I would be dead without that place. I would be dead. It changed my life. And I never stopped going back. And it was because of Chrisanne.

“That’s been our marriage. I just like to come up with ideas and go, ‘Hey, I’ve got an idea! Let’s ride a camel.’ She’s like, alright.”



JB That's so beautiful. So wonderful. You know, TPAN saved my life too. There's another commonality. I know our paths had to have crossed many times in the course of the last 30, 40 years. But it's nice to finally come back and join together again for this. So, thank you for taking the time.

Absolutely.

JB I want to talk just a little bit about the scholarship program.

The scholarship is called the Alexandra Billings scholarship. It's funded through the USC [University of Southern California] School of Dramatic Arts here in California. We designed it specifically for LGBTQIA artists, young artists that want

to come and study acting at USC, so we could give them money because tuition is insane. But I specifically wanted it for queer people, non-binary people, trans people, so that we could get those voices heard. And it has done really well in the sense that it has attracted people. Even the people who just come into the program now—we still need many, many more—but we have a much higher percentage of queer people that are coming into the program, not necessarily through the scholarship, but coming anyway because of the scholarship, because they feel that they are welcome. It's the only scholarship that I know of, I may be wrong, that is named after a mixed race trans woman who's living with AIDS. I don't know of another scholarship like that in our country. It sends a big message not just for the LGBTQIA artists, it sends a message to the cis humans, to the patriarchy, to the white humans, to the people who are not marginalized. Not only are we here, but we stand for each other. We are creating safe places for each other because as I said, many places for trans people are cis created. That's not what this is. I created this for us, to us and by us, so—give money!

JB That's what we hope to be able to help promote as well. And you know, I wanted to ask you about Schmengie, but I can just direct people to Schmengie, Inc. So that's just a word that you use for everything.

It's a word I made up when I was about five or six years old when I couldn't think of the word, and so when Chrisanne and I wanted to do a production company, I said, *well, let's think of something that means everything,* and I thought of Schmengie, because Schmengie can mean anything. So Schmengie, Inc. is about all things are possible.

JB One last thing, just a favor.

Oh, yes. Remember, that you are made of stardust. And because that is true, anything is possible. **PA**

This interview has been edited for length and clarity.

This Time for Me: A Memoir by Alexandra Billings with Joanne Gordon is now available at Amazon.com or wherever you like to buy your books. GO TO schmengieinc.com for more information about Alexandra Billings and the scholarship program.



WHEN HIV THERAPY FAILS

Some basic information from U.S. treatment guidelines
BY ENID VÁZQUEZ

First, the good news: People can stay healthy for decades on the same HIV medicine.

My friend Joe just went off Kaletra after having been on it for about 15 years. Kaletra is a medication that's so outdated, we no longer even include it in our annual HIV drug guide. We list it under "legacy drugs." He had taken other HIV medications before—starting with AZT in 1987. Joe didn't have any problems with Kaletra, but his doctor said, "we should think about a change." After a couple of years, Joe took the plunge. He has no problem with his new regimen of Pifeltro and Tivicay, except for the cost difference. But that's another story.

There are many people like Joe, but others aren't so lucky when changing their drug regimen. Sometimes, for any number of reasons, an HIV regimen starts to fail. That's when it no longer does what it's supposed to do—most importantly, keep HIV viral load down to undetectable levels.

People may then need to switch to a new drug regimen. (While not recommended, many people like to use this as an opportunity to take a break from their meds.)

Whether people are taking HIV therapy for the first time or switching to a new one, there are guidelines from the U.S. Department of Health and Human Services (DHHS) to help lead the way. There are also guidelines from the International AIDS Society-USA (IAS-USA).

Reasons for changing a drug regimen can include side effects, drug-drug interactions, and even such things as cost considerations.

But the biggest issue here is usually drug resistance. Not a person's resistance to taking medication—especially over a long period of time—but to the development of drug resistance in a person's HIV.

Revenge of the mutant virus!

Here we come to a scary word: *mutation*. It sounds like something out of a horror film.

But all it means is *change*. There's a change to a person's HIV genome—the genetic structure of their virus. (As a living organism, HIV has its own set of genes, like we do. Weird, huh?)

HIV drugs control the virus, keeping a lid on it. But the virus resists and fights back. This can cause mutations that lead to drug resistance taking place in the virus—as a result, the medications may now no longer work as well. There are different mutations that can develop due to the different drugs. Moreover, these changes might also affect the entire drug class for that medication as well (cross-resistance). And depending on the resistance pattern or the amount of resistance found, switching regimens may be necessary and, more importantly, pose a real challenge.

This is usually called "virologic

The number one goal of HIV drug therapy is to get a person's virus down to undetectable levels.

failure”—meaning that the medication's control of the virus has started to fail. Viral load is no longer undetectable.

Looking at it another way, maybe we should say “viral success,” since HIV starts winning its struggle against the drugs. *Revenge of the mutant virus!* Indeed.

Undetectable

Again, the number one goal of HIV drug therapy is to get a person's virus down to undetectable levels. “Undetectable” means too low to be picked up by a viral load test. These tests can measure down to 50, 40, or 20 viral copies per mL (milliliter) of blood, depending on the test being used.

When there are fewer than 20, 40, or 50 copies, this is called “undetectable viral load” for that particular test. Undetectable viral load, however, is considered less than 200. (There's an older test that measures down to only 200 copies, but it's rarely used today.)

When viral load goes to 200 or above, that's when drug resistance testing can be called upon to see what's going on—what mutations can be found—and can be used to help switch therapies if needed. Resistance testing is also done when someone is diagnosed with HIV, before they start any therapy at all, but those tests are looking for any transmitted resistance at that point.

Having detectable viral load is not an uncommon situation. DHHS guidelines note that, “After receiving an HIV diagnosis, about 75% of individuals are linked to care within 30 days. However, only 57% of persons who receive an HIV diagnosis are retained in HIV care. It is estimated that only approximately 55% of persons with diagnosed HIV are virally suppressed [have undetectable viral load] because of poor linkage to care and retention in care.”

The best way to prevent drug resistance is to take medication as directed—once a day, with or without food, and so forth. This is called “adherence.” (Adherence refers to other things as well, such as getting to doctor appointments.) The guidelines provide extensive information on helping people with adherence. Adherence is known to be difficult in HIV. Since the guidelines are written for medical providers, the panel of experts writing them examine this aspect of providing care.

Measuring the mutants

According to the DHHS guidelines, “The first steps for all patients with detectable viral loads are to confirm the level of HIV viremia [repeat the viral load test] and assess and address adherence and potential drug-drug interactions (including interactions with over-the-counter products and supplements) and drug-food interactions.”

People who “do not typically

require a change in treatment” are those whose viral load is between that lower 20, 40, or 50 number and fewer than 200 copies: “Although there is no consensus on how to manage these patients, the risk that resistance will emerge is believed to be relatively low. Therefore, these patients should continue their current regimens and have HIV RNA [viral load] levels monitored at least every three months to assess the need for changes to ART [antiretroviral therapy] in the future.”

Resistance mutations can emerge as medications stop working against the virus. The longer this goes on, the greater the chance for drug mutations to develop. Another thing that can happen is that when medications are stopped, mutations may seem to “go away” on a resistance test by hiding out, invisible to the test. This is referred to as “archived” resistance, like putting away a folder in a filing cabinet, hidden from view. Or put away in Google docs, if you prefer. This is one of the reasons why getting a treatment history is important.

For people with viral loads between 200 up to less than 1,000:

“In contrast ..., those with levels that are persistently equal to or greater than 200 copies/mL develop drug resistance, particularly when HIV RNA levels are greater than 500 copies/mL. Patients who have persistent plasma HIV RNA levels in the range of 200 copies/mL to 1,000 copies/mL are considered to be experiencing virologic failure, and resistance testing should be attempted, particularly in patients with HIV RNA levels [greater than] 500 copies/mL.”

The guidelines go on this way for viral loads above 1,000.

See the box “For treatment-experienced individuals who are experiencing virologic failure” for general principles from the DHHS guidelines (next page). While this section covers general information, the guidelines continue to discuss changing drug

regimens by discussing the current drugs and considerations for switching them and what to switch to. For example, “A new ARV regimen can include two fully active drugs if at least one has a high resistance barrier, such as the second-generation integrase strand transfer inhibitor (INSTI) dolutegravir (DTG) or the boosted protease inhibitor (PI) darunavir (DRV).”

There are several such statements under “Key Factors to Consider When Designing a New Antiretroviral Regimen.” Not to be confused with the heading “Antiretroviral Drug Strategies.”

Or check out “Table 11: Antiretroviral Options for Patients with Virologic Failure.” Also of special interest is “Table 5: Recommendations for Using Drug Resistance Assays.”



For treatment-experienced individuals who are experiencing virologic failure

Key considerations and recommendations from the HIV treatment guidelines of the U.S. Department of Health and Human Services (DHHS)

See glossary on page 25. See ratings based on clinical trials and expert opinion in the guidelines. GO TO clinicalinfo.hiv.gov.

Assessing and managing a patient who is experiencing antiretroviral therapy (ART) failure can be complex. Expert advice can be critical and should be sought in many instances.

Evaluation of virologic failure should include an assessment of adherence, drug-drug and drug-food interactions, drug tolerability, HIV RNA level and CD4 T lymphocyte (CD4) cell count trends over time, ART history, and prior and current drug-resistance test results.

Drug-resistance testing should be performed while the patient is taking the failing antiretroviral (ARV) regimen or within 4 weeks of treatment discontinuation. If more than 4 weeks have elapsed since ARV drugs were discontinued, resistance testing can still provide useful information to guide therapy, although it may not detect previously selected resistance mutations.

The goal of treatment for ART-experienced patients with drug resistance who are experiencing virologic failure is to establish suppression (that is, HIV RNA levels below the lower limits of detection of currently used assays).

A new regimen can include two fully active ARV drugs if at least one with a high resistance barrier is included (e.g., dolutegravir or boosted darunavir). If no fully active drug with a high resistance barrier is available, then every effort should be made to include three fully active drugs.

In general, **adding a single ARV agent** to a virologically failing regimen is not recommended, because this would rarely result in full viral suppression and, therefore, may risk the development of resistance to all drugs in the regimen.

For some highly ART-experienced patients with extensive drug resistance, maximal virologic suppression may not be possible. In this case, ART should be continued with regimens that are designed to minimize toxicity, preserve CD4 counts, and delay clinical progression.

When it is not possible to construct a viable suppressive regimen for a patient with multidrug-resistant HIV, the clinician should consider enrolling the patient in a clinical trial of investigational agents or contacting pharmaceutical companies that may have investigational agents available.

In patients with virologic failure, it is crucial to provide continuous adherence support before and after ARV regimen changes.

When switching an ARV regimen in a patient with hepatitis B virus (HBV)/HIV coinfection, ARV drugs that are active against HBV should be continued as part of the new regimen. Discontinuation of these drugs may lead to the reactivation of HBV, which may result in serious hepatocellular damage.

Discontinuing or briefly interrupting therapy may lead to a rapid increase in HIV RNA, a decrease in CD4 count, and an increase in the risk of clinical progression. Therefore, this strategy is **not recommended** in the setting of virologic failure.

Help with therapy

There's more than just talk about drugs in the guidelines. There's a lot about helping people with their medication regimen and other challenges in life. There's even an understanding that the term "adherence" has come to have negative connotations because of the pressure placed on people to be adherent. All of this is important whether treatment-naïve or treatment-experienced.

"Provide an accessible, trustworthy, non-judgmental multidisciplinary health care team," say the guidelines, the very first statement in Table 19—"Strategies to Improve Linkage to Care, Retention in Care, Adherence to Appointments, and Adherence to Antiretroviral Therapy."

And in the section's conclusion, they reaffirm giving support to people living with HIV: "Engage a patient who is struggling with adherence at any step on the care continuum with a constructive, collaborative, nonjudgmental, and problem-solving approach rather than reprimanding them or lecturing them on the importance of adherence. ... Tailor approaches to improve adherence to an individual's needs and barriers, for example, by changing ART to simplify dosing or reduce side effects, finding resources to assist with copays or other out-of-pocket costs (see Table 19) to maintain an uninterrupted supply of ART and access to clinicians, or linking patients to counseling to overcome stigma, substance use, or depression."

There are so many life situations that can affect a person's ability to take their HIV medication as prescribed and give them their best shot at avoiding drug resistance. The panel of HIV experts behind the guidelines, including community representatives, sensitively address these issues. This is probably even more important for the many providers who take care of only a few people living with HIV.

Help with adherence

Here are the suggestions from the guidelines under "Limitations to Treatment Safety and Efficacy: Key Summary of Adherence to the Continuum of Care":

- Linkage-to-care and adherence

Resistance mutations can emerge as medications stop working against the virus.

There's more than just talk about drugs in the guidelines. There's a lot about helping people with their medication regimen and other challenges in life.

to both antiretroviral therapy (ART) and clinic appointments should be regularly assessed.

- An individual's barriers to adherence to ART and appointments should be assessed before initiation of ART and regularly thereafter.
- Patients with ART adherence problems should be placed on regimens with high genetic barriers to resistance, such as dolutegravir (DTG) or boosted darunavir (DRV). Side effects, out-of-pocket costs, convenience, and patient preferences also need to be considered.
- Patients having difficulties with adherence to appointments or ART should be approached in a constructive, collaborative, nonjudgmental, and problem-solving manner.
- The approach to improved adherence should be tailored to each person's needs (or barriers to care). Approaches could include, but are not limited to:
 - Changing ART to simplify dosing or reduce side effects
 - Finding resources to assist with treatment costs to maintain uninterrupted access to both ART and appointments
 - Allowing flexible appointment scheduling
 - Assisting with transportation, or
 - Linking patients to counseling to overcome stigma, substance use, or depression.
- Multidisciplinary approaches to find solutions to ART and appointment adherence problems are often necessary, including collaboration with social work and case management (to the extent available). The clinician's role is to help the patient understand the importance of adherence to the continuum of care and reveal barriers to adherence, and link the patient to resources to overcome those barriers.
- A summary of best practice interventions to improve linkage, retention, and adherence can be found at a Centers for Disease Control and Prevention compendium ([cdc.gov/hiv/research/interventionresearch/compendium/index.html](https://www.cdc.gov/hiv/research/interventionresearch/compendium/index.html)).

That's not all, folks

There's way too much in the guidelines on these topics to distill here. Remember, however, that the guidelines are written to help guide medical providers. Although they are written clearly and straightforwardly, the language can be technical. See the glossary on the following page as well as the one at clinicalinfo.hiv.gov/en/glossary.

Still, how about a summary of the treatment-experience part of the guidelines? The summary paragraph for the DHHS guidelines section on "Management of the Treatment-Experienced Patient" serves as a good overview of what you need to know, listed here sentence by sentence:

The goal of treatment for ART-experienced patients with virologic failure is to establish virologic suppression.

The management of ART-experienced patients with virologic failure often requires expert advice to construct virologically suppressive regimens.

Before modifying a regimen, it is critical to carefully evaluate the potential cause(s) of virologic failure, including incomplete adherence, poor tolerability, and drug-drug and drug-food interactions, as well as to review HIV RNA and CD4 count changes

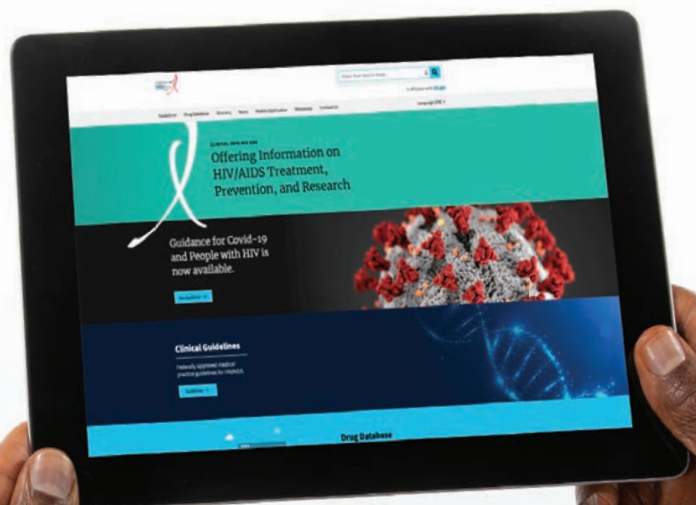
over time, complete treatment history, and current and previous drug-resistance test results.

If HIV RNA suppression is not possible with currently approved agents, consider the use of investigational agents through participation in clinical trials or expanded/single-patient access programs.

If virologic suppression is still not achievable, the choice of regimens should focus on minimizing toxicity and preserving treatment options while maintaining CD4 counts to delay clinical progression.

And if your eyes haven't glazed over yet, there's a huge section on drug-drug interactions you might be interested in. The biggest problems for HIV meds are covered there.

Get more HIV guidelines, from the International AIDS Society-USA, at iasusa.org.



TERMS OF ART

A TREATMENT GLOSSARY

active: in drug resistance, “active” means that a drug has activity against HIV, which in turn means that the drug can control HIV (as opposed to “resistant”)

agent: not a spy, but simply a drug or substance; HIV drugs are “agents”

antiretroviral: HIV is a retrovirus, so medications used for treating it are “anti-retrovirals”

ART: short for “antiretroviral therapy;” the term “highly active antiretroviral therapy,” abbreviated as HAART, is no longer used because most HIV regimens on the market today are highly active—in other words, very effective against HIV

ARV: the abbreviation for “antiretroviral”

assay: an “assay” is a test

barrier to resistance: some HIV medications have a “high barrier to resistance,” which means that they’re hard for HIV to develop resistance mutations against

BIC: abbreviation for the HIV medication bictegravir, the primary drug in Biktarvy

boosted darunavir: see *darunavir*; this HIV medication must have its drug levels boosted—raised—by taking it with Norvir or Tybost

clinical progression: refers to signs or symptoms of disease

continuum of care: the stages from HIV diagnosis to getting into medical care to getting onto treatment to establishing undetectable viral load

darunavir: the generic name of the HIV drug Prezista, which is also found in Prezcobix

DTG: abbreviation for dolutegravir

dolutegravir: the generic name of the HIV drug Tivicay, which is also found in Dovato, Juluca, and Triumeq

DRV: abbreviation for darunavir

HIV RNA: refers to the genetic material of the virus—what’s measured by a viral load test

hepatocellular damage: damage to the cells of the liver

investigational agent: a drug that’s still in research development

multidisciplinary: using the skills and resources of different workers and professionals; for example, doctors, pharmacists, and peer navigators

mutation: does not refer to a physical deformity, but simply to a change in HIV genes (its genetic code). Mutations may lead to drug resistance.

regimen: the drug or drugs taken for therapy; in HIV, multiple drugs can be taken as one pill that makes up the entire regimen (called “single-tablet regimens”—STRs).

resistance: “when a bacteria, virus, or other microorganism mutates (changes form) and becomes insensitive to (resistant to) a drug that was previously effective. Drug resistance can be a cause of HIV treatment failure.”—*Clinical Info*

suppression: lowering HIV viral load, especially to undetectable levels

viral suppression: see “suppression”

viremia: the presence of virus in blood

virologic: refers to “virus”; for example, “virologic suppression”

virologic failure: “A type of HIV treatment failure. Virologic failure occurs when antiretroviral therapy (ART) fails to suppress and sustain a person’s viral load to less than 200 copies/mL. Factors that can contribute to virologic failure include drug resistance, drug toxicity, and poor adherence to ART.”—*Clinical Info*

.....
CHECK OUT clinicalinfo.hiv.gov/en/glossary.

Testing and treating

Highlights from Virtual CROI 2022

BY ENID VÁZQUEZ

For the third year in a row, the **Conference on Retroviruses and Opportunistic Infections**—CROI—was held remotely via the internet. Tons of reports and presentations kept to CROI's high standards. Next year is the 30th anniversary of what is arguably the most important HIV research conference in the world. It would be especially great to get together in person at CROI 2023. Some cake would be in order.

Go to croiconference.org for more on the following presentations along with many others.



POLLYANNA R. CHAVEZ, PhD

Self-testing to help end HIV

"CDC estimates that one in eight people with HIV do not know they have it. One of the goals of the federal Ending the HIV Epidemic in the U.S. initiative, called EHE, is to diagnose all people with HIV as early as possible," said Pollyanna R. Chavez, PhD, an epidemiologist with the CDC's Division of HIV Prevention. "HIV self-testing is a key innovation being used in pursuit of this goal. HIV self-testing is important because it can help provide testing to people who may not have easy access to in-person prevention services, especially during COVID-19. To support the EHE, CDC created a program to promote and mail 100,000 HIV self-tests to three priority populations: Latin, Hispanic, and Latino gay and bisexual men; cisgender

Black women; and transgender women."

People had the option of ordering one or two tests, and the majority (76%) requested two. Of the respondents to a follow-up survey, 26% reported that they had never before been tested for HIV. In less than eight months, all the tests were mailed out to people in all 50 states, Washington, D.C., and Puerto Rico.

While it's unknown how many tests came back positive, the CDC report noted that, "This program highlights the demand for HIV self-tests, even reaching persons who never were tested for HIV. Clinicians, community-based organizations, and testing clinics should be aware that persons with preliminary positive HIV self-test results will require further testing and care."

Changes in HIV and STI testing during COVID

Another institution in a good position to gather data is Kaiser Permanente in Southern California, which is both a healthcare provider and an insurer. Serving 12.5 million in eight states, Kaiser's patients are racially and ethnically diverse.

Kaiser conducted an analysis of the electronic health records of more than four million participants over a four-year period. In

the three years before the COVID shutdown, HIV and STI testing had consistently increased. For the year after COVID hit, however, testing saw a reversal, and this may hurt public health.

"There were really dramatic declines in the diagnosis of HIV and chlamydia of more than 25% each," said Jennifer Chang, MD, of Kaiser. "We saw a smaller 7% decline in gonorrhea cases and a 32% increase in the diagnosis of syphilis compared to the three years before the pandemic. Because HIV and chlamydia are not often immediately noticeable in terms of symptoms in contrast to syphilis and gonorrhea, which often have symptoms that prompt patients to seek care, we believe that this data suggests, really, a widespread under-diagnosis of HIV, chlamydia, and gonorrhea and declines in testing for HIV and STIs can potentially have a really long-term impact on public health efforts to slow the spread of infections."

Asked how to reverse this setback, Dr. Chang said, "I think that an emphasis on primary care and really bolstering our support for primary care as much as possible, not just within Kaiser Permanente, but across all healthcare systems, is absolutely essential.

And while I can't speak to specific strategies, as this was more of an exploratory study, I think using telehealth and other modalities that maybe remove personal interaction in some ways and destigmatize the act of asking for an HIV test—if we can deploy those public health measures systemwide in the same way or in similar ways that we've approached COVID-19 testing, that would be an amazing approach."

Providing six months of PrEP along with self-testing

Using medicine to prevent HIV (pre-exposure prophylaxis, known as PrEP) can be burdensome—there's labwork to be done, multiple clinic visits, and more. One research team looked at providing six months' worth of PrEP at a time, along with HIV self-tests (HIVST). Their innovative strategy succeeded.

"Dispensing six months of PrEP with HIVST for interim testing at three months reduces the number of PrEP clinic visits in half without compromising HIV testing, PrEP refilling, or PrEP adherence," the team of researchers based in Seattle and Kenya reported. "HIVST to support PrEP continuation can enable models of care that require less frequent contact with the health system."

Less contact with the clinic also equaled lower cost, thereby helping to control another barrier to HIV prevention. See Abstract 146, *Six-Month PrEP with HIV Self-Testing Delivery Kenya: A Randomized Trial*.

Hormone levels with PrEP in transgender people

"Drug-drug interactions are not expected between gender-affirming hormone therapy and PrEP, primarily due to different metabolic pathways," said presenter Jill Blumenthal, MD, MAS, of the University of California San Diego.

And that's what her U.S. team of researchers found. "Serum hormone concentrations were not affected by [Truvada for PrEP] use, and there were no changes in the



JILL BLUMENTHAL, MD, MAS

perceived effect on [hormone therapy] in those taking PrEP.”

This was a larger group of individuals (172 trans men and women and non-binary people in the hormonal sub-study) and a longer period of time (three months) than has been seen with previous studies.

See Poster 990 and Abstract 84, *The Bidirectional Effects of Hormone Therapy and PrEP in Transgender Individuals*.

One shot to prevent pregnancy and HIV

Exciting early report: good news on a long-acting injectable for the prevention of both pregnancy and HIV.

How early are the results? They're from mice. Next, the product will be studied in non-human primates—the research is that early.

Still, the good news from these little mice is finding adequate drug levels for both PrEP and contraceptive medicine over three months, with no safety concerns.

The product studied was a biodegradable and removable in-situ (in its original place) forming implant (ISFI).

Two different HIV medications were used for PrEP evaluation—cabotegravir or dolutegravir. Cabotegravir was actually approved as a long-acting injectable PrEP medication by the U.S. Food and Drug Administration (FDA) late last year, under the brand name Apretude, taken as one shot every two months.

The contraceptive medication evaluated in the ISFIs were etonogestrel (ENG) or medroxyprogesterone acetate (MPA).

See Abstract 80, *Long-Acting Injectable for Prevention of HIV and Unplanned Pregnancy*.

HIV and syphilis go together

“HIV and syphilis are common sexually transmitted infections globally and in sub-Saharan Africa (SSA); however, most prevalence data come from clinical cohorts,” reported a research team based at Columbia University.

The group looked instead at population data and found that people living with HIV (PLWH) were more likely to also have an active syphilis infection compared to the rest of the population in their respective country. PLWH were 2.5 times more likely to have syphilis in Uganda, 3.7 times more likely in Zambia, four times more likely in Tanzania, and 5.9 times more likely in Zimbabwe.

“The high prevalence of active syphilis among HIV-positive persons from the general population and a considerable number of infections among HIV-negative individuals in four SSA countries indicates the need for consistent and frequent screening for syphilis among PLHIV and at-risk groups and improved access

to effective treatment for syphilis,” the Columbia team reported in their abstract (No. 141, *Presence of Syphilis and HIV/syphilis Coinfection in 4 Sub-Saharan Countries*).

“The findings from the study are unique because they're based on results from a nationally representative random sample from the general population of each country. Additionally, some possible interventions supported by this study include the increasing of dual HIV/syphilis testing, and partner notification for individuals diagnosed with syphilis,” said presenter Rose Killian, an MPH candidate at Columbia Mailman School of Public Health. “Among HIV-positive individuals, we did not find significant associations based on demographic categories such as sex, education, place of residence—urban or rural, or socioeconomic status. However, behavioral characteristics such as having two or more sexual partners in the past 12 months was significant among HIV-negative individuals. Older age, lower education, poverty, and being divorced, widowed, or separated were associated with syphilis.”

Hanging on to tenofovir—the NADIA trial

Tenofovir maintained its effectiveness—despite the presence of drug resistance—for people needing a new HIV treatment regimen.

The NADIA clinical trial research team hopes its new longer-term data will convince the World Health Organization (WHO) to change its guidelines once and for all. WHO did not change its guidelines when NADIA previously found that keeping tenofovir in a regimen despite the

presence of some drug resistance was non-inferior compared to switching it over to zidovudine (AZT), as WHO guidelines recommended. That was 48-week data.

But this year, 96-week data reported in a latebreaker abstract showed that keeping tenofovir onboard was actually superior to switching.

The NADIA study also found that the protease inhibitor darunavir (brand name Prezista, also found in Prezcofix and Symtuza) was non-inferior to the newer gold standard dolutegravir in the WHO recommendations.

“Dolutegravir and darunavir-based regimens maintain high levels of viral suppression at 96 weeks in second-line therapy, even when used with NRTIs [nucleoside reverse transcriptase inhibitors, like tenofovir and zidovudine] that have no predicted activity. Dolutegravir resistance does not increase substantially during later follow-up. Tenofovir is superior to zidovudine and may protect against dolutegravir resistance,” the NADIA team said in its conclusion. “Guidelines that recommend a switch from tenofovir to zidovudine for second-line therapy in the public health approach should be reconsidered.”

NADIA stands for “Nucleosides and Darunavir/ Dolutegravir in Africa.” It was the first controlled clinical trial to test the WHO recommendation on switching tenofovir. See statement from Dr. Nicholas Paton, on page 30. WHO guidelines are important around the world, while HIV treatment in the U.S. follows guidelines from the Department of Health and Human Services (DHHS) and the International AIDS Society-USA. See Abstract 137. [GO TO doi.org/10.1016/S2352-3018\(22\)00092-3](https://doi.org/10.1016/S2352-3018(22)00092-3).



THE DAPIVIRINE RING VS. THE FDA

This PrEP method is still a desirable option in the U.S. for cisgender women

BY ENID VÁZQUEZ

I remember years ago when the dapivirine vaginal ring showed a 50% drop in HIV infections. *Wow, I thought. That's great. Cutting the risk of HIV in half!*

But is that good enough? Not, apparently, for the U.S. Food and Drug Administration (FDA). At

least, not in a country that offers women 99% protection against HIV with Truvada for PrEP and with the new

long-acting injectable Apretude—just one shot every two months. To put a new drug on the market, the FDA wants to see something as good as, or better than, what's already available.

Yet, the U.S. is far behind in PrEP use given the availability, such as it is. HIV prevention workers in the United States, such as those at the Centers for Disease Control and Prevention (CDC), continue to struggle to leverage the promise of PrEP to help end the epidemic.

And both community advocates and providers say there are other issues to consider when weighing the ring—a high level of effectiveness is not the be-all and end-all for prevention.

Stopping the ring

In December, the dapivirine ring was withdrawn from FDA consideration for a New Drug Application (NDA) by the nonprofit International Partnership for Microbicides (IPM). According to IPM, "This decision was made following feedback during the agency's review that current data are unlikely to support U.S. approval at this time given the context of the current HIV prevention landscape for women in the United States." IPM had filed its NDA on March 9, 2021.

"IPM is disappointed that the HIV prevention portfolio in the United States will not include the monthly dapivirine ring as an option for women who cannot or choose not to use systemic PrEP but still need a way to reduce their risk of infection," the organization reported.

"I'm really upset," said longtime prevention advocate Jim Pickett, a member of the CROI Community Liaison Subcommittee, in a session bringing together providers and advocates. "And I think a lot of people in the United States are upset that American women, who are very vulnerable to HIV, will not have access to the ring."

In that session, "Rings

and Injectable Things: Moving from Options to Choices for HIV Prevention in Cisgender Women," longtime advocate Julie Patterson, director of the AIDS Funding Collaborative in Cleveland, wrote in a chat box comment, "U.S. women are mad as hell that the ring is not going to be an option for us at this time."

According to a statement issued in February by the International Community of Women Living With HIV Eastern Africa (ICWEA), "Disappointingly, the FDA decision primarily affects Black and Brown women in the U.S. as one of the communities who already have limited access to oral PrEP compared to other vulnerable groups." The statement called for accelerated global access to the ring. "Women need more products than only limiting their choice to daily oral PrEP."

The World Health Organization (WHO) in January of last year recommended the dapivirine ring "as an additional prevention choice for women at substantial risk of HIV infection as part of combination prevention approaches." Following the IPM decision in December, WHO reaffirmed its support for the ring.

The dapivirine vaginal ring is made of flexible silicone and users can insert it themselves, similar to a diaphragm for birth control. The ring slowly releases the HIV drug dapivirine over the course of a month. Dapivirine is still in development and is used here as a microbicide (such as a spermicide). It's a low dose, 25 mg. About the worst side effect that's been experienced is that sex partners may sometimes feel the ring.

Ring research in the U.S.

In the U.S., the MTN-023/IPM 030 study reported back in 2017 at the conference of the International AIDS Society that the dapivirine ring was safe and acceptable in adolescent girls. Both blood

levels and residual drug on used rings indicated high levels of adherence. Moreover, adherence to study visits was 97%.

“‘Can women adhere?’ We know that’s foolishness,” said Danielle M. Campbell, MPH, co-moderator of “Rings and Things,” of the question. A member of the CROI Community Liaison Subcommittee, Campbell is a sociobehavioral scientist who is both a researcher and an activist.

Adherence—the use of a medication or a product as prescribed—has been a concern of PrEP studies in women. Sometimes a significant number of women were found to have drug blood levels that were lower than needed to prevent infection.

Good adherence, however, has long been a concern in HIV in general. “Take one pill a day with or without food” may not be as easy as it sounds. It’s not just about women and HIV prevention.

Researchers worked to do more to improve adherence in women’s PrEP research. The REACH study is but one which bore good results. Overall PrEP use was higher than in previous studies.

REACH for more: vaginal ring preferred to oral PrEP

At this year’s CROI, the REACH study reported that adolescent girls and women preferred HIV prevention using a vaginal ring rather than taking daily Truvada for PrEP.

“Effectiveness is not the only variable that users care about when selecting a method,” said Kenneth Ngunjiri, MD, of Jomo Kenyatta University School of Agriculture and Technology, in Nairobi, who presented the REACH findings at CROI and joined the “Rings and Things” session. “What REACH has taught us is that young women want choice.”

Asked how he would respond to people who question the need for a

ring when a highly effective, long-acting injectable is available, Dr. Ngunjiri replied, “It’s an interesting question and it’s something that we’ll need to think through in terms of messaging. But as you’re seeing, efficacy is not the only thing that people think about. You can have an efficacious product, but if it’s not used, then it’s worse off, probably, than a lower efficacious product that is used.”

REACH participants used both oral PrEP and the ring, for six months each. For the crossover part of the study, they were then able to continue with one or the other PrEP method of their choice. Two-thirds of the 227 participants in the crossover portion chose the dapivirine ring over oral PrEP.

Drug level testing showed some-to-high use of the ring and moderate-to-high level of oral meds. Overall PrEP use was “much higher than has been reported in other clinical trials or other implementation studies,” said Dr. Ngunjiri. Adherence was “similarly very high for the two products.” REACH provided adherence support, such as daily text messages, that were chosen by participants from a menu of options. There was also a community workshop before the study began. Young women reported a desire for friendly clinics and friendlier providers among their preferences for PrEP delivery. The women who showed a high-level use of the oral PrEP preferred to continue using it.

The girls and women were in South Africa, Zimbabwe, and Uganda. See Late Breaker Abstract 88 at croiconference.org.

Learning from contraceptives

A lesson learned from contraceptives for women is that more choices lead to greater use, said Dominika Seidman, MD, MAS.

Dr. Seidman, an obstetrician/gynecologist and PrEP provider based at

Zuckerberg San Francisco General Hospital, spoke at the “Bringing Choice to HIV Prevention” symposium at CROI.

The world of LARCs—long-acting reversible contraceptives—shows that women and providers might see choices differently.

LARCs, such as the IUD (intrauterine device), are highly effective, said Dr. Seidman. They may not require daily, weekly, or even monthly maintenance, so there’s little concern over adherence. They have an acceptable, sometimes even desirable, side effect profile. They are, as her name says, reversible. And on top of all that, they’re cost effective.

Yet, she reported, research discovered that the medical establishment, often through education campaigns, had to urge women to use LARCs. There were negative results and unintended consequences. There were high discontinuation rates, and many of the women came to distrust their providers.

Moreover, at least one study, showing providers hypothetical case studies, reported that for low-income women, the providers were more likely to recommend the use of LARCs if they were Black or Latina over low-income White women; among White women, providers were more likely to recommend long-acting methods for poor White women than for middle-income White women. The findings “demonstrated how racism and classism influence provider practices,” said Dr. Seidman.

“There are many other qualitative studies demonstrating how Black and Latinx individuals perceive subtle provider preferences, which negatively affect not only their contraceptive use but their future healthcare experiences,” Dr. Seidman said.

She quoted one woman whose doctor refused to remove her long-acting contraceptive: “My provider was really hesitant to remove the [IUD]. She kept telling me,

‘Well, we should wait three months and see if your symptoms have worsened.’ And I waited three months and she’s like, ‘Well, you should wait some more.’ And I’m like, ‘No. So take it out or I’m going to a different doctor.’” Dr. Seidman said she thinks of that story every time a patient asks her to remove an IUD.

Another woman told a researcher, “I don’t know if it makes [providers] look bad if you have an IUD removed ... I don’t know if they have some chart somewhere, like a contest board in the breakroom...”

“These stories clearly come much farther down the implementation path than where we are today with PrEP,” said Dr. Seidman. “However, they provide an important cautionary tale, as the family planning community is now playing catch-up to rebuild trust and after not only exclusively emphasizing the importance of effectiveness, but also pressuring users into using methods based on the provider biases and discriminatory practices around who needs, rather than who wants, long-acting methods.”

She said that REACH shows the same concept for HIV PrEP—effectiveness is not the only thing that matters.

Nearly two years ago, in its first ever podcast, the HIV prevention advocacy organization AVAC covered the topic of partial protection. “Whether it’s condoms, a flu shot, oral PrEP, or the dapivirine vaginal ring, proven products fall short of 100 percent protections against disease, and there’s a lot to know about how and why an intervention may offer imperfect but still useful protection,” AVAC reported at the time. Asked how a product with a 50 or 60% protective effect translates into a benefit, panelist Penny Moore of the University of Witwatersrand in South Africa responded, “It’s stacking the odds in your favor.” **PA**

SECOND-LINE TREATMENT RECOMMENDATIONS

The NADIA study

Statement by Nicholas Paton, MD, of the National University of Singapore:

“We did the NADIA trial to address two major questions in the evidence base for the W.H.O.’s recommendations in the second-line treatment recommendations in the public health approach. **Firstly, whether it’s optimal to give dolutegravir in second line when you’ve got extensive nucleoside resistance, and secondly, whether you need to switch people who are failing on a tenofovir-based regimen to zidovudine [AZT],**

which is what the W.H.O. has been recommending for the last 12 years, but it’s never been tested in a controlled trial.

“So we tested these two questions in a randomized controlled trial called NADIA. It was done in program settings in Uganda, Kenya, and Zimbabwe, and we made sure that the monitoring strategy was relevant to the public health approach, and essentially randomized people to each of those questions. So dolutegravir versus the best-in-class PI [protease inhibitor] darunavir, and then to stay on tenofovir or to switch to zidovudine. And there were four main findings, each of which has potential to have a big impact on the public health approach and beyond.

“The first finding was that dolutegravir works extremely well, even if it was paired with nucleosides which you would predict to have no activity because of cross-resistance. And this is important because it firstly supports the W.H.O. recommendation from 2018 that everybody should use dolutegravir second line, and that the evidence really wasn’t solid for that at the time, but also it supports this global program-wide switching from people who are stable on efavirenz to dolutegravir without viral load testing, which has been happening in many places and people have been concerned about the risk of background resistance, whether this would create a public health catastrophe. So our results are very supportive of these approaches.

“Sort of to counter that, the second major finding was that we found nine cases of emergent dolutegravir resistance, which may not sound like a lot, but it’s actually quite remarkable

compared with what normally happens in first-line therapy, where you really hardly ever see dolutegravir resistance. So the significance is not clear. We’re not sure how this would play out in programs and individuals. But it’s an important thing to bear in mind and think about mitigation strategies for that.



“The third important finding was that darunavir, the PI, also did extremely well. So if you take dolutegravir now to be the gold standard, the best treatment actually, darunavir stood up to that standard and it’s the only PI that’s done that in recent trials and second-line therapy. And that’s important because currently darunavir sort of languishes in third place in the W.H.O. guidelines behind lopinavir and atazanavir, and really, it should be higher. And there’s now a generic formulation made by Hetero [Labs Ltd] of darunavir/ritonavir fixed-dose combination. The price has come right down to 210 U.S. dollars a year, so it’s probably time, and the evidence from this trial supports it, to move darunavir into sort of pride-of-place PI in the public health approach.

“And then lastly, and perhaps the most important and disruptive finding, was that we found that patients who stayed on tenofovir and did not switch to zidovudine did better in terms of viral load suppression and lower rates of rebound, and also less dolutegravir resistance. So this sort of longstanding mantra from W.H.O. that you must switch from your failing tenofovir in first-line onto zidovudine as a new drug—and it’s a basic principle in infectious diseases—is actually wrong. And W.H.O. needs to change those guidelines after 12 years, now that there’s some evidence that gives the right answer.

“And finally, it also tells us that resistance testing, which we as clinicians, we are perhaps over-interpreting these in vitro data largely. So you know, you’d expect a K65R [resistance mutation] to predict people to do very badly on tenofovir and do well on zidovudine. And that’s not the case. So I think it’s telling us that we need to have a bit more nuanced view of interpretation of resistance, and application in clinical practice in taking into account the entire context.”

ANCHOR study

Anal cancer screening proves effective

BY JEFF BERRY

Dr. Joel Palefsky, University of California San Francisco presented final results from the ANCHOR study, which looked at whether treatment of anal precursors to cancer prevents the disease in people living with HIV (PLWH).

Anal cancer is the fourth most common cancer in PLWH. To many it would seem common sense that treating pre-cancerous lesions would prevent cancer. Dr. Palefsky explained in a press conference why it was necessary to verify this in a randomized clinical trial, and gave four reasons why it wasn’t a “given” that treatment would work in the anus:

- In many at-risk people lesions are large and multifocal—these are the lesions most at risk of progressing
- Clinicians may miss lesions—HRA (high resolution anoscopy, the current standard of care) is difficult
- Clinicians may inadequately treat lesions—if the clinician can’t see the lesions, they can’t treat them completely
- New lesions often arise

This was a large study of 5,050 people living with HIV over the age of 35 years. Upon entering the study, a high-resolution endoscopy was performed to look for anal HSIL (high grade squamous intraepithelial lesion, or anal dysplasia). If no anal HSIL was detected, the person was not enrolled in the study. Half of the enrolled participants were randomized to treatment (such as hypercautery or topical creams) and half did not but were actively monitored. The primary endpoint was time to cancer. Nobody died of anal cancer in this study. One-third were diagnosed with advanced cancer, but most were diagnosed at an early stage. The study followed 4,446 individuals, but was stopped early because it was found that screening and treatment of anal HCl was effective—57% reduction in the treatment arm versus the monitoring arm—in reducing the incidence of progression to anal cancer.

These **data support the standard that PLWH over age 35 should be treated.**

Dr. Palefsky stated that these recommendations should be incorporated into guidelines for PLWH, and could be translated to other populations at risk who are not living with HIV, such as those who receive transplant grafts, as well as women.

HIV and aging at CROI

'There are many added layers and dimensions to consider'

BY JEFF BERRY



MARC THOMPSON

It's significant that CROI 2022 started and ended with HIV and aging, because it emphasizes the increasing amount of interest and research being devoted to the topic. Marc Thompson, the co-founder of PrEPster.info and a long-term survivor of HIV, has been at the forefront of HIV activism and prevention in the U.K. for over 30 years. He opened the conference with the Martin Delaney Memorial Lecture, "We're Still Here: HIV, Aging, and the Invisible Generation."

In his talk, Thompson shared his personal story of survival along with universal themes that people living and aging with HIV experience. "There is one universal truth," says Thompson. "One thing that all of us who are here today share—we're all aging. We can't escape it. It's a process and a journey that is inevitable. But for those of us who have HIV, there are many added layers and dimensions to consider."

He then outlined what he identifies as the key issues facing people living and aging with HIV:

- 1. The impact of HIV on aging.** "What does it mean to be living with HIV across a lifetime, to our bodies, to our minds, to our emotional state, to the way that we socialize and engage with the world?"
- 2. The threats to continuity of care.**

"The success of effective antiretroviral therapy has changed HIV from where it was many years ago...Sadly, care outside of specialized HIV care is often not equipped to manage the issues connected with HIV."

- 3. Experiencing co-morbidity and several non-HIV related conditions.** "We don't fully understand the impact of HIV on non-HIV conditions, particularly cardiovascular disease and diabetes. Plus, we now have to deal with the challenges of managing care with multiple doctors and other providers."
- 4. Polypharmacy issues.** "This includes the interaction between HIV medications and medication for non-HIV related conditions."
- 5. The increased need for support services.** "Is it time to rethink the need for the provision of community-based services for older people living with HIV?"
- 6. Persistent loneliness and isolation.** "We have enough evidence that tell us that people with HIV already experience loneliness and isolation. In a world where old age already renders you invisible, this will only increase."
- 7. Heightened concerns about stigma and discrimination.** "HIV stigma is not a one size fits all. We need an intersectional response, one that looks at HIV stigma through the lens of race, gender, sexuality, and in this context, age."
- 8. Quality of life and aging well.** "It's not enough for us just to be grateful that we are still here."

Says Thompson, "After decades of surviving, we want to continue to survive, but we also want to thrive."



On the last day of the conference there was a highly-anticipated symposium on HIV and aging moderated by Peter Hunt, of the University of California, San Francisco.

Mark Siedner, Harvard Medical School, gave a great overview and global perspective on aging and comorbidities with HIV. Nicholas Funderburg, The Ohio State University, discussed some of the potential and underlying biologic mechanisms that influence inflammation and promote age-related comorbidities in PLWH. And a presentation by Kristine Erlandson, University of Colorado,

looked at ways that we might integrate frailty and functional outcomes into clinical trials and in the clinic. Erlandson notes that it's important to find people early to be able to treat frailty.

The presentations were followed by a panel discussion which opened with two amazing HIV community advocates, Jules Levin of NATAP in New York City, and Venita Ray from Houston, with Positive Women's Network-USA.

Levin said that when he started focusing on aging and HIV 16 years ago, he anticipated that we would have a problem, but that it's actually much worse than he ever thought it would be. "We have a broken HIV healthcare system, despite spending \$1 billion in the Ryan White Care Act and tens of millions of dollars for Medicaid and Medicare. Something has to change." He also outlined what he thinks needs to happen to advance the research and improve care.

Speaking out

Venita Ray eloquently and emotionally described her experience as a 63-year-old Black woman in the South who never expected to be aging with HIV. "As I was writing out my talking points today, I'm not going to cover the scientific. I think you heard it. I was in tears and I'm emotional now. Because while the rest of the world is telling us about our life expectancy being the same as our peers who are not living with HIV, we know it is not the case. It is not the case.

"There's a real concern in the HIV community about issues related to aging. We know that already almost 50% of us are over 50. We're grateful to be living longer, but we're not prepared for the other conditions that are coming with it. We weren't prepared to be living, going through this. I remember going through menopause a few years ago and my ID doctor—no one could give me information about the impact of menopause and my medicine and things—and it was very frustrating to know what to do.

"There is historical distrust and disconnect between the science, the researchers, and our community. We often feel that we're treated as subjects—widgets—but not people. We often feel like the humanity is lost when you are talking to us, that there's a lack of meaningful inclusion into what our real daily lives look like."

Ray stated that the vulnerabilities to HIV acquisition are rooted in race and racism, and that CDC (U.S. Centers for Disease Control and Prevention) and others have talked about how systemic racism is a public health issue. "But yet we use terms like social determinants of

health, to not mention the words race and racism, right? We know that the data shows it is not just about behavior. It is not about black condomless sex. It is about the systemic conditions that make us vulnerable in the first place, that are rooted in poverty.

"I live in the South. We're dealing with rural communities, intersectional stigma, and I want you to remember that intersectional stigma is about the multiplicity of stigmas that we live with—homophobia, transphobia, being Black in the South, mass incarceration. There is still huge stigma. Never mind that those of us aging, feeling isolated, with not preparing to be here because we did not expect to be here. So, it is frustrating for some of us that the same system that made us vulnerable for acquisition is the same system that is not calling out what is really needed—addressing the root causes that created the vulnerability in the first place.

"Black women bear a higher burden of acquisition. We represent 60% of all women living with HIV in the epidemic, and when you ask why, using references to 'we don't take care of ourselves' or that 'down-low brother' and all of this, versus that intersection of race and gender, that we live with the gender inequities, the pay gap, all of those things that prey on Black women that don't persist anywhere else—we are not talking about dealing with any of that. We want to talk about how many pills we can get into us, and we want to study us and use nice terms instead of getting at the solution and calling it what it is, the South is the epicenter...

"What we want is an ongoing partnership with researchers in ways that include us from the beginning, and not just as test subjects. We think research can be enhanced with our contribution. It has been talked about by us, but it's not being talked about with y'all, and I know you all are working with other people. But chances are, if it's in the U.S. and I don't know about it, it probably ain't happening.

"And we do have some women that are working around aging and HIV, but we are not connected. We are not influencing what happens. So, we need you all to come out of your scientific bubbles and have those uncomfortable conversations with us about intersectional stigma, about what's really going on about weight gain. My breast size has tripled in the last three years. And when I mentioned it, there was no concern because you know, that's just a part of it. When the side effects get to be too much and

we stop taking our medication, then folks use terms for us like *falling out of care, not being adherent, and compliance*, which are not terms used on any other disease state other than HIV. They're stigmatizing, they're disempowering.

"So, we appreciate the opportunity to be here today to talk with you, and I talked with a lot of people before I came to talk with you all today, and my job is to represent them in my discussion. I'm a Black woman, I'm a grandmother, I'm all of these things—and community. I'm an attorney by training, but my training didn't prepare me for living with HIV. It didn't prepare me for the stigma and the shame that came with it, it didn't

This should be a beautiful time in our lives, but for many of us it is not.

prepare me to be dehumanized in the way that we're talked about, in language that is blaming and shaming for our own diagnosis or oppression.

"We experience both the fear of dying and the fear of living every day. This should be a beautiful time in our lives, but for many of us it is not. There is a lot of fear and anxiety, even with the joy of seeing my great nephew born last April, and I'm delighted to be here with him. I say to you all I appreciate the opportunity to speak. Five minutes is not enough for me to tell you what this is like. And to know in the last couple years, I can't even count the number of folks that have died. Last year two of our founders passed away of HIV-related complications, renal failure—

it is just on and on.

"We need you to partner with us, we need you to help us help you with answers. We need you to help us make things happen for us on the ground, not in the research bubble. We are living this now. And we invite you to join us." PA

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EDITOR'S NOTE: All government-funded HIV research around the globe includes community-based advisory boards. If you are interested in providing feedback to HIV researchers, check out your local research group if you have one. ACTG (AIDS Clinical Trials Group) and HPTN (HIV Prevention Trials Network) are just two groups working across the U.S. and around the world.

Report from the community HIV cure research workshop

HIV cure research highlights

BY KARINE DUBÉ, LYNDA DEE, JEFF BERRY, AND MICHAEL LOUELLA

The annual Community HIV Cure Research Workshop took place virtually this year. A perennial highlight of CROI, the workshop was broken up into two sessions, February 8 and March 1. The Community HIV Cure Workshop sessions aim to foster dialogue between biomedical HIV cure researchers and community members, and to deepen community understanding of the science involving the search for an HIV cure. The CROI meeting itself occurred virtually February 12–16 and 22–24. The Community HIV Cure Research Workshop was sponsored by Treatment Action Group (TAG), AIDS Treatment Activists Coalition (ATAC), AVAC, BEAT-HIV Community Advisory Board (CAB), Delaney AIDS Research Enterprise (DARE) CAB, I4C CAB, Enterprise for Research and Advocacy to Stop and Eradicate HIV (ERASE-HIV), HOPE Collaboratory, CRISPR for Cure Collaboratory, PAVE Collaboratory, REACH Collaboratory, University of Washington/Fred Hutch Center for AIDS Research (CFAR) Cure Scientific Working Group, NMAC, and European AIDS Treatment Group (EATG).

SOME WORKSHOP HIGHLIGHTS

Case of HIV ‘cure’ in a woman of mixed race

Likely the most significant case report from CROI 2022 was a case of HIV “cure” presented by Ivonne Bryson from UCLA. A middle-aged cisgender woman of mixed race from New York was found free of HIV 14 months after interrupting ART (antiretroviral therapy—her HIV treatment) following a haplo-cord transplant from a donor homozygous (inherited from both parents) for the delta-32 gene deletion, making the woman’s cells resistant to HIV. **Both her leukemia and HIV are “in remission” and experts are hopeful that the woman will remain without HIV.** Following the Berlin patient, Timothy Ray Brown (2009); the London patient, Adam Castillejo (2019); and the Dusseldorf patient (2019), she is referred to as the “New York” patient and is the fourth confirmed case of HIV “cure” following a stem cell transplant (although most media reports called hers the third case). Her case provides hope that cord blood cells can be used to achieve cure in people with both HIV and cancer, which would open up this method of curing someone with HIV and a life-threatening cancer to others. Her health will

continue to be monitored. For details, GO TO the conference session webcast, bit.ly/CROI2022-the-New-York-patient.

Community HIV cure research workshop

Nora Jones from the BEAT-HIV Delaney CAB and Danielle Campbell from the BEAT-HIV and DARE CABs opened the workshop with a review of ethical considerations in HIV cure research. There are several guideposts that must be in place. Besides ensuring autonomy, maximizing benefits, and minimizing risks, presenters emphasized the critical importance of equity and community-based principles including social justice and community involvement, to **ensure research remains ethical and acceptable to communities of interest.** GO TO bit.ly/CROI22-ethics-in-HIV-research.

Toni D’orsay from the HIV + Aging Research Project-Palm Springs (HARPPS) moderated a lively **panel discussion on black transgender women and HIV cure-related research.** The other panelists were Sydney Rogers, aka Miss Barbie-Q, and Brighton “Bee” Meki. The discussion emphasized ensuring inclusion of transgender women at all stages of planning both biomedical and socio-behavioral HIV cure research. The

panel noted the importance of incorporating awareness for gender-affirming care and wrap-around services in research study designs, acknowledging the intersectionality of oppression, and ensuring intentional inclusion at all levels—including advocacy, policy, leadership, and funding. GO TO bit.ly/CROI2022-black-transgender-women.

Natalia Laufer and Gabriela Turk from the INBIRS Institute in Argentina presented the case of the Esperanza patient, **the second woman (after Loreen Willenberg) who has cleared HIV without antiretroviral treatment.** The Esperanza patient, a Caucasian woman first diagnosed with HIV at 23 in 2013, was recently, in 2021, found to have no virus capable of replicating itself. Her case gives potential clues to advancing “block and lock” approaches that keep HIV permanently silenced inside the body. GO TO bit.ly/CROI22-Esperanza-patient.

Lynda Dee, DARE CAB Community Engagement Coordinator, and Karine Dubé from UNC Chapel Hill led a discussion on HIV cure research terminology—weighing the pros and cons of using various expressions such as ‘sterilizing cure,’ ‘functional cure’ and ‘remission.’ Several members of the community converged on **the need for patient/participant-friendly language to describe the science of HIV cure.** There was a consensus that the term ‘sterilizing cure’ should be discouraged and not used because of its association with disinfecting and forced sterilization. Other words that are unacceptable are ‘subjects’ and ‘HIV-infected person’. For details, GO TO bit.ly/CROI22-research-terms.

Community HIV Cure Research Workshop

Marina Caskey from The Rockefeller University provided **an overview of broadly neutralizing antibodies (bNAbs) being investigated in several HIV cure-related trials**—some of which will be initiated in 2022. Antibodies find specific targets on the virus and have

numerous properties that make them attractive. For example, bNAbs are specific, diverse, and have a memory. Antibodies can either block free-floating HIV (not in infected cells) or help clear infected cells. There is emerging evidence that a combination of bNAbs will be necessary to maintain viral suppression after ART interruption. Some challenges remain, such as diversity of the HIV reservoir, and pre-existing resistance to bNAb-based approaches. **GO TO bit.ly/CROI2022-bNAbs**.

Thumbi Ndung'u from the Africa Health Research Institute (AHRI) provided an overview of **HIV cure research in low- and middle-income countries (LMICs)**. Dr. Ndung'u discussed some of the approaches that may be more appropriate for LMICs, such as early ART, bNAbs, and immune-based approaches. The Female Rising through Education, Support and Health (FRESH) research team in Durban, South Africa will soon initiate a trial to study post-treatment control of HIV in young women diagnosed during acute HIV. Dr. Ndung'u said that HIV cure studies need to prioritize LMICs with the highest burden of HIV in those settings. For details, **GO TO bit.ly/CROI2022-LMIC**.

Philister Adhiambo Madiega, MPH, a community member from Kenya, spoke about what motivates her to advance HIV cure research. She discussed **important considerations for HIV cure research in LMICs**, including ongoing cure research education, acknowledging how HIV cure is interpreted in different communities, the need for careful language to manage expectations, avoiding myth and misconceptions, discussing safety of interventions, and challenging issues around accessibility, affordability, acceptability, and appropriateness of interventions for all populations, including hard to reach groups and women of all ages. **GO TO bit.ly/CROI2022-cure-considerations**.

Drs. Deborah Persaud, Lishomwa (Lish) Ndhovu, Katie Bar, and Luis Montaner provided a report back on **HIV cure-related science presented at CROI 2022**, including a question-and-answer session. For details, **GO TO youtube.com/watch?v=vhP38HkRdlo&t=147s**.

ADDITIONAL SELECT CROI 2022 HIGHLIGHTS

Peter Hunt from the University of California San Francisco (UCSF) provided **an overview of advances in HIV cure with clinical perspectives**. Regarding latency-reversing agents, novel agents are being identified in animal models,

while more research will be needed to make them safer before research in humans is undertaken. He said we will also need to focus on effective strategies towards HIV clearance, and that combination approaches will be needed for immunotherapy strategies. For gene therapy, there are many promising approaches in development, and again the focus will need to be on both safety and scalability. Dr. Hunt also urged that more research should be directed towards 'block and lock' approaches which will hopefully keep latent reservoirs in a deep state of latency. The 'block' agent might also help reduce persistent inflammation.

Ole Søgaard from Aarhus University, in Denmark, presented the results of a study that used 3BNC117, a bNAb, and romidepsin, a latency-reversing agent, when ART was initiated. The trial enrolled 60 participants in Denmark and England and found that **starting 3BNC117 at ART initiation led to faster reduction of viral load and helped eliminate HIV-infected cells**. There was also improved immunity and delayed time to virus rebound in the groups of participants that were sensitive to the 3BNC117. One participant remained with undetectable viral load in the group that used both 3BNC117 and romidepsin.

Jim Riley from the University of Pennsylvania discussed the attractiveness of **chimeric antigen receptor (CAR) T cells for HIV cure-related studies**. His team presented the results of a pilot study utilizing T cells modified by CCR5-specific zinc finger nucleases, a form of gene therapy, and CD4 CAR receptor. Of the eight participants who were able to be evaluated, one maintained very low viral loads and has remained off ART for approximately 65 weeks (more than five years). This person also participated in two previous gene therapy studies and will continue to be closely monitored.

"River Deep, Mountain High: Pathways Towards a Cure for HIV": At the Margarita Breakfast Club, a CROI-related community session free to everyone, **scientists and advocates from across the globe held a passionate discussion via Zoom** about the big news of the "possible cure" of HIV in a woman of mixed race, in addition to some more nuanced news from CROI 2022. Moderators Danielle M. Campbell and Michael Louella stirred up conversation with Dr. Katherine Bar and Moses Supercharger that inspired much comment and reflection about the issues raised by the news. The end result is a conversation

informed by global perspectives and an example of why we ought to always include a variety of voices if we wish to understand the global impact and implications of HIV cure research.

ADDITIONAL RESOURCES ON HIV CURE-RELATED RESEARCH

There is a community resource related to HIV cure research that is free to all. Called the CUREiculum, it consists of **six modules about various topics related to HIV cure research**. They are free for all to download and use and edit. All modules are available for use by individuals or groups interested in spreading the word about HIV cure research! CUREiculum 2.0: **treatmentactiongroup.org/cure/cureiculum-2-0/**

ADDITIONAL INFORMATION ABOUT CROI 2022 COMMUNITY EVENTS

Treatment Action Group. 2022 Pre- and Post-CROI Community HIV Cure Research Workshop. **GO TO bit.ly/CROI2022-TAG-workshop**.

GO TO croiconference.org for these and other reports.

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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, and a member of the Delaney AIDS Research Enterprise (DARE) Community Advisory Board (CAB). She also leads the BEAT-HIV Social Sciences initiative and is part of the Global Gene Therapy Initiative (GGTI).

JEFF BERRY is chief editorial officer of TPAN and editor-in-chief of POSITIVELY AWARE. He is the inaugural chair of the CRISPR for Cure CAB, and a member of the Third Coast Center for AIDS Research (CFAR) Community Constituency Board and the AIDS Treatment Activists Coalition (ATAC).

LYNDA DEE serves as the DARE community engagement coordinator, executive director of AIDS Action Baltimore, and a member of the AIDS Treatment Activists Coalition (ATAC) and the GGTI.

MICHAEL LOUELLA serves as the DARE CAB co-chair, defeatHIV community engagement project manager, University of Washington (UW) AIDS Clinical Trials Unit (ACTU) outreach coordinator, UW Fred Hutch Center for AIDS Research (CFAR) community liaison, and serves on the GGTI.



BEING BRIDGETTE
BRIDGETTE PICOU

Humanizing science

There is a method to the madness of everyday life with HIV. Everyone has their own method of dealing with madness, right? Our own little theorem and experiments when it comes to dealing with the highs and lows and processes of understanding our life with the virus.

I've been in the mindset of science since February when I attended CROI 2022. It stands for Conference on Retroviruses and Opportunistic Infections. A mouthful to say and, trust me, a brain-full to take in. CROI is HUGE in the HIV treatment community and is a way for science and research to share ideas and studies and failures and successes. Any area of HIV treatment you can imagine—there are 10 other subcategories you never thought about under that. *And they are all relevant!* Although I thought my little A's in science from high school and my nursing license were going to help me play Marie Curie on Zoom, I was very quickly reminded that the science of nursing is different from the science of HIV and research! bNAb's (broadly neutralizing antibodies) and SHIV challenges and glycoproteins, *oy vey!* Science and the business of science-ing is hard! Nonetheless, it did give me an "a-ha" moment in relation to our role as people living with HIV, and the role of scientists in HIV.

While we're all trying to find a way to live with HIV, scientists are trying to find a way for us to not only live healthily *with* HIV, but also *without* it. With medical mistrust at an all-time high, I think it's more important than ever to stay focused on the human element of science. If I asked you about the human impact and input to science, what would that mean to you? The human bodies that contribute to it? The blood and tissue we donate?

We have to broaden our definition of human participation in research and studies. It's never just about the patient's perspective of trying to stay adherent to their medication or the process of functioning with the disease, but it's also the element of hope for a cure that keeps a lot of us moving

forward. Even if we are using a holistic and non-medication methodology of controlling the virus, it's important to respect and know a little bit about the science of why those things work (or don't work).

My *a-ha* moment was realizing that while science is made of research and hypothesis, experiment and conclusion, *humans* are behind those formulas. I think we sometimes forget that. Even though their reasons for wanting to find a cure may be different from ours—the hope that sustains them as people is the same. The disappointment that we feel when another "promising treatment" or "cure" we hear about in the news turns out to be a bust, is the same disappointment they must feel at its not working. I'm choosing purposely to use "not working" rather than "failure" because at the end of the day, any time someone misses the mark while purposely trying to help me, it's not a failure. It's a "We'll get 'em next time, Tiger" moment. After all, the alternative is what? No one doing anything? Let that marinate a little.

So, while science ain't for everybody, science is most definitely for everyone.

Even though after the conference I know what broadly neutralizing antibodies are, I don't totally know how they work. I'm okay with that. I'll leave it to science. The science that for me, has a new, *humanized* element to it.

Be well. You matter.

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

With medical mistrust at an all-time high, I think it's more important than ever to stay focused on the human element of science.



How has aging with HIV affected your sex life?

We asked our followers on social media. They responded with some candid—and brave—answers



Note: Some of the following is graphic in nature. Responses have been edited for clarity.

“More health complications

like back pain, arthritis, heart issues, blood pressure, diabetes, lowered libido, neuropathy, just to name a few. Let me focus on the neuropathy to start. If it gets bad in your feet, it can be a real “distraction”—heart and blood pressure issues and the meds to treat them can really hinder a man’s performance. Back pain issues and arthritis can definitely create issues in the bedroom.”

—D. ELIJAH VANLUE, JR.

“I like to think that I am a very sexual person, with a lot of love and affection to give. It seems I have developed a very low level of self-esteem, so I have been celibate for a few years, unfortunately. It seems like I have placed some unnecessary things on me, telling myself that I am

not desirable because of my disability and my HIV status. What is ironic is that I speak to groups about the wonders of U=U [Undetectable = Untransmittable], but don’t apply it to my own life.

“I have placed on myself the expectation that others see me as ‘untouchable’, because when I remove my Cochlear implant and hearing aid, I am deaf. The fact that I use a cane to walk is not an issue to many, but I have made it one for me.

“I guess that the largest barrier in my life towards a sexual relationship are my own barriers. I need to learn how to celebrate the person that I am, enjoy my life, and things will fall into place—knock on wood.”

—MARK L. GRANTHAM

“My sex life was destroyed the day I was diagnosed. Although I was in a marriage, the trauma associated with an HIV diagnosis became

a diagnosis that was associated with sex for me. It’s actually kind of painful to talk about. U=U gave me my womanhood back. Stigma continues to take it away. So, I have become comfortable living a sexless life.”

—DONNA

“I have been HIV-positive since 1984, with no effect on my sexual function. In August 1995, after 23 years in New York, I got sick and three days later was home in the UK, and diagnosed with AIDS. Since getting on that plane, I have never been sexually aroused or ever had a full erection. I realise now, it will never return, and every kind of treatment or pill has failed miserably. Not the end of the world, but sure makes for a lonely existence.”

—P. MICHAEL HEBINGTON

“I have not been touched in over four years. It is my understanding that it takes being actually physically touched for it to be called sex. Zoom and Skype don’t count. I have been living with AIDS for over half of my life. I am 63 years old, and I am not dead yet.”

—ROB T.

“My husband and I are 69 and 70. Both of us live with HIV. No, HIV did not in any way change our sex life. It’s less frequent now but that’s age, not HIV. We are a long married heterosexual couple.”

—VERITEE REED HALL

“Fifty-two years old here. Somehow sex with my life partner is not as intense as cuddling and deep conversation now. Daily activities and the need to rest more make sex not the first priority.

“I guess it’s not about HIV but how we decided to spend

our time based on our life priorities.

“My previous partner was HIV-negative, understood U=U, and had no problem with barebacking. My current partner is HIV-positive, so we have more freedom to talk about HIV-related issues because we’re in the same boat.”

—AAN RIAN TO

“My sex life changed dramatically at age 45. It became more difficult to get and keep an erection. At 61, things haven’t gotten better. My infectious disease specialist didn’t respond when I asked for a Viagra prescription. Friends have suggested Cialis, but I’m concerned about my blood pressure since it’s varied so much since 2007. At one point it was low, then under control, now somewhat better/borderline. My thing to compensate is by presenting myself as a ‘still sexy 61-year-old’ if and when I meet the right guy who will not have a problem with my erectile dysfunction. ED is slowly becoming more and more common. The male ego is hesitant to want to talk about it.”

—MILTON BENNETT

“Sex is a four-letter word to me and that word is none.”

—PETE BROMLEY-SPIEGLE

“It’s all happening for me in the metaverse now.”

—KARIM

“It’s disintegrated to nothing. Maybe if the meds hadn’t caused lipodystrophy it would have been a different story.”

—DOMINIC

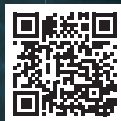
“Mine has largely been replaced with other forms of affection and intimacy. And that’s OK.”

—HARRY

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