POSITIVELY AWARE

MAY+JUNE 2023

UNRELIABLE SOURCES

AUTHENTICITY

PARTNERS IN RESEARCH

CONFERENCE UPDATE

SEX TALK AT CROI 2023

DAVINA CONNER flies to Cleveland to be at the side of **BRYAN C. JONES** as he undergoes treatment for cancer

TAKING CARE OF OUR OWN

POSITIVELY AWARE

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

BE GREEN.
SHARE OR RECYCLE
THIS MAGAZINE.

THE CONVERSATION

In mailboxes, pharmacies, medical offices and elsewhere, the annual HIV Drug Guide and the 2023 HIV Drug Chart could be found, and readers shared their enthusiasm.

"I went to my medical care provider this week, and look what I found in the waiting room."

—**DAN**
OAKLAND, CALIFORNIA

"Received mine in the mail yesterday! Love the cover... a couple friends are there: Timothy S. Jackson and D D'Ontace Keyes."

—**WANDA BRENDLE-MOSS**

"The poster was in the exam room yesterday."

—**DAVIDMICHAEL PHILLIPS**

Got my copy of PA today! The 27th annual Drug Guide issue is fabulous! Well done!

—**JESS WIEDERHOLT**

"Looks great. We got ours last week."

—**@GSOBERANIS**

"Best issue of the year!"

—**@MISHSIMEK**

That was then, this is now

Twenty-seven years later, Sylvia and Sanford reflect on having appeared on the cover of our first HIV drug guide

BY RICK GUASCO

Living with HIV was very different in 1997, the year when the POSITIVELY AWARE annual HIV Drug Guide was first published. It was also early days for Sylvia O'Shaughnessy and Sanford E. Gaylord in their journey living with HIV when they agreed to be photographed for the cover of that first drug guide. (The third person on the cover was an HIV-negative model.)

"The cover says *Out and About*. I was out and about, and lo and behold! At the doctor's office when I saw myself and PA."

—**SANFORD E. GAYLORD**

MAY+JUNE 2023

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> *'They did so much for incarcerated women and women living with HIV locally [the Los Angeles area] and nationally.'*
>
> —SUSAN FORREST, **PAGE 8**

PHOTO: KAREN OCAMB

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BEHIND THE COVER

Private moments

“Bryan and I, we love Sean,” says Davina Conner about photographer Sean Black. “He did a piece on me, and we have been close ever since. Bryan, the same way. It was great just having him there, taking the photos and capturing those moments, but also sharing that time together.”

Even within the tightknit community of HIV activists, the three long-term survivors of HIV share a special friendship. So, when Bryan C. Jones called Conner with the news that he was about to undergo treatment for his fourth bout with cancer, she reached out to Black for support and to document this profound chapter in their lives. They agreed to share the experience with POSITIVELY AWARE for this issue’s cover story, which begins on page 14.

> I think that having a photographer like Sean around, it changes the atmosphere, because of who he is, his energy.

GETTING READY TO GO FOR CANCER TREATMENT

“With all the negativity in the world, this is the type of story that I want people to read about,” Black says. “Dee brings a maternal force and energy to her work. She shines bright. She is a sister to many of us. Bryan is an incredible leader, storyteller and a fighter with a great wit. During a previous trip, he took me to his childhood home. I am enthralled by his years on Broadway as a chorus singer. When I heard from Dee that Bryan was undergoing cancer treatments again and that she was going to Cleveland to be with him and help out, I was moved.”

“I think that having a photographer like Sean around, it changes the atmosphere, because of who he is, his energy,” Conner says. “When he’s taking pictures, it doesn’t feel like he’s intruding on your space. You don’t feel nervous that someone’s snapping photos, because he makes you feel comfortable. He’s just capturing the moment, sharing these moments with us.”

—RICK GUASCO

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SEAN BLACK

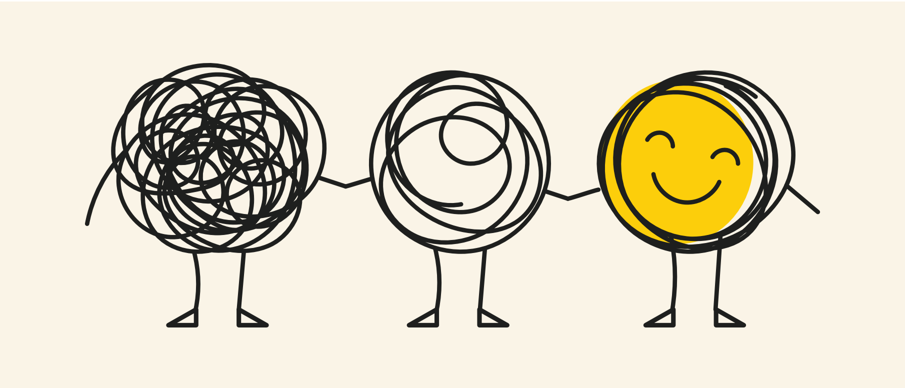
NOTE FROM THE ACTING EDITOR-IN-CHIEF

Rick Guasco
@rickguasco

In friendship

I don't know where I'd be without my friends. While I'm close to my family, they moved to Los Angeles 25 years ago and I chose to stay here in Chicago. My family is a FaceTime call away, but when I've needed someone literally by my side, it's been my friends who've been there.

When I received my HIV diagnosis, I was paralyzed with fear. It was only after the strongly worded urging of my boyfriend Eric at the time that I took the next step and got into care. When I was homebound during the most difficult days of my anal cancer journey, a few of my friends sent or dropped off soup and ice cream—food that was mercifully soft and easy to digest. My roommate Andy knew I needed laughter and not pity to pull through. And then there's my friend John, who would pick me up from the hospital after my surgeries, partly because he thought it was funny to see me so chatty while feeling the after effects of anesthesia.



That's not to say that there haven't been times I felt utterly alone with my HIV, my butt cancer (as I prefer to call it), or with whatever else troubling me. You can have wonderful, caring friends, and there can still be moments when you feel the profound absence of friends.

As people living—and now aging—with HIV, we are at a point where many of us must look to each other for support. That's why it was deeply moving to learn that HIV activist Bryan C. Jones was about to undergo chemotherapy and radiation treatment for his fourth bout with cancer and that some of his friends were going to Cleveland to keep him company, including his dearest friend Davina ("Dee") Conner.

There are many different kinds of friends. Bryan and Dee have a deep abiding *friendship*. They have nicknames for each other, names they've shared for so long, they don't even remember when or how they came up with them. They're just Jethro and Ella.

Entering into the picture, in every sense, is photographer Sean Black. An activist himself, Sean came to know Bryan and Dee through his work, and developed a close friendship with them. Sean wanted to be there for his friend, but he also wanted to document this moment when friendship comes into service for the people we love. A camera clicking and whirring during such an intense personal experience would be the ultimate intrusion, so it says something that Sean's presence was instead a part of the moment. You can share in that experience with this issue's cover story, starting on page 14, "Taking care of our own," a photo essay shot by Sean, written by Dee and with a personal reflection by Bryan.

Also in this issue, the second installment of our four-part series, "Partners in Research" (page 24), offers firsthand accounts by long-term survivors, including the perspective of an HIV-negative partner, in the search for an HIV cure. Also featured is a resilience framework for clinicians to consider so that they can provide support and care for participants in cure research.

There was plenty of sex talk at CROI, reports associate editor Enid Vázquez (page 34). The conference highlighted efforts to "beat off" sexually transmitted infections, particularly through the use of the antibiotic doxycycline as post-exposure prophylaxis—doxy-PEP. Separate studies found that long-acting PrEP was safe, effective for—and well received by—adolescent cisgender girls and Black folk in protecting them from HIV.

"Anyone who wants to see the end of the HIV epidemic in the U.S. should pay attention to this case," writes attorney Scott Schoettes in his Poz Advocate column (page 38). A conservative judge in Texas has ruled that the Affordable Care Act ("Obamacare") violates the religious freedom of businesses by forcing them to provide insurance that includes preventive services—such as PrEP—that go against their religious beliefs. The case is expected to go all the way to the Supreme Court.

Being true to who you are is hard work, says columnist Bridgette Picou in Being Bridgette (page 40), but it can also be healing. Her words speak to all of us.

Read the responses on page 23 to "The Category Is" and the question we posted on social media: *Do you have a support network you can turn to when you need care?* Even as some people said they had no support and felt cut off, a few other commenters reached out to them.

"Hey, Rob. Long-time warrior here, too," replied one person in response to a post. "Always around to listen and help."

It's up to each of us to reach out and look out for one another. We all need a quality of friendship that makes us feel connected and supported.

You are not alone.

Rick

JOHN GRESS • ILLUSTRATION: ISTOCK

Briefly

ENID VÁZQUEZ Enid.Vazquez@positivelyaware.com

Doxy-PEP cuts STI cases

But study adds that possible resistance merits a closer look

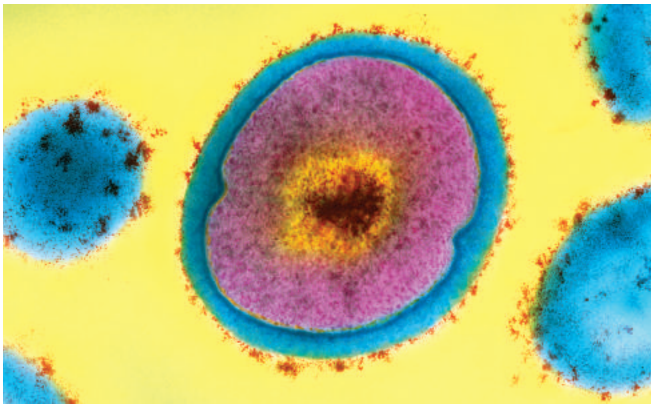
The oral antibiotic doxycycline reduced the acquisition of sexually transmitted infections (STIs) by two-thirds among men who have sex with men and among transgender women when taken within 72 hours of condomless sex as a form of post-exposure prophylaxis (PEP), a study reported in the *New England Journal of Medicine.* However, the study also found a slight increase in antibacterial resistance.

Researchers at the University of California at San Francisco and at the University of Washington, Seattle, recruited 501 participants who were age 18 years or older who were on HIV treatment or were taking PrEP for HIV prevention, and who had been diagnosed with gonorrhea, chlamydia or syphilis within the past year. In the open-label, randomized study, two-thirds of the study participants were given 200 mg of doxycycline (often referred to as "doxy") to take within 72 hours of condomless sex; the remaining third were given standard care without doxy. All participants were tested quarterly for STIs to monitor rates of acquisition.

Among the 327 participants on PrEP for HIV prevention who were given doxy-PEP, 10.7% were diagnosed with an STI during their quarterly screenings, compared to 31.9% for those on standard care.

Among the 174 people living with HIV (PLWH) taking post-exposure doxy, 11.8% were diagnosed with an STI; the PLWH group who were on standard care had a rate of 30.5%.

Gonorrhea was the most often diagnosed STI. Diagnoses among the doxy-PEP group were about 55% lower than in the standard care group. Chlamydia and syphilis were each reduced by more than 80%.



ELECTRON MICROGRAPH OF A SECTIONED STAPHYLOCOCCUS AUREUS BACTERIUM

SCIENCE PHOTO LIBRARY

However, researchers discovered that the doxy-PEP group had a slightly higher percentage of tetracycline-resistant *Staphylococcus aureus* living in the nose after 12 months. It was found in 38.5% of the doxy-PEP group who were diagnosed with an STI, compared to 12.5% in the standard care group. Doxycycline is used for treating methicillin-resistant *Staphylococcus aureus* skin and tissue infections. Additional research and longer follow-up periods will be needed to determine how intermittent use of doxy-PEP might affect antimicrobial resistance.

"Given its demonstrated efficacy in several trials, doxy-PEP should be considered as part of a sexual health package for men who have sex with men and transwomen if they have an increased risk of STIs," according to Annie Luetkemeyer, MD, professor of infectious diseases at Zuckerberg San Francisco General Hospital at UCSF, and co-principal investigator of the study, in a press announcement. "It will be important to monitor the impact of doxy-PEP on antimicrobial resistance patterns over time and weigh this against the demonstrated benefit of reduced STIs and associated decreased antibiotic use for STI treatment in men at elevated risk for recurrent STIs."

Of the 501 participants, 67% were White, 7% Black, 11% Asian or Pacific Islander and 30% Hispanic or Latinx. The study was funded by the National Institutes of Health. For more information, **GO TO** clinicaltrials.gov, study number NCT03980223. **READ** the *NEJM* article at bit.ly/NEJM-doxy-pep-study-2023.

—**RICK GUASCO**

AMA elects gay man as president

Jesse M. Ehrenfeld, MD, MPH, was set to be inaugurated in June as the first openly gay doctor to lead the American Medical Association (AMA). Dr. Ehrenfeld is a senior associate dean, tenured professor of anesthesiology and director of the *Advancing a Healthier Wisconsin Endowment* at the Medical College of Wisconsin. He has served on the AMA board of trustees since 2014. A combat veteran who deployed to Afghanistan during both Operation Enduring Freedom and Resolute Support Mission, he conducts research focused on understanding how information technology can improve surgical safety and patient outcomes; he also teaches and conducts a clinical practice. He is a longtime advocate for LGBTQ rights and health care. Dr. Ehrenfeld and his husband have two children.

Honoring the mother-son connection

The bond between a son and his mother or a maternal figure is unique. A new campaign, "Mother to Son," launched by ViiV Healthcare, celebrates this special relationship and the importance it can play in affirming the health of Black

TOP OF THE NEWS

➤ HIV activist couple die within hours of each other ➤ Status neutral, please ➤ Honoring the mother-son connection ➤ AMA elects gay man as president ➤ Community-based podcast looks at Black HIV in the South ➤ Doxy-PEP cuts STI cases, study says, but possible resistance merits a closer look ➤ Advocates take to Capitol Hill for the 30th annual AIDSWatch

and Latinx gay, bisexual, trans and queer men.

"Whether biological or chosen, maternal support is essential to getting men connected, engaged and retained in HIV care and other health services," the website states. "It is a mother's love, support, patience and compassion that combats learned self-hate that can lead these men to unhealthy decisions, behaviors and practices. It's a mother's love that empowers these men to see themselves as whole, worthy and valuable."

The campaign features a series of mother-son portraits such as writer and advocate Darnell Moore with his mother Diane, stylist Ty Hunter with his mother Connie, and Blair Khan with legendary ballroom icon Luna Luís-Ortiz, among others.

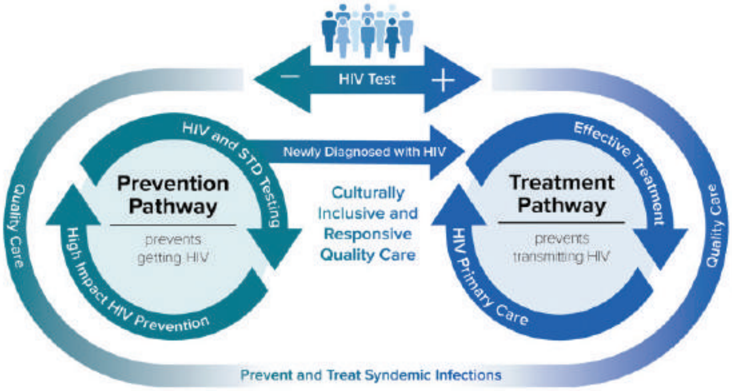
"I want her to see me as I am: self-assured, family-oriented, big hearted and queerly happy," says Moore about his mother.

A booklet of the portraits, along with comments by the sons and their mothers, includes a series of questions meant to inspire dialogue and can be viewed and downloaded at the campaign's website: viivhealthcare.com/en-us/supporting-the-hiv-community/positive-action/mother-to-son/. A version in Spanish is also available: viivhealthcare.com/content/dam/cf-viiv/viivhealthcare/en_US/pdf/ms-booklet-spanish.pdf.

The campaign draws its name from *From Mother to Son*, a poem by the Black American poet and social activist Langston Hughes, who was a leader of the Harlem Renaissance.

—**RICK GUASCO**

Status neutral, please



STATUS NEUTRAL HIV PREVENTION AND CARE
Follow CDC guidelines to test people for HIV. Regardless of HIV status, quality care is the foundation of HIV prevention and effective treatment. Both pathways provide people with the tools they need to stay healthy and stop HIV. **—Centers for Disease Control and Prevention (CDC)**

HIV treatment and prevention are in bed together more than ever, so to speak. They both use some of the same medications and are affected by the same negative social forces, such as stigma and unstable housing.

Appropriately then, the U.S. Centers for Disease Control and Prevention (CDC) now promotes a *status neutral* approach to HIV prevention and care to bring the two together.

"A status neutral approach continually addresses the healthcare and social service needs of all people affected by HIV so that they can achieve and maintain optimal health and well-being. ...Ultimately, status neutral approaches promote health equity by putting client needs above HIV status to improve care and eliminate stigma," the CDC stated March 1 in announcing a training module for medical and service providers.

The training takes off from the CDC's Issue Brief, "Status Neutral HIV Care and Service Delivery: Eliminating Stigma and Reducing Health Disparities," posted on November 28, 2022.

Status neutral care begins with an HIV test and goes from there. The CDC notes, however, that services should not be denied because a person hasn't taken an HIV test.

"How can we evolve the institutional structures that maintain a 'serodivide' in service delivery and that may maintain that same 'serodivide' and resulting stigma in the lives of people affected by HIV?" wrote Demetre C. Daskalakis, MD, an infectious disease expert on loan from the CDC to the White House for the national mpox response, in the Spring 2023 issue of *HIV Specialist*. "People don't care who funds their services. They are concerned with getting the services they need to support their health and well-being. 'Statusing' a place or a service may be aversive to people who could benefit from that place or service."

Status neutral HIV prevention and care was first introduced by the New York City Department of Health and Mental Hygiene, where Dr. Daskalakis championed the concept and led the city to the lowest number of new diagnoses seen in years.

GO TO cdc.gov/hiv/effective-interventions/prevent/status-neutral-hiv-prevention-and-care/index.html for the training page. **GO TO** cdc.gov/hiv/policies/data/status-neutral-issue-brief.html to read the issue brief.

Community-based podcast looks at Black HIV in the South

For Black HIV/AIDS Awareness Day (February 7), Chicago-based The Qube devoted a podcast series to *Black HIV in the South: How Did We Get Here?* According to a press statement, the Qube "takes a deep dive into

HIV activist couple pass within hours of each other

Hard-core HIV/AIDS activists Mary Lucey and wife Nancy MacNeil died February 11 within hours of each other. The two women dedicated their lives to fighting on behalf of women and people living with HIV who are incarcerated, among other struggles. MacNeil died of natural causes, but Lucey's cause of death has yet to be reported.

"It is with great sadness that I report that both Mary and Nancy died over the weekend," wrote long-time HIV activist and former POSITIVELY AWARE writer Susan Forrest in an email sent February 13. "They did so much for incarcerated women and women living with HIV locally [the Los Angeles area] and nationally." She attached each woman's bio, provided by ACT UP L.A. (the AIDS Coalition to Unleash Power) and reprinted below.

Forrest said that Mary Lucey "died of a broken heart."

GO TO "ACT UP/LA's Mary Lucey & Nancy MacNeil's legacy of compassion" by Karen Ocamb at losangelesblade.com/2023/02/27/act-up-las-mary-lucey-nancy-macneils-legacy-of-compassion, which contains vintage photos of the HIV activism movement; also, "R.I.P. Lesbian AIDS Activists Mary Lucey and Nancy Jean MacNeil" by Trent Straube at poz.com/article/rip-lesbian-hiv-aids-activists-mary-lucey-nancy-jean-macneil-act-up-. **GO TO** https://www.poz.com/article/cure-life-love-loss-mary-lucey-nancy-macneil#search-query=cure%20life%20love%20loss%20Mary%20lucey for a personal story about the couple by friend Keiko Lane.

MARY LUCEY

"In 1989, Mary Lucey was fighting drug addiction while simultaneously pregnant and diagnosed HIV positive. She had also recently completed an 18-month sentence at California Institute for Women, Frontera.

"After nearly 10 years into the epidemic there was only one medication that was available to Lucey, the highly toxic AZT which she had to take around the clock. She boldly faced the discrimination, stigma and fear associated with an HIV/AIDS diagnosis, which at the time was still considered a death sentence.

"In 1990 Lucey got a handle on her addiction, met her future wife Nancy MacNeil, and found her voice in ACT UP Los Angeles. She joined the group after they attended the first Women's Caucus meeting in June of 1990.

"Lucey, a loud and proud lesbian, was among the first HIV positive women in Los Angeles to be out about her status. Fueled by a sense of outrage at AIDSphobia, she fought for several years in ACT UP to expand the CDC's definition of AIDS to include women's opportunistic infections and for healthcare for incarcerated women with AIDS. In 1992 Lucey's advocacy work for compassionate release for women in prison with AIDS led to the first U.S. of release of such a prisoner, Judy Cagle, enabling her to die at home with dignity.

"Lucey became more powerful, fearlessly outspoken, and willing to confront government officials at every level. She was often asked by ACT UP to provide testimony to government agencies and legislators: the National Commission on AIDS, the CDC [Centers for Disease Control and Prevention], the NIH [National Institutes of Health], the Department of Health and Human Services, congressmen and state senators. Following ACT UP LA demonstrations Lucey was often interviewed for numerous newspapers and magazines, such as the *Orange County Register*, the *LA Weekly*, the *Lesbian News*, the *Weekly Reader*, *Glamour* and *Time* magazine.

"In 1994 Lucey worked as the first woman City AIDS Coordinator on an interim basis where she, along with other staff, funded the first needle exchange program from the City of Los Angeles. This program, an offshoot of ACT UP LA originally called Clean Needles Now, is currently known as the LA Community Health Project. It was calculated to prevent 12,000 new HIV infections each year.

"Lucey also founded the first peer support group for positive women in 1990 and co-founded Women Alive, a support and advocacy group. She raised money for and organized the 1997 National Conference on Women and AIDS held at the Convention Hall of the Los Angeles Staples Center. It was the largest gathering of positive women in the country at that time."

Lucey continued to stay involved as a community activist. She won a position on her local community services board representing the town of Oceano, serving for two consecutive terms. As a long-term survivor, she often asked, "Where is our vaccine? Where is our cure? And why on earth are people still getting infected?"

NANCY MACNEIL

Nancy MacNeil was born in Los Angeles and grew up running the Avenues of Highland Park. In the Vietnam War era, Nancy organized sit-ins and walk-outs with fellow students at risk for the draft in high school. She continued to attend peace rallies, marches, and pickets. She joined the Black Panther Party [BPP] to fight against police brutality and helped with their breakfast programs in downtown LA. (The BPP encompassed Black people and poor Whites.)

NANCY JEAN MACNEIL & MARY LUCEY

PHOTO: KAREN OCAMB

MacNeil was labeled an 'outside agitator' on California college campuses, enduring multiple encounters with vicious men cloaked in police uniforms while protesting against war and police brutality. Engaged on various levels with People's Park in Berkeley and the Isla Vista Uprising in Santa Barbara, she witnessed the infamous burning of the Bank of America in protest of the use of napalm in North Vietnam.

She attended the Institute for The Study of Non-violence in Palo Alto and visited federal prisons housing the boys

who said ‘no’ to the draft. She passed out flyers at the L.A. induction center every Tuesday morning, encouraging draftees to resist going to war and assisted Peace House in Pasadena, helping young men file papers for conscientious objector status.

Employed at the [U.S. Postal Service], MacNeil was a steward for the American Postal Workers Union, Venice Local, negotiating union contracts between management and the rank and file. She filed numerous grievances for blatant violations of contractual agreements on behalf of persecuted employees.

In the ’70s and ’80s she became active in the gay and lesbian community, joined several women’s rights groups as well as the Lavender Left. MacNeil organized for queer liberation, civil rights and protested police harassment. In May of 1979 she participated in the ‘White Night’ riots in San Francisco when the verdict of voluntary manslaughter was announced acquitting Dan White of first-degree murder for the killing of Supervisor Harvey Milk. MacNeil was again brutalized by police and sustained multiple injuries from whirling billy clubs.

From the onset of AIDS, while it was still being referred to as gay cancer or GRID [gay-related immune deficiency], MacNeil was losing friends to the disease. Her first friend to die of AIDS was Julian Turk in 1982. He’d been diagnosed by Dr. Michael Gottlieb at UCLA, [the doctor] who was the first to report the disease that would come to be known as HIV and AIDS. She was exhaustively surrounded and saddened by the weekly loss of so many close and dear friends. This compelled her to try and turn the tables. She joined ACT UP in 1990 after attending the first Women’s Caucus meeting. She also joined the Prisoners with AIDS subcommittee and the ACT UP National Network. MacNeil attended the AIDS Clinical Trials Group in Washington, D.C. to confront researchers about scientific and ethical questions surrounding women in the government-funded treatment studies. Dosages and effects of AIDS medications on women’s bodies were still unknown and inclusion of women in clinical trials was urgently needed.

MacNeil joined fellow activists as they perpetually disseminated information, analyzed clinical data, wrote letters and postcards, zapped the opposition with faxes and phone calls and helped to organize demonstrations. She also helped to organize enormous die-ins to illustrate mass deaths to shock and shame the government and media into publicizing the AIDS crisis that was being ignored.

MacNeil became the founding executive director of Women Alive, an organization by and for HIV-positive women with a membership of over 500. She established a treatment-focused newsletter (quarterly distribution of 10,000), the first National women’s AIDS hotline and empowered women with AIDS to become their own advocates.

She identified as a “situational pacifist dedicated to fighting for social justice [who] sincerely believes that women and queers will save the world.” She said that it was “written in my heart.”

the complicated historical intertwinings of how systemic racism, economics and culture within the healthcare system contributed to the nearly 52% of new infection rates of Black people living in impoverished communities, particularly in the Bible Belt.” Co-hosts radio personality Anna DeShawn and photographer Duane Cramer and their guests brought a down-home family feel to their talk. DeShawn and Cramer are also the co-founders of The Qube, which presents a streaming platform of music and podcasts produced by and for Black, brown and queer and trans people of color. The series showcased four topics:

- The History of Black HIV in the South
- The Fear of Black HIV in the South
- The Community of Black HIV in the South
- The Solutions to Black HIV in the South

FIND The Qube at theqube.app.

Report offers data on PLWH in state and federal prisons

The number of people incarcerated in state and federal prisons who are living with HIV decreased in 2021 for the 23rd consecutive year, down to 11,810, according to a U.S. Department of Justice report that was released in March. The 2021 figure dropped by 2% from the previous year, a downward trend that has continued since data were compiled in 1991.

Issued by the U.S. Department of Justice’s Bureau of Justice Statistics (BJS), *HIV in Prisons, 2021–Statistical Tables* is a by-the-numbers look at people living with HIV who were in state and correctional facilities in 2021.

“While about one percent of persons in state and federal prison were living with HIV, testing and monitoring remain important to assess long-term trends,” said BJS director Alex Piquero, PhD.

The 2021 report cites data from 49 states and the federal Bureau of Prisons. Not included in BJS figures, however, are people held in privately run prisons. Among the statistics presented in the report:

- Of the estimated 11,810 persons living with HIV (PLWH) who were in custody at the end of 2021, 1,216 were in federal facilities and 10,600 were in state custody. The two states with the largest numbers of PLWH were Florida (1,863) and Texas (1,583).
- By year’s end in 2021, 0.9% of individuals in federal custody were living with HIV; 1.2% of people in state custody were PLWH. The states with the highest proportions of PLWH in custody were Florida (2.8%), Louisiana (2.5%) and Mississippi (2.5%).
- Of the 50 jurisdictions whose HIV testing practices were cited in the report, 16 conducted mandatory testing during intake. HIV testing was offered during routine medical examination by 18 jurisdictions, up from 11 in 2017. HIV testing at the person’s request was the most commonly reported testing practice during discharge in 29 jurisdictions in 2021, compared to 27 in 2017.

Since the federal prison system began collecting HIV data, one to four jurisdictions a year have not provided numbers. To produce national and state totals on the number of PLWH in prison, data are imputed for non-reporting jurisdictions.

Statin drug significantly cuts cardio risk for people living with HIV

A review of data found that a daily statin medication cut the risk of cardiovascular disease among people living with HIV by 35% compared to a placebo. The findings were so conclusive, the REPRIEVE study, which had been ongoing for eight years, came to an abrupt end.

The significant reduction prompted the study's independent Data Safety and Monitoring Board to recommend that REPRIEVE be stopped early, and that the participants who had been on the placebo be switched to the statin.

The rate was "more than we hypothesized," said the study's principal investigator, Steven Grinspoon, MD, of Harvard University and Massachusetts General Hospital.

People living with HIV have "higher than expected risk of cardiovascular disease and this is occurring often in younger patients who have relatively low to only moderate traditional cardiovascular risk," Grinspoon said. "In other words, they don't typically have high cholesterol and other risk factors, and typically they wouldn't be recommended for statin therapy."

The largest randomized HIV study in progress, REPRIEVE began in 2015, enrolling 7,769 participants ages 40–75 living with HIV from 12 countries in Africa, Asia, Europe, North America and South America. All participants were on stable antiretroviral therapy, had CD4+ T cell counts of over 100 cells/mm^3 and were at low to moderate risk for cardiovascular disease. Nearly one-third of the participants were women.

Statin drugs reduce cholesterol, and have been shown to lower the risk for heart attack and cardiovascular disease in most people, but it was uncertain whether they would benefit PLWH. Participants were given either a 4 mg pitavastatin Livalo pill or a placebo pill once daily. They were monitored for major cardiovascular events such as myocardial infarction, chest pains and stroke or having stents or coronary bypass surgery. Side effects and drug-drug interactions were monitored, although pitavastatin is believed to be safe with HIV medications.

"These latest findings represent the culmination of an unprecedented eight-year effort to generate evidence that can help clinicians better support the unique cardiovascular health needs of people living with HIV," said Gary H. Gibbons, MD, director of the National Heart, Lung and Blood Institute (NHLBI). "REPRIEVE is important because there are limited existing interventions to help prevent adverse cardiovascular outcomes in this population."

Participants were notified of the findings and will continue to be monitored for several months, according to the National Institutes of Health (NIH).

REPRIEVE was primarily funded by by the National Institute of Allergy and Infectious Diseases (NIAID) and the NHLBI with additional funding from the NIH Office of AIDS Research. The AIDS Clinical Trials Group conducted the study.

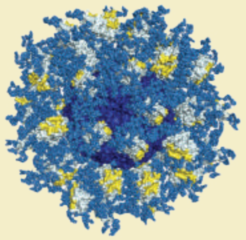
READ the REPRIEVE abstract on the *New England Journal of Medicine* website: bit.ly/nejm-reprieve-abstract

—**RICK GUASCO**

Nanoparticle looks promising in early vaccine trial

An experimental nanoparticle vaccine has been shown to be safe in its first in-human trial. The results of the early phase study were published in the journals *Science Translational Medicine* and in *Science*. While the vaccine is not intended to provide HIV protection by itself, researchers found that it prompted a robust immune response in 35 of the study's 36 adult participants.

Results showed that the engineered outer domain germline targeting version 8 60-mer nanoparticle—or, eOD-GT8 60-mer—increased production of a rare type of antibody-producing immune B cell that is capable of producing broadly neutralizing antibodies (bNAbs) to protect against diverse strains of HIV.



The eOD-GT8 60mer nanoparticle is based on the engineered protein eOD-GT8. Yellow shows where eOD-GT8 binds antibodies; white is the protein surface outside the binding site; light blue indicates the sugars attached to the protein; dark blue is the nanoparticle core to which eOD-GT8 has been fused.

PHOTO: SERGEY MENIS AND WILLIAM SCHIEF, THE SCRIPPS RESEARCH INSTITUTE

This is significant because the human immune system is often overwhelmed and outsmarted by HIV. The virus mutates rapidly, producing new and different versions of itself that the immune system eventually fails to recognize. For a vaccine to work, it will most likely need to induce the body's production of bNAbs that will be able to identify multiple strains of HIV. Only a handful of people living with HIV—the Berlin patient and the London patient, for example—have been cured, and often only through treatment that was torturous and not scalable. Still, they are proof that the immune system *can* do the job.

The first step of what would be a multi-step vaccination regimen is to prime the immune system to make more bNAb-precursor B cells. That's where the eOD-GT8 60-mer protein nanoparticle comes into the picture. It "teaches" the immune system to identify and target HIV.

In the study, eOD-GT8 60-mer was administered by injections eight weeks apart; participants received doses of either 20 or 100 mcg. Additionally, antigen-specific CD4 T helper responses were observed in 84% and 93% of vaccine recipients, respectively. Participants reported mild to moderate side effects that disappeared within a couple of days. The study also showed that the vaccine bolstered B cell production; subsequent booster shots could further coax B cells into making HIV-protective bNAbs.

"[W]e found that induction of vaccine-specific peripheral CD4 T cells correlated with expansion of eOD-GT8-specific memory B cells," concluded researchers in their abstract. "Our findings demonstrate strong human CD4 T cell responses to an HIV vaccine candidate priming immunogen and identify immunodominant CD4 T cell epitopes that might improve human immune responses either to heterologous boost immunogens after this prime vaccination or to other human vaccine immunogens."

Principal investigator was Kristen W. Cohen, of Seattle's University of Washington and the Fred Hutchinson Cancer Center, as well as William J. Fulp, Allan C. deCamp and Andrew Fiore-Gartlan.

—**RICK GUASCO**

Advocates take to Capitol Hill for 30th annual AIDSWatch

More than 350 HIV advocates from 37 states came to the U.S. Capitol in late March for the 30th annual AIDSWatch, the largest ever constituent-led HIV advocacy event. The advocates met with lawmakers and their staffs in 182 congressional offices.

AIDSWatch is produced by AIDS United, the U.S. People Living with HIV Caucus and the Center for Health Law and Policy Innovation at Harvard Law School.

"We've never missed a beat. We've never missed a year, whether virtual or in person, of telling Congress our stories," said AIDS United president and CEO Jesse Milan, Jr. at the opening rally on Capitol Hill.

Elizabeth Kaplan, director of health care access at the Center for Health Law and Policy Innovation, has been living with HIV for 38 years. "There have been times when I have told my story, especially as a younger person, because I wanted to be seen, and because I wanted HIV to be seen," she said at the rally. "And there have been times when I have not told my story, because HIV does not define me or how I live my life. This is a space where I want to share my story, because **telling our stories and being seen is the heart and the strength of AIDSWatch**. We are stronger when we weave our stories and voices together, and together, we can create change."

Martha Cameron, vice chair of the U.S. People Living with HIV Caucus, laid out some of the items on the advocates' agenda. "We must ask for access to comprehensive care for people aging with HIV and long-term survivors, people who were born with HIV," she said. "Very soon, people who acquired Medicaid during COVID might be losing it by the end of this month. I think that's unacceptable. In this era of inflation, we got flat Ryan White funding, and then there's also the need to continue fighting for employment services for people living with HIV."

—RICK GUASCO


GATHERING IN FRONT OF THE U.S. CAPITOL BEFORE MEETING WITH 182 CONGRESSIONAL OFFICES.


AIDSWATCH ADVOCATE DAVID FOLKES IN A MEETING WITH THE OFFICE OF CONGRESSWOMAN NIKEMA WILLIAMS (D-GA.).


AIDS UNITED PRESIDENT AND CEO JESSE MILAN, JR. SPEAKING TO ADVOCATES AT A RALLY OUTSIDE THE U.S. CAPITOL.


ADVOCATES MEET IN THE OFFICE OF THE RESIDENT COMMISSIONER OF PUERTO RICO, JENNIFFER GONZÁLEZ COLÓN.

PHOTOS BY DENIS LARGEON, COURTESY OF AIDS UNITED

Taking care of our own

STORY BY **DAVINA CONNER** • PHOTOGRAPHY BY **SEAN BLACK**

From the first days of the AIDS epidemic, people living with HIV have looked to one another for care and support. Today, people living with HIV are living long enough to face other, sometimes greater, health challenges. This is Bryan C. Jones' fourth bout with cancer—throat cancer this time—so when he started chemotherapy and radiation treatment, he reached out to another longtime HIV survivor and activist. Davina Conner flew from her home in Las Vegas to be with Jones, accompanying him to the hospital for his daily treatment.

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As I sit on the plane for the four-hour flight to Cleveland, Ohio, there are many thoughts racing through my mind about my good friend Bryan C. Jones. Wondering if he is having a tough time with the chemotherapy and radiation treatment, and if it has started to affect him. I can't wait to land so that I can give him a great big hug, to let him know that I'm here for him. I call him Jethro and he calls me Ella. Don't ask me how that happened, it just did.

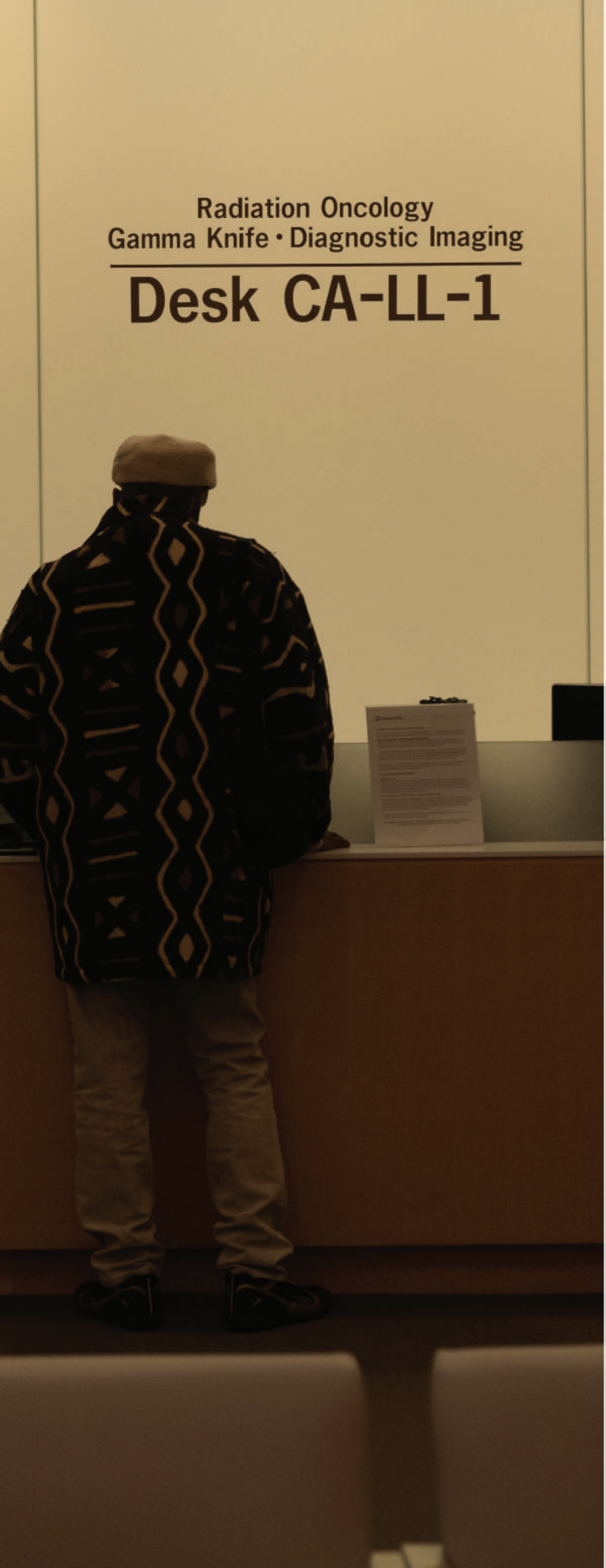
He started chemo and radiation a little over a week ago, and I knew I had to be there to support him. He doesn't know that I cry for him almost every time we hang up the phone because I love my friend very much and want him to be O.K. Sometimes I ask the Creator why He gave me such a big heart to love people so strongly, especially the ones I am close to. I know I shouldn't question it, but I have always to hear an answer.

Jethro and I can laugh and stay on the phone for hours at a time, but we also share many thoughts and feelings about love, relationships, advocacy and life. When you have someone close to you going through something that may damage them, you worry about them. I try to be optimistic, but thoughts of him being in pain, or even passing away come across my mind. But I quickly push that kind of negative energy away even if it's hard to do. Why am I thinking this way, why have I allowed expectations of the worst to sink into me? I know that with faith all things are possible. I have always known that all things are possible when you have faith, but I have been struggling with this since he told me what was happening.

> I can't wait to land so that I can give him a great big hug, to let him know that I'm here for him.

I grew up with four sisters, but always wished I had a brother. As my twin sister and I grew older, we were always closer to the men in our lives whether it was a cousin, a friend from school, or an uncle. Because we were so close to our father, there was something inside me where I just got along better with men as great friends than with women. That's the closeness I feel with Jethro.

I have experienced a lot of deaths in my family over the years, especially since the beginning of COVID. The thought of losing someone this close to me again kills me inside. Although he says he's doing okay,



'I'm still standing'

Reflections on surviving several bouts of cancer, while living with HIV

BY **BRYAN C. JONES**

Even now that the radiation is over and I'm taking chemo pills, I don't know what tomorrow may bring for me. I've been through worse, having had stage 4 cancer with one leg chained to a bed while I was in prison and being told I was going to die. But one thing I know about myself and the people whom I've grown accustomed to and have welcomed into my life, we are all resilient people. We come with our own set of strengths and weaknesses. That's not to say that I haven't had some scary nights in this ordeal, dealing with this cancer, not being able to get up and walk, falling down and passing out, but I still manage to come out on the other side.

I tell people that when I'm living my worst life, I'm living my best life because I learn so many things while in that valley trying to claw my way up and out. I've learned so many things that have helped me in these dark moments. I've thought about what advice I would give somebody in this situation. It's always a message of hope, so I take my own advice and I push on, move out and climb up to the next plateau, ready to take on the next fight.

Prior to my cancer diagnosis, I was feeling good. My little organization was starting to blossom, and then when the diagnosis came, it was one thing after another. First, I had this massive abscess, then I had to do six weeks of IV antibiotics at home. After that cleared up the doctors said, When we were giving you the IV, we saw that your appendix ruptured, so they needed to remove my appendix. While removing it they found the colon cancer. Right on the heels of the colon cancer is when I got the neck and tonsil cancer. Having already had cancer three times, I said, *okay, here we go with this again*. I felt that this, too, shall pass. Once the radiation treatment started, though, I really felt down. I was at a low and then Derek came back into my life. He has been a tremendous help.

Davina said early on that she would come and help me through treatment. In the back of my mind I said, yeah right, she's coming to my house for a month to help me get through this. Not that I doubted her friendship; I just felt that that was a lot for any one person to say they would do. But Davina being Pozitively Dee [as she is known in the world of HIV advocacy], she came and we conquered. She moved in, cleaning and cooking and giving me the moral support and strength I needed. I often tell people you don't know how strong you are until being strong is your only option.

I want people to know that just because you hear the word cancer we automatically get afraid and think that it's the end of the world, but for me cancer and HIV are two words that I have knocked down brick by brick, fight by fight and I'm still standing.

I know it can be mentally difficult for him. Bryan is a warrior inside and out, and a lot of times I wish people understood him the way that I do. He has the biggest heart and would take his shirt off his back to give to someone else if he had to. I know we connect well because we are the same when it comes to caring for others and knowing what that means to people.

What do you say to someone who says, *I have cancer?* What do you say to someone who is having radiation on their neck and stomach every day for weeks at a time, and watch as he just pushes through it? I know that he appreciates me being here with him because I was sitting in the living room, and he called my name as he walked by. I say what's up, Bryan? He says, thank you. What for? I ask, and then he says for being here and coming all the way from Las Vegas; I just love you for that, Ella. When he said that to me it filled my heart with joy because he knows that a friend who loves him is here to support him.

At times I wonder what support looks like for me as I age with HIV, and it does scare me. Especially since I know that when living with HIV, we are susceptible to other illnesses. This is a thought that runs through my mind more often than it should: I do not want to die alone. It makes me wonder if there are other people who feel the same way. My friend has been living with HIV for over 35 years and he told me that he never thought that he would be living this long with HIV, and on top of having cancer five times. He said that people don't realize how sick he really is, and that it could be worse. I feel that everyone who lives with HIV deals with other health issues to worry about than HIV. Especially people who are aging with HIV. Just dealing mentally with what could come is difficult enough, and without support it's even harder for people who feel alone.

Our thoughts and emotions about life and the uncertainty of what's ahead can be frightening. All I know is that being in the presence of people who need us is what matters, and we celebrate life with them now and not when it is too late. But we also must remember to take care of ourselves as well. Let go of grudges, and love people for who they are and not for who you think they should be. I think what I am trying to say is that Bryan (my Jethro) is who he is, and I love him for that. Although he may say things that I do not agree with sometimes, I know that what he does is out of love. He is passionate about the HIV community just like a lot of us are. He is my friend, my shoulder to lean on, my partner in advocacy and my brother. I wouldn't have it any other way.

I wish I could have stayed longer than two weeks. I didn't want to leave him. The plane ride home, I had such mixed emotions, but I knew he was well cared for. His partner Derek is such an amazing man. He shows up for Bryan in all ways that he can. Having that kind of love and partnership with someone is absolutely beautiful. I joke and say I don't see how Derek does it, but I know that it's because of the compassion he shares with Bryan. If others could love more, and care more for people this world would be such a beautiful brighter place to be in.

DUMITRU OCHIEVSCHI-ISTOCK

Unreliable sources

Amid COVID-19, misinformation and disinformation target HIV

BY **RANIER SIMONS**

One of the most dangerous forms of misinformation and disinformation targets public health. **Misinformation** is defined as inaccurate or false information spread among large groups of people as fact. Misinformation is believed to be accurate and based on unsubstantiated rumors, misguided anecdotal evidence, misinterpretation of fact, and even bias stemming from universally shared cultural beliefs. **Disinformation** is deliberately targeted malicious misinformation propagated to deceive people into believing something for financial profit, political gain, or even malevolent ideological destabilization of evidence-based foundational norms. HIV isn't immune from either one.

Medical misinformation has dire consequences. It can be a matter of life and death. It maintains confusion, mistrust of fundamental science and undermines public health efforts. People who believe medical misinformation and disinformation lose their power to make decisions in the best interests of their health. As a result, they turn down well-established life-saving treatments, engage in harmful or potentially deadly treatments, and exacerbate conditions that would typically benefit from early intervention by delaying proper treatment.

A plethora of medical misinformation and disinformation continues to circulate regarding HIV and COVID-19. Recently circulating is a false causal claim linking HIV and COVID-19 vaccines. Conservative commentators such as Hal Turner, a right-wing radio host, claim that there has been a 500% increase in new military HIV diagnoses due to COVID-19 vaccines being instituted.[1]

In an effort to combat this misinformation, the Associated Press published data fact-checking the false claim. According to the U.S. Department of Defense and the Congressional Research Service, 1,581 service members, including the National Guard and Reserves, have been diagnosed with HIV since 2017.[1] Approximately 317 service members were diagnosed with HIV in 2017; 280 in 2018; 314 in 2019; 237 in 2020; 309 in 2021; and 124 in 2022.[1] There were 72 more cases of HIV diagnosed in 2021 compared to December 2020, when COVID-19 vaccines became available to the public.[1] That was only a 30% increase, not 500%. Moreover, in 2022 when the vaccines had been widely adopted, there were 185 fewer diagnosed HIV cases. That was a 60% drop from 2021.[1] Right-wing conservative media reported numbers they claimed came from leaked data from DMED, the Defense Medical Epidemiology Database. DMED is an internal database accessible only by military medical personnel.

The Associated Press reported that the Defense Health Agency's Armed Forces Surveillance Division explained there had been data corruption which resulted in the appearance of a significantly increased occurrence of all medical diagnoses in 2021 because of the under-reported data for 2016–2020. The cause of the corruption was identified, and the database was made whole. No evidence exists that COVID-19 vaccines have caused HIV or other immune deficiencies. Conservative right-wing media has also linked COVID-19 vaccinations to a non-existent fabricated condition called VAIDS, vaccine-acquired immunodeficiency syndrome, in an attempt to cast doubt upon factual COVID-19 vaccine data.

Other disinformation campaigns from conservative sources regarding COVID-19 were the ivermectin and hydroxychloroquine treatment fallacies. Former President Donald Trump explicitly promoted both. In a November 2020 *Journal of Medical Internet Research* study, researchers quantified the potency of his misinformation. For example, their Twitter analysis found that his first tweet on March 21, 2020, promoting hydroxychloroquine and azithromycin, had 385,700 likes and 103,000 retweets. This equates to an estimated impression reach, or user views, of 78,800,580.[2]

America's Frontline Doctors (AFLD), a scam group of right-wing physicians, also perpetuated misinformation and profited from it. AFLD used telemedicine scams to make a profit, promising telemedicine appointments for people who wanted to be prescribed ivermectin for COVID-19.[7] Patients were charged for virtual visits whether they received them or not. They were also billed hundreds of dollars for ivermectin and hydroxychloroquine prescriptions filled by third-party mail-order vendors. AFLD was created by the Council for National Policy, a network of conservative activists.[7] *Time* magazine found no proof that any physicians involved had expertise in directly caring for COVID-19 patients.

America's Frontline Doctors (AFLD), a scam group of right-wing physicians, also perpetuated misinformation and profited from it.

An Ohio State study found that conservatives are more susceptible to believing false information than liberals.[3] Overall, liberals and conservatives tend to believe claims that support their views. Additionally, both liberals and conservatives are able to adequately distinguish between falsehood and truth when the truth is presented as politically neutral. Neutral means that the factual truth does not overwhelmingly support the political views of either side. However, researchers found that liberals are much better at distinguishing falsehoods from truths that support liberal ideology. Conservatives in the study were significantly biased toward false information that supported a conservative political agenda, even when the claims were deemed outlandish and starkly in contrast to evidence-based facts. Researchers also explained that the odds were stacked against conservatives being able to distinguish fact from fiction because there is a much higher volume of right-leaning misinformation in the American media and information environment.[3]

The most effective way to combat medical misinformation and disinformation is to be just as proactive about promoting factual and truthful information. In an effort to battle misinformation, the U.S. Surgeon General, Dr. Vivek H. Murthy, issued a 22-page advisory in 2021.[4] The advisory details specific ways the media, health professionals, the public and even technology platforms can take effective action. YouTube has partnered with providers and organizations like the Mayo Clinic, the American Public Health Association and Massachusetts General Brigham to create evidence-based content and highlight videos from high-quality sources when people search for health subjects using Google.[5,6]

REPRINTED WITH PERMISSION FROM THE ADAP ADVOCACY ASSOCIATION. TO READ THE ORIGINAL VERSION WITH FOOTNOTES, GO TO bit.ly/covid-misinformation-targets-HIV.

If you're living with HIV, *do you have a support network*—friends or loved ones—you can turn to when you need care?

We asked our social media followers. They answered—and even responded to each other's need for support

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"My friends and coworkers are 100% supportive. With so many of us where I work living with HIV and our company culture is HIV-focused, we are there for each other. Also, I go to Positive Attitudes, a weekly support, discussion and educational group in the Ft. Lauderdale area."

—ROBERT HADLEY

"I'm one of the founding members of a Facebook group called Straight and Positive, for heterosexual men living with HIV. It's a private group, so contact me to join. It's been really great to connect and build something, bringing in so many stories and watching this group grow."

—DEREK CANAS

"Sadly, my support system is not local. It seems like the only ones who have any type of support are the youth and the newly diagnosed. Here in southern Appalachia, support is hard to find. Long-term survivors and people over 50 are disregarded and ignored in this area."

— MARK L GRANTHAM

"There's HAG: HIV & Aging group on Facebook, my family and congregation; I've been going to AA 12-step groups for over 30 years. I guess you could say that my life is one big support group."

—LILLIAN THIEMANN

"I've been living with HIV for nearly 40 years. My best friend is a doctor. I have a network of older Black friends, some of them are also living with HIV, some of them aren't. We are all long-term survivors. We support each other on all fronts."

—@IAMPHILLWILSON

"As a senior citizen and long-term survivor of AIDS, stroke, heart attack and ensuing kidney failure, I have no one. I have recently relocated to be near my hospital and doctors. It's self-care and good planning, as all my friends are dead. My biological family has never been helpful. I have a cat."

—@ROBNDA216

@ROBNDA216: "Hey, Rob. Long-time warrior here, too. I am also diabetic, have afib and live with degenerative arthritis. Always around to listen and help."

—@McINNIS

"My support network is a close group of other long-term survivors from across the country. No one 'gets it' like other survivors, with whom we can talk on Zoom in a shorthand for which no explanations are necessary."

—BRUCE WARD

"I have my Thriving at 50 & Beyond group—we discuss challenges, successes and new medications, including injectables. I also seek professional speakers to speak on HIV and aging, diabetes, gastrointestinal issues, heart, bone loss, mental health, stigma and isolation. We meet at a park to have our discussions."

—LILLIBETH GONZALEZ

"I have been living with HIV for over 30 years. My support group includes my kids, my grandkids, my ex-wife, my parents before they passed and my good friends. Everyone who is in my life has always supported me and helped me out. When I first found out I was positive, I sent an email to everyone I knew, telling them what was going on in my life. Nobody stepped away. I just love them all, and I do not know how I could've gotten through all of this without them."

—TRACEY KELLY

"I've moved to the middle of nowhere Tennessee with a friend so I can better my mental health. What I'm realizing I sacrificed was comprehensive HIV care and a support network."

—@RYANKNOWSBEST

@RYANSKNOWSBEST:
"Hey Ryan! I'm sorry to hear that... it's wild how different services are depending on where you live."

—@SHAWNDECKER

@SHAWNDECKER:
"It's an hour to Nashville to get help. No transportation that I know of. No local help to access meds. I'm due for Cabenuva at the end of August and have no access to get it outside of market price through a local doctor."

—@RYANKNOWSBEST

"I have @network_alive as my support group."

—@BUKENYASIMONPE8

"I live in Washington, D.C. with my seronegative husband who loves me, with insurance that keeps the medicines coming and allows me to see HIV-aware and gay-affirming doctors close by. Yet I need to connect more with other people who are living with HIV. I used to have more HIV friends when I was less healthy."

—@LIVINGPLUSLY

"I have @rrpplus, a network of people living with HIV in Rwanda."

—@CHARLENEJOURNEY

"I wish there was a professional support group for us, especially for newly diagnosed people. I was totally lost in the beginning of my journey."

—RODGE @RODGELIFEPLUS

"There are no support groups in my area."

— JAMES SOTO

PARTNERS IN RESEARCH PART 2

Active involvement

People living with HIV share their experiences as cure research participants

CONTRIBUTING EDITORS **TOM VILLA, BILL FRESHWATER, JEFF TAYLOR, GAIL GRAHAM, JOHN SAUCEDA** AND **KARINE DUBÉ**

To develop an HIV cure, most clinical studies involve an analytical treatment interruption (ATI)—a study participant who is living with HIV voluntarily temporarily stops taking their antiretroviral treatment (ART) regimen. Currently, this is the only way to determine if a potential cure strategy will work without ART.

ATI trials hold potential promise for a cure but have potential risk for participants, who might experience the unexpected return of virus, and to their partners, who might become vulnerable to HIV acquisition.

Continued work to develop effective cure strategies will require more and larger trials involving ATIs in order to expand the diversity of participants so that the results will benefit all communities. An HIV cure must be a cure that works for all. As research continues, the health and safety of participants must be ensured.

A team of community advocates is working with POSITIVELY AWARE, sharing their experience and insights as HIV cure research participants in this series, Partners in Research.

As clinicians and participants in cure research, we advocate for a Participant Readiness and Resilience framework to help ensure that HIV cure research remains acceptable to community. Each HIV cure trial experience is unique, so we envision a comprehensive program that supports participants, their partners and family members during their entire journey that provides the following:

- Trusted and communicative research teams to help participants navigate intense, complex research protocols and the uncertainty and anxiety the cure trial might entail.
- A modernized informed consent process that provides understandable and easily digestible information about complex topics that are easily accessible to diverse groups and learning styles.
- Assessments of the understanding and psychosocial readiness of participants and their partner(s) before and during ATIs to minimize psychological harms.
- On-demand and low barrier psychosocial support as needed by participants or partners.
- Sharing of outcomes and findings directly with the participants who made the research possible at no charge and in ways accessible to them and with the communities in which the research was conducted.

Get involved in HIV cure-related research

For a list of ongoing and past HIV trials, GO TO treatmentactiongroup.org/cure/trials

Share your thoughts of the Patient Readiness and Resilience Framework (page 27).

CLARK HAWLEY

Feeling good about being part of the scientific process

I am a retired teacher; I taught first through fourth grade. I also helped children of migrant farmworkers keep up with their classmates in school for 15 years before I retired. That's the career stuff. Then there was not realizing that I was a gay man until I was 36 years old after being married at 23. I have two grown sons, and have been in a loving relationship for almost 10 years.

According to scientists, I am the earliest, most acute person diagnosed with HIV. I had signed up for a pre-exposure prophylaxis (PrEP) trial. When they took my information and enrolled me into the program, my antibody test came back negative, but my viral load came back at a very low number, around 92 copies/mL. Researchers called me and said I had a questionable result. That meant I was on the way to testing HIV-positive, and I started HIV treatment quickly.

My first HIV treatment interruption lasted around six months. My second one was about two months. During the first interruption, I went on a planned trip to Disney World. The research team arranged for me to be able to give blood (for safety tests) during the treatment interruption to make sure that I was safe. I did rebound right after I got back from the trip and could feel my body experiencing flu-like symptoms.

I felt safe and comfortable during my research participation. People were watching out for my best interests. I felt it was my responsibility to humanity and to my community to be as cooperative as possible. How many people have the opportunity to have their bodies teach scientists something that humans don't know yet? If your body has something to teach humanity, let it.

We did a lymph node removal, a gut biopsy (a few times) and a leukapheresis (removal of blood to collect specific cells) a few times. The researchers were setting the protocols based on my safety more than their desire for the things that they were investigating. I felt their professionalism, restraint and academic caution.

I felt I was fully informed before the start of the treatment interruption. In this last study, the research team organized to have a car sent out. All I had to do was go out my front door, get into the car, and get driven to San Francisco. Researchers did all of the tests and drove me back home.

At the end of the first treatment interruption, I would have felt more comfortable if I had been tested twice a month. In my last treatment interruption, the researchers trusted me to tell them how my body was feeling. They listened to me and made me feel that I was part of the process.

During treatment interruptions, my partner and I simply did not have unprotected sex. We simply used condoms or went oral. I felt my researchers were concerned about me being aware of what was safe, and they were as concerned for my partner's health as I was concerned for my partner's health.

I would be willing to participate again in a treatment interruption. It was completely hassle-free. It is meaningful to me that I am still HIV antibody-negative even despite the ATI. My body just simply has not had enough time to make antibodies. If I participate in an intervention study, I will probably have to go HIV antibody-positive to get that whole process to where your body fights off HIV to see if there is a functional cure. Being part of research can be incredibly satisfying. We are just coming out of the COVID-19 pandemic, for which the vaccine was based off research that was done for HIV cure.

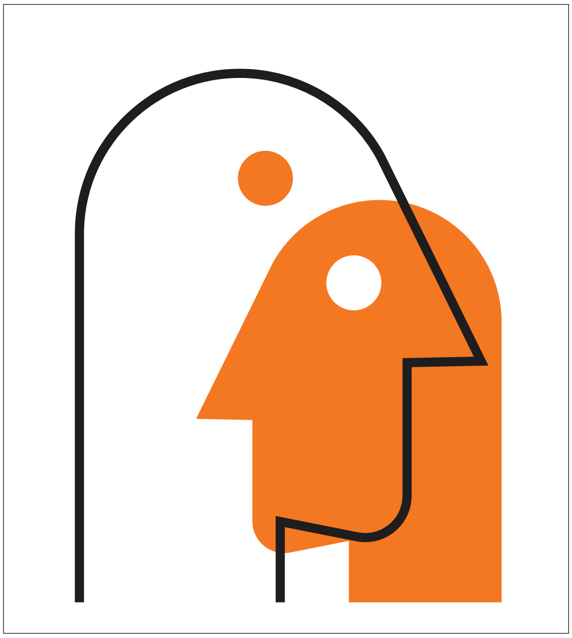
There's the possibility that me suiting up and showing up could have helped countless people. That makes me feel good about being part of the scientific process.

TOMOZIN-ISTOCK

ANONYMOUS

An HIV-negative partner's perspective

We had been together 25 years. Together, we had seen the HIV therapeutic landscape change dramatically—from medications that made him sick often, through complications with early protease inhibitors and finally to our nearly normal lives with him taking mostly benign ART once a day.



I was so thankful for the positive changes that had helped make him healthier and happier, our lives easier and more predictable. I was well aware that they were only possible because of the participation of many individuals in clinical studies. And yet, when he told me he was seriously considering taking part in an ATI study, I tried to talk him out of it.

You are doing so well. Why take the chance that the virus cannot again be suppressed after the treatment interruption? What if you get sick again? I read some of the literature. While the approach seemed potentially promising, it did not strike me as any sure thing. There were many unknowns and uncertainties. The time and travel required seemed unreasonable: overnight stays monthly for a year, an initial week-long visit, and periodic treatments that might unpredictably require longer stays. *Who can accommodate such a schedule?* And, of course, a number of the treatments carried significant risks. *Everything considered, I am not at all sure you should do this,* I suggested.

My arguments were not successful. In the end, it was his decision, and he decided to go ahead. He did so after considering my views and those of others. He chose to participate for two major reasons: he hoped to help advance HIV cure science. He also wanted to honor those who went before and help improve the lives of those who come after. I greatly respected his decision.

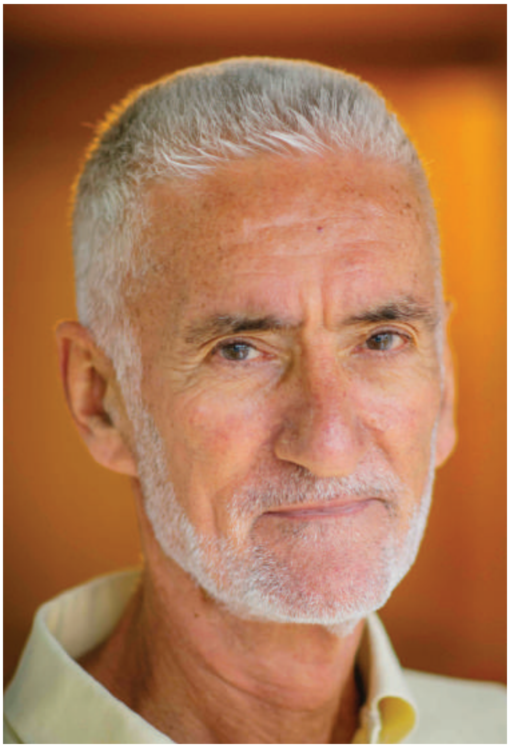
In hindsight our sacrifices were not great. As a long-term committed sero-different couple, a short-term modification of our intimate behavior was not a deal breaker. I had recently retired and had available time. We had no children or others dependent upon us. For other potential participants, the logistics may well be more difficult to manage. After the fact it appears that my partner suffered no apparent ill effects. We also know that the experimental product was proven ineffective. But as a result of the study, clinical research efforts and resources can be directed towards more promising therapies. And we—primarily my partner—played a small but essential role in moving clinical HIV research forward. So, we can feel good about our participation, and feel that the risk was worth the effort and uncertainty.

RICHARD STRANGE

Serial ATI participation

I am an 81-year-old white, gay male who first tested HIV-positive in January 1993. My initial instinct was to get involved in the scientific work to defeat this virus by volunteering for trials at the NIH [National Institutes of Health]. Over the course of 15 years I was a participant in 10 studies, mainly phase 1 drug trials. In one trial, I was one of the first two humans to receive the drug after testing in non-human primates! My rationale then was, as it is now— **if not me, then who?”**

Six of the 10 studies in which I participated included an analytical treatment interruption (ATI). In one study I thought my results suggested that I might be a “partial



controller." So, I volunteered for what promised to be a scientifically exciting and significant study of how the body's own immune system can control HIV. The study involved closely monitored periods without taking ART, the longest of which for me was 914 days. More recently, I have worked with NIH staff to ensure that my body will be donated expeditiously on death to enable this rewarding history of scientific contribution to be rounded out.

I was aware that there was some risk involved in suspending ART, so I discussed the risks with the study clinicians as well as with my own physician. I always felt that they gave me honest, scientifically-based assessments of the risks and I never felt any pressure to participate or resistance to terminating participation. I was grateful and impressed by the amount of time that senior study clinicians devoted to giving detailed answers to questions I had about the design, rationale and progress of the studies.

I took a close interest in the clinical data being gathered during the ATIs, in particular absolute and trend values for HIV viral loads and CD4/CD8. I remained healthy throughout all the studies with no side effects or adverse events attributable to the studies.

My experience with ATI was uniformly positive and uneventful with no wishes for different outcomes.

I am fortunate to have had a scientific education studying physiology—but that was in 1960–1963, an earlier era! This enabled me to look into developments and issues in HIV research as I got involved. Informed consent processes present a challenge: they must above all be written in language that is clearly understandable by any prospective participant, no matter what their educational background. But they also need to be scientifically precise. I think lay members of CABs (community advisory boards) can contribute usefully in honing informed consent forms to ensure that they are intelligibly accurate.

THOMAS J. VILLA

ATI: 'A trial interruptus'

Over the years I have participated in perhaps two dozen clinical studies, so participation in an HIV cure-related clinical trial was a logical step to contribute to my community.

I took part in an ATI trial to test if a first in-human combination of two monoclonal antibodies was safe and effective to control HIV without taking daily ART. The trial was to last 12–18 months, with each participant undergoing two ATIs.

I started the first ATI at my baseline clinic visit and continued for about five weeks until my viral load became detectable at a low level (200+ copies/mL). At the next clinic visit, I was given an infusion that took about an hour. I had no reaction whatsoever and returned home in time for lunch. I restarted taking ART the following day, and my HIV viral load was back to undetectable levels after four weeks. I carried on with daily HIV meds and normal life for three months before starting the next phase of the trial.

The second ATI, expected to last 16–24 weeks, was to see how long my immune system, now fortified by the investigational product, could keep HIV under control without daily ART. I was comfortable with the frequency of safety labs (every two weeks), clinic visits (monthly) and ready availability of my research team by telephone during the ATI.

This ATI was interrupted after eight weeks when much of the nation's research staff was redirected to address the COVID-19 pandemic. While disappointed, I understood this decision and restarted ART immediately. I was surprised by how much this early termination of the trial affected me over the next several weeks—at how emotionally invested I had become in safely completing my participation—so I would like to emphasize the need for mental health support services both during and after ATI participation. In addition, we should use our experiences with early ATI trials to create formal mechanisms to react to future external shocks like COVID-19. Let's prepare now.

I also suggest enhancements to the informed consent process to provide more complete information that keeps pace with rapidly advancing cure science. While I committed to abstaining from sex during the ATI to remove any risk of HIV transmission, this approach may not be practical or acceptable to other participants. Special attention to partner protection strategies is urgently needed before ATI trials are scaled up to large numbers of participants in diverse settings and/or as the duration of ATI lengthens to many months or years.

We also must assess the impact of ATI participation on other people in participants' immediate social circles—spouses, sex partners, family members, neighbors and co-workers among them. Their needs must be understood and addressed for ATI trials to continue successfully.

A journey approach to HIV cure research

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

Before an ATI

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

Enhance the informed consent process to include multi-media and a multi-modal informed consent process that accommodates the disparate learning styles, literacy levels, cultural, linguistic and socioeconomic backgrounds of prospective participants.

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

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

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

Ensure that treatment costs for adverse events resulting from an ATI are not borne by the participant.

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

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

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

During an ATI

Conduct close monitoring without overburdening trial participants.

Build support around partner protection measures.

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

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

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

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

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

After an ATI

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

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

Monitor for potential long-term effects of ATIs.

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

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

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

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

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

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

ATI support program goals

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

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

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

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

Create an ATI participant experience database and research hub.

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

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

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

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

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

Develop community-centered education materials around ATI trials.

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

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

Another survey with HIV long-term survivors:

Have we learned anything new?

BY **HANK TROUT**

On Wednesday, March 22, the Survivors of HIV Advocating for Research Engagement (SHARE) Board conducted a webinar highlighting the results of their survey “Aging with HIV: What do you need to thrive?” They sought to answer questions such as, “What are the key health-related questions/issues that research should address around HIV and aging?,” “What matters most to people aging with HIV?” and “What health outcomes are of most relevance to people aging with HIV?”

Sadly, the SHARE survey and report revealed nothing new.

Their overall conclusions were that:

- Community members living with HIV can be and need to be included in research projects;
- Care concerns in long-term survivor groups may reflect the loss of friends and the potential of stigma from family members, necessitating need for paid care;
- Planning for older adulthood is challenged further when living into advanced age wasn’t anticipated; and,
- A significant need exists for financial management, housing, and medication burden support.

It is notable that SHARE meant for the survey not only to identify priority research issues that matter to long-term HIV survivors, but also to facilitate collaboration among long-term HIV survivors, policy makers, clinicians and researchers.

They recruited a group of 267 long-term survivors (whom they defined as 50 years or older who had lived with HIV for 10 years or more), ranging in age from 42 to 77, with an average length of diagnosis of 29 years. Survey respondents were heterosexual (36%), gay (29%), bisexual (19%) and lesbian (13%), with reported race/ethnicities of Black or African American (33%), Hispanic (28%) and white (52%) from both rural and urban areas around the country. Participants completed a survey and interviews by phone, Zoom or face-to-face.

The survey revealed slightly different priorities among those who have lived with HIV for less than 20 years compared with those who have lived with HIV for more than 20 years, but overall, the six most frequently reported needs among long-term survivors were: (1) enhancing quality of life (by far the most prominent issue), (2) addressing mental health and cognitive decline, (3) maintaining physical health, (4) addressing loneliness and isolation, (5) issues of medication, including polypharmacy concerns and (6) accessing appropriate healthcare.

We already know what we need. When, if ever, will those needs be met?

Care planning and caregiving were also identified as critical issues, with more than 50 percent of respondents stating, “I’m not sure who would provide care for me,” particularly among those who were diagnosed more than 20 years ago. More than 80% of respondents also reported having experienced stigma based on race/ethnicity, gender identity, sexual orientation, age and HIV status.

Since January 2016, I have studied and reported on issues faced by us long-term HIV survivors, including several community-based surveys and studies such as this one. I have attended (via Zoom) several webinars reporting on the findings of those studies. While I make no unwarranted claim to expertise in the field of HIV, I can and do claim a great deal of lived experience with HIV as well as knowledge gained through my studying and reporting.

For many years, we long-term survivors have known and made public our concerns about being included in research projects that affect our lives and other issues identified in the SHARE survey. One need look no further than The San Francisco Principles 2020, which five of us long-term survivors wrote and distributed after the virtual AIDS 2020 conference.

In the Principles, we identified the same issues (stigma, financial stress, mental healthcare needs, the lack of trained geriatricians, concerns about the effects of the virus and our medications on our bodies, the lack of political will to address those issues, etc.) and proposed solutions. We were not alone—several major AIDS-related groups have long insisted on the inclusion of us long-term survivors in any and all research and clinical trials that affect us. “Nothing about us without us” is more than just a catchy slogan—it is a priority that many of us have demanded since as early as 1983 when people living with AIDS promulgated the Denver Principles.

For me, this webinar raised several questions:

What is being done to get the results of this survey, and others, into the hands of policymakers, clinicians and researchers who can actually do something with them?

What concrete actions are being taken as a result of these many community surveys?

How many times must we ask the same questions, getting the same answers, before our answers to those questions are implemented in meaningful ways?

It seems to me, and to many of my fellow survivors, that our needs—for informed healthcare, for financial help to afford medications and living expenses, for mental healthcare, for community-based solutions, etc.—have been known for long enough. What we need is policies and actions that address those needs.

We already know what we need. When, if ever, will those needs be met?

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FAIRYWONG-ISTOCK


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STERN


BERRY


D. CAMPBELL

Diversity in studies and community input in cure research today

Highlights from the 2023 Pre-CROI Community HIV Cure Workshop

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

Held just before the start of the conference, the Pre-CROI Community Cure Workshop provides HIV cure research education and fosters dialogue between biomedical HIV cure researchers and community members, with the goal of promoting meaningful community involvement in HIV cure science.

During the workshop, an underlying theme emerged around the need for early community engagement while HIV cure-related research is still in the lab, the pre-clinical phases of the pipeline. Current engagement efforts must be demographically and geographically expanded, with a focus on key populations, and must be well funded and not approached as an afterthought. And incorporating social and behavioral research throughout the research enterprise as more clinical trials begin to investigate potentially curative therapies will be paramount for the field.

The 2023 **Community HIV Cure Workshop** was sponsored by Treatment Action Group (TAG), AIDS Treatments Activists Coalition (ATAC), AVAC, BEAT-HIV Community Advisory Board, CRISPR for Cure Collaboratory, DARE Community Advisory Board, Enterprise for Research and Advocacy to Stop and Eradicate HIV (ERASE-HIV), European AIDS Treatment Group (EATG), HOPE Collaboratory, I4C Collaboratory, National Minority AIDS Council (NMAC), PAVE Collaboratory, REACH Collaboratory, RID-HIV Collaboratory, and the University of Washington/Fred Hutch CFAR Cure Scientific Working Group.

Among the workshop highlights:

MORNING SESSION

Treatment Action Group's (TAG) **Richard Jefferys** and researcher, educator and activist **Liz Barr** provided an overview of the current landscape of HIV cure-related research. Since 2014, TAG has maintained a listing of HIV cure-related clinical trials and observational studies. As of February 2023, there have been 93 interventional trials (90 adult and 3 pediatric), and 38 observational studies (37 adult and 1 pediatric). Of those, 34 involved analytical treatment interruptions (ATIs). Most studies have been conducted in the Global North, and the majority (69%) obtained some community input. These **statistics underscore the urgency of implementing HIV cure clinicals in resource-limited settings**. Obtaining community input in research protocols will ensure that these protocols are community-friendly, as well as ethical and indicated for specific international populations. To date, over 14,000 people with HIV have participated in HIV cure-related studies, most of whom are men. For more information about demographics of participants in HIV cure-related clinical research, GO TO treatmentactiongroup.org/cure/resource-on-the-demographics-of-participation-in-hiv-cure-related-clinical-research/.

Shelly Karuna, Chief Medical Officer at Greenlight Biosciences, discussed ATI studies in Antibody-Mediated Prevention (AMP) trial participants. Two studies were described: HVTN 704/HPTN 085, occurring in the Americas and Europe in men who have sex with men (MSM) and transgender people, and HVTN 073/HPTN 081, occurring in sub-Saharan Africa in heterosexual women. All participants started ART early and received a combination of broadly neutralizing antibodies. The post-AMP ATI trial in Africa (HVTN 805/HPTN 093/ACTG 5393) began in early 2020 after extensive stakeholder engagement. The research team is following robust informed consent to facilitate decision-making. So far, of the 13 participants enrolled, one participant has maintained antiretroviral treatment (ART) suppression for over 18 months, and two additional participants have been off ART for 5–6 months. Dr. Karuna emphasized the possibility of conducting ATI trials safely in Africa. **ATI trials require meaningful early stakeholder engagement and input** to ensure that they remain community-friendly and ethical, no matter the specific context of any given country or group of potential participants.

Jessica Salzwedel (AVAC) moderated a panel discussion on community engagement for studies involving ATIs. Panelists included **Michele Andrasik** (HVTN), **Gail Brocher** (HVTN), **Krista Dong** (Ragon Institute), **Udom Likhitwonnawut** (independent consultant, Thailand), and **Kenly Sikwese** (AfroCAB). They discussed balancing participation while ensuring adequate safeguards, illustrating **the need to maintain quality community engagement in HIV cure trials**. They also questioned how in the era of Undetectable = Untransmittable (U = U), we discuss stopping antiretroviral therapy with potential participants. The panel emphasized the need to integrate socio-behavioral science studies that engage with HIV care providers and local ethics review committees, and acknowledged the role of partners, including referral for pre-exposure prophylaxis (PrEP) for partners without HIV. To design ethical studies, panelists stressed the need to engage communities early and often. We must understand participants' needs and perspectives if we are to design human-centered clinical trials with analytical treatment interruptions.

Russell Campbell and **Brian Minalga** provided an overview of the Office of HIV/AIDS Network Coordination (HANC). Founded in 2004, HANC's mission is to support the science and operations of the HIV/AIDS Clinical Trials Networks by increasing efficiency and resource sharing. HANC also coordinates critical activities across the networks and research and advocacy. HANC created a Representatives Studies Rubric (RSR) to guide and monitor enhanced representation in clinical research (e.g., age, drug use, ethnicity, gender, pregnancy, race, sex assigned at birth). A number of **community resources are available through HANC**, including guidance on how to review clinical trial protocols, a bill of rights and responsibilities for study participants, mentorship programs, and the Red Ribbon Registry. The HANC Webinar Library is at hanc.info/resources/webinars-and-presentations.html.

AFTERNOON SESSION

Jared Stern (Fred Hutchinson Cancer Center [Fred Hutch]) presented on the **effects of long-term ART on the HIV reservoir** (excerpts from the presentation appear in the March+April issue, "What makes HIV such a retro-virus?"). Dr. Stern described through an extended metaphor of a cookbook to help people understand the mechanisms of HIV persistence in people on suppressive ART, as well as ways ART changes the composition of the HIV reservoir over time. HIV establishes a chronic infection in T cells, (known as the reservoir), stressing that some viruses are more active than others. While on ART, active HIV-infected cells are cleared faster by the immune system than the inactive cells, resulting in the HIV reservoir becoming less active over time. Dr. Stern concluded that differences in the composition of the HIV reservoir may require tailoring different HIV cure interventions.

Jeff Berry (The Reunion Project) moderated a **panel discussion on long-term survivors (LTS) and HIV cure research**. Panelists included community members and researchers **Bill Hall** (Seattle), **Pat Migliore** (Seattle), **Jared Stern** (Fred Hutch) and **Andrew Clark** (ViiV Healthcare). The panel brought up the differences between LTS who were diagnosed with HIV at birth and people who are aging with HIV. Strategies to engage (LTS) in HIV cure research were explored. The role of medical mistrust in clinical research was acknowledged, together with the need to engage LTS communities in defining research questions. Ensuring a broad and diverse engagement of all LTS will enrich existing HIV cohorts.

Danielle Campbell (BEAT-HIV Collaboratory) noted that 51% of PLWH are women, presenting a **community call to action to prioritize inclusion and enrollment of women in HIV cure research**. She called for full support of women's bodily autonomy and decision-making processes, considering women's sexual and reproductive freedoms, providing no-cost contraception and ensuring representation and enrollment of women at all phases of research. Involving more women and communities from the Majority World (also known as the Global South) is called for, including socio-behavioral research to understand and address barriers to women's enrollment, utilizing benchmarks for enrollment, engaging community-based organizations to assist with accrual and retention and performing sex-based analyses. For more details about the call to action, GO TO bit.ly/call-to-action-women-in-HIV-cure-research.

The pre-CROI Community HIV Cure Research Workshop made clear that all these years into the AIDS pandemic, **real diversity in HIV clinical research is desperately needed**, with social justice for all people who are disparately affected by HIV. Further community input is needed to ensure that clinical trials remain ethical, centering around the priorities of people living with HIV, and that socio-behavioral studies are embedded with biomedical interventions. Without these elements, clinical trials, already struggling to accrue and retain participants, will result in insufficient data that represent all people affected by HIV.

For more information about the 2023 Pre-CROI Community Cure Workshop, including recordings and slides from each presentation, GO TO Treatment Action Group—2023 Pre-CROI Community HIV Cure Research Workshop: treatmentactiongroup.org/webinar/2023-pre-croi-community-hiv-cure-research-workshop.

About the writers

Karine Dubé is an associate professor at the University of California San Diego School of Medicine and Global Public Health. She is a socio-behavioral scientist focused on integrating a patient/participant perspective into HIV cure-related research in the United States and South Africa, and is a member of the Delaney AIDS Research Enterprise (DARE) Community Advisory Board (CAB). She also leads the BEAT-HIV Social Sciences Initiative and is a member of the Global Gene Therapy Initiative (GGTI).

Lynda Dee co-founded AIDS Action Baltimore in 1987. She has worked with academia, industry and government to expedite drug development and provide access to HIV medications. Dee has served on many advisory boards, including various FDA approval panels, NIH Advisory Boards and industry CABs, and is a founding member of the AIDS Treatment Activists Coalition. She has also worked in the HIV cure research arena as co-chair of the Martin Delaney Collaboratory (MDC) CARE CAB, co-chair of the amfAR Cure Institute CAB, and is now the DARE MDC Community Engagement Coordinator.

Jeff Berry is executive director and co-founder of The Reunion Project, the national alliance of HIV long-term survivors, and serves as National Steering Committee Chair. Berry most recently served as chief editorial officer of TPAN and editor-in-chief of POSITIVELY AWARE, serving as editor from 2005–2022. He is the inaugural chair of the CRISPR for Cure CAB of the Martin Delaney Cure Collaboratories, and a member of the Illinois Commission on LGBTQ Aging, the Community Collaboration Board (CCB) of the Third Coast Center for AIDS Research (CFAR), the Fair Pricing Coalition (FPC), and the AIDS Treatment Activists Coalition (ATAC).

Michael Louella is proud to serve as a co-chair for the DARE Community Advisory Board. He has worked in HIV treatment research for 23 years, engaging communities affected by HIV in Seattle and across the U.S. in clinical trials towards the treatment and potential elimination of HIV from the body. He joined the defeatHIV Martin Delaney Collaboratory as its Community Engagement Project Manager in 2013, focusing his efforts around cell and gene therapies for HIV cure. He serves on the steering committee for The Reunion Project, working to develop more events for HIV long-term survivors. Recently he joined the Global Gene Therapy Initiative, an alliance of key stakeholders including clinicians, scientists, engineers, advocates and community members brought together to enable access and implementation of gene therapies as curative medicines for presently incurable diseases in Majority World countries.

Sex talk at CROI

Beating off STIs with DOXYVAC, doxy-PEP, Apretude, vaginal ring, implant and booty butter

BY **ENID VÁZQUEZ**

The world can stop HIV and STIs with medication. Medication taken by people living with the virus and medication taken by people not living with the virus. At the 30th anniversary of CROI—the **Conference on Retroviruses and Opportunistic Infections**, also known as the Retrovirus Conference—several research teams reported on advances in the battle against HIV and sexually transmitted infections. As the DOXYVAC study team noted, "There is no magic bullet. There's an interest in combined approaches." Note: All of these reports were presented via a webcast; GO TO croiwebcasts.org.

DOXYVAC study: Vaccination fights off gonorrhea

Incidence of gonorrhea was cut by more than half with two shots of a meningococcal B vaccine, reported the ANSW 170 DOXYVAC study team from Paris. The vaccine fights bacteria that's similar to gonorrhea. Based on early successful results, randomization was stopped and everyone in the study was offered the vaccine.

All study participants were also offered doxycycline ("doxy" for short) for post-exposure prophylaxis (PEP) against STIs. This involved taking 200 mg of doxycycline within 72 hours of condomless sex. ("Prophylaxis" means prevention.)

The DOXYVAC study looked specifically at these two interventions together because the international IPERGAY study had previously reported that doxy-PEP fights off chlamydia and syphilis incidence by about 70%, but had no significant effect against gonorrhea.

The DOXYVAC study enrolled 502 men who have sex with men (MSM) who were already taking pre-exposure prophylaxis (PrEP) against HIV in a larger study.

The question of drug resistance is always a concern with antibiotics. In a separate presentation from the DoxyPEP study in the U.S., the researchers reported that, "In this subset of doxy-PEP participants with antimicrobial resistance data, we did not find markedly increased doxycycline resistance." (SEE more in Briefly on page 6.)

Doxy-PEP based on STI

A research team found that for using doxy-PEP, "**The most efficient prescribing strategies are based on STI history rather than HIV status or PrEP use**." The group analyzed the electronic health records of more than 10,000 patients at Fenway Health, a Boston clinic focused on LGBT health. More than half the patients were taking PrEP.

While doxy-PEP "is highly efficacious," said presenter Michael Traeger, PhD, of Harvard Medical School, the team found that "those prescribing strategies giving patients doxy-PEP after they've been diagnosed with an STI are slightly more efficient, which means you need to prescribe less doxy-PEP to fewer people to prevent the same number of STIs."

Long-acting HIV prevention with Apretude for adolescent girls

The HIV Prevention Trials Network (HPTN) reported early research showing safety and tolerability with the use of a long-acting injectable form of PrEP, cabotegravir LA (CAB-LA, brand name Apretude), in adolescent girls. Apretude is administered as one injection every two months.

"There was high interest in the study and we enrolled very quickly," said presenter Sybil Hosek, PhD. This was all the more remarkable given that the study began just as the global COVID shutdown took hold. "The product was found to be acceptable by the adolescents. **Their adherence was exceptional**. In fact, 100% of injections that were expected to occur did occur. There was no safety signal, no serious adverse events, no HIV infections and no discontinuation of product due to injection site reactions.

SYBIL HOSEK, PhD

"These studies are critically important when we have a new product because our ultimate goal is simultaneous licensure of new products for adolescents and adults so that there's no access issues for those in the young age range," said Dr. Hosek.

HPTN 084-01 was a Phase 2b safety study of CAB-LA among African adolescent cisgender girls under the age of 18. Most participants, some of whom were as young as 12, chose to continue using CAB-LA rather than be switched to Truvada for PrEP, Dr. Hosek said. Fifty-five girls from Uganda, Zimbabwe and South Africa were enrolled, all during the COVID pandemic.

Vaginal ring and PrEP during pregnancy

"Pregnancy represents a high-risk period for HIV acquisition," noted the MTN-042/DELIVER study team. "The monthly dapivirine vaginal ring (DVR) has been clinically shown to reduce HIV risk with no safety concerns in non-pregnant reproductive-aged cisgender women; however, data during pregnancy are limited." Taking this issue head-on, the team enrolled more than 300 pregnant individuals and provided them with either the ring or oral PreP.

Cutting to the chase, the team reported that, "In this first study of a long-acting HIV prevention agent in pregnancy, adverse pregnancy outcomes and complications were uncommon when DVR and TDF/FTC [PrEP] were used in the third trimester of pregnancy and were similar to rates observed in the communities where the study is being conducted. These **data support plans for subsequent investigation of DVR safety earlier in pregnancy**."

"I would just like to emphasize that studying safety of an investigational product is hard in pregnancy, but it can be done,” said presenter Katherine E. Bunge, MD, of the University of Pittsburgh. “We are doing it and it should be done, because pregnant people deserve better.”

The DELIVER team noted that **pregnant people are three times more likely to acquire HIV per sex act than non-pregnant individuals**. The study took place in Uganda, Malawi, Zimbabwe and South Africa.

Refillable PrEP implant

How about an implant under the skin to prevent HIV? Early results with monkeys (specifically, rhesus macaques) showed the ability to sustain prevention drug levels needed to prevent simian HIV (SHIV) for nearly two years. There is **hope for a refillable implant for people that can last three years**.

“In the PrEP efficacy studies with repeated low-dose SHIVSF162P3 challenges, the implants conferred 100% protection against rectal and vaginal infection. The implants were well tolerated with mild local tissue inflammation and no signs of systemic [throughout the body] toxicity,” a research team from the Houston Methodist Research Institute reported. They used islatravir, a long-acting medication under development for the treatment of HIV as well as for PrEP.

Booty butter: rectal PrEP insert

A fast-dissolving rectal insert containing two medications used for preventing HIV showed good results in early research from the Microbicide Trials Network (MTN).

Credit longtime HIV microbicide advocate Jim Pickett for the phrase “booty butter”—it’s been one of his war cries for more than a decade.

“Currently, the only on-demand product option for PrEP is the tenofovir 2-1-1 regimen [two pills followed by two more pills around the time of sex], which really has only been tested in cisgender men,” said presenter Sharon Riddler, MD, of the University of Pittsburgh. “So if proven to be effective, **a product that is discreet and provides protection, potentially both vaginally and rectally, would be a real game changer**.”

The MTN-039 study reported safety and high localized drug levels with low systemic exposure. The medications used in the insert, which looks like a tiny bullet, were elvitegravir and tenofovir alafenamide (TAF), both of which are currently available as oral drugs for the treatment of HIV.

The 21 HIV-negative study participants all received one insert and then a week later, 19 of them received two inserts. (Two of the participants had already moved away from the study site area by then, in a research trial taking place during the COVID shutdown, with the research team unsure that the study could even be completed.)

Setback: doxy-PEP in women

For all the great news about doxy-PEP over the past several years, one research team found that it didn’t work for cisgender women.

“This was the first trial evaluating doxycycline-PEP for cisgender women,” said presenter Jenell Stewart, DO, MPH, of the University of Minnesota. “Unfortunately, our primary outcome found that it was statistically not significant. **We did not see a reduction in STIs among cisgender women**, which is in stark contrast to my colleagues’ studies here among cisgender men and transgender women.”

JENELL STEWART, DO, MPH

Which shows, again, the need for research. Among the potential differences, “We don’t know the extent to which perfect adherence is needed to prevent STIs in the endocervix or the opening of the uterus,” said Dr. Stewart. She noted that the women reported high rates of adherence.

The research team is also going to look at the effect of any drug resistance in their setting of Kenya. Nearly 500 ciswomen ages 18 to 30 in the study were already taking HIV PrEP. There was a high incidence of STIs at baseline, but no acquisition of HIV.

“It’s very clear that STI prevention is really important, especially with the impact it can have on the uterus,” Dr. Stewart said. “I’m more motivated than ever to continue figuring out why this did not work, and to find interventions that work for cisgender women.”

Stopping HIV in Black folks with Apretude

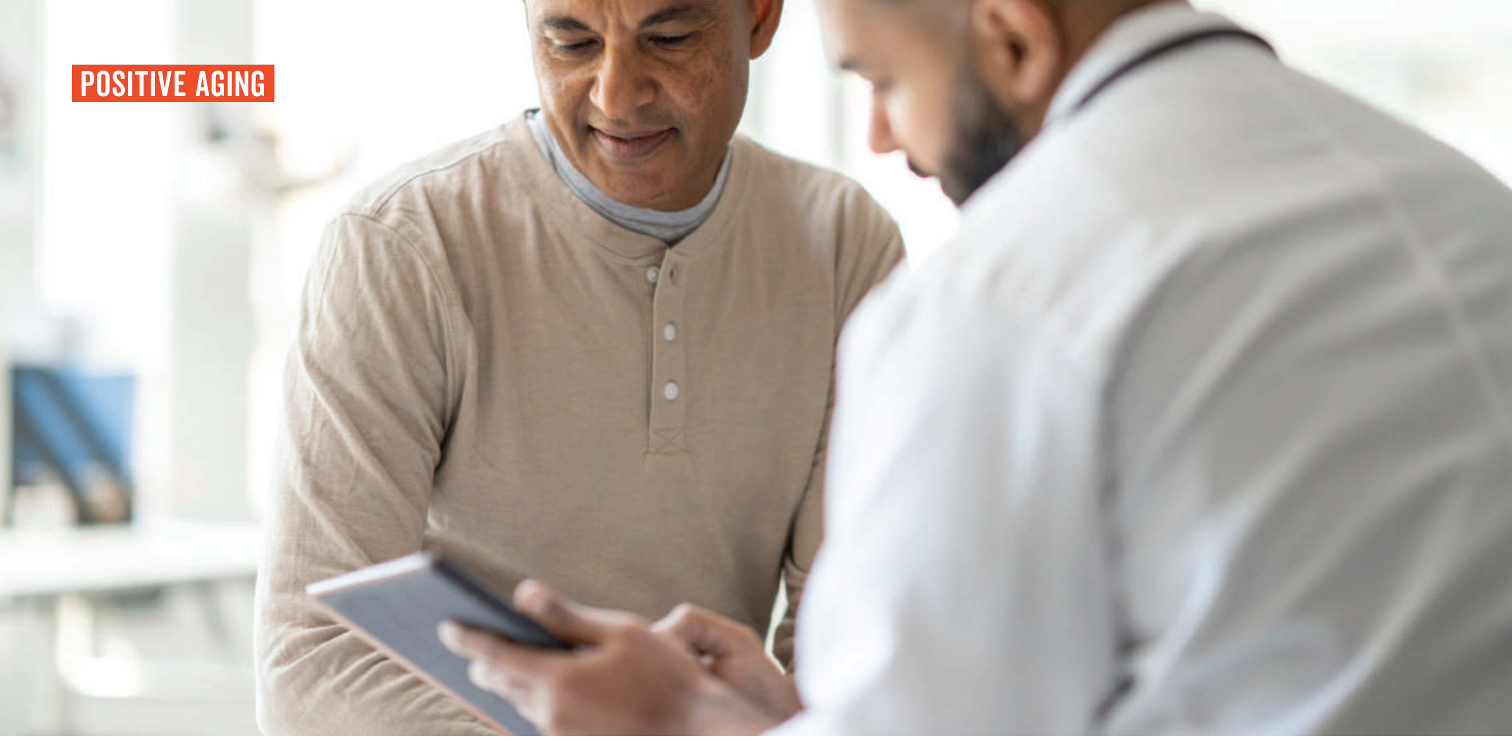
Apretude has shown superior efficacy in preventing HIV compared to Truvada for PrEP. Apretude is taken as one injection every two months, while Truvada for PrEP is prescribed as a daily pill.

Apretude was also better at stopping HIV for Black folks specifically, according to research findings reported by the HPTN 083 study team.

“[Apretude] is an extremely powerful HIV prevention tool to increase access to PrEP and address the continued disparities in the United States that we continue to see, and implementation really needs to focus and prioritize addressing these disparities by making access universal and easy,” presenter Hyman Scott, MD, MPH, of the San Francisco Department of Public Health, noted in his conclusions.

Half of the 1,698 individuals in the U.S. part of the international study self-identified as Black or as mixed race including Black. The vast majority of all participants, more than 90%, were men who have sex with men (MSM). About 7% of all individuals were transgender women who have sex with men. Black MSM and trans women bear the brunt of the HIV epidemic in the U.S., the HPTN 083 team pointed out. The study is ongoing.

HYMAN SCOTT, MD, MPH



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Meds and labs: By the numbers

How understanding your lab test results can help you stay healthy

BY **MARC FISCHER**

Many people are intimidated by lab test results. Numbers and strange medical terms can seem confusing and too complicated to understand. But once you start to develop a basic grasp of what they mean, they can serve as a guide, measuring stick for progress or a map to chart your course. Understanding your lab results can also help inform the questions you ask your care provider about your health.

Laboratory tests give primary care providers invaluable assessments of a patient's health. They can also help people living with HIV (PLWH) to understand their health status and determine what they need to do to stay healthy or to improve their health.

How lab tests help maintain HIV health

The goal of antiretroviral treatment is to decrease viral load, disrupt replication of the virus and increase CD4 cell counts to strengthen the immune system.

For PLWH, lab tests can answer a number of essential questions such as:

- **Are prescribed HIV medications working?**
- **Are the meds causing side effects** that can impact a person's ability to live and perform basic tasks? If so, what other medications can be considered?
- **Are the medications affecting key bodily functions** such as those of the liver and kidneys?
- **Has the virus become resistant** to the current drug regimen or has the virus mutated to the point that current meds are no longer controlling HIV?
- **What is the status of the immune system?**

"While monitoring CD4 counts is important to doctors, the main number that matters to patients is viral load. As long as that is undetectable, the meds are working and the virus is under control," said Justin Goforth, RN, BSN, who has 30 years' experience providing treatment adherence, medical case management, clinical staff training and community outreach for HIV/STI prevention, education and testing. "The most important action a patient can take to keep the virus undetectable is to take meds daily. Take your meds. That's what matters most." It should be noted, however, that not everyone might be able to get "undetectable" despite their adherence; this does not necessarily mean that their treatment is failing or inferior.

Healthy living with HIV requires attention to other health challenges

Patients and doctors who work together as partners can produce optimal medical outcomes that result in the best life possible for the individual in care. An Individual Health Inventory in four major areas collects and shares key information to treat and look for emerging health challenges. In addition to HIV health, the other three are:

Patient history: Effective care plans know and address key events and conditions that make up a person's unique medical history, including any risks for conditions that may arise. Lab tests answer the question, *How is the patient doing now?* If tests indicate attention is needed, the results can help the care provider determine what needs to be done to repair or control the medical issue.

Family medical history: The health of parents and grandparents can often play a part in a person's health. Health conditions from one generation may sometimes be passed on to the next. Genetic health challenges may be mitigated or monitored by sharing family medical history with primary and specialty care providers. Such information helps interpret health events and detect emerging issues with lab tests. Early detection and treatment can minimize harm and make treatment easier.

Chronic conditions: The CDC reports that, "six in ten Americans live with at least one chronic disease, like heart disease and stroke, cancer, or diabetes. These and other chronic diseases are the leading causes of death and disability in America, and they are also a leading driver of health care costs."

The likelihood of chronic conditions emerging increases with age and are often controlled or managed through daily medicines and recommended behavioral changes (such as regular sleep habits, quitting smoking, reducing alcohol consumption). Lab tests identify the need for treatment and monitor the effectiveness of medications over time.

Aging with HIV

More than 40 years into the HIV epidemic, today's approaches to care are far more responsive to patient needs, and current medications deliver long-term viral suppression without the significant side effects that were common with earlier drugs. While much has been learned about the long-term impact of the virus and HIV medications, much still needs to be studied. HIV.gov points out, "People aging with HIV share many of the same health concerns as the general population aged 50 and older: multiple chronic diseases or conditions, the use of multiple medications, changes in physical and cognitive abilities, and increased vulnerability to stressors. In addition, while effective HIV treatment has decreased the likelihood of AIDS-defining illnesses among people aging with HIV, many HIV-associated non-AIDS conditions occur frequently in older persons with HIV, such as cardiovascular disease, diabetes, renal disease, and cancer. These conditions are likely related to a number of interacting factors, including chronic inflammation caused by HIV. Researchers are working to better understand what causes chronic inflammation, even when people are being treated with ART.

"HIV and its treatment can also have effects on the brain. Researchers estimate that between 25–50% of people [living] with HIV have HIV-associated neurocognitive disorder (HAND), a spectrum of cognitive, motor, and/or mood disorders categorized into three levels: asymptomatic, mild and HIV-associated dementia. Researchers are studying how HIV and its treatment affect the brain, including the effects on older people living with HIV."

Treatment for PLWH over age 50—many of whom have lived with HIV for years or even decades, and now comprise more than half of all PLWH in the U.S.—represents a new frontier. Regular lab tests and physician consultations are essential to tracking bodily functions and responding promptly to emerging needs.

Understanding results of common non-HIV lab tests

The overall purpose of labs is to monitor key bodily functions to be sure each is within the medically established range recognized as consistent for good health. Reports for laboratory tests have three columns: name of the test, your test score and the "reference range," usually the range for what is considered a "normal" test result.

A care provider reviews the test results, compares them to the established ranges, factors in the specifics and other details about the patient's health, and, if needed, recommends a target range that is appropriate and achievable for the individual. The patient and the provider then discuss and agree upon a treatment strategy.

The goal of such conversations is to help the person living with HIV know what's needed, why the action is necessary, what behavior changes will be the most beneficial and what timing or pace is reasonable to achieve the targeted outcomes.

MARK FISCHER (he, him), a retired educator and business executive, has lived with HIV since 1986. As past co-chair of the Metropolitan Washington, D.C. Ryan White Planning Council, he has provided technical assistance to other Ryan White planning councils to strengthen their PLWH participation, and is committed to empowering communities through training and mentoring. Mark and his husband live in Washington, D.C.

Find detailed information about lab tests for various illnesses and other conditions, and what they mean, here:

CDC
Cervical cancer testing and what their results mean: cdc.gov/me-cfs/pdfs/wichita-data-access/lab-tests-code.pdf
Cholesterol testing: cdc.gov/me-cfs/pdfs/wichita-data-access/lab-tests-code.pdf

Diabetes testing: cdc.gov/diabetes/basics/getting-tested.html

Hepatitis C testing: cdc.gov/hepatitis/hcv/HepatitisCTesting.htm

HIV testing—what does a negative test result mean: cdc.gov/hiv/basics/hiv-testing/negative-hiv-results.html

HIV testing—what do lab test results mean: bit.ly/nih-what-do-hiv-test-results-mean

Prostate cancer screenings: bit.ly/cdc-prostate-cancer-screening

An alphabetical listing of tests and their ranges (downloadable PDF): cdc.gov/me-cfs/pdfs/wichita-data-access/lab-tests-code.pdf

American Cancer Society
Cancer and understanding lab test results: cancer.org/cancer/diagnosis-staging/tests/understanding-your-lab-test-results.html

American Diabetes Association
Understanding the A1C test for diabetes: diabetes.org/diabetes/a1c

American Heart Association
Understanding blood pressure readings: heart.org/en/health-topics/high-blood-pressure/understanding-blood-pressure-readings

American Lung Association
Understanding lung function tests: lung.org/lung-health-diseases/lung-procedures-and-tests/lung-function-tests

Additional resources

Kaiser Permanente
Understanding lab test results: healthy.kaiserpermanente.org/health-wellness/health-encyclopedia/he.understanding-lab-test-results.zp3409

National Library of Medicine's Medline Plus
A database of what tests are conducted for a wide variety of illnesses and other conditions: medlineplus.gov/lab-tests

POZ ADVOCATE

SCOTT SCHOETTES
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Tipping the scales on PrEP

How a conservative Texas judge's ruling threatens HIV prevention nationwide

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Given the alternative that long-acting injectable pre-exposure prophylaxis (PrEP) offers people who don't want to take a daily medication, everyone should be able to get behind PrEP as a highly effective prevention tool. Even initial concerns over side effects—which were in fact relatively minimal from the outset—have been further reduced in recent years by new formulations. Best of all, PrEP doesn't "slow your roll" on the way to sexual activity or interfere with sensation or the experience of intimacy.

With all these terrific attributes, who could possibly be opposed to PrEP? The answer is right-wing activists who want to impose their minority world view on everyone else. If you haven't heard about *Braidwood Management Inc. v. Becerra*, the Texas lawsuit aimed at undermining access to certain types of preventive health care, this column will bring you up to speed. The plaintiffs have already prevailed in the trial court, and the case is likely on its way to the U.S. Supreme Court (SCOTUS), with a brief layover in the Fifth Circuit Court of Appeals. Anyone who wants to see the end of the HIV epidemic in the U.S. should pay attention to this case.

The lawsuit—filed in 2022 by the attorney who devised the Texas bounty hunter abortion law allowing private citizens to collect a monetary award by suing doctors for performing abortions *even in other states*—alleges that the religious freedom rights of the plaintiffs are being infringed because they are required under the Affordable Care Act (ACA) to purchase health insurance that covers PrEP and a few other preventive services. Their legal theory is that in purchasing such health insurance they are being forced to support/promote sexual activity outside of marriage ("opposite sex" variety, of course), which is contrary to their religious views.

For (not) good measure, they also allege more broadly that the ACA provision mandating that specific preventive services be included in plans without a co-payment is unconstitutional because it gives a non-legislative body, the U.S. Preventive Services Task Force, the ability to determine which preventive services must be provided for free under the law.

'Shopping for a judge'

It was not happenstance that this case landed before Judge Reed O'Connor, a federal judge in the Northern District of Texas. A very conservative jurist appointed by George W. Bush, Judge O'Connor has been the Right's go-to judge for several years. For two years, he was the only judge in a small division of the Northern District of Texas, and plaintiffs knew that if they filed in that division, their case would be assigned to Judge O'Connor.

After the Chief Judge of the Northern District announced that she would be hearing 15% of the cases filed in Judge O'Connor's division, plaintiffs with a conservative agenda started filing in a different division in which Judge O'Connor also heard cases where he was the only *active* judge. As before, plaintiffs' lawyers—including the Attorney General of Texas—knew that if they filed in this division, they were very likely to end up before Judge O'Connor.

To some extent, lawyers for causes on both sides of the aisle engage in "forum shopping"—or "forum selection" when you are the party doing it—with progressives placing their cases within the First, Second, or Ninth Circuit and conservatives opting for the Fifth, Eighth or Eleventh Circuit. But this blatant selection of a particular trial judge takes this tactic to new heights (or depths) and skirts the mechanisms in place to prevent gaming the system in this way.

But Judge O'Connor has delivered for conservatives every time, making it understandable why they feel compelled to take advantage of the circumstances allowing them to choose him.


JUDGE
REED
O'CONNOR

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Fortunately, most of these rulings have been reversed by SCOTUS or overtaken by subsequent events and legal developments. Though his Braidwood ruling likewise may not stand the test of time, PrEP advocates should not count on a favorable outcome this round, in part because SCOTUS is very different now.

Making the case for PrEP

Here are a few of the arguments HIV prevention advocates should advance as this case moves to the Fifth Circuit and (likely) SCOTUS:

First, PrEP is designed to prevent disease transmission, not to promote sexual activity. People don't need encouragement to have sex, and the plaintiffs have introduced no studies demonstrating that sexual activity has risen since PrEP was introduced. The percentage of condomless sex likely has increased, but plaintiffs' purported religious views are anti-sex, not pro-condom. (They are also anti-birth control, so they should be happy about the rise in condomless sex, right?)

And while courts must accept as genuine almost anything a plaintiff presents as their religious views, courts need not accept unsubstantiated allegations about PrEP's influence on rates of sexual activity. This second part of the equation is crucial to plaintiffs' claim that government-incentivized PrEP coverage infringes on their religious freedom rights, and plaintiffs should be required to present evidence to support this aspect of the allegation.

Second, in addition to a lot of gay men, PrEP is used by some heterosexual people, including sero-different couples trying to conceive a child. Procreative sex within a heterosexual marriage is the *one* type of sex of which plaintiffs do approve, so they can't claim they are religiously opposed to PrEP in all circumstances. Taking offense at some—or even most—but not all uses of PrEP reveals that the lawsuit embodies their desire to deny preventive medicine to certain people and has little to do with religious freedom.

Third, the "heckler's veto" is antithetical to the whole system of health insurance. My premiums pay for health services I don't use and yours pay for health services you don't use—that's just how the system works. Perhaps someone's religious views are that the "body is a temple" and therefore people should not smoke cigarettes; does that mean health insurance should not pay for the treatment of lung cancer caused by smoking? And Christian Scientists, who often refrain from medical care because they believe in the power of prayer to heal the body, are not exempted from the mandates of the ACA. If they insisted upon the "heckler's veto" that the Braidwood plaintiffs want to impose, mandating any kind of healthcare coverage could be deemed a violation of their religious freedoms.

But that is the point for the conservative activists behind the Braidwood case. Sure, they are anti-gay and anti-trans and anti-women and anti-(fill in the blank), but this lawsuit is really aimed at undermining the ACA and the more equitable system of healthcare it strives to create. Conservative activists tried three times to have the ACA struck down on constitutional grounds—with Judge O'Connor providing the trial court victory needed to advance the third case—and were successful in forcing the feds to separately fund certain types of women's contraception for the employees of religious employers who believe those contraceptives are more akin to abortion.

The accommodation of conservative activists, signified by the agreement to fund coverage for contraceptives separately for employees of some religious employers, is coming back to bite them because conservative activists have returned to chip away at another piece of the ACA on the same religious freedom grounds. And though this column does not detail Braidwood's claim regarding the legitimacy of th U.S. Preventive Services Task Force (USPSTF) to determine which preventive care services are required under the law (because it gets into some complex areas of constitutional law), that attack on the ACA's preventive services mandates is broader and more dangerous.

PrEP is designed to prevent disease transmission, not to promote sexual activity. People don't need encouragement to have sex…

Who doesn't support easy access to preventive medicine? People who want to maintain the status quo because they think it benefits them. And just like on contraception and abortion, they want to take the country backwards. If that is to be prevented—or at least stalled—HIV and healthcare advocates need to start thinking two steps ahead of them in court and in the halls of Congress.

SCOTT SCHOETTES is an attorney and advocate who lives openly with HIV. He engages in impact litigation, public policy work, and education to protect, enhance, and advance the rights of people living with HIV.

BEING BRIDGETTE

Bridgette Picou

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Showing up as who you truly are takes effort, but it's worth it

Ever notice how some words become the new "buzz" and get interjected into everything? Articles, podcasts, TV shows, etc....? Suddenly it's on everyone's mind, and folks are trying to top one another in how many ways they can use it or who can parlay it into the new must-take self-help course, or the must-attend mental health forum?

Authenticity is one of those words these days. Live fully as your authentic self! Be true to yourself and to your relationships! Show up as your authentic self and screw what anybody has to say about it! I'm not saying it's a bad thing, just that folks can latch onto things but forget there is work behind the words. The actual process of putting it to work can get lost in the shiny new buzz.

Authenticity on the surface is easy. Say who you are, be who you are, be true to who you are. Easy enough to say. I'm Bridgette, I am a nurse, I love nursing. Except nothing is that easy in life. Life, and we as people, are layered. I am Bridgette, but do you have any idea how often I get told I don't "look like" a Bridgette? Or that I spell it wrong? Bridgets are blond, blue-eyed and white. It took years for me to not be taken aback and upset when people said that. It felt like they were saying I was too ugly or too Black to be a Bridgette. I am a nurse, but to some people since I'm an LVN and not an RN, I'm either not a "real" nurse, or not the nurse I could or should be. I do love nursing, but sometimes humans annoy my soul and make me question my life choices, LOL. Do you see what I mean? There is heart work and sometimes healing work that goes into being fully aligned. I haven't even mentioned the work it takes to show up as a Black woman with HIV. Those things are absolutely part of my living as who I am authentically, but the work of it is exhausting sometimes.

Having said all that there is freedom in being true to your authentic self. One of the cooler aspects is once you figure out what that means for yourself, people can't take it from you. No one can tell you that you are doing wrong. Well, they can, but it doesn't hold weight. There is peace and confidence that comes from knowing thyself. For example, for me, stigma is far less weighty in and on my spirit since I walk in my truth of HIV. Stigma stings less and I pay less attention. Don't get me wrong, I still get pissed occasionally when it's thrown in my direction, but it's more about the disrespectfulness of it as opposed to it hurting or stirring up feelings of shame. It's also been a very long time since using my voice as a passionate and full-throated Black woman expressing myself kept me from speaking for fear of being misconstrued as an "angry black woman." Maybe you are familiar with being told you are too much, too loud, too little, or too opposite of something.

These are just my examples of things that could keep a person from being truly who they can be. These are things that people who are uncomfortable with their own authentic selves use to tell you how *your* authenticity is too much of something. Their discomfort is what makes them tell you that you are doing it wrong. Who are you? How do you wish you could show up that is different from how you do now? What changes could living authentically bring in your life? It requires effort, but it's worth it!

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

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