POSITIVELY AWARE

MAY+JUNE 2024

A COMEDIAN AND A DANDELION WALK INTO A ROOM...

Two long-term survivors trade experiences and jokes about living with HIV

REACHING T.K.

A first-year nurse bonds with his patient over a cult comedy classic

BUTT OF THE JOKE

How one physician uses humor to reduce stigma in the face of rising STIs

THE COMEDY ISSUE

‘Comedy brings laughter and laughter is hope’

ANDY FEDS, a comedian born with HIV, uses humor to educate

12 YEARS AND COUNTING

Marc Franke, known as ‘the Düsseldorf Patient,’ reflects on his post-cure journey

CONFERENCE UPDATE

CROI 2024: LONG ROAD TO A CURE

POSITIVELY AWARE

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

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MAY+JUNE 2024

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EVERY ISSUE

4
THE CONVERSATION
Hope stays strong. Making the cover. Kidney corrections.

5
EDITOR'S NOTE
The power of laughter
Humor can empower us at our weakest or most difficult moments.
BY **RICK GUASCO**

6
BRIEFLY
UNAIDS: HIV care helps other conditions. STI awareness. MISTR adds doxy-PEP to its PrEP offerings. Continuum of care in the European Union. European Union: PrEP. PrEP inequities in England. Young woman tells her story through TikTok. Meth, stigma and HIV in Latino men. KFF: Discrimination against LGBTQ+ community. Youth activists call on Congress. LGBTQ+ documentary examining trauma and resilience of gay men premieres at L.A. film festival. Activists urge Congress to make HIV a funding and policy priority.

19
THE CATEGORY IS...
Laughter
When it comes to living with HIV, humor can be a coping mechanism, a way of diffusing a situation or disarming stigma. We asked our social media followers:
What role does humor play in your life?
COMPILED BY **RICK GUASCO**

31
BEING BRIDGETTE
Humor me
Find your funny bone. Reset and center yourself by finding the humor in things.
BY **BRIDGETTE PICOU**

THIS ISSUE

12
Standup act
A long-term survivor and a dandelion walk into a room. Comedian Daniel G. Garza has been living with HIV since 2000. Andy Feds bills himself as the first comedian born with HIV. The two trade reflections and jokes about life with HIV.

16
Butt of the joke
Using humor to reduce stigma and stifle the surge in STIs.
BY **LARRY BUHL**

20
Reaching T.K.
'God willing, we will meet again in *Spaceballs 2*!
BY **CHRISTOPHER HETZER**

32
Anal cancer awareness
BY **LARRY BUHL**

33
Anal cancer isn't necessarily about anal sex
BY **ENID VÁZQUEZ**

34
PARTNERS IN RESEARCH
12 years and counting
Cured through a stem cell transplant, Marc Franke—first known as 'the Düsseldorf patient'—comments on his journey since then.
INTERVIEW BY
THOMAS J. VILLA
CONTRIBUTING EDITOR
KARINE DUBÉ, DrPH

2024 CROI CONFERENCE UPDATE

22
Two pills a week or two shots a month
Good news on long-acting therapy includes an exciting advance for people with adherence problems.
BY **ENID VÁZQUEZ**

24
What's new in HIV cure research
New paths, but still a long way to go.
BY **LARRY BUHL**

25
'A lack of respect' by HIV scientists
Activists send letter to CROI organizers after many attendees leave opening plenary early during speech by leading Ugandan gay activist.
BY **RICK GUASCO**

26
Diabetes drug reduces liver fat by nearly a third for people living with HIV
But more research is needed on the long-term implications of semaglutide.
BY **LARRY BUHL**

28
Four children have achieved remission—what does that mean for babies with HIV?
Dr. Deborah Persaud explains how a clinical trial may open new treatment options for newborns.
BY **LARRY BUHL**

Hope stays strong

THIRTY-FOUR YEARS HIV-positive, 27 years spent in prison and 15 of those spent in solitary confinement has not been enough to take away my hope.

And now that I'm two years away from freedom, I have game-changing injectable meds to look forward to (Winter 2023)! Wow! Simply amazing.

My heartfelt thanks to the medical and scientific communities as well as the activists who work on behalf of those of us who are HIV-positive.

For anyone who is discouraged—I have been shot, stabbed, overdosed three times and have spent half my life in prison. If I can deal with being positive, then so can you! This is not the end of our story.

RICHARD SMITH

Kidney corrections

*Thanks to **Nina Martinez**, the first kidney donor living with HIV, for correcting three points of fact in "Recipients and donors living with HIV: Transplanting HOPE" (February+March 2024):*

The 1984 National Organ Transplant Act didn't ban the use of organs from donors who had HIV, the 1988 amendment to NOTA did. Thus, the HOPE Act was 25 years in the making, not 30.

Dr. Elmi Muller's transplants in South Africa began in September 2008, not "early in 2000." People with HIV didn't start to receive transplanted organs from donors without HIV until the early 2000s.

"Morales would become the second person in the United States to receive a life-saving kidney donation from someone living with HIV." He is the third.

Making the cover

OH MAN! Thank you so much! The true story is that I was there on my sofa and saw the A Day with HIV campaign come across my social media. It made me think of how each day of living HIV affects me as a human.

When I first started doing advocacy for "people that looked like me," I decided I would do it for the human part of HIV because that was the most difficult part I had to deal with. It took a while for me to smile in that sunshine but I am glad I did. I would do the journey all over again. This cover means so much to me!

MARCO MAYS

THIS CAME in the mail... had no idea! What a pleasant surprise! #Covergirl

—MICHELLE RIGDON

Knowing that editor-in-chief Rick Guasco is a major fan of a particular sci-fi franchise, columnist Bridgette Picou, LVN, ACLPN, sent this email: While attending CROI [the Conference on Retroviruses and Opportunistic Infections], I wanted to let you know I discovered that the hotel I stayed at, The Curtis Denver, has a *Star Trek*-themed room. Well, it's mostly a mural, but still. LOL!

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EDITOR'S NOTE

Rick Guasco
@rickguasco

The power of laughter

My friend Bob used to say, "If years from now you'll look back and laugh, you might as well laugh about it now." I don't think he meant to be flippant. He didn't know it at the time, but Bob gave me my most essential coping mechanism.

Humor is not about not taking things seriously. Humor can empower us at our weakest or most difficult moments.

It got me through HIV and anal cancer and all the embarrassing, painful episodes that come with them. There are few things more powerful—and empowering—than looking at something (or someone) in the face and laughing back. Or making light of a situation when you would otherwise feel embarrassed or awkward. Humor can be subversive, disarming, determined and wickedly clever. Humor can be resilience.

I'm going to share with you words I've never put to print before. I was bullied all through eighth grade. The turning point came near the end of the school year, when I finally stopped taking one bully so seriously and I laughed back at him. Others saw he wasn't so intimidating after all. And suddenly, I started to feel less afraid, less ashamed and less alone.

Using humor in all its forms to make people laugh is how I create my safe space. I want people to laugh with me or because of me; I just need to know they aren't laughing *at* me.

As people living with HIV, we've used humor from the beginning—to protect ourselves, to educate, to protest, to whistle past the graveyard during the darkest times. That's why when my friends Charles Sanchez and Mark S. King suggested a humor issue—I think they were half-joking—I took them seriously.

This issue's cover feature is a chat between two comedians living with HIV. Daniel G. Garza is a gay 54-year-old Latino who's been living with HIV for nearly 24 years. Andy Feds is the stage name of a 31-year-old straight Black man who was born with HIV. They pepper their conversation with jokes as they compare notes and ask about each other's lives, starting on page 12.

In "Butt of the Joke" (page 16), Dr. Ina Park uses humor to help educate physicians, researchers and public health professionals about potentially awkward subjects such as sex and sexually transmitted infections. It's part of her effort to make medical professionals more sex positive.

"If you can get somebody to laugh, and if you can use humor without stigmatizing or making fun of any type of population, then you hook people in," she says. "It's a [better] way to get people's attention to deliver a more serious message."

People can bond over comedy. That's what contributing writer Christopher Hetzer discovered as a first-year nurse who found himself caring for T.K., who was in his final days of living with AIDS (page 20). Their small talk evolved from T.K.'s one-word answers to conversations, and then one day he asked if they could have a movie night together to watch the Mel Brooks sci-fi parody and cult comedy classic *Spaceballs*. I'll just say that Christopher shows how humor can be poignant.

Elsewhere in the issue, associate editor Enid Vázquez and contributing writer Larry Buhl report on the significance of some of the developments announced at CROI 2024, the Conference on Retroviruses and Opportunistic Infections held in March in Denver.

In "Two pills a week or two shots a month" (page 22), Enid writes about how two drugs—islatravir and lenacapavir—show early promise to become the first complete weekly regimen, and how the long-acting injectable Cabenuva has been shown to be effective for people with a detectable viral load and who may have challenges with adherence to oral meds.

Larry looks at the long road to a cure, but with various promising strategies to get there (page 24). And while semaglutide (the active ingredient in Ozempic and Wegovy, which are used to manage diabetes and encourage weight loss) has made headlines for also reducing liver fat in people living with HIV, Larry takes a step back to ask about long-term implications (page 26).

Larry also talks with pediatrics professor Deborah Persaud, MD, about the news at CROI of four children who achieved "HIV remission" as a result of receiving antiretrovirals soon after birth (page 28). It leads to a discussion that examines the concept—and vocabulary—of what is an HIV "cure."

Daniel G. Garza reappears in the issue, this time talking about being a survivor of anal cancer (page 32). Anal cancer is rare in the general population, but it's one of the most common cancers affecting gay and bisexual men, who are 20 times more likely to develop anal cancer than heterosexual men. The reason is HPV, which can be transmitted through bottoming. But in a sidebar (page 33), Enid explains why women are also vulnerable to anal cancer—regardless of anal sex.

Living with HIV is often serious business. That's why we need to laugh—*out loud!*—when we can. As Bridgette Picou says in her column (page 31), "Comedy brings laughter and laughter is hope."

To borrow another line from Bridgette, "Have a laugh, have some hope."

You are not alone.

Rick

JOHN GRESS · ISTOCK

Briefly

ENID VÁZQUEZ 𝕏 @enidvazquezpa

UNAIDS: HIV care helps other conditions

Tending to HIV health care helps countries to address other conditions as well, says a report from UNAIDS and Friends of the Global Fight Against AIDS, Tuberculosis and Malaria.

For example, “In Colombia, **a model of care specifically developed for HIV is now being used for the provision of comprehensive, coordinated care for other chronic diseases, including diabetes, cancer and cardiovascular diseases.**” Laboratory developments in Cote d’Ivoire that resulted from HIV funding now help improve outcomes for maternal and child health, tuberculosis, viral hepatitis and COVID-19.

The 24-page report, released in April, also reviews findings from Jamaica, South Africa, Thailand and Uganda.

According to *Expanding the HIV Response to Drive Broad-Based Health Gains: Six Country Case Studies*, evidence shows that the world can end AIDS as a public health threat by 2030 and that “clear pathways exist to reach this goal.” In fact, the advancements made to reach that goal stand out as a “beacon of hope” while other health targets haven’t done as well.

The report ends with six recommendations. In brief:

- “National HIV program planners and donors should be more purposeful in leveraging HIV platforms to achieve broad-based benefits.
- “The HIV response must make the case for the broad health value of HIV investments.
- “HIV investments should be further strengthened and sustained.
- “Particular action is needed to maintain and further strengthen investments in strong, sustainable community networks of people living with HIV and key populations, including networks led by women and young people.
- “Health must be elevated as a priority for investments.
- “The principles and values of the HIV response should be mainstreamed across health systems.”

GO TO bit.ly/3xJ0JiN.

STI awareness

STI Awareness Week this year was April 14–20, highlighting “the stigma, fear and discrimination associated with STIs,” reported HIV.gov.

Ask. Test. Treat. Repeat., an education campaign, promotes routine screening, testing and treatment of STIs among people with HIV or who are vulnerable to it.

Another campaign, *Prepare Before You’re There*, “encourages [all] people to learn more about what puts them at risk for STIs and to have a game plan regarding safer sex and STI prevention before ‘the heat of the moment.’”

Yet another campaign encourages people, regardless of HIV status, to talk with their partners—*Talk. Test. Treat.*

GYT (Get Yourself Tested) specifically addresses young people, encouraging them to protect themselves and their partners.

HIV.gov noted that **many times STIs go unnoticed because they often have no symptoms**.

“Testing is the only way to know for sure. If untreated, STIs can increase your chances of transmitting or getting HIV,” the government website noted. “An untreated STI can also lead to health problems, such as long-term pelvic or abdominal pain, difficulty getting pregnant and other pregnancy complications that can lead to serious health conditions for your baby.”

The website noted statistics from the *CDC 2022 STI Surveillance Report* (the latest edition available):

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TOP OF THE NEWS

➤ UNAIDS: HIV care helps other conditions ➤ MISTR adds doxy-PEP to its PrEP offerings ➤ Continuum of care in the European Union ➤ Young woman tells her story through TikTok ➤ European Union: PrEP ➤ Meth, stigma and HIV in Latino men ➤ KFF: Discrimination against LGBTQ+ community ➤ Youth activists call on Congress ➤ STI awareness ➤ PrEP inequities in England

- The highest number of syphilis cases seen since the 1950s (207,255—an 80% increase since 2018)
- More than 3,700 cases of congenital syphilis among newborns
- No increase in chlamydia cases
- Cases of gonorrhea actually fell for the first time in a decade
- More than 2.5 million cases of chlamydia, gonorrhea and syphilis in the U.S.

“We encourage individuals, healthcare providers, federal and non-federal agencies and others to learn more about the campaigns, plan activities and help spread the word about prevention, testing and treatment during STI Awareness Week and throughout the year,” HIV.gov concluded.

GO TO bit.ly/4aBGXUM.

Young woman tells her story through TikTok

“At the tender age of 10, my world was turned upside down when I discovered I was living positively with HIV,” writes Adelaide Hamese. Now 23, she revisits her adolescent years of coming to terms with her status, including getting through denial, and the ups and downs of dealing with teen realities, including sexual attraction.

“To anyone grappling with the weight of HIV stigma, please know that you’re not alone,” said Hamese in a piece for *Thought Catalog*, an online magazine devoted to young voices. “**Reach out for support, speak your truth and never allow shame to silence your voice**. Together we can rewrite the narrative surrounding HIV, fostering a future filled with empathy, understanding and love.”

Hamese’s TikTok handle is @HivtalkswithAdele. **READ** the *Thought Catalog* piece at bit.ly/3U3bwM4.

ISTOCK

PrEP inequities in England

There are medications to prevent HIV, but the inequities in accessing them seem to be neverending. Simply referred to as PrEP (for *pre-exposure prophylaxis*), these medications are considered essential to ending the epidemic.

In a detailed article from Great Britain’s aidsmap.com, Krishen Samuel summarizes the findings of a study looking at what happened when England made PrEP available for free.

“Contrary to what researchers expected to see **with more accessible PrEP, the equity gap for these two groups [Black African women and white men] increased** between the periods [that were looked at], and substantially,” Samuel writes.

There were other groups of people with a gap between their PrEP use and the number of new HIV cases. They included Black Caribbeans, people who are older and individuals living outside of London.

TO READ Samuel’s article, **GO TO** bit.ly/3Q774uC.

The study’s lead author, Flavian Coukan, of the Imperial College London, and colleagues noted in their conclusion that using a combination of prevention methods, including HIV testing, can help the country achieve its goal of ending new HIV transmissions by 2030. Equity, not equality, will help ease barriers to PrEP, they wrote. Meaning that PrEP availability is not divided equally, but rather is provided where needed most.

The study, *Impact of national commissioning of pre-exposure prophylaxis (PrEP) on equity of access in England: A PrEP-to-need ratio investigation*, was published online March 20 in the medical journal *Sexually Transmitted Infections*, an official journal of the British Association of Sexual Health and HIV (BASHH). The article is available free online. **GO TO** bit.ly/446QwsD.

MISTR adds doxy-PEP to its PrEP offerings

The former gay dating app now serves as a telemedicine provider of HIV prevention in the form of PrEP and now adds doxy-PEP for the prevention of STIs. MISTR provides free doctor consults and helps people apply for patient assistance programs and other services to lower the cost of medication

Doxycline is an antibiotic that is used to prevent gonorrhea, chlamydia and syphilis. Unlike PrEP (pre-exposure prophylaxis), PEP (*post*-exposure prophylaxis) is used *after* a possible exposure to an STI.

MISTR announced in April that it was adding doxy-PEP. “Gay-owned and -operated, MISTR has brought together a network of the best doctors, pharmacists and problem solvers to make PrEP, doxy-PEP and long-term HIV care available to all who need it. **No doctor’s office, no paperwork and free delivery**,” MISTR declared.

GO TO heymistr.com.

Meth, stigma and HIV in Latino men

The National Institute on Drug Abuse (NIDA) has awarded a five-year, $950,000 research grant for examining the connection between stigma and vulnerability to HIV by Latinos who use crystal methamphetamine.

University of Connecticut assistant professor of human development and family sciences Raymond L. Moody, PhD, was awarded the K01 Mentored Career Development Award in April.

“**Methamphetamine use is one of the most significant predictors of HIV vulnerability among sexual minority men**,” Moody was quoted by the university’s news service. “As many as one in three new HIV infections [among sexual and gender minorities] are among people who use methamphetamine.”

A clinical psychologist, Moody is passionate about examining the role of internalized stigma, which he said are “these negative beliefs [people have] about themselves related to characteristics around their sexuality or around their drug-using status, and the consequences of internalizing those beliefs."

To read more, **GO TO** bit.ly/3w8Yl4a.

KFF: Discrimination against LGBTQ+ community

The Kaiser Family Foundation (KFF) released data showing that **LGBTQ+ adults experience more discrimination than other people their age**. The latest report from the *KFF 2023 Survey of Racism, Discrimination and Health* was released in April. An earlier release covered the survey's findings on racism and discrimination in health care.

Key findings include:

- "LGBT adults face higher rates of discrimination and unfair treatment in their daily lives compared to non-LGBT adults, including in health care settings.
- "LGBT adults are more likely than non-LGBT adults to report adverse consequences due to negative experiences with health care providers and to say they take steps to mitigate or prepare for unfair treatment when receiving care.
- "Among LGBT adults, those who have lower income, are younger or are women are more likely to face challenges with discrimination or unfair treatment in their daily life and while receiving health care."

KFF is an independent non-profit reporting on health policy research and polling. To **READ** the report, **GO TO** bit.ly/3w1vm2n.

Continuum of care in the European Union

The European version of the U.S. CDC released a report on its **latest statistics (2023) for the HIV continuum of care**—from living with HIV, to being diagnosed, to starting treatment and achieving undetectable viral load. According to the report, for the 45 countries reporting all four steps:

- 83% of all people living with HIV were diagnosed
- 84% of people diagnosed were on HIV treatment
- 93% of people on treatment had an undetectable viral load (which improves their health and prevents transmission)

An estimated 35% of all people living with HIV (PLWH) did not have undetectable HIV, however. According to the report, of the individuals living with "transmissible levels of virus" in 2023, it was estimated that:

- 48% were undiagnosed
- 37% were diagnosed but not treated
- 15% were on treatment but had "an unsuppressed viral load"

"This suggests that a rapid and sustained scale-up of treatment and care to reduce the number of [PLWH] with transmissible levels of virus could have as much of an impact as current efforts to reduce the undiagnosed population through testing," the report noted.

The European Centre for Disease Prevention and Control (ECDC) estimated that 7% of individuals treated did not reach a suppressed HIV viral load. The report was released in April. **GO TO** bit.ly/3U4uHVN.

The U.S. Department of Health and Human Services (HHS), which produces HIV treatment guidelines, uses a different continuum of care which includes testing and staying in medical care.

European Union: PrEP

What about preventing HIV with the use of medications in the first place? The European Centre for Disease Prevention and Control (ECDC) produced another report in April, looking specifically at PrEP. The ECDC noted that greater PrEP uptake is needed to meet the UNAIDS goal of ending the global AIDS epidemic by 2030.

"By 2023, 30 countries in Europe and Central Asia had developed and implemented national PrEP guidelines, and PrEP was available free through the public healthcare systems of 15 countries. However, even within these countries, **PrEP is not always available everywhere and some countries have restrictions on who is eligible for it,**" the report stated in its conclusion. "In particular, PrEP remains inaccessible for certain key populations, including prisoners and undocumented migrants. While progress has been made on increasing PrEP accessibility in Europe and Central Asia, countries reported several barriers which may be encountered when attempting to access the treatment, including stigma, discrimination and distance to clinics."

The report listed five action steps, which include talking with people who have newly acquired HIV to "understand and address the barriers individuals face while attempting to access PrEP."

Another action step states that, "To reach a wider population, countries are encouraged to remove restrictions on who can access PrEP and review and expand the settings in which PrEP is available. For example, they are encouraged to explore how PrEP could be provided in more non-medical settings such as through community-based organizations."

GO TO bit.ly/3xE2a1Y.

ISTOCK

YOUTH ACTIVISTS CALL ON CONGRESS

The day before April 10’s National Youth HIV & AIDS Awareness Day (NYHAAD), **activists from Advocates for Youth met on Capitol Hill with congressional lawmakers and staff** from the office of Rep. Barbara Lee (California, 12th Dist.) for a briefing on what Congress can do to support young people living with HIV. While Congress saved HIV funding from Republican-proposed cuts, the activists called on lawmakers to ensure that those dollars are allocated to the most-needed programs.

“Through my work as a peer support advocate for people living with HIV, I know firsthand how hard it is for young people like me to access care and navigate the medical system,” said DáRon Davis Henderson, NYHAAD youth ambassador from North Carolina. “We need government funding for HIV-inclusive sex education to make sure everyone understands how to prevent and treat HIV.”

The activists and Advocates for Youth asked Congress to co-sponsor the Real Education & Access for Healthy Youth Act (REAHYA). Co-sponsored by Reps. Lee, Pramilia Jayapal (Washington, 7th) and Alma Adams (North Carolina, 12th), and Senators Mazie Hirono (Hawaii) and Cory Booker (New Jersey), the measure would provide the first federal grants for comprehensive sex education in the U.S. and end abstinence-only education. It would also increase funding for HIV prevention, treatment and care for young people.

“When health classes don’t address HIV treatment and prevention, students leave with misconceptions that continue the cycle of stigma and discrimination against people living with HIV,” said Amaka Agwu, NYHAAD youth ambassador from Maryland. “There needs to be a more standardized, comprehensive sexual health curriculum taught by educators with the relevant and accurate knowledge to help young people practice safer sex habits, know the ways in which we are at risk and reduce stigma.”

COURTESY OF ADVOCATES FOR YOUTH

In addition to REAHYA, Advocates for Youth is urging Congress to support a number of other appropriations for fiscal year 2025. Among them:

- $395 million for the Ending the HIV Epidemic plan, including $100 million to create a National PrEP Program to support equitable access to HIV prevention medications
- $3.082 billion for the Ryan White HIV/AIDS Program
- $150 million for the Minority HIV/AIDS Fund and $610 million for other programs of the Minority HIV/AIDS Initiative
- $150 million for a teen HIV prevention program from the Office of Adolescent Health, under the Department of Health and Human Services
- $100 million for the Centers for Disease Control and Prevention’s Division of Adolescent and School Health

“Young people face unique barriers to accessing health care. Many of us don’t have parental support, medical insurance, reliable transportation or even flexible schedules that allow us to make appointments,” said Peggy Owusu-Ansah, NYHAAD youth ambassador from Tennessee and the District of Columbia. “These barriers are even harsher for Black youth, who are more likely to contract HIV but often encounter misinformation, stigma and medical mistrust. Young people’s needs have to be taken into account when we consider creating inclusive care for all people.”

—RICK GUASCO

LGBTQ+ documentary examining trauma and resilience of gay men premieres at L.A. film festival

A new documentary explores traumas experienced by men who are part of the LGBTQ+ community.

Speaking Out features three racially diverse and openly proud gay men and their journey towards healing. It plays out like a movie with actors performing scenes, in addition to hearing from the men. As they reveal the mental and physical abuse they endured and the strengths they've gained, mental health experts join in to provide insights on both the trauma and the recovery. The film makes its premiere at the Los Angeles Latino International Film Festival.

"I created *Speaking Out* from a vision of vulnerability and love with the ultimate hope that it can heal people from the inside out," director John Solis says. "As a Latino filmmaker, I'm honored and awestruck that *Speaking Out* will premiere at LALIFF, giving us the opportunity to begin our journey of sharing this important message of healing with the world."

José Ramos is one of the men featured. In 2009 he founded Impulse Group, a non-profit organization dedicated to building healthy communities for gay men around the world. Impulse Group produced the documentary in association with the AIDS Healthcare Foundation.

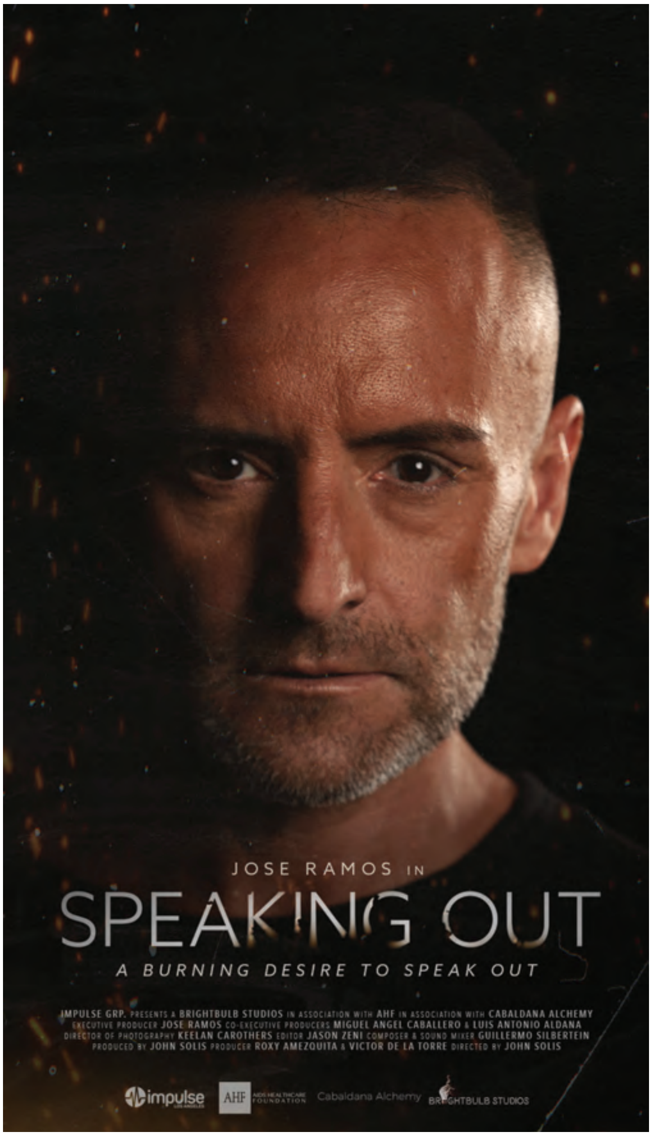
"**As a team predominantly composed of Latinos, being selected to showcase our work at LALIFF holds deep significance for us**," Ramos says. "It represents not only a validation of our creative endeavors but is also an affirmation of the importance of representation in the film industry."

Co-executive producer Miguel Angel Caballero says, "I believe *Speaking Out* serves as both a mirror and a megaphone for the LGBTQ+ community, especially for gay men who have endured trauma and sexual assault. In a world where stigma still looms large, *Speaking Out* stands as a beacon of hope, reminding every gay man that their voice matters, their pain is valid, and they are not alone in their journey towards healing and resilience."

The team believes the film "showcases the power of storytelling to drive social impact and promote inclusivity." The documentary is helping to end the silence and shame surrounding trauma experienced by the gay community. *Estamos hablando.* We are talking.

LALIFF runs May 29–June 2. *Speaking Out* was produced by BrightBulb Studio and Cabaldana Alchemy.

GO TO impulsegrp.org.



POSTER PHOTO: KEELAN CAROTHERS; MOVIE STILLS: COURTESY OF SPEAKING OUT DOCUMENTARY

Activists urge Congress to make HIV a funding and policy priority

More than 400 advocates from 35 states came to Capitol Hill in mid-March to urge members of Congress to support funding for HIV-related programs and legislation to address racism and inequity.

Organized by AIDS United, the annual AIDSWatch lobbying campaign was held March 17–19 with a series of activist workshops and training sessions that culminated in a day of meetings in about 120 congressional offices with staffers as well as senators and members of Congress.

Positive Women's Network-USA, the largest national organization of women living with HIV, was among the groups that sent members to the Hill.

"A large part of our advocacy centered around appropriations [federal spending authorization]," said Tana Pradia, one of the 51 PWN-USA members who took part. "We need Congress to ensure people have access to HIV prevention, like the PrEP Access and Coverage Act (HR-4392/S-2188). Congress should protect Medicaid from cuts and go further by ensuring universal healthcare access for everyone."

Katie Willingham, a transgender activist living with HIV, also came to D.C. "I attended a workshop about transgender health and safety in the southern states, and the need for comprehensive sex education," she said. "These issues are important to me and my state."

She added, "My state brought the second largest delegation to AIDSWatch, with 19 people from Alabama—seven of whom are living with HIV. We all visited the offices of our senators, Tommy Tuberville and Katie Britt."

PWN-USA member Susan Mull highlighted some of the priorities and tactics. "Sometimes the metrics are the only thing that legislators understand," she said. "Out of 1.2 million people living with HIV in the United States, at least 100,000 are unhoused. We used that statistic as we spoke to staffers in the Senate and the House of Representatives. Folks told their own stories of being unhoused, and patiently explained that one cannot remain adherent to life-saving medication if one does not have stable housing. Housing is healthcare!"

This year, 56% of AIDSWatch attendees self-identified as living with HIV.

—RICK GUASCO

PHOTOS BY DENIS LARGEON, COURTESY OF AIDS UNITED

‘There’s this concept of *if there’s not a seat at the table for me, I’m gonna make my own damn table.’*

—Daniel G. Garza

COMIC'S CHAIR: ISTOCK

STANDUP ACT

Two professional comedians share their experiences living with HIV

A long-term survivor and a dandelion walk into a room. Actually, the dandelion is also a long-term survivor. **Andy Feds** is the stage name of “the first-ever HIV-positive-born comedian,” as he bills himself. His standup act and social media focus on HIV education, empowerment and entertainment. **Daniel G. Garza** had already progressed to what was classified as AIDS at the time when he was diagnosed in 2000. He lives in southern California, but spends much of his time on the road doing comedy and advocacy work. The two comedians traded reflections and jokes about life with HIV.

This conversation has been excerpted and edited.

DANIEL: May I ask how old you are?

ANDY: I’m 31.

DANIEL: So you’ve actually lived with HIV longer than... I’ve been living with it for 23 years. It’ll be 24 years this September. I’m 53 years old, and very proud of my 53 years, but that just blew my mind thinking that there was no *before* for you; there has always been *this*.

ANDY: Yeah. I’m always on TikTok Live, teaching people about HIV. A lot of them think that life is done after being diagnosed with HIV. What was it like after your diagnosis?

DANIEL: Back in 2000, when I was diagnosed, a lot of Latinos got their information from talk shows. There was a Latina TV talk show host, Christina [Saralegui], who was like the Latina Oprah. She had on her show people who were dying of AIDS. So my family thought, *Well, you have AIDS, you’re gonna die and now you’re taking all of us with you*. And I was like [sarcastically], *Wonderful*. We’re Mexicans; we’re fatalistic. I’m dying, so you’re dying with me. But now, 23 years later, a lot of my family members are like, *Oh, you’re alive? You look healthy and you’re living a life and you have a partner? You have a boyfriend?* And I’m like, *Well, yeah, I have needs*.

ANDY: Oh, I definitely want to talk about relationships and HIV. Oh, man. As you saw on my TikTok, I made a video of me and my girlfriend, talking about couples. And when I tell you the dumbassery—I don’t know if they’re going to put that word in the magazine—but the dumbassery that I had to deal with...

DANIEL: We’re gonna make that word official here. *Dumbassery*. So, what is the dumbest thing somebody’s ever asked you?

ANDY: I think the dumbest thing that somebody ever asked me was, *How are you still alive?* I’m like, *You’re talking to me right now, what do you mean?* I always have to tell people, *Yeah, I was born with this thing. But I’ve been taking my meds, I’ve been going to the doctor. I’ve been actively taking care of myself, just like everybody else except the only difference between me and somebody who’s HIV-negative is that I have to take medicine for this.* That’s it.

DANIEL: I think the dumbest thing I’ve ever been asked was after a presentation, I had shared my life story, having been diagnosed in 2000 not just with HIV, but with AIDS. Somebody came up and asked, *How dare you be out in the world?* And I was like, *What do you mean?* He said, *Well, you have AIDS, anybody can get it.* And I thought, did you not just sit through my presentation? Did we not just talk about the hows and how-nots? So I said [sarcastically] *I’m gonna go home and pray and hope God forgives me*. He said, *Good*, and then walked away.

That HIV is somehow some kind of punishment is another silly thought.

ANDY: I get a lot of those comments, too, on social media—*Oh, God can heal you. All you gotta do is just ask for forgiveness*. I was born this way!

DANIEL: How has sharing your story on TikTok changed you?

ANDY: I actually started on Facebook. I had been doing standup comedy about five years, and I was like, *Hey, I’m gonna switch up my standup, folks, and teach y’all about my life with HIV*. I was shocked by all the support that I got. Then when it came time for me to come up with new material and going out on stage, the first thing I said was, *Hey, my name is Andy Feds. I’m the first-ever openly HIV-positive-born comedian*. And the whole room was like deers in headlights. They couldn’t believe that I said HIV and comedy in the same sentence. And immediately, nobody was listening. They were like, *Nope, we’re not listening to this*. And so I had to constantly retouch and refine my material to have people understand that yes, I’m a comedian. And just like every other comedian who gets to talk about their issues, I’m a comedian talking about mine, too. Since then, I’ve just been retooling and retouching, and my following has been growing.

DANIEL: It’s like somehow, sharing or disclosing your status completely erases everything that you’ve ever done in your life. It happens with cancer, too—I’m also an anal cancer survivor. But somehow, everything that you’ve done in your life, the moment

PHOTO COURTESY OF DANIEL G. GARZA

'If I'm gonna share dessert with you, I need you to know what's going on with me.'

that you disclose an illness, a diagnosis, whatever condition, people are like, *Oh, that is all you are now*. They make you a walking poster child.

ANDY: So let me ask you a question then. Do you think there's a difference between how society sees you as somebody who acquired HIV through sex versus somebody who might have had it since birth?

DANIEL: I think from my experience as a Latino man, there's a shock—*What do you mean? HIV is a White man's thing*. Especially Latino people, they think HIV is something that happens to White gay men. But then I add that I'm gay, and they're like, *Of course you would have it*.

ANDY: It's funny that you say that because I'm a heterosexual man. And because I'm a Black heterosexual man, when I tell people that, yes, I am a straight Black man living with HIV, a lot of people are like, *He must be DL* [on the down low]. *No, I just told you I'm a heterosexual man. What are you talking about?*

I'm like, *Where is my representation?* And I say that very humbly, saying 'my representation,' meaning other straight Black men who were born HIV-positive. Where's our representation? I've seen so many magazines, so many social media posts, and it's never us. There's never any straight man. I didn't speak about my HIV until I was 24 years old, seven years ago. That was because I didn't see anybody that looked like me. And finally, I was like, *Alright, well, I guess I gotta be the damn voice because we're not being seen*.

DANIEL: There's this concept of *if there's not a seat at the table for me, I'm gonna make my own damn table*. We do get invited to conversations sometimes, but sometimes I'm the token Latino. I'm in a sea of white and I'm the only person of any color. And anything that has to do with Spanish, everybody looks to me and asks, *Okay, how do we reach out?* And then I'm like, *Oh, this is why you need me here, because, I'm the diversity*.

Six years ago, I was part of an HIV awareness campaign that kind of pushed me to the forefront. They said, *We want you to be this representation*. It was like being in a boy band—*this is your part, this is what you're gonna say*. And you learn your lines, you learn them well, you do your best, but then you come out of that and go, *Wait a minute, I know other stuff. I know how to do other things*. So I started to create my own spaces. I'm proud of you for doing that, too. I'm not gonna say I'm a fan, because then it's gonna go to your head.

ANDY: I already got a big head. This hat is XXL, by the way.

DANIEL: What would you like young people to learn from you?

ANDY: That you can get HIV in more ways than just sex. Nobody says *HIV* anymore. A lot of people think that it can't happen to them, or they're like, *I'm in a monogamous relationship*. And it's like, No, you should still be getting tested, you should still know your status. And let's have conversations. Let's create dialogues with our partners, with our doctors, with our friends, our family, our kids, so that we can protect each other.

DANIEL: How does the conversation come up for you when you're seeing someone?

ANDY: A lot of people will be like, *Oh, I wait until we get really close* or, *I'll wait a few months*. If I think that I'm gonna see a future with you, before I enter the bedroom or whatever, I want to tell you some stuff about me so that we can have a conversation as adults to protect each other.

DANIEL: I'm so glad you said that. Because these are adult conversations. I always thought that if there's something physical, mental or spiritual going on with me, I want to tell you about it. And you need to know it right before we order dessert, because I don't like to share dessert with just anyone. If I'm gonna share dessert with you, I need you to know what's going on with me.

ANDY: I always do tell people that when it comes to dating and disclosing, I'm not gonna let someone make me love myself less just because they don't want to deal with my HIV. *Girl, there's the door*. Because if you can't deal with my HIV, that means you don't care for me, because that's just a small part that I already have under control.

My girlfriend and I met on a Christian dating site, Christian Mingle. We were talking for a minute and then I passed off my number and next thing you know, we were on FaceTime. It was the second FaceTime conversation that I told her I was positive. She was shocked. But then she was like, *Alright, well, it's just a part of you and you're taking your medicine*. She works in the medical field, too, so she knows a little bit about HIV, especially what it means to be undetectable. So it has never been an issue.

DANIEL: I'm gonna ask this question because it happens for me sometimes—does it ever, in the back of your head, become an issue for you?

ANDY: No. Simply because we do have conversations. We do talk about it a lot. She knows about PrEP and PEP. We use condoms, too, when we want to. We always know how to protect ourselves.

I'm still relatively new to advocacy. Like I said, I've only been doing this for seven years. I've always known about HIV because I've been taking medication since birth. My doctors and nurses taught me about it. When I tell people that I'm living with HIV and the first thing they say is, *I'm sorry*, I think, *What are you sorry about?* Because I don't have a life of sorrow. I live a normal, happy life, you know? I got things that will make me cry—my bills, the cost of living—but HIV isn't one of them. It's one thing that I've had under control for years, or decades now.

DANIEL: I don't think I can add anything to that. I have my own mental health issues to deal with. I suffer from anxiety, the lower side of agoraphobia, and I suffer from seasonal depression. There are other things that I can get sad and depressed about. Every once in a while at midnight, which is when I take my meds, the alarm will go off to remind me and I'm like, *Shit*. It's like a Cinderella moment.

ANDY: I've heard people talk about that. And that is not to downplay anything, I've never felt that pill fatigue. To me, it's just always been normal.

I tell people that HIV is a mental battle as well as physical, because a lot of people do face these challenges of realizing that they are HIV-positive—how will my family and friends think of me? What will society think of me? These challenges play in people's heads, and I fully 100% get that because we all need to give and get support from other people who are also going through the same things.

DANIEL: I've learned that if I want to show up to a place as just me, I have the right to that choice. I have shown up to places where I'm like, *Hi, I'm Daniel G. Garza and I'm Latino and I'm gay and I'm HIV-positive...*

ANDY: And in Spanish, too, like in those TV commercials.

DANIEL: *¡Soy Daniel! ¡Soy de VIH! Para más información...* I've learned that there's the personal and there's a professional persona. Yes, the line is so blurred because I'm advocating for something that's me. Sometimes people can't separate the two and I need to do it for them.

ANDY: Yeah. Sometimes I want to stay away from Andy Feds because sometimes I just want to talk about what's going on in life.

DANIEL: I'm very conscious of the fact that once I started using the word *advocate* or *community leader* or whatever, that that carries some responsibility. It's like being on a ship. If it starts to sink and they know that you can save lives, you are going to be asked to help save lives.

I'm a life coach too. And I teach this to my clients—you're not the only one on a path. There's somebody somewhere else that is doing something similar. My timeline will not be the same as someone else's, but we all have goals to reach. And I wholeheartedly believe that you are hitting those marks beautifully. I don't know what your ultimate goal is, but from my standpoint I'm going, *Wow, look at this dude kickin' ass*. I'm not gonna lie. I was envious for a little while. But what I've learned about myself, when I have that reaction towards someone, it's because there's a mirror in front of me. And I need to take a look at it—what is it that you're being jealous about and what can you learn from it?

ANDY: I tell people I'm just a normal person from Chicago. That's it. I'm just sharing my story.

DANIEL: You're more than that. You are a voice, and as somebody slightly older than—shut up, I'm barely older than you, we could've been born twins—you're a voice for the table that you sit at. And if we're going to build these tables you need to have a message to go with that voice.

ANDY: I look at it the same way. I got two friends, Masonia Traylor and Ci Ci Covin, who are both in a documentary on Netflix right now, with [producer] Sheryl Lee Ralph. It's called *Unexpected*. It just got nominated for two Daytime Emmy Awards [best daytime special and best song]. I'm so freakin' proud of them. And the late Hydeia Broadbent, who unfortunately passed away. We're all doing the same work by telling our stories. Gina Brown is a prime example. Everybody knows Gina. Our stories start to make people realize that HIV and AIDS is still a thing that we still need to talk about and that we still need to prevent.

DANIEL: There's Charles Sanchez, who's one of my good friends. He is a voice in the community. He's a fellow actor and comedian. He produced his one-man show and talks about his life story. I always tell him, *I'm so immensely proud of dropping your name in a conversation*.

Is there one thing that you've never been asked that you wish somebody would ask you?

ANDY: Oh, that's a great question. I guess it is, *How can we make your representation matter?* It goes back to the beginning of our conversation. I feel like being a straight Black man living with HIV, our voices aren't heard at all. I want us to matter to people. How about you?

DANIEL: One thing that I wish somebody would ask me is, *What do you want people to learn from your life?* We need to be more open about sex and have conversations about sex.

ANDY: Let's continue to have conversations about prevention and awareness. I think that's the real cure, because that's how we stop the next person from getting diagnosed. There's a lot of us living with it, but if we can just stop new diagnoses, we'll end HIV.

'I tell people I'm just a normal person from Chicago. That's it. I'm just sharing my story.'

PHOTO COURTESY OF ANDY FEDS

DANIEL: Let's find a way to break the barrier created by culture, religion and social norms. Because I believe that over that wall is where the answers are.

I'm so happy that we got to do this together.

ANDY: Likewise, likewise.

BUTT OF THE JOKE

Using humor to reduce stigma and stifle the surge in STIs

BY **LARRY BUHL**

Ina Park, MD, MS, a professor at the University of California San Francisco and medical director for the California Prevention Training Center, believes that STI education and outreach doesn't have to be alarming. In fact, she says, messages that are delivered with cheeky humor can have a greater impact.

Dr. Park, who's also a medical consultant to the Division of STD Prevention of the Centers for Disease Control and Prevention (CDC) and co-authored the *2020 CDC STI Treatment Guidelines*, believes storytelling and public engagement can fight stigma and fear around STIs. Her book, *Strange Bedfellows: Adventures in the Science, History, and Surprising Secrets of STIs*, skewers some misconceptions about STIs. But it may be her work with the CDC-funded HPV Impact Monitoring Project, which monitors the population-level effects of HPV vaccination, that's getting the biggest buzz.

Her talk, "Butt of the Joke," which she's presented to researchers, clinicians, public health professionals, health educators and doctors in training around the U.S., starts with a personal anecdote. She recounts that as a peer educator at UC-Berkeley she donned a body condom, a safer sex promotion that launched a career. Emphasizing that STIs and HIV are no laughing matter, Dr. Park nevertheless encourages an injection of tasteful humor to spark engagement and make STI testing as routine and trauma-free as an oil change (assuming people get their oil changed without fear or loathing). I recently spoke with Dr. Park, who also sees patients at the San Francisco City Clinic, about humor as a way to reduce stigma and quell the surge in STIs.

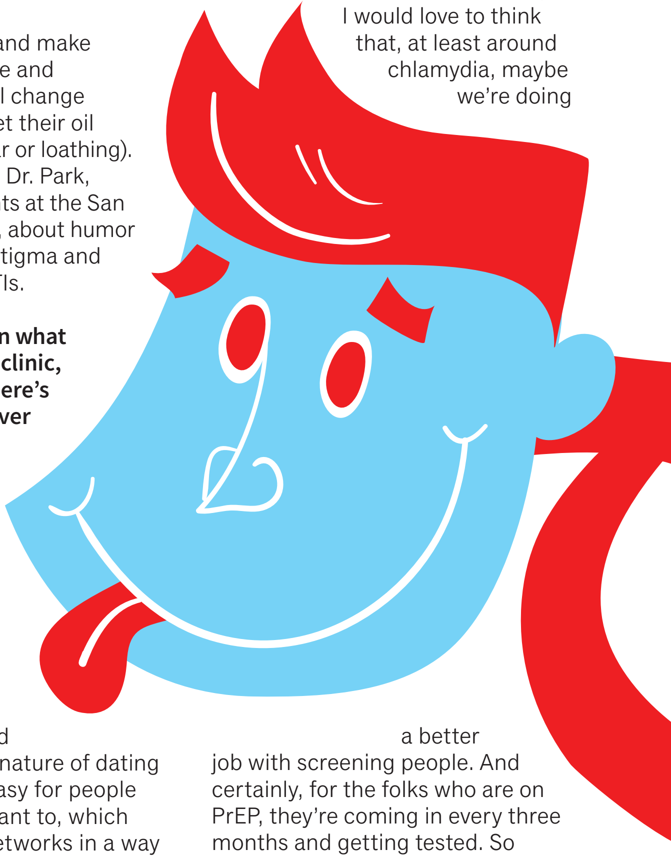
> ‘Number one, I think it's the rise and now the ubiquitous nature of dating apps making it so easy for people to hook up if they want to’

Larry Buhl: Based on what you've seen in your clinic, why do you think there's been a rise in STIs over the past few years?

Ina Park, MD, MS: There are multiple theories and I think that it's not any one thing. But I'm going to tell you four things that I think are contributing. Number one, I think is the rise and now the ubiquitous nature of dating apps making it so easy for people to hook up if they want to, which also mixes sexual networks in a way that didn't happen before, when most people just like hooked up with people at their corner bar in their neighborhood, and you're in your circle of friends. Now, I think it's much easier to hook up outside of different networks.

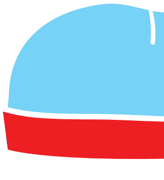
Then, especially around syphilis, and especially around women, there's the intersection of syphilis and the meth epidemic. Here in the West, about a third of the women with the most infectious stages of syphilis are also using meth. So there's that piece of it. And I speculated that we were already on an increase, because people are a lot less afraid of HIV, now that we have PrEP and the whole concept of U=U around HIV treatments. So people living with HIV are undetectable, not passing it onto their partners. People who don't have HIV are taking PrEP.

And the final reason, I would love to think that, at least around chlamydia, maybe we're doing a better job with screening people. And certainly, for the folks who are on PrEP, they're coming in every three months and getting tested. So we're finding more STIs that way.



Your presentation is about challenging the negative messages often heard around STIs. What are those messages and where do they come from?

I think STIs are often seen as a punishment by many people for sex you're having outside of some heteronormative relationship. I diagnosed an older gentleman with HIV the other day, and he said 'God is punishing me.' I'm not talking about 30 years ago. This is happening right now. So I think



ISTOCK

'There is a generation of folks that not only got messages about STIs as a punishment, but also that sex equals death.'

somehow STIs are a reflection of some indication that you somehow did something wrong, or that you're quote-unquote *promiscuous*.

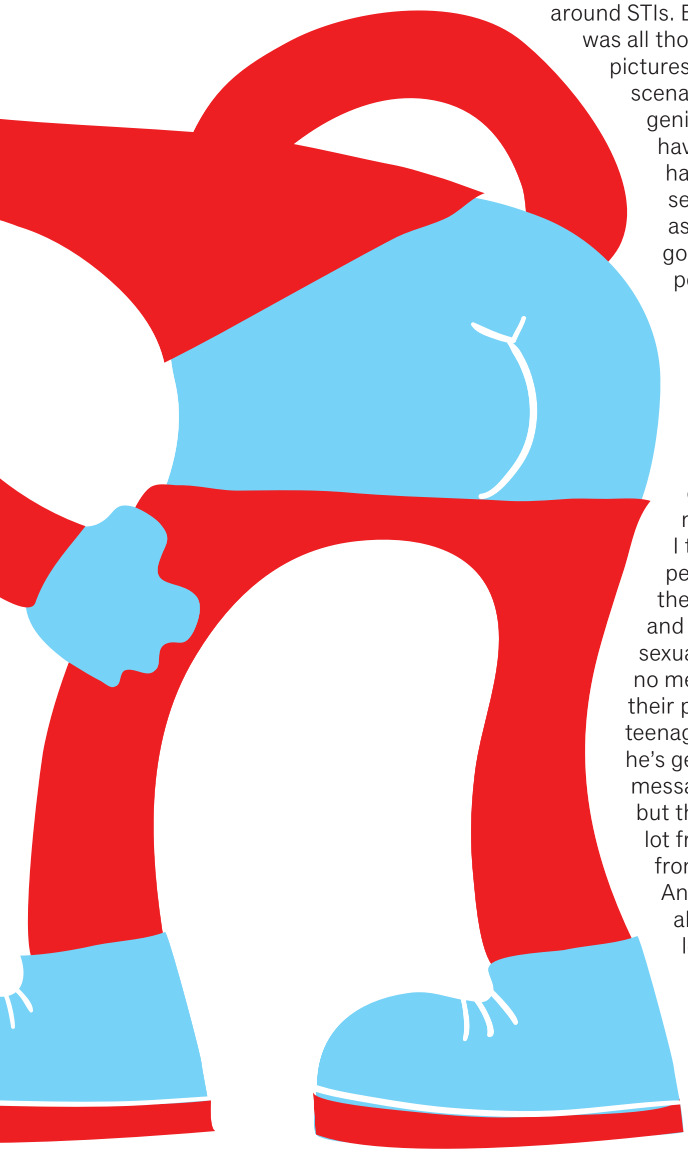
I'm trying to tell a different narrative, which is that STIs are the cost of doing business as a sexually active person, and normalizing the fact that everybody's probably going to get something at some point. But it's a hard message to undo. Because we have a culture in the U.S. around purity, saving yourself for marriage. These are things that even I heard growing up.

Where do you think most people are getting their messages about STIs? Is it from media? Or their family or their social circles? I'm trying to think of where I got my messages and can't recall a source, at least not positive ones.

Did you get any messages from school, Larry?

Sex ed was basically a fifth grade class explaining how you reproduce.

In school, I got some messaging around STIs. But my messaging was all those horrible pictures of the worst case scenarios of people's genitals. And if you have sex, if you have unprotected sex, which they're assuming you're going to have with a penis and a vagina involved, that this is what's going to happen to you. So those are the messages that I got in my upbringing. I got nothing from my parents. And I think a lot of people make it all the way to adulthood, and even become sexually active, with no messages from their parents. I have a teenager who's 16, and he's getting a lot [of messages] from me, but they are getting a lot from each other, from their peers. And then they're also getting a lot from social media, which is sometimes well done, and sometimes it's just ridiculous.



I came of age at the height of the AIDS crisis in the 80s, where I thought if I ever have sex, I'm going to die a horrible death.

A lot of my gay friends and colleagues essentially were fatalistic about HIV. There is a generation of folks that not only got messages about STIs as a punishment, but also that sex equals death. But the generation of younger queer folks that I'm taking care of now, they don't have that. I had it. I was so deathly afraid of catching HIV when I was becoming sexually active. And this generation doesn't feel it and I'm happy about that.

But then they also say, 'what's the point of using condoms?' So, we have to maintain more vigilance and more testing. Because what's going to come with the territory is more STIs. I'm prescribing doxy-PEP [doxycycline prescribed after exposure] to prevent STIs, and that's another reason that they don't have to use barriers. But I don't think that means we need to stop testing. We need to make it easier and less of a barrier.

There's also stigma with sexual health clinics. And if a primary care physician is not sex-positive, you might worry about opening up about your whole sexual history.

A lot of patients that I've seen have had a terrible experience with somebody who judged them, or maybe didn't call them a slut but essentially implied that they were. And so, they felt terrible and they're never going to see that person. Or they can't be honest about the choices that they think their physician is going to judge them for.

We doctors are so poorly equipped for this. In medical school, we get so little education about STIs in general, and forget how to make a sex-positive statement to somebody, and that's something that you have to dedicate yourself to learning afterwards. It's not standardized, and it's generally not very many hours, and a lot of us come out very ill prepared. And then some of us are thrown into a situation where we're taking sexual histories a lot, and then you get more comfortable. And then some folks do it so infrequently, that every time it's very difficult for them. Most of the people that CDC funds us to teach are either working in public health, or people who are already practicing in some way, but I would love to do more medical student teaching.

Which brings us to your presentation. What do you hope will be the result? Like a health department taking up some of the ideas here and making STIs less frightening at least?

'If you can get somebody to laugh, and if you can use humor without stigmatizing or making fun of any type of population, then you hook people in.'

I say kudos to San Francisco, because it is a quite a sex-positive place. And at least in the clinic, where I am seeing patients, we're trying to make it welcoming and trying to make it less stigmatizing. But my hope [for this presentation is] I want people to shift their thinking and making [STIs] another component of sexual health and thinking about it more from an empowerment perspective. Like getting tested frequently is taking charge of your sexual health. It's not about, 'well, how many partners did you have?' Or, if someone has more than one, then labeling them as 'high risk.' I really want to get away from that; that doesn't help anybody. It just prevents people from wanting to come in to see you. I'm really all about lowering barriers to testing and making sticking a swab up your butt as inviting as possible.

When I'm tested and get asked about how many partners I have, I feel defensive.

Right. I think it just matters for someone to reflect on, 'who am I playing with here and how much risk do I have?' If somebody answers that they've had 20 partners in the past three months, then I would say they should be coming in every three months and getting checked, like having an oil change. Like you drive your car more, you need to come in more to get checked out. I look at it not as an absolute number, but it's a reflection of how to stay on top of your sexual health.

INA PARK, MD, MS

COURTESY OF DR. INA PARK

What are some of the ways that you think it's important for someone in sexual health to use humor? And I guess it depends on whether the messaging is from the health department, or from a clinician doing intake.

I've seen some campaigns from health departments that use either humor or humorous images or fun images. It doesn't always have to be funny, but making messages kind of fun and making graphics or making your marketing materials fun and upbeat, as opposed to showing somebody who looks depressed or sad, or all doom and gloom. There's a lot you can do just with the messaging. Humor is disarming. If you can get somebody to laugh, and if you can use humor without stigmatizing or making fun of any type of population, then you hook people in. It's a [better] way to get people's attention to deliver a more serious message. And sometimes I do that when I'm doing my own teaching, because I do a lot of teaching of different doctors and nurses, and I've taught in colleges, I put myself at the center of the joke and I share my own history and experience with sex education in my own household. It's safe, they can laugh at me and everyone's in on it. You can't make fun of other people unless they're in on it with you and they've consented to be in on the joke.

Can you think of some STI awareness campaigns that used humor well?

In my talk there was one done in Canada around gonorrhea, which I thought was really cute, where they have a short video with a spelling bee and they have kids trying to spell gonorrhea. It was really funny because everyone is familiar with the spelling bee, and it was well done and the production value is pretty high. It almost seemed like a little *Saturday Night Live* skit. You don't expect that kind of thing from the health department, which is why I think it's so disarming. And I'm sure you've noticed that sometimes there are some funny billboards around Los Angeles as well. A few years ago, STD Check did a Pokémon campaign, *'cuz you don't want to catch 'em all.*

Have you had any former students who come back and say they took some of your ideas about incorporating humor into learning into their practice or their outreach campaign?

I've had students and doctors reach out to me and say, 'I liked that approach,' or said that they felt inspired. And a couple of the doctors that I've taught are now working in sexual health, which is really gratifying. People can take my jokes, no problem. I'm happy if they steal my material.

THE CATEGORY IS...

LAUGHTER

When it comes to living with HIV, humor can be a coping mechanism, a way of diffusing a situation or disarming stigma. POSITIVELY AWARE put the question to its social media followers:

What role does humor play in your life?

COMPILED BY **RICK GUASCO**

"I prefer laughter over sadness. Sometimes you have to cry in silence or aloud, but I'll take laughter any ole day."

— RANDY BOWLING

"I laugh nonstop. I've nicknamed every med and given it a personality based on its side effects."

— DEREK CANAS

"I've always been cynical. My diagnosis just pushed that to previously unknown heights. I enjoy humor, especially when dealing with other people's half-knowledge or ignorance about HIV; I tend to double down. It's made me able to laugh about myself as well."

—CHRISTOPHER KLETTERMAYER @ONGOINGVIRAL

"I use humor to keep me from crying about the loss of loved ones to HIV/AIDS. I find humor in the tiniest possible ways, even if it's jokingly calling my antiviral pills 'girls.' For example, 'What is that girl Symtuza going to do to my body today? Did she pay a bill yet? Or she going to be evicted out of my body?' LOL."

—JACK R. MILLER @BIGGROAST

"I always maintain a happy attitude because living with HIV is not fun, but you make the best of it! I laugh, cry and keep on going. Life is full of surprises; you just have to know how to juggle them."

—LILLIBETH GONZALEZ

"Humor is the saving grace to my insanity."

—WANDA BRENDLE-MOSS

"I laugh more than should be allowed for everything being considered."

—@DREKSANGELSANDWARRIORS

"Humor allows me to combat all the depression and side effects of living with HIV. Without humor, it would be quite difficult to bear all the daily challenges with the disease."

—@ YOMIKAWAIIYOUKAI

"I have what is described as a 'wicked' sense of humor. Every situation has the potential of providing some humor. I love to laugh."

—ERIC MOORE

"Laughter recharges the soul! Much like dancing, the more you do it freely and with abandon, the more infectious to your soul it becomes! Find laughter daily! Trust me on this one!"

—MARCO MAYS

"I'm 77 years old. I call my enlarged belly 'my baby.' Sometimes I accuse my mate of 'knocking me up.' Laughter is the best medicine."

—ANNA FOWLKES

"It's not just humor, but the decision to live every day in the happiest way possible!"

—@GRACIA_VIOLETA

"Humor is a tool for me to use on a daily basis. I am not the most humorous person, but I need to be enveloped by the positive energy that it creates. I have been through hell and back. Humorous events and people provide me with the antidote to the negativity in the world. Being a substitute teacher affords me the opportunity to experience laughter and happiness. If we can learn from the youth of today, our tomorrows will be brighter."

—MARK L GRANTHAM

"Scene in the hospital, while I was in renal care because of extremely elevated levels of creatinine kinase:

ATTENDING PHYSICIAN: I was looking over your chart...
ME: (bursts into laughter)
HER: With the new serious diagnoses facing you, I guess it's good that you can have a sense of humor about it. Can you tell me what those diagnoses are?
ME: Fracture of the lesser tuberosity resulting from a fall from bed caused by a seizure apparently originating near a new suspected neoplasm in the right hippocampus.
HER: What's so funny about all of that?
ME: After over 41 years, and HIV *still* doesn't get to be a major cause of concern."

—DAVIDMICHAEL PHILLIPS

ISTOCK

REACHING T.K.

‘God willing, we will meet again in *Spaceballs 2!*’

BY **CHRISTOPHER HETZER**

T.K. was my first patient with AIDS. Not that this should define him by any means, but it was all he allowed me to know in the beginning. After receiving a limited report from the previous nurse, I walked into his room. I was still in my first year of nursing and was truly unprepared for what I saw.

As I fussed over some IV tubing, I looked at a human being who had been reduced to skin and bones, eyes that expressed emptiness and a sadness so profound that the room felt like it was sinking into an eternal nothingness. He resembled the stereotypical AIDS patient often depicted from the ’80s and ’90s.

T.K. had stopped taking his medications; at the time, I did not know why. He would not acknowledge me. He wouldn’t talk. He wouldn’t move. He just laid there. It was profoundly heart-wrenching to see someone who had lost the will to live.

My first shift with him was horrible. I couldn’t make him comfortable. The antibiotics gave him the worst diarrhea and every hour he needed to use the bedpan. I could literally lift him up with one arm; he was so fragile. The alkaline nature of his bowel movements would slowly burn his skin no matter how much protection was used.

Every shift, I would request to care for T.K. I put everything I was as a nurse into his care. I would pick up extra shifts just so he would have someone with him. Our small talk gradually became more in depth. His one-word answers became full conversations.

Over the weeks, I learned he came from a very religious family. Religious trauma weighed heavily on T.K.’s shoulders to the point where his guilt over being gay overpowered his will to live. And then to be diagnosed with HIV was the last straw for his biological family. This led him to stop taking his medications.

His family shunned him. They abandoned him. I was beyond angry! How could a family who had a son not come to see him? To think that someone could give birth to a child, raise them, and then leave them on their deathbed, alone. It is a type of “Christ’s love” I will never understand nor give grace to.

I learned he loved having movie night with friends. We talked about our favorite movies—*Star Wars*, *Lord of the Rings*, *Robin Hood: Men in Tights*, *Pirates of the Caribbean*, the Harry Potter films, *The Land Before Time*, *Indiana Jones*, *Mrs. Doubtfire*, *Hocus Pocus* and various Disney movies. One morning, he made his first and only request: “Can we watch *Spaceballs*?”

FOR ANYONE NOT FORTUNATE to have seen it, *Spaceballs* is a 1987 American space opera parody directed by Mel Brooks. It satirizes *Star Wars*, *Star Trek*, *Alien*, *The Wizard of Oz*, *2001: A Space Odyssey* and *The Planet of the Apes*. It’s a cult movie that has developed a large following who revel in inside jokes.

Through those jokes we began to connect. T.K. had no idea what beast he just unleashed! I immediately went to work, preparing all the necessities for movie night. If religion was failing him, I promised myself that *the Schwartz* would not!

OVER THE NEXT few days his eyes became more alive with anticipation of movie night. He thanked me and everyone who cared for him. I simply answered, “Please, please, don’t make a fuss. I’m just plain Yogurt.”

He smiled and said, “Well, then, ‘may the Schwartz be with you.’ ”

One morning, I said, “Let’s get that hair washed,” and without missing a beat, we both exclaimed with another line from the movie, “Someone shot my hair! Son of a bitch!”

For the first time, I heard T.K. laugh.

The day had finally come! I rolled in the comfiest chair in the hospital I could find. Pulling out each item of movie night “merchandise,” I announced, “We have *Spaceballs, the pillow! Spaceballs, the TV! Spaceballs, the pudding! Spaceballs, the socks!*” Holding up an improvised contraption, I yelled, “*Spaceballs, the flame thrower!*”

And as I pulled out a blanket, he wittily added, “They’ve gone plaid.”

As we watched the movie, we finished quotes said by various characters:

Dark Helmet: “Comb the desert!”

Radar Technician: “I lost the bleeps, I’ve lost the sweeps and I’ve lost the creeps.”

Dot Matrix: “It's either the Fourth of July, or someone's trying to kill us!”

Dark Helmet: “I am your father's brother's nephew's cousin's former roommate.”

Lone Starr: “What’s that make us?” To which Dark Helmet answers, “Absolutely nothing! Which is what you are about to become.”

As the movie ended, I helped T.K. to bed. It had been a long and exciting day for both of us. I placed the call light in his hand and picked up the remote off the bed. I was about to leave his room when T.K. let a mischievous smile run across his face. “What?” I asked.

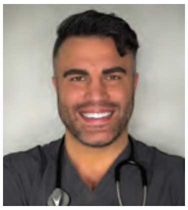
“Looks like your Schwartz is as big as mine,” T.K. proclaimed.

“Now let’s see how well you handle it,” I rebutted. And we engaged in a Schwartz Ring fight.

One morning, he made his first and only request: 'Can we watch *Spaceballs*?'

I DIDN’T KNOW that that would be the last night he and I would share. The next morning, I learned that T.K. had transitioned in his sleep.

After my own personal dark chapter, I went to a spiritual medium for shits and giggles. By this time, I was an ICU nurse. I can’t explain how, but I knew T.K. had found peace when he reached back to me through the medium. She said, “We’ll meet again in *Spaceballs 2*!”



CHRISTOPHER HETZER, MSN, RN, ACRN, (he, him) started his nursing career in trauma and neuroscience intensive care. After his own experience with polysubstance use and HIV, he has found a new passion of bringing sexual health advocacy to the forefront of conversation for all ages. He works closely with the Association of Nurses in AIDS Care (ANAC). Follow him on Facebook and Instagram (@christopherhetzer) and on TikTok (@freakbetweenthesheets).

ISTOCK

Two pills a week or two shots a month

At the **Conference on Retroviruses and Opportunistic Infections**, news on long-acting therapy includes an exciting advance over adherence problems

BY **ENID VÁZQUEZ**

ISTOCK

There was good news out of CROI 2024 in the continuing quest for HIV treatments that don't need to be taken every day.

One study reported early success using just two pills a week.

Another, the LATTITUDE study, continued to cause excitement, just one month after having shown the world that long-acting injectables can work for people with trouble adhering to their oral HIV treatment.

Islatravir plus lenacapavir

"**The combination of islatravir (ISL) and lenacapavir (LEN) has the potential to become the first weekly oral complete regimen for the treatment of HIV**," said presenter Amy Colson, MD, MPH, of the Community Resource Initiative (CRI), in Charleston, Massachusetts.

Islatravir plus lenacapavir successfully maintained viral suppression (undetectable viral load) in treatment-experienced people.

The study, NCT05052996, is still early. It's in Phase 2, and the results are only out to 24 weeks (six months). It enrolled people who had stable undetectable viral load while on Biktarvy, arguably the most commonly taken HIV treatment in the U.S.

Fifty-two individuals were switched to weekly therapy.

Another 52 persons continued taking their Biktarvy, for comparison purposes, as a control group.

At 24 weeks, 94.2% of the ISL + LEN group had maintained their undetectable viral load. This compared to 92.3% of the Biktarvy group who had stayed undetectable. (The figure was actually 100% of the people on Biktarvy, but there was some lack of data as a result of dropouts or missing study visits. This happened in both groups—two individuals, or 3.8%, for the weekly group and four individuals, or 7.7%, for the Biktarvy group.)

One person in the weekly group had low-level detectable virus at the six-month mark (an HIV RNA of 251 copies). This individual stayed on the therapy and regained viral suppression at 30 weeks (less than 50 copies).

The most common adverse events seen in the ISL + LEN group included arthralgia (joint stiffness) and fatigue (three individuals each, 5.8%), diarrhea (7 individuals, 13.5%) and upper respiratory infections (6, 11.5%).

Islatravir is part of a new class of HIV medications not yet on the market—nucleoside reverse transcriptase translocation inhibitors (NRTTIs). Lenacapavir is also from a new drug class, capsid inhibitors (CAIs). Islatravir is already on the market as a once-weekly injection, under the brand name Sunlenca. The two medications are being studied in both oral and injectable formulations. Both drugs are also being studied for HIV prevention (PrEP).

To read the study abstract (summary), **GO TO** bit.ly/3QlOFds. For the webcast presentation, **GO TO** bit.ly/49Pb4He.

Cabenuva works for people with detectable viral load

The LATTITUDE study showed that **people with problems taking their oral therapy can reach the holy grail of undetectable viral load using Cabenuva**, the long-acting injectable HIV treatment that is a complete regimen by itself. (**SEE** February+March, *Briefly*.)

LATTITUDE (Long-Acting Therapy to Improve Treatment Success in Daily Life), also known as the ACTG A5359 study, showed success with using Cabenuva as two long-acting injectables once a month. (Cabenuva can also be used just every other month.)

Sure, that's standard today out in the real world with Cabenuva. But this study was for people who had challenges taking their oral medication, a group that's usually excluded from HIV drug studies. Currently, the U.S. Food and Drug Administration (FDA) requires that people have suppressed viral load (be undetectable) before they can be given Cabenuva.

At a CROI press conference, presenter Aadia Rana, MD, of the University of Alabama, put aside the data for a moment to make clear the promise of the LATTITUDE study.

> **The LATTITUDE study showed that people with problems taking their oral therapy can reach the holy grail of undetectable viral load using Cabenuva**

"Our hope is that this study will expand the HIV treatment guidelines for long-acting injectable treatment to include people with a history of non-adherence and influence the payer decisions," Dr. Rana said. "I'm tremendously excited, in addition, that this study is a clear demonstration that large, randomized treatment trials in a population with challenges to adherence can be successfully done. It is a call to action to include these populations, historically described as *hard to reach*, earlier in the process of drug development, particularly in the long-acting therapeutic space.

"Our next challenge," she added, "is to continue implementation of this strategy in those who have benefited most."

ACTG, a clinical trials group based in the U.S. which historically studies HIV, looked to Cabenuva to fill a special need.

"Only about 65% of people with HIV diagnosed in the U.S. are estimated to be virally suppressed on daily oral tablets due to issues including mental health and substance use challenges, competing responsibilities and financial constraints and stigma," said Dr. Rana.

"The ACTG LATTITUDE study, which started enrolling participants in March 2019, compared monthly injectable HIV medications, cabotegravir plus rilpivirine, to daily oral tablets in people with HIV who had a history of challenges taking their daily medications. Participants in this study first received comprehensive adherence support, including conditional financial incentives, to achieve viral suppression on oral therapy. Of those who are successful in achieving viral suppression, they were then randomized to monthly injections or to continue on their daily oral pills for approximately one year," Dr. Rana explained. "At a planned review of this study conducted [in February] by an independent safety monitoring board, the monthly cabotegravir and rilpivirine injections were found to be more effective in suppressing HIV compared to daily pills. The board recommended halting randomization and offering all participants long-acting injectable therapy.

"This study is critically important because it shows that long-acting injectable HIV medications can provide substantial benefit to a broader population than those covered by the current regulatory approvals, including those by the U.S. FDA," Dr. Rana said. "If guidelines were to recommend such broader use, it would be expected to have a larger impact on rates of new HIV infections, as most are transmitted by persons with HIV who are aware of their diagnosis but are not virally suppressed."

READ the abstract (Abstract 212), **GO TO** bit.ly/3JCnjfB.

What's new in HIV cure research

New paths, but still a long way to go

BY **LARRY BUHL**

After four decades, the search for an HIV "cure" remains elusive. And while antiretroviral therapy (ART) suppresses the virus, it does not eliminate HIV, partly because of the presence of viral reservoirs in CD4 T cells and myeloid cells. That's why even in a session about research into potential cures at the Conference on Retroviruses and Opportunistic Infections (CROI) in March, presenters used the C-word only when describing research that could be one of many more steps toward a cure.

LIANG SHAN, PHD

TRACY DIAMOND

RASMI THOMAS

ANDRÉS FINZI

Four presenters shared promising research that boosts the understanding of the biology of viral reservoirs and possible mechanisms that may, eventually, help clear the virus from people living with HIV (PLWH).

CARD8 and the secondary effect of NNRTIs

The first presenter, Liang Shan, PhD, a professor of immunology at Washington University in St. Louis, summarized research on how a now-common class of anti-HIV drugs—non-nucleoside reverse transcriptase inhibitors (NNRTIs), which inhibit reverse transcriptase (RT) and target early stages of infection—could be used to kill virus particles hiding in reservoirs, even those with intermittent viral expression.

The process uses a mechanism called CARD8 inflammasome, which he said can be **a promising approach to clear viral reservoirs for PLWH on ART**. "We started with a question: Can our immune system sense immutable components of HIV-1 and trigger cell death?" Shan said. The goal, he explained, was to identify immune sensors that detect the function of HIV key enzymes, because the virus cannot change the functionality of these enzymes to help it replicate.

CARD8 inflammasome activation by HIV protease can act as a "tripwire sensor" that may make sense for reservoir targeting because it is expressed by all lymphocytes, including lymphoid and myeloid.

Shan said the entry of HIV can immediately trigger CARD8 to sense it and "snip" the virus through protease cleavage. The team has demonstrated, both in vivo (in mice) and in vitro (using T cells from PLWH), how the CARD8 inflammasome works by driving CD4 T cell loss as HIV enters the body, he said. Further in vivo experiments in non-human primates will be needed, Shan concluded.

How NNRTIs could lead HIV to sabotage itself

Presenting the research of a large group of scientists, Tracy Diamond, principal scientist and infectious disease researcher at drug manufacturer Merck, summarized how compounds already in use, NNRTIs, could induce selective cell death in HIV infected cells through molecules termed TACK, or Targeted Activator of Cell Kill.

"NNRTIs inhibit reverse transcriptase, but some NNRTIs also have the ability to act through this CARD8 mechanism described by professor Shan," she said. But this pre-clinical work on TACK molecules did not use currently approved NNRTIs like efavirenz (brand name Sustiva), which is orders of magnitude less potent than what's needed for cell death. But **at larger doses, certain NNRTIs could potentially kill enough HIV-infected cells to deplete the HIV reservoir**.

Focusing on a previously secondary effect of certain NNRTIs, researchers invented extremely potent reverse transcriptase-targeting TACK molecules. "These differ from standard NNRTIs through monomeric RT-p66, which can start a process of premature intracellular HIV protease activation," she said.

NNRTIs have the ability to trigger an HIV booby-trap early inside the cell, where a cellular protein detects HIV protease and recognizes it as a threat, then encourages the virus to sabotage itself. Diamond reiterated that it's not clinical research, but that a next step could be to demonstrate activity in primary cells and in vivo in viremic mice.

Regarding Merck's next steps and possible involvement in clinical solutions, she said the company is interested in the mechanism and understanding how that translates to the clinic.

"We're developing different ways to test how this mechanism could provide benefit in vivo and also considering how to test those hypotheses in clinical studies."

Using transcriptomics to study rare cells that harbor HIV

Transcriptomics is the study of all RNA molecules in a cell or organism at a given timepoint or condition, unlike genomics, which looks only at DNA. At the same CROI session, Rasmi Thomas, a researcher at the Walter Reed Army Institute of Research, explained how **single cell transcriptomics could be used to identify the host and viral transcripts in individual cells from PLWH**.

In single-cell transcriptomics, a cell remains isolated and each cell type has a distinct expression profile. This is important, Thomas explained, because it

CONTINUED ON PAGE 27 »

‘A lack of respect’ by HIV scientists

Activists send letter to CROI organizers demanding action after many attendees leave opening plenary early during speech by Ugandan gay activist

BY **RICK GUASCO**

It’s not unusual at a big conference—especially a major medical or HIV conference like CROI—that in a room with 1,000 or more attendees, people would start to get up and leave early as a plenary session draws to a close, or even as the last speaker takes the stage.

But this time was different.

At this year’s CROI, HIV activists were angered that a significant number of attendees—many of them clinicians, researchers and other scientists—ducked out as HIV activist Frank Mugisha spoke about battling homophobia and laws that criminalize LGBTQ+ people in his home country, Uganda, and around the world, including the United States.

Activists sent a letter to organizers of the conference, CROI Foundation and IAS-USA, as well as to the CROI Scientific Planning Committee and the Community Liaison Subcommittee, calling on them to “clearly and unequivocally condemn this appalling lack of respect for community lives. We demand a direct apology to Dr. Frank Mugisha.”

The letter details the incident. “This year’s opening plenary at CROI, which took place Sunday evening March 3 in Denver, Colorado, included talks from Dr. Barney S. Graham, who spoke about modern vaccinology and the legacy of HIV research, and Dr. Dorothy Mboir-Ngacha, who reflected on ending pediatric HIV.”

The final speaker was Mugisha, whose powerful speech drew a standing ovation.

“Sadly, the audience was significantly smaller than the audience for the other lectures,” the letter says. “When it was Dr. Mugisha’s turn to speak, hundreds of researchers at the foremost scientific HIV conference in the world got out of their chairs, turned around and walked out.”

Devan Nambiar, director of GHIS in Toronto, Canada, was at the plenary. “I was sitting at the back,” he said in an email to POSITIVELY AWARE. “It was shocking to see many researchers and scientists casually walk out the moment Dr. Frank Mugisha started to speak. This is extremely rude, shameful and homo/bi/transphobic behavior on the part of researchers and scientists. Many of the Ugandan LGBTQ+ people living with HIV, and various health issues, are not able to access basic health care and medication and live in fear of violence, being fired from jobs and being evicted. What do equity, diversity, inclusion and accessibility mean when people most marginalized have no access to basic health care and life-saving antiretroviral medication to reduce deaths and end the HIV epidemic globally? Would it be too much to ask HIV researchers and scientists for 20 minutes to listen to a worthy cause to reduce HIV health disparities by one of the most well-known LGBTQ+ and HIV activists in the world?”

One of the most visible advocates for LGBTQ+ rights in Uganda, Mugisha, 45, is executive director of Sexual Minorities Uganda (SMUG). His activism earned him the Robert F. Kennedy Human Rights Award, the Thorolf Rafto Memorial Prize in 2011 and an honorary doctorate from the University of Ghent.

Many of the letter’s authors are advocates who worked with conference organizers.

“As members of the CROI Community Educator Scholars and Mentors, who officially represent community at CROI, we are appalled at the actions of these hundreds of HIV researchers,” the letter says. “Their behavior was shameful, unprofessional and unacceptable. The message they sent was one of disdain and contempt for the community of people directly impacted by HIV. Their message was also homophobic and deeply stigmatizing.”

The letter continues, “These researchers are well aware of the disproportionate burden of HIV on gay and bisexual men, other men who have sex with men and transgender individuals in every part of the world. Yet they could not be bothered to give 20 minutes of their time to listen to Dr. Mugisha, one of our world’s top activists who risks his life daily to fight back against homophobia, homo-hatred and trans-hatred.”

AT THE OPENING PLENARY OF CROI 2024, UGANDAN GAY ACTIVIST FRANK MUGISHA WAS THE LAST SPEAKER WHILE MANY ATTENDEES LEFT EARLY.

The IAS-USA Secretariat, which organizes CROI, apologized to Dr. Mugisha sometime after the Sunday plenary and before the letter was delivered to them the following Wednesday, on March 6, according to Jim Pickett, one of the letter’s authors. Pickett led the writing of the letter, which was a group effort informed by the Community Educator Scholars and Mentors group and other advocates.

“Frank indicated he was pleased and then emphasized how much great feedback he received from various folks who saw the talk,” said Pickett.

“This kind of disrespect is not new and happens all the time. Over and over,” Pickett said. “This time around was just the last straw, especially considering the context of the talk and world events.”

In May 2023 Uganda passed the Anti-Homosexuality Act, one of the most severe anti-LGBTQ+

CONTINUED ON PAGE 27 »

Diabetes drug reduces liver fat by nearly a third for PLWH

But more research is needed on the long-term implications of semaglutide

BY **LARRY BUHL**

ISTOCK

MASLD (metabolic dysfunction-associated liver disease), the new nomenclature for nonalcoholic fatty liver disease, a condition in which excessive fat builds up in the liver, is a common issue for people living with HIV (PLWH). Results of one study presented at CROI 2024 showed that a weekly injection of **a low dose of semaglutide reduced liver fat for PLWH by an average of 30% with few adverse effects**. Participants also had improvements in weight, waist circumference, fasting glucose, body mass index (BMI), ALT (a liver enzyme that can signal liver damage) and concentrations of triglycerides (a type of fat in the blood). Semaglutide is the active ingredient in Ozempic and Wegovy, which are used to manage diabetes and encourage weight loss.

Jordan E. Lake, MD, MSc, author of the study and a professor of infectious diseases at McGovern Medical School at UTHealth Houston, presented findings from a phase 2b open label pilot, called the SLIM LIVER study, the first study to evaluate semaglutide as a treatment for MASLD among PLWH. Among the 49 participants enrolled, all were virally suppressed on ART and had an elevated waist circumference as well as some measure of insulin resistance or pre-diabetes. The median age of enrollees was 52, with 37% cis women, 6% transgender women and 57% cis men. More than two-thirds were people of color.

Researchers measured changes in participants' liver fat content using specialized MRI scans to measure intrahepatic content (content within the liver). If the MRI showed 5% of liver volume composed of intrahepatic triglycerides (IHTG), that participant was started on injections of semaglutide, beginning at .25 mg weekly, increasing to .5 mg at week two and boosted again to 1.0 mg from week four to the conclusion of the study at week 24.

Results showed overall significant reductions of IHTG at 24 weeks. More than half (58%) had a 31% relative reduction in IHTG and 28% had complete MASLD resolution at 24 weeks. "It was notable to us that greater IHTG reductions were observed in Hispanic and non-Hispanic White participants and people over 60 years" the research team reported.

Semaglutide induced weight loss across all populations in the study, and Dr. Lake noted that the mean weight loss was 17 lbs. (8 kg), with greater losses among women, non-Hispanic White participants and people over 40 years. "For those who lost weight under semaglutide there was an even greater reduction in liver fat," Dr. Lake said.

She concluded saying low-dose (1 mg/weekly) semaglutide is an effective therapy for MASLD in PLWH over 24 weeks, and was well tolerated with very few adverse events. She noted a limitation of the study, that it didn't track participants beyond 24 weeks. "There are some remaining questions about secondary benefits such as lean mass loss, the durability of benefits and strategies to maintain the benefits."

Previous studies on semaglutide in the general population also saw improvements in blood sugar, insulin resistance and levels of blood triglycerides.

With MASLD, triglycerides and other fats can build up in the liver, disrupting its function. Although it is considered a "silent killer," doing organ damage before significant symptoms appear, severe cases can progress to fibrosis (scarring of the liver) and liver cancer.

MASLD is a particular concern for PLWH, and likely acts with HIV to accelerate liver injury and organ dysfunction, according to the clinical trials network Advancing Clinical Therapeutics Globally for HIV/AIDS and Other Infections (ACTG). Other risk factors for PLWH include inflammation and oxidative stress from the virus and ART-related weight gain. Studies have estimated that about a third of PLWH have at least mild MASLD.

Semaglutide did not significantly change muscle fat

Weight loss can generally be accompanied by muscle loss, but not much is known about the effect of weight loss drugs on muscles. In a related session at CROI, Grace Ditzenberger, PT, DPT, a PhD student from the University of Colorado, presented a secondary analysis from SLIM LIVER, exploring effects of semaglutide on muscle structure and function for PLWH enrolled in the study.

Researchers examined the psoas muscle, which is used in walking and maintaining balance, through capturing liver magnetic resonance imaging proton-density fat fraction (MRI-PDFF) at baseline and at week 24. Researchers also analyzed participants' ease of motion in rising from a chair and walking.

Analysis concluded that participants experienced a decrease in muscle volume (quantity) with weight loss, but no significant change in muscle fat (quality) or physical function, and that PLWH over age 60 years had the largest decline in muscle volume. Chair rise time and gait speed did not decline despite loss of psoas muscle volume, and the changes in function were not correlated with change in overall weight or BMI, Dr. Ditzenberger said.

"More research is needed on long-term implications of semaglutide and on strategies to preserve muscle mass with weight loss interventions," she concluded.

……

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

» What's new in HIV cure research

CONTINUED FROM PAGE 24

reveals single-cell heterogeneity and subpopulation expression variability of thousands of individual cells.

"We wanted to use single-cell transcriptomics because… knowledge of viral factors that restrict HIV in cells that become infected is sparse," she said. "These cells contribute to reservoir seeding and represent a source of rebounding virus after treatment interruption."

Newer technologies such as single-cell RNA sequencing provides for wider and deeper investigation of rare cells harboring HIV, she said, and such an approach can be used in an unbiased manner to find host factors that restrict HIV in vivo. The ultimate goal, she said, is identifying novel targets for therapeutic intervention.

CD4 mimetics and exposing hidden HIV cells

Introducing his presentation, Andrés Finzi, a professor of microbiology and immunology at the University of Montréal, reminded the audience that in order for virus particles to be killed, they have to be seen. That's a hurdle, because antibodies don't see infected cells.

"The cells look like they're sealed in a can," Finzi said. "We're looking for a 'can-opener,' that once it opens the can will allow HIV-1 cells to be killed efficiently." A so-called can opener studied by Finzi and his team is CD4 mimetics, which opens the HIV "can," through the virus envelope glycoprotein gp120/gp41. CD4 mimetics are small organic molecules that bind with the glycoprotein, forcing it to expose more of the virus in an infected cell. Adding antibodies to CD4 mimetics further exposes the cell.

"Once you have this cocktail of antibodies with CD4 mimetic, the effector cells are able to engage and kill," he said.

Indoline CD4 mimetics with improved antiviral potency and breadth have been developed. They're called CJF-III-288, and they've displayed favorable pharmacokinetics and toxology in humanized mice, Finzi said. In these HIV-1 infected mice, **a cocktail of CJF-III-288 and CD4i antibodies significantly decreased the size of the viral reservoir, with very little viral rebound**. "Something is keeping the virus in check," he said.

Finzi added that new antibody cocktails have been developed to eliminate infected cells. "It is preliminary research but we're very excited by this."

One thing all presenters emphasized is that more investigation in all of these avenues is needed.

» 'A lack of respect' by HIV scientists at CROI

CONTINUED FROM PAGE 25

laws in the world, stoking violent homophobia in the country. The law's constitutionality is being challenged in Ugandan court. In late February, the parliament of Ghana passed its own anti-gay bill, but the country's president has said he will wait for Ghana's supreme court to rule on its legality before deciding to sign it.

The letter also calls for changing the speaker lineup of the opening plenary, so the community speaker would appear either first or second, not last. This would help to ensure that conference attendees not only pay attention but would serve as a demonstration of overcoming stigma and the marginalization of people living with HIV.

"At these conferences, nearly every talk gives lip service to stigma as a barrier; that disinterest proves that it's just that—lip service," said Jeff Taylor, executive director of HARP-PS (HIV+Aging Research Project-Palm Springs) and one of the letter's co-authors. "This is nothing new at science meetings. All too often the community presentation—if they have one at all—is at the end and people leave before it starts. Which is why we're asking that, going forward, they schedule them at the beginning or in the middle."

Coming from Istanbul, Türkiye (formerly Turkey), Arda Karapinar, founder of the Red Ribbon Association of Istanbul, offered his own observations in an email to POSITIVELY AWARE. "Especially at a conference like CROI, where community participation is so important, the fact that scientists at all levels so easily dismiss the community's problems, their responses to them and the community's agenda, shows that something is wrong," he said. "As community representatives from all over the world, we respect scientists and we do our best to make their work more effective and reach more people, so I think it is not too much to expect the same from all scientists in this field and to expect them to listen to our words.

"We are here," he added. "We will continue to be here. We will continue to work passionately and speak from the heart. And if we are to achieve a global common goal of shared success on HIV, it is a necessity, not a choice, that scientists heed all this."

The letter's authors have posted their letter to change.org, urging people to show their support. To sign onto the letter, **GO TO** bit.ly/letter-to-CROI.

ISTOCK

Four children have achieved remission—what does that mean for babies with HIV?

Dr. Deborah Persaud explains how a clinical trial may open new treatment options for newborns

BY **LARRY BUHL**

A milestone in treating children with HIV was announced at CROI when Deborah Persaud, MD, a professor of pediatrics, shared the results of four infants who had achieved remission with antiretroviral drugs. An NIH-funded clinical trial, IMPAACT P1115 (International Maternal Pediatric Adolescent AIDS Clinical Trials Network) enrolled 440 infants who had been born to women living with HIV in Brazil, Haiti, Thailand, the United States and throughout sub-Saharan Africa. The 54 babies who were born with HIV were given antiretroviral medication within days of birth, initially starting on an older HIV regimen, including AZT (Retrovir) or abacavir, lamivudine and nevirapine. Lopinavir/ritonavir (Kaletra) was added later. Of the 54, six met the criteria for an analytical treatment interruption, halting their HIV treatment to observe what would happen. Four have remained HIV-free so far, more than 48 weeks later.

> ‘For clinical trials purposes, we define remission as being off [ART] for 48 weeks or more without having the virus come back.’

Dr. Persaud, IMPAACT’s scientific chair of the HIV CURE Scientific Committee, is also a pediatric infectious disease specialist at the Johns Hopkins Children’s Center, where she heads the fellowship program in pediatric infectious diseases. Dr. Persaud shared the trial’s results and her observations with POSITIVELY AWARE.

(This interview has been shortened and edited for clarity.)

Could you describe the results that you presented this year at CROI?

What we found in this study is four of six children [who were eligible for an analytic treatment interruption] were able to stay off of their antiretroviral drugs for 48 weeks or more. So almost a year. This is an unprecedented finding because we know that almost every person living with HIV, adults and children, when they begin antiretroviral therapy (ART), it’s a lifelong course of treatment. This is because of viral reservoirs that allow HIV to stay in a person’s T cells for their lifetime. [Our results show] for infants with HIV, not those that have HIV that's already been established for years, there's a window of opportunity to treat them and potentially get more kids into a state of remission, where they can stay off therapy for an extended period of time.

How is remission defined?

For clinical trials purposes, we define remission as being off [ART] for 48 weeks or more without having the virus come back. These kids are followed very closely and regularly during clinical trials with frequent viral load testing to really identify whether the virus would come back or not. It’s still in the phase of experimental medicine. But

we're very hopeful that at least we can identify one strategy for newborns that could potentially get us to this phase of ART-free remission for children.

The concept around getting to remission through this strategy started in 2013, when we reported on the case of the Mississippi baby, an infant who had an unprecedented 27 months off of antiretroviral treatment with no sign of HIV present. In that case, what we discovered that was different about that baby was starting a three-drug regimen 30 hours after birth. Infant prophylaxis did not consist of a three-drug regimen. And so we thought that perhaps this three-drug regimen that was meant for prophylaxis gave this remission outcome.

At that time the word "remission" was not used. You were considered "cured" of HIV as was the Berlin patient [Timothy Ray Brown, the first person living with HIV to be cured] in 2009. And then the field came up with this terminology of "functional cure." So when we first reported the Mississippi baby, we used the term *functional cure*. But we've learned that because the virus rebounded, it was a period of remission. So with that case being reported, in the U.S. and in resource-rich settings, some places had incorporated a now-standard of care, testing in the first 48 hours of life.

Testing and getting newborns on ART is not standard of care for infants who are born with HIV in sub-Saharan Africa, right?

In sub-Saharan Africa, testing in the first 48 hours is not done. In fact, testing is not done until six weeks of age. So most infants don't get identified and treated until two to three months or even later, because the turnaround time [for results] differs in different countries.

There has been significant progress in preventing vertical transmission, that is, in infants acquiring HIV through their mothers. Identification of HIV in mothers is key, and treatment of the mother to suppress viremia to prevent transmission is our goal. But standard of care is not treatment. It is not testing [for HIV] in infants and newborns. So even though we've made significant progress in knowing how to prevent vertical transmission of HIV, we still have about 135,000 cases per year and most of those occur in sub-Saharan Africa. In the U.S., we still have about 50 to 60 new cases of [newborns with HIV]. I believe our study will influence thinking around testing.

How might your findings impact the standard of care for newborns with HIV?

I think with the report of the Mississippi baby [as a] guide—[U.S. Department of Health and Human Services] guidelines to public health recommend testing an infant born from a mother who is believed to have HIV within the first 48 hours after birth. There is guidance in the U.S. and in Europe for infants who are considered highly vulnerable to HIV—meaning their moms are not on antiretroviral treatment, or on therapy but not suppressed—to consider starting this three-drug regimen and testing awaiting confirmation of HIV diagnosis.

In sub-Saharan Africa, that has not been recommended; there's no infrastructure in place to test [newborns]. And so we believe that this finding of potential to achieve remission could provide some evidence and guidance around consideration for incorporating testing in the first 48 hours after birth.

What is a potential longer-term goal for children who achieve HIV remission?

I think *ARV-free remission* is the better terminology because there's no way these treatment strategies are going to completely clear reservoir cells from a person. ARV-free remission is being off ARVs for a meaningful period of time, to spare that person from taking daily [pills]. And for our clinical trials, we picked 48 weeks as a substantial amount of time to spare a child and family from taking medications every day. Obviously, we want to move the needle beyond a year; we want to make it five years. But can we figure out a way to give a child a therapeutic vaccine that can generate HIV-specific immune responses to help control any virus that would pop back? The way we think about this is someone living with persistent herpes simplex where you get cold sores, but your immune system eventually controls it and it goes back into its sleepy state until it comes back again. The same for chickenpox and zoster—you get an outbreak of zoster shingles, but your immune system keeps it in check. Can we get to that point in HIV, where if the virus reawakens, your immune system can keep it in check? Obviously, that's a very long-term goal, maybe a five- to 10-year goal here. But for us getting to 48 weeks, close to a year, is substantial progress.

When the virus did rebound in children, what was the result?

Two to four weeks is the usual time when any person, a child or adult, who goes off treatment can expect the virus to come back. We had one child rebound at three weeks, and the second child rebounded at eight weeks. I'll tell you, for the adult trials, if they see eight weeks, they're excited. But we will consider those two-, three- and eight-week rebounders as early rebounders. One of the early rebounders developed acute retroviral syndrome similar to adults presenting with acute HIV infection, where it feels like a cold and sore throat, mild symptoms that evolved into an acute syndrome with fever and a rash. That led us to modify our protocol to really jump on any signs or symptoms to get a viral load test. And this is why they should still only be done in a clinical trial setting. [The test] has a turnaround time of 90 minutes, so the child stays in the clinic while we do the viral loads.

To the early rebounders, we suppress their virus with the regimen that they were on before they went off treatment.

PERSAUD: ERIC BOND, EGPAF

And they were [re-suppressed] very quickly, within eight weeks. There was one child who took 20 weeks, because of problems with adherence, but all became virally suppressed. And re-suppression on the same regimen suggests no resistance developed.

How can addressing treatment and testing gaps, especially in sub-Saharan Africa, make it possible to achieve the remission results you found in the trial?

Many pregnant women living with HIV [in sub-Saharan Africa] don't know their status. It's very complex in terms of—even if you know your status—staying compliant and staying suppressed.

Access to drugs could be problematic. We've learned from our clinical trials experience, the women travel very far to participate. People who live in rural areas don't have access to care or regular access to drugs, even though the PEPFAR program has done well in focusing on coverage of pregnant people.

PERSAUD: ERIC BOND, EGPAF

The bottom line is that women are susceptible to acquire HIV at any point during pregnancy, and even when the pregnancy is over. And even in women who have escaped acquiring HIV, they can get HIV during the breastfeeding period, which puts infants at continuous risk for HIV [acquisition]. So we need close attention to testing people in general. We need more near point-of-care tests to make it easier for people to get results on the spot. For adults, it's easier because antibody tests can identify infection in most cases. But for infants, it's more complex. You need to do special PCR tests to detect the virus' nucleic acid in the bloodstream of the baby to detect and identify infection, because the antibody crosses the placenta. And so a positive antibody test in a baby tells you the baby has been exposed but it doesn't tell you that the baby has HIV.

But I think there has been such progress made in these near point-of-care tests to get results in 90 minutes, they're not so hard to do. Efforts should be made to test and treat very early. If we can identify [HIV] in infants within the first six weeks and implement early testing and treatment programs in the first six weeks of life, I think we can make a difference in treatment outcomes and survival in children, because we've clearly demonstrated that early treatment is lifesaving for children. Getting treatment early is critical to child survival and retention in care.

What are the next steps of your clinical trial?

We're very excited because before this [trial] there was really no focus on infant treatment and better drugs for children. It's why we still had a regimen of AZT and lamivudine and nevirapine to start with, and had great success. But these are older drugs and the treatment landscape has changed towards integrase inhibitors. If you can block the virus from integrating into your host cell, that's your best shot at preventing establishment of reservoirs in children through very early testing and treatment.

The trial has moved on from a first version with archaic regimens that still worked, to integrase inhibitors and broadly neutralizing antibodies. We are including immunotherapy into this very early treatment approach to see if we can do better with virologic suppression.

We're still in the phase of experimental medicine in terms of trying to understand the outcome in these four children and not more children. But a 7% outcome in a first proof of concept clinical trial should give the field enough information to think to what extent we should try this on a larger scale. And especially since this outcome occurred with not the best drugs to treat HIV in infants. But these are clinical trials, and we don't do implementation where we could inform policy through our findings. I think the key messages are that very early testing of newborns to identify those who [acquired HIV] in utero has a potential for very early treatment with promising outcomes, and the hope of getting to ARV-free remission for more individuals with different strategies could be expedited for children.

[The trial] opened up the treatment landscape for infants and children with this lens on ARV-free remission, rather than just virologic suppression, which I must emphasize that nearly 45% of our kids on treatment are not suppressed. It's very hard for kids to take medications daily. Taking medicine at the start of life, that's lifelong therapy for decades. We need to do better, and that's what this treatment approach and clinical trials testing approach is doing; it's changing how we think about lifelong treatment for our children.

BEING BRIDGETTE

Bridgette Picou

Humor me

I have a twisty sense of humor. Not to be confused with *twisted*, although sometimes the things I find amusing might give people pause. I could blame the morbid piece of my humor on nursing, but the fact is that it was around before then. I say it's *twisty* because I don't necessarily find the same things funny at any given time. I enjoy a good stand-up routine either live or on YouTube, and I also enjoy old comedy films.

Humor me for a second. Will Ferrell is a funny guy, but *Elf* is not his best work. True fans will argue me into the ground over that statement, while others don't think he is funny at all, which I find shocking. I am always amused by Ferrell and that kind of ridiculous, tongue-in-cheek comedy. *Talladega Nights* is raunchy, wildly inappropriate and it makes me laugh out loud every time I see it. Aside from that, my sense of humor depends on when you catch me. Most often it is born of sarcasm and sharp wit.

Comedy brings laughter and laughter is hope.

I thankfully never lost my sense of humor in the beginning of my HIV diagnosis, but I did find myself having to look for hope. Or maybe to *remind* myself is a better way to think of it. I hoped to feel like myself again. I hoped to be happy again. I hoped I wasn't going to be alone forever. Humor helped with that. Laughing at the mundane or even the obnoxious was, and is, a reminder of resilience. I occasionally enjoy the slapstick and physical comedy of folks like Steve Martin or Jim Carrey. I may have dated myself a bit referencing Steve Martin, but who can resist laughing at movies like *The Jerk* or *Planes, Trains, and Automobiles*? Actually, let me correct myself. I know lots of folks who can resist those types of movies. Not everybody finds the same things funny and that's part of the joy of comedy. There is something for everyone. What is most important in all of this is that I need laughter in my life. Comedy brings laughter and laughter is hope. I've never had a clear idea of why these two things are tied together so tightly for me, but they are. Laughter is hope.

Hope is an interesting thing. How people think of hope depends largely on if they consider themselves emotional or more analytical. Sustained hope depends on being encouraged and nurtured and tied to positive outcomes. It feels like emotion, but it is a cognitive process. You learn to hope. You learn something (experience), you feel it (processing) and then you tuck it away in your brain (memory) so you can draw on it when you need it again. It's a combination of perception and memory and language. Which are all elements of laughter as well, so it seems I do know why they are tied together. One thing I learned recently is that there is science to suggest that through laughter, people may feel more empowered to problem-solve. Laughter reduces stress and increases connection with others. It also activates the limbic system which helps to moderate positive emotional responses.

Considering all this is part of why I love comedy and laughter. It also is why I get sad at the state of things these days. Being able to laugh at the ridiculous or off-color helps me deal with the hard parts of life. HIV can be heavy to live with, let alone work in. The number of times I've wanted to quit or let depression or anxiety get to me can't be overstated. Laughter is one way to hit reset and try again. Even self-depreciating humor is a tool for recentering. I have opportunities to talk to people from all kinds of places and spaces in the world. More and more, people are struggling to find hope. The world is not a happy place. Folks are stressed, depressed and angry. Everything offends everyone and it's hard to say anything even mildly controversial, let alone off-color or twisted without setting off a firestorm. Can you imagine TV shows like *The Jeffersons* or *All in the Family* airing on prime time these days? Me neither, which is a shame, because while sometimes shocking, they also offered lessons in laughter and a way to examine who we are and want to be.

I was never a fan of HIV jokes even before my diagnosis, but I also know folks use humor to cope with a diagnosis, or the jokes create a safe, "it can't happen to me" space in others' minds. Most Magic Johnson jokes, or jokes about downlow (or DL) men, continue to do harm in Black communities and keep people from being sexually healthy and getting tested. They perpetuate hate and stigma as the punchline. I have admittedly laughed at some HIV jokes over the years, but as I think about it, they tend to be the ones that are about dispelling myths around HIV and use humor to educate. Advocate and HIV-positive comedian Andy Feds (who appears in this issue's cover story in conversation with fellow comedian Daniel G. Garza, who is also living with HIV, starting on page 12) comes to mind in this category.

Find your funny bone. Reset and center yourself by finding the humor in things. I pray something silly makes you laugh till your sides hurt and the tears run down your face. Have a laugh, have some hope.

Be well, you matter.

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

PICOU: CHAD SAIN • LAYLABIRD-ISTOCK

ISTOCK

Anal cancer awareness

BY **LARRY BUHL**

In 2014, Daniel Garza, a comedian and sexual health advocate, was experiencing constipation and slight bleeding from his rectum. Still, his primary care doctor didn't think it was a big issue and suggested laying off spicy Mexican food. The problems persisted, and it wasn't until a follow-up from an unrelated hernia surgery that the operating surgeon became concerned about a growth in Garza's anal sphincter. It was cancer, and the diagnosis came on Cinco de Mayo, 2015, something that Garza, being Mexican, found ironic.

Anal cancer is rare in the general population, but it's one of the most common cancers affecting gay and bisexual men.

There were anal polyps as well, which the doctor believed resulted from unprotected anal intercourse when Garza was younger. The cancer very likely came from the same sexual activity, through the human papillomavirus (HPV). The practice of bottoming without protection also led to HIV, which Garza learned about years earlier, but not until his T cells were well under 200.

"The polyps, HIV and HPV basically got together and caused cancer," Garza said.

Anal cancer is a big risk for bottoms

Anal cancer is rare in the general population, but it's one of the most common cancers affecting gay and bisexual men. In fact, gay/bi men or individuals who identify as men who have sex with men (MSMs) are 20 times more likely to develop anal cancer than heterosexual men. The reason is HPV, which can be transmitted through bottoming, from the penis to the anal canal.

More than 90% of anal cancers are caused by HPV, specifically one strain: HPV-16, which can cause anal and genital warts. Millions of people acquire some strain of HPV every year and in most cases the immune system can fight it and clear it from the body. People with suppressed immune systems (unsuppressed HIV for example) are less likely to clear the infection.

There are vaccines to prevent HPV infection, and they've been approved for boys and men between ages 9 and 45 years. The thinking behind the age cutoff is that by midlife most men have had the bulk of their sexual partners and therefore have already been exposed to many strains of HPV. Most insurers won't cover HPV vaccination if you're over 45, so if you're older a full series of three shots could run $1,000-plus out of pocket. Some doctors say getting the shots later in life is still worth it, if you can afford it.

Using condoms for anal sex, a practice more common during pre-PrEP days, can also reduce the risk of HPV and other STIs. PrEP, while highly effective at preventing HIV transmission when used as directed, is only effective at preventing HIV, not other STIs.

If you've ever bottomed and never been tested for anal cancer and especially if you have HIV, it's a good idea to ask your doctor to screen for it. There are three key screening tools for detecting abnormal or pre-cancerous lesions in the rectum:

Digital rectal exam, where the doctor inserts a gloved finger into the anus to feel for lumps or warts. A doctor can also explore the prostate for abnormalities this way.

Anal cytology or Pap smear, which collects cells from the anus to be examined in a lab.

High resolution anoscopy, where a small microscope is attached to the end of a plastic tube, which is inserted into the anus. If the microscope finds an abnormality, a biopsy can be taken.

A recent study showed that it's possible to diagnose, through a Pap test or high-resolution anoscopy, and treat abnormal cells in the anus before they develop into later stage cancer.

But doctors are not likely to automatically screen for anal cancer, according to Alan Nyitray, an associate professor of psychology and behavioral medicine at the Medical College of Wisconsin.

"There are a lot of barriers to anal cancer screening, and no national consensus recommendation to screen," Nyitray said. He added that doctor-patient conversations about anal cancer risk aren't happening.

"Even for people with HIV, their HIV docs don't bring up anal health much, which is important because people with HIV are at much higher risk of HPV and anal cancer," he said. "A lot of providers are not comfortable doing an anal exam. There is a lot of stigma associated with the anus."

Nyitray suggested that MSMs educating themselves on the risks of HPV, and advocating for home testing, could make a positive impact on anal cancer rates. He authored a recent study to learn whether people would be likely to engage in screening for anal cancer if they received an at-home kit or if they got screened at a clinic.

For the study, 240 participants—both cis and trans men plus trans women—were randomized into two arms: one in which they had to call one of five clinics to request an anal cancer screening appointment and show up for it, and the other group took the at-home test.

Nyitray found that people who got the kit at home were more likely to engage in screening: 89% returned the kit versus 74% who made an appointment at a local clinic and had the swab done there. Those results were what Nyitray expected, but he was surprised at how important home testing is for people who are Black. In the home-based arm, 96% of Black participants used the home test but only 63% accessed the clinic. Nyitray speculates that the reasons for the disparity are lack of access to nearby health care or not having health insurance. "Medical mistrust (among Black people) is one reason for much lower engagement in health care settings."

Nyitray added that home testing for anal cancer was cost-effective. "There wasn't one person in the home-based arm who said they had to miss work, but a lot of people in the clinic arm had to miss work."

Being an advocate for your bum

HPV vaccines were not available when Daniel Garza was younger. Now 53, Garza uses an ostomy bag due to the removal of most of his sphincter. The bag is a lifesaver he admits—he's cancer free—but definitely inconvenient and not ideal.

In addition to being a stand-up comic, Garza does presentations on HIV and HPV at community colleges, universities and high schools where he shares very personal details about his butt. The most important thing he emphasizes for young men is protection, which means not just PrEP, but condoms—something that MSMs have been increasingly resistant to using.

"If (your anus) hurts or if you're bleeding, go to the doctor to get checked. And all young men should get the HPV vaccine," Garza says.

It takes some fortitude to initiate delicate conversations about sexual practices and personal risks of HPV and other infections if the doctor doesn't bring it up.

Asking for the vaccine or anal cancer screening requires being a self-advocate.

"Even if your doctor is gay, don't assume they will understand what you need," Garza said.

Daniel G. Garza trades observations with fellow comedian Andy Feds, who was born with HIV. **READ** "Stand up act," starting on page 12.

It's not all about anal sex

To be clear, you don't need to have anal sex to get anal cancer—especially for women.

"Some people suggest that if you have a history of anal sex you may want to get checked for anal HPV, which is correct. But studies suggest, and this is particularly true for women, that history of anal intercourse is not a strong risk factor for anal HPV," said Jessica Wells, PhD, RN, an associate professor at the Nell Hodgson Woodruff School of Nursing at Emory University. "For women, this is due to the geographic location of the cervix to the anal canal. A lot of times cross-contamination occurs. So if a woman has a history of cervical HPV, just due to the proximity of the anal canal, she is also at risk of anal HPV."

Human papillomavirus (HPV) is the most common sexually transmitted infection, according to the Centers for Disease Control and Prevention (CDC).

Dr. Wells explained, however, that, "People living with HIV have a significantly higher incidence of anal cancer." She called the rate "alarming."

In the general population, she noted, anal cancer is very rare, about eight cases per 100,000 persons.

However, she added, "Reports have shown on average 60.1 new cases per 100,000 among men *and* women living with HIV. And men who are same-gender-loving have an even higher increased risk for HPV, with reports as high as 141 cases per 100,000."

The CDC recommends HPV vaccination for individuals who are immunocompromised, including people living with HIV, cancer survivors and transplant recipients.

"HIV and HPV are both sexually transmitted viruses, so co-infection is common. One study found that anal HPV among a sample of women was actually more prevalent than cervical HPV. Additionally, studies have shown that HIV-positive individuals are more likely to have persistent HPV infection. It's that persistent HPV infection, coupled with being immunocompromised, that drives the increased risk of HPV-related anal cancer," she said.

To be clear, you don't need to have anal sex to get anal cancer

Other risk factors associated with anal cancer include smoking, a history of anal intercourse, [a higher] number of lifetime sexual partners, history of other STIs and history of HPV or dysplasia (abnormal cells).

The answer is to vaccinate. *Vaccinate. Vaccinate. Vaccinate.* Get the three vaccine shots that safely and effectively prevent several types of cancer, including anal. Gardasil-9 is the only HPV vaccine in the U.S.

Dr. Wells describes additional details, including how to easily and quickly get vaccinated for free, in her March presentation for the community HIV education series THERAThursdays from Theratechnologies. **GO TO** theraeducation.com.

She also explains how anal Pap tests are done and walks you through the anal canal. No, a colonoscopy will not help find anal cancer.

HPV can cause cancer of the cervix, a section of cells between the vagina and the uterus. Cervical cancer is an AIDS-defining illness.

Information about the subject isn't getting out because people are uncomfortable talking about anal sex or anal cancer, and that includes medical providers. Dr. Wells discusses strategies for this as well.

As a researcher, Dr. Wells invites clinics to reach out to her to address anal cancer in the HIV community.

To view the presentation, **GO TO** bit.ly/44pDy9g.

—ENID VÁZQUEZ

12 years and counting

Cured through a stem cell transplant, Marc Franke—first known as ‘the Düsseldorf patient’—reflects on his journey since then

INTERVIEW BY **THOMAS J. VILLA** • CONTRIBUTING EDITOR **KARINE DUBÉ, DrPH**

My name is Marc Franke. I’m 55 years old. I’m the “Düsseldorf Patient” described in the *Nature Medicine* March 2023 article where my case was presented 10 years after a stem cell transplant—the most-reviewed case of the handful of people who have been cured of HIV. I think that's significant. Of all the people who have been cured, I have survived the longest after stem cell transplantation. I am currently in my twelfth year.

I was diagnosed with HIV in 2008. At the time, antiretroviral treatment (ART) was not immediately started in Germany, where I live. As I was diagnosed early (not more than three months after acquiring HIV), it was two and a half years before I started treatment with ART. A few months after starting ART, I was diagnosed with pneumonia in January 2011 and then with acute myeloid leukemia (AML). Doctors suggested I immediately start chemotherapy. After seven months of treatment, I went to physical rehab. By the end of the year, I started working and everything seemed fine.

In October 2011, I had a relapse of AML. My doctors said a second round of chemo would not work, and that I needed a stem cell transplant. They searched for possible donors and found several potential matches, then asked if I would like to try the same treatment that was given to Timothy Ray Brown, the “Berlin Patient” [the first person to be cured of HIV]. I saw a documentary about Timothy and thought, *If this worked before, why wouldn’t it work for me?* The blood samples from possible donors had to be re-scheduled to look for the [CCR5-delta32] gene mutation, the same mutation involved in Timothy’s case. That took extra time, about four months. In five possible donors, doctors found one with the gene mutation. Knowing that the gene mutation is present in 1 percent of the Caucasian population, it was very lucky to find the match among just five donors and not among the statistical 100.

Thomas J. Villa: Marc, thank you for sharing your story as the conclusion to our year-long series, *Partners in Research*, presenting the personal experiences of participants in HIV cure-related clinical trials. I’m especially excited because your experience shows that steady progress is being made toward successful cure strategies. I’m awestruck by the adversity you overcame during various treatments and by your humility in speaking about it. I’d like to ask a few more questions about your journey.

How did you feel while waiting without knowing if doctors would find a donor?

Marc Franke: I had two more mild chemotherapy treatments while we waited and thought the transplant might work like the chemo. The preparation was similar. I didn't think much about it because all the chemo went well for me.

It was *after* the transplant that so many things went wrong. After transplant, 100% of your immune cells should be replaced by donor cells. Unfortunately, after half a year it was found that 30% of my own immune cells were detectable in my blood again. With a special treatment plus the administration of T cells from my donor, my cells were cleared. Everything was fine after that. I learned later that this approach works for few patients. I was lucky that it worked for me.

I then had problems with my liver and had to take cortisol. The cortisol gave me diabetes so I had to start injecting insulin. Six months later, I fell in the hospital, broke my hip and had to get a new hip. Prior treatment with chemotherapy and cortisone had made my bones brittle. All during this time I was taking immune suppression medications because of the transplant, so the researchers couldn’t interrupt my ART yet. After stopping the immune suppression, I immediately got graft versus host disease. I had big problems with dry eyes. About a year after the immune suppression was stopped, we interrupted ART. It was at the end of 2018.

When I see pictures of Timothy [Brown] in the documentary [*The Berlin Patient*] walking across the street and unpacking his suitcase at the hotel, I can imagine how he felt because I was in a wheelchair or using a walker to get around for weeks and had some bad times. I’m doing well now, but it was a rocky road.

Is there anything that you wish had been done or perhaps done differently?

I was lucky that the doctors learned from Timothy that radiation is not needed for clearing the immune system [to make room for the transplant]. I think

Timothy had many problems because of the radiation. So, I was lucky.

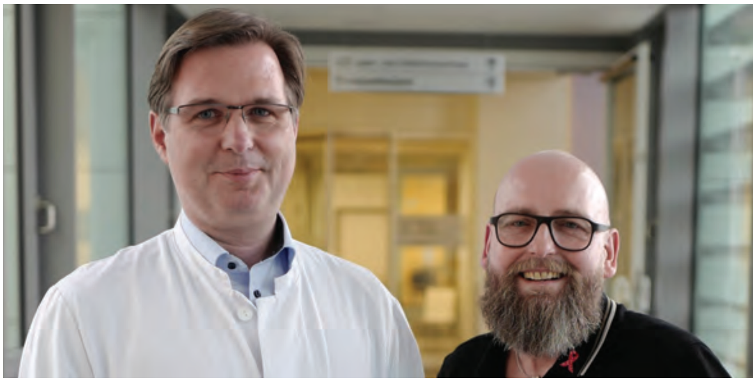
Living with HIV was easy compared to being a transplant recipient. Someone who hasn't gone through it can't imagine the highs and lows of this procedure. The worst is that you can't plan your life because with every day, anything can change. Then you go back to the hospital for another treatment. Many of the patients I was in hospital with are not living anymore. With AML, I think 50% live five years after the transplant. My oncologist told me as recently as this month [April] that my chance of surviving the transplant and any complications at the time was less than 10%.

For an HIV cure, this is not the way for everyone. Stem cell transplants should only be done for people with HIV who also have leukemia or another cancer where the procedure is needed. If ART works well for you, I think one pill a day or perhaps long-acting injectable ART plus going to the doctor every three months is easier. If only the stigma didn't exist.

Well, thankfully things did work for you. Is there anything that would have been helpful to you during that time?

I had the biggest help you can imagine because the power of love guided me through everything. I met my husband Ingo at the end of January 2011, before my AML was diagnosed. We chatted on a gay dating app, and he visited me the next day, then every day. I wanted to get back on my feet so that we could have a normal life together. Now we are married, we built a house and we have our dog Motte, a Hungarian pointing dog [Magyar Viszla]. Everything is fine now. So, if you meet someone and he has no problem with HIV and no problem with cancer, this is your very special someone. I got through all the chemos because I knew there was someone visiting me in the evening, and I had to be prepared.

FRANKE (LEFT) WITH HIS HUSBAND, INGO, AND THEIR DOG, MOTTE.



DR. BJÖRN-ERIK OLE JENSEN (LEFT) AND FRANKE.

FRANKE, INGO, MOTTE: INGO LAMMERT • JENSEN, FRANKE: INGO STRÄTER

That's wonderful! This question is completely optional, whether or not you would like to discuss this: Is there anything that you would share with regard to how you approached sex after you stopped your HIV medication and were not yet sure whether you had been cured?

I have to protect myself because PrEP doesn't work for me because it would make a very unlikely resurgence of infection not detectable. The CCR5-delta 32 gene mutation only protects me against the most common HIV strain. I can acquire HIV again by a different strain, so I have to protect myself.

Okay, thank you. Is there anything that you would like to have been done differently during this follow-up time that may be helpful to you or to other people going through a similar experience in the future?

I was the second person successfully transplanted with the gene mutation after Timothy. Now there are more cases to compare. After the transplant, I had to take over 40 pills a day. So the one HIV pill, I didn't care about. I waited so long to stop ART that when my doctor, Dr. Björn-Erik Ole Jensen, told me it was time to stop, I thought he is very sure, and it wasn't a special day for me.

After stopping the pills, we started with HIV tests twice a week. I had to drive more than 100 kilometers [over 60 miles] to the university hospital twice a week. To save travel time, after a few weeks I went to my doctor here in my hometown. I started working again, and I learned to take the blood samples myself to send them to the lab in Cologne. That worked very well. Once a month, I went to the university hospital. Now we take the samples every two months. I think they are really sure that nothing will happen if they stretch the time so much.

And then 10 years after the transplant, Dr. Jensen told me that he's writing an article for *Nature Medicine*. That was another clue that he is very sure about my HIV cure. So, I decided to go public with my story. I feel very safe with my doctors. If HIV had been detected it would just be a matter of starting to take medication [ART] again and everything will be fine. For me, the great sword of Damocles is leukemia, not HIV. Being cured of HIV is a side effect, a great side effect, but if I hadn't been lucky enough to be cured of leukemia, I would have gladly continued taking the HIV pills.

With the cancer, I have lost five years of my life. First, because of the chemo, I was out of the office for seven or

> **If ART works well for you, I think one pill a day or perhaps long-acting injectable ART plus going to the doctor every three months is easier. If only the stigma didn't exist.**

STEM CELL DONOR ANNA PRAUSE (LEFT) AND FRANKE.

eight months. Then with the transplant, I was ill for three and a half years. I'm lucky that I can work again, although it's not easy because I have fatigue. My concentration is not so good. I'm working part-time now, 30 hours a week, and for my severe disability I get five extra days of leave per year.

Other people don't see that you have problems with your brain because of all the chemo and they think, 'Well, he looks normal, so he has to work normal.'

Are you able to talk about this comfortably with people at work? Do they understand what you're going through?

That's the problem, because my colleagues had to work for me during the time I was in hospitals. After I came back, colleagues' attitudes changed. I don't think that they can imagine what I went through, the dry eyes and not seeing so well, plus the concentration problems. Other people don't see that you have problems with your brain because of all the chemo and they think, "Well, he looks normal, so he has to work normal." It's hard for them to understand what you have experienced.

I hope that the scientists learn so much from the lymph nodes and tissue samples from my stomach that someday they will be able to recreate the cure without the transplant. If there is someone with HIV who gets leukemia, perhaps they will be able to offer stem cells prepared with the CRISPR Cas9 technique so that the gene mutation can be created via gene therapy.

I was lucky that they searched worldwide for the best laboratory for each different test. The doctors formed a great team over the years, and many of them became my friends. Some of the doctors look at me as their child. It was very inspiring to meet one of the doctors that only knew me as *Number 19* in that database. I think it was very inspiring for the doctors to see me and think, "Well, he's alive. And he's a great person. And here he is." They invited me to the labs. I will go to the Netherlands to visit the doctors and their students to inspire them for research.

So you have a global family out of this—new brothers and sisters. How wonderful. That's a really hopeful and inspiring way to look at this.

Oh, yeah, because now the number of persons cured is rising. I was very happy that "The Three Musketeers," that's the name of our WhatsApp group—Adam, Paul and I—were on stage together at the Hawai'i to Zero Conference in Honolulu in 2023. I don't want to make a business out of my advocacy. I want to have a little bit of my normal life. But, if someone asks me to join a conference, gala or something similar, I will be glad to be invited. I'm happy that in 2024 the IAS conference will take place in Munich, so it will be easy for me to get there. I will participate in some sessions.

Franke is thankful for his stem cell donor Anna Prause. Without her stem cells, he said, the procedure would never have been possible. In Germany, donors and recipients are allowed to get to know each other. "It was indescribable to stand face-to-face with my genetic twin! We noticed a lot of similarities," he said.

Franke encourages people to register as stem cell donors and urges support for worldwide HIV cure research.

For more information, **GO TO** aidsfonds.org/hiv-cure. **READ** the *Nature Medicine* March 2023 article at bit.ly/49Pk7b2.

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