

NOV+DEC 2019

Four special edition foldout covers to commemmorate A Day with HIV





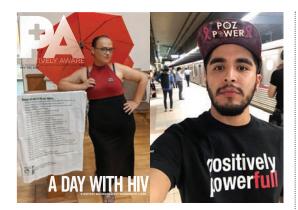






FRONT COVER(S) BACKSTORY

ONE ISSUE, FOUR COVERS featuring photos from A Day with HIV, POSITIVELY AWARE's annual anti-stigma campaign, On September 23, 2019, people across the U.S. and in 10 other countries captured a moment of their day to depict 24 hours in the lives of people affected by HIV. In addition to a selection of photos appearing on pages 37-44, there are four different versions of a foldout cover for this issue, shown here.



1:27 PM: PETERBOROUGH, ONTARIO, CANADA

Brittany Cameron: Holding space for sex workers as we explore the intersections of street-based sex work and harm reduction.

11:39 AM: LOS ANGELES, CALIFORNIA

Carlos Moreno: A Day for High Impact Visibility. Not all are able to be out and loud about their status, but that doesn't make them any less resilient or brave. Let us shed our layers of stigma and shame, and unite to show how beautiful our community is.



8:16 AM: LUSAKA, ZAMBIA

Precious Kanik: I proudly say I am HIV positive. I will not allow anyone to make me feel inferior in my own skin. I am U=U.

9:45 PM: PALM SPRINGS, CALIFORNIA

Captain Chad Sain; Retired, USN: HIV positive since 2008, celebating life through photography and raising awareness to end the stigma.



5:00 PM: HACKENSACK, NEW JERSEY

Artie M. Jordan: I'm not only a PrEP counselor and HIV tester, I also have the pleasure of being the person behind all the social media platforms here at Buddies of New Jersey. Equality for all people no matter their status or gender!

11:20 AM: TUSCUMBIA, ALABAMA

Katie Willingham: I take my meds every day and it's no big deal; it's just a pill. I take a multivitamin because my doctor says it's good for me, and it's no big deal; it's just a pill. I take meds for depression and anxiety because mental health matters, and it's no big deal; it's just a pill. I take my antiretrovirals to control my HIV because it helps me to live a long, healthy life and it also prevents the spread of the virus, ending the epidemic with me. I do this every day. and it's no big deal; it's just a pill.



5:00 PM: ATLANTA, GEORGIA

Eddie Wiley: I took this picture to show there's no shame in being HIV positive. Because I'm undetectable, I can't sexually transmit the virus!

5:03 PM: INDIANAPOLIS, INDIANA

Madison Markley: Sitting in a local Starbucks. I took this photo to remind myself to fight for others, that even in public spaces I can be active in speaking out for those who may not be able to or want to speak for themselves. Education is one of the biggest barriers to having a fully inclusive environment; we could all use a day to spend speaking for and acting out for those with HIV.





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JOIN US IN 2020 FOR **OUR 30TH ANNIVERSARY.** LIVE LIFE POSITIVELY AWARE.

SINCE 1989. PUBLISHED BY

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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.

Autumn 2019

Dear POSITIVELY AWARE reader,

POSITIVELY AWARE is more than a magazine. For many people, it's a first step, a lifeline of information, a connection to others, and a source of hope and inspiration.

In 1989, TPAN began publishing PA as a modest newsletter, telling readers about emerging treatments and care options while our friends were dying and we only had one another to lean on. Today, after 30 years of publication, PA is the go-to source for up-to-date treatment information and moving stories of survivorship and leadership around HIV advocacy.

More than 100,000 readers like you access the pages of PA's every issue. It's delivered to homes across the country, and read in community centers and care settings in every state—often the places where people most need expertise and insight from peers about how to navigate HIV care and support.

Most importantly, we know from the letters and emails we receive from our readers that POSITIVELY AWARE is a vital resource for individuals who are isolated and living with stiama.

> "When I was incarcerated, I had no one to talk to and no idea what questions to ask. PA gave me hope and the information I needed to survive—PA saved my life."

So, this is more than a magazine. This giving season, we hope you will consider a donation to TPAN to help us deliver POSITIVELY AWARE to readers who need it most. PA is still the only magazine of its kind published by a nonprofit, and we rely on support from friends like you to ensure it remains a widely-read, powerful resource for all who need it.

Please consider a year-end gift of \$30, \$50, or \$150 to help TPAN deliver PA to the people who need and value it most—individuals, families, and caregivers addressing HIV in our daily lives. Information on how to donate is below.

Thank you—for your readership, for your support, and for helping us reach thousands who are affected by HIV. We wish you a healthy and wonderful holiday season.

In gratitude,

Jeff Berry

EDITOR, POSITIVELY AWARE

Christopher Clark

CHIEF EXECUTIVE OFFICER, TPAN

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EVERY ISSUE

FRONT COVER(S) BACKSTORY One issue, four covers

for A Day with HIV.

THE CONVERSATION

In the right direction. An ally shares support. The spirit of Freddie Mercury at the POSITIVELY AWARE booth at USCA.

EDITOR'S NOTE

Dismantling stigma.

BRIEFLY

The FDA approves Descovy for PrEP. Delstrigo and Pifeltro approved as switch treatment. Bictegravir, dolutegravir, and Tybost for children, along with the the hepatitis C drug Harvoni. Shingles vaccine update. HIV and heavy drinking. Second living kidney donation by a PLWHIV.

POSITIVELY AGING **CROSS-GENERATIONAL** COLLABORATION

Coming together for HIV advocacy. BY **JEFF BERRY**

IN THIS ISSUE

16

CHALLENGES ACCESSING PrEP IN ENGLAND

Access to PrEP is uneven and problematic, and not just in the United States. BY KIMBERLY LEVITT AND LINDSAY TAYLOR

ACUPUNCTURE AND LONG-TERM SURVIVORS

BY ELIZABETH SOMMERS, PHD, MPH, LAC

THE FUTURE IS ALREADY HERE

Technological advances in HIV treatment and prevention. BY MICHELLE SIMEK

USCA 2019

ACTIVISTS HALT CONFERENCE TO PROTEST CDC

BY MARK S. KING

DON'T CALL IT PrEP

Lessons learned from D.C.'s PrEP for Women Initiative. COMPILED BY ENID VÁZQUEZ

BLACK AND LATINO QUEER MEN AND PLEASURE

Choosing power over stigma. BY ENID VÁZQUEZ

TWO SPIRIT

A conversation with David Herrara of the Montana Two Spirit Society. BY ENID VÁZQUEZ

24 HOURS IN THE LIVES OF PEOPLE AFFECTED BY HIV

DRIVING OUT STIGMA

'Dee' Conner and Deirdre Johnson hit the road to raise awareness in the South.

DEEP AND SOUTHERN STRONG

A look at the 7th annual Rural HIV Research and Training Conference. BY SEAN BLACK

MENTAL HEALTH AND SELF-CARE

Some thoughts to consider.

THE PASSING OF A FOUNDER

Remembering Bill Rydwels, a founding member of TPAN.

SUDDENLY SUNDERED

HIV and the Foreign Service. BY MICHAEL VARGA

READER SURVEY

Tell us about yourself, and what you'd like to see in POSITIVELY AWARE.

9:45 AM: SCHENECTADY, NEW YORK

Jasán Maurice Ward: Ás a long-term HIV survivor of 23 years, at 47, I am now living with HIV and cancer. I was diagnosed with cancer in June, and am currently in recovery from chemotherapy and radiation. Through it all, I still wake up feeling ready to fly, rising higher each day, in order to keep fighting, inspiring other people, and living my best life! A SPECIAL SECTION OF PHOTOS TAKEN ON A DAY WITH HIV STARTS ON PAGE 37.

THE CONVERSATION

IN THE RIGHT DIRECTION

For "In the Clinic" in the September + October issue, John J. Parisot, PhD, MSN, RN, of Michael Reese Research and **Education Foundation** in Chicago, noted, "It's not just newly diagnosed people who need education. I've had long-time patients say, 'I know there are two important numbers, but I can't remember which one is supposed to go up [CD4 count] and which one's supposed to go down [viral load.]"

His observation inspired KATHERINE E. SHUMATE, MPH, a health planning administrator at the Ohio Department of Health, to create the following illustration.

"In reading the comment by Dr. Parisot, a solution just jumped out at me that might be helpful. The '4' in CD4 points up (the direction you want the count of these cells to go) and the 'V' in viral load points down (the direction you want this measure to go). It is a visual mnemonic device that is easy to remember. This is a quick graphic that I threw together with only limited tools available—someone else could certainly do a better job.

"I can't believe I have worked in HIV for more than 30 years and only when I saw John's quote did this really obvious tool hit me." ENID VÁZQUEZ RESPONDS: Thank you for your letter and your graphic. That's what "In the Clinic" is about—providers inspiring each other, and the people they serve, with information that could lead to better service. SEE THIS ISSUE'S "IN THE CLINIC" ON PAGE 12

AN ALLY SHARES SUPPORT

Even though I don't have HIV, I have friends who live with the virus. One of them was so happy for being part of the top favorites.

top favorites.
I helped him take the pictures.
The history of HIV has been sad. One of my friends lost his boyfriend due to complications with the virus. Since then I had educated myself about the subject, and I have aimed my acting skills and writer's skills in the social consciousness of ending discrimination in Puerto

Rico, where I live. I had a partner with HIV, and it was sad for me to see him constantly feel not loved, or afraid of being rejected by others. Projects like yours help those living with the virus feel loved and accepted.

I'm a law student right now.
One of my aims is to fight discrimination through law. I do hope
#adaywithhiv was a success this
year and that you keep on working
on similar projects

-IRVING RODRIGUEZ ACOSTA







Freddie Mercury was the star of POSITIVELY AWARE's booth at September's U.S. Conference on AIDS in Washington, D.C. Actually, it was a painting of the legendary lead singer of Queen that was the attraction. Coincidentally, the conference opened on what would have been Mercury's 73rd birthday; Mercury died in 1991 of bronchial pneumonia resulting from AIDS. PA's booth was turned into a "social media living room," providing the opportunity for conversation and selfies. The painting, along with the booth's living room furniture, were provided by Miss Pixie's Furnishings and What Not, a local resale shop popular within D.C.'s gay community and known for donating to HIV-related causes. Making themselves at home were (above, from left) Charles Sanchez, Victoria Noe, Mark S. King, Robert Reister, Nancy Duncan, and Ernesto Aldana.

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JOIN IN THE CONVERSATION inbox@tpan.com



@posawari

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Dismantling stigma

stig·ma

1. a mark of disgrace associated with a particular circumstance, quality, or person. "The stigma of having been accused of a crime will always be with me."

ccording to the CDC, "HIV stigma and discrimination affect the emotional well-being and mental health of people living with HIV. ... HIV internalized stigma can lead to feelings of shame, fear of disclosure, isolation, and despair. These feelings can keep people from getting tested and treated for HIV."

As I was reading through this issue of POSITIVELY AWARE I was struck by the many different ways we encounter and experience stigma, and the myriad ways we seek to address it in our lives, and in our world. The ways in which we speak truth to power, and the power that there is in sharing our stories, can all begin to dismantle the stigma associated with HIV.

At the United States Conference on AIDS in September, just being in the same space with over 3,000 other advocates can be a powerful experience. The layers of shame and isolation begin to peel away as you realize you are not alone. Read our coverage of the conference beginning on page 28.

One story you'll read about in this issue is how two activists, Davina Conner and Deirdre Johnson, sought to address stigma in a unique way by getting behind the wheel of a car and driving through the southern U.S. to educate others and raise awareness. The goal was to "show people the impact of HIV, stigma, and depression among women of color, and women of color who are of trans experience," said Conner.

Michelle Simek writes about some of the technological advances in HIV treatment and prevention, such as long-acting injectables and implants, in her article beginning on page 20. As Dr. Judith Currier points out, many people living with HIV say that the ritual of taking a pill every day can be a barrier to adherence—"a daily reminder of HIV. If we can demonstrate that long-acting injectable treatment will overcome this barrier, it will be a major advance."

The stigma people encounter sometimes can come from those who work in the very agencies that are supposed to be helping them. Read about multiple, intersecting stigmas, such as the stigma that sex workers face, in "Black and Latino gueer men and pleasure," by Enid Vázquez on page 30.

Sometimes stigma we've experienced in the past can motivate us to effect change in the future. In "Deep and Southern Strong," Sean Black covers the 7th Annual Rural HIV Research and Training Conference recently held in Savannah, Georgia. Fayth M. Parks, PhD, founded the conference in memory of her brother who died due to AIDS in 1989. She recalls the quarantine imposed by the hospital, and the probing, personal questions from the doctor about her brother's "lifestyle." She felt angry and confused by it all, but went on to make HIV/AIDS her life's work.

In "Suddenly Sundered," long-term survivor Michael Varga relates his experience in the 1990s when he was diagnosed with HIV, and was subsequently pushed out of the Foreign Service while working for the U.S. government in Canada. He eventually became a playwright, actor, and fiction writer, and says the experience drove him to continue to be of service to others and to share his story.

In our annual A Day with HIV photo campaign, you'll read about a wide variety of individuals from around the world who came together on one day and shared what it means to live in a world with HIVpositive or negative, we are all affected. Many of this year's participants talk about stigma that they've experienced, what they are doing to overcome it, and the power of resilience and community. Sometimes just being open about your status, or sharing your story with someone you trust, can be a powerful weapon in the fight against stigma.

We all experience, and address, stigma in our own personal way, and it is only through our combined efforts that we will break down the walls of stigma once and for all.

Take care of yourself and each other.

P.S. Please take our Reader Survey on page 55, and help us get to know you a little better!

Sometimes just being open about your status, or sharing your story with someone you trust, can be a powerful weapon in the fight against stigma.



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ENID VÁZQUEZ 🏏 @ENIDVAZQUEZPA BRIEFLY

FDA approves Descovy for PrEP

S THIS ISSUE WENT TO PRESS, the FDA approved 225 the drug Descovy for use as PrEP (pre-exposure prophylaxis) in the prevention of sexually acquired HIV. However, the FDA did not approve Descovy PrEP for receptive vaginal sex, saying that its effectiveness had not been evaluated in this context.

The only other medication approved for HIV prevention, Truvada for PrEP, approved in 2012, does cover receptive vaginal sex.

Gilead Sciences, maker of Descovy and Truvada, entered into a post-marketing commitment (PMC) with the FDA to conduct a clinical trial evaluating the safety and efficacy of Descovy for PrEP in cisgender women and adolescent girls weighing at least 77 pounds (35 kg). The PMC will include a group taking Truvada for PrEP for comparison. Of note, some transgender men have a vagina and some use it for receptive sex with other men.

Descovy and Truvada are both HIV medications containing a pro-drug of tenofovir. Simply put, the pro-drug is converted into tenofovir (becomes active) after it enters the body. The pro-drug in Descovy is tenofovir

alafenamide (or TAF) while the pro-drug in Truvada is tenofovir disoproxil fumarate

TAF and TDF are converted in different ways, and some research data indicate that TAF may not reach protective

levels as high or as quickly in the vaginal tract as does TDF.

Descovy was studied as PrEP in gay men and transgender women. It was not studied in cisgender women. The most common side effect with Descovy PrEP was diarrhea.

Truvada is more than 92% effective in preventing sexually acquired HIV. Both Descovy and Truvada are taken as one pill once a day, whether used for HIV treatment or as PrEP.

See the FDA announcement at bit. ly/20dwwQ2. Read more about Descovy, Truvada, and Truvada for PrEP in the POSITIVELY AWARE HIV Drug Guide.

FOLLOW avac.org and treatmentactiongroup. org for more information and advocacy updates. Treatment advocates have expressed concern over Descovy for PrEP, including preliminary indications that Descovy might be wrongly promoted as safer than Truvada.

Tivicay (dolutegravir) plus two nucleoside reverse transcriptase inhibitors (NRTIs) is now an alternative regimen for first-time treatment for children aged three and up who weigh 44-55 pounds (20-25 kg). It was previously recommended for children weighing more than 55 pounds. Dolutegravir plus two NRTIs is found in the single-tablet regimen Triumeg. It is also found in Dovato and Juluca. Tivicay can also be taken separately with Descovy or Truvada.

For more information, GO TO aidsinfo.nih.gov and the POSITIVELY AWARE HIV Drug Guide at positivelyaware.com/ hiv-drug-guide.

Harvoni for children

In September, the FDA approved the hepatitis C medication Harvoni for use by children 3-11 years old. (Harvoni was already approved for pediatric patients ages 12 and up.) Children must have:

- genotype 1, 4, 5, or 6 without cirrhosis or with compensated cirrhosis
- genotype 1 with decompensated cirrhosis, for use in combination with ribavirin
- genotype 1 or 4 and be liver transplant recipients without cirrhosis or with compensated cirrhosis, for use in combination with ribavirin

The weight-based dose is given once daily with or without food. Those with difficulty swallowing Harvoni tablets (available in different doses) can use the oral pellets

Delstrigo, Pifeltro switch approved

The FDA has approved a switch indication for Delstrigo and Pifeltro.

Anyone with undetectable viral load of less than 50 on a stable HIV antiviral regimen can now switch to the single-tablet regimen Delstrigo or to a drug combination that includes Pifeltro. Individuals must be on a stable regimen for at least six months and have no drug resistance to doravirine (brand name Pifeltro, also found in Delstrigo) or to the

other medications contained in Delstrigo, and no history of treatment failure.

Individuals could have previously been switched to a doravirine-containing medication using off-label prescribing. New Phase 3 data from the DRIVE-SHIFT clinical trial gave the FDA the evidence they needed to make a switch indication (usage) official in September.

READ more about Delstrigo and Pifeltro in the POSITIVELY AWARE HIV Drug Guide.

Bictegravir and dolutegravir for children

In September, U.S. pediatric HIV treatment guidelines updated recommendations for therapy.

The single-tablet regimen Biktarvy (bictegravir/ FTC/TAF) is now a preferred therapy for first-time treatment for adolescents aged 12 and older weighing at least 55 pounds (25 kg). Biktarvy is also an alternative regimen for initial use in children ages 6 and older weighing at least 55 pounds.

BRIEFLY

formulation instead.

Harvoni is made up of two medications in one tablet. ledipasvir and sofosbuvir. The FDA also approved sofosbuvir by itself (brand name Sovaldi) for children 3 to 11, but this drug is only rarely used nowadays.

SEE the FDA announcement for treatment duration and more at bit.ly/2moWswc.

Tybost now for children

Tybost can now be used in children. Although not an HIV drug, Tybost is used as a "booster" to increase levels of the HIV medications Prezista and Revataz.

- Cobicistat (Tybost's generic name) and darunavir (the generic name of Prezista) are also in the single-tablet regimen Symtuza.
- There are also fixed-dose drugs with cobicistat in combination with Prezista or Reyataz (Prezcobix and Evotaz).
- Cobicistat is also in the single-tablet regimens (STRs) Stribild and Genvoya; these two medications have already been studied in children and approved for their use.

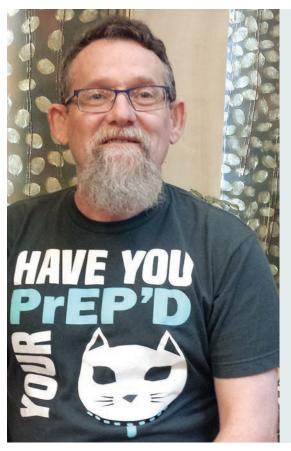
The FDA approved Tybost for pediatric use following new clinical trial data showing safety and efficacy in adolescents aged 12-17. Pediatric approval was made in October.

Children taking Tybost with Prezista must weigh at least 88 pounds (40 kg). Children taking Tybost with Reyataz must weigh at least 77 pounds (35 kg).

READ more about Tybost (and these other medications) in the POSITIVELY AWARE HIV Drug Guide. SEE the FDA update at bit.ly/356Waf9.

TB treatment update

Thanks to new findings in tuberculosis (TB) research,



IN THE CLINIC

There was one guy who came in, and after I spoke with him about PEP [post-exposure prophylaxis], he said very coldly, "I thought it was a pill." Oh, did you think it was like a morning after pill? No, it's two pills every day for one month. He didn't want to do it. I talked with another guy for 20 minutes about PrEP [pre-exposure prophylaxis] and he was very interested. Then his HIV test result came back negative and he said, "Never mind." Maybe what he was really interested in was PEP because he thought he might have been exposed to HIV over the weekend. We know that if you were exposed on Friday, you're not going to test positive on Monday.

-Christopher Reynolds, Community Liaison, ASP Cares, Las Vegas, speaking from the audience at a session on PEP at USCA 2019 in Washington, D.C. in September

SHARE your clinical and medical insights with POSITIVELY AWARE for In the Clinic. EMAIL e.vazquez@tpan.com.

treatment updates for people also living with HIV were made in September.

The new research in TB diagnostics, therapeutics, pharmacology, and drug resistance led to changes in the U.S. HIV guidelines covering opportunistic infections (OIs) in adults and adolescents. Key highlights from the update announcement are below. READ MORE at aidsinfo.nih.gov.

- For people starting HIV therapy who are at high risk for developing TB-associated immune reconstitution inflammatory syndrome (TB-IRIS), preemptive prednisone is recommended as adjunctive therapy.
- The 3HP regimen (weekly isoniazid plus rifapentine for 3 months) for the treatment of latent tuberculosis infection (LTBI) is now recommended as an

- alternative regimen when provided as self-administered therapy or directly observed therapy (DOT).
- Four months of daily rifampin monotherapy is now recommended for the treatment of LTBI in patients who cannot receive isoniazid.
- When dolutegravir (Tivicay, also found in Juluca and Triumeq) is given with concurrent rifampin, it is recommended that the dolutegravir dose be increased to 50 mg twice daily. (Tivicay, which is normally taken as one 50 mg tablet once daily, would be taken twice a day. With Juluca or Triumeg, a 50 mg Tivicay tablet would be added to the daily regimen, ideally 12 hours apart from the Juluca or Triumea dose.)
- Bictegravir (found in Biktarvy) is not recommended to be given with

- rifamycin-containing TB treatment.
- Isoniazid preventive therapy is not recommended for pregnant women until after delivery unless they are close contacts of a known patient with active TB disease.
- Prednisone is no longer recommended for the treatment of TB pericarditis.
- Isoniazid-monoresistant TB should be treated with 6 months of rifampin, pyrazinamide, ethambutol, and either levofloxacin or moviflovacin

Shingles vaccine update

U.S. HIV treatment guidelines in September updated the recommendations on using a vaccine against shingles in people age 50 or older. Healthy adults 50 years and older, including those living with HIV, should get

two doses of Shingrix, separated by 2 to 6 months. You should get Shingrix even if in the past you had shingles, received Zostavax, or are not sure if you had chickenpox. There is no maximum age for getting Shingrix.

Shingles is a painful rash that usually shows up as a stripe around the torso, but can occur anywhere on the body. You cannot get a shingles infection from the Shingrix vaccine.

In addition, the guidelines say that:

- Shingrix is preferred over Zostavax.
- If Shingrix cannot be used because of allergy, intolerance, or unavailability, Zostavax can be taken as one subcutaneous dose (a shot under the skin). Zostavax should not be used by anyone with less than 200 T cells.

Shingles (herpes zoster) is caused by the varicella-zoster virus (VZV). VZV also causes chickenpox (varicella), usually in children and adolescents. VZV is not a sexually transmitted infection.

The section on ocular (eye) complications of VZV has also been expanded.

Shingrix is recombinant (inactive) zoster vaccine, or RZV. Zostavax is zoster vaccine live, or ZVL.

Due to a manufacturing problem, Shingrix is on back order; check with your pharmacy for availability.

GO TO aidsinfo.nih.gov for more information.

8-week Mavyret in cirrhosis

Mavyret can now be taken for just eight weeks by individuals with compensated cirrhosis who are taking hepatitis C therapy for the first time (called "treatment-naïve").

Previously, only treatment-naïve individuals without cirrhosis could use

Mavyret for eight weeks. Those with compensated cirrhosis had to take it for 12 weeks

The FDA approved the new treatment duration in October, reporting that, "Mavyret is now the first eight-week treatment approved for all treatment-naïve adult and pediatric patients ages 12 years and older or weighing at least 45 kg [99 pounds] with HCV genotypes 1-6 both without cirrhosis and with compensated cirrhosis."

Twelve or 16 weeks of Mavyret must still be used by most individuals who had previously taken hep C therapy (called "treatment-experienced").

Mavyret is a combination of glecaprevir and pibrentasvir.

The FDA added new data to the Mayvret label, as well as other information on topics such as liver function and drug interactions. READ the FDA update on its Mavyret changes at bit.ly/2nyFX1w.

Ol updates: histoplasmosis

The U.S. guidelines on opportunistic infections (OIs) in people living with HIV were updated in September regarding histoplasmosis, a lung infection that is caused by fungal spores found in soil or in the droppings of bats and birds.

Medications taken to prevent histoplasmosis should not be discontinued by individuals on anti-HIV treatment until they have achieved at least six months of undetectable viral load with a T cell count greater than 250.

More information has been added on treating people who do not tolerate itraconazole, voriconazole, and posaconazole, which are used to prevent and to treat histoplasmosis. There is also additional discussion of data on measuring the Histoplasma antigen (a substance which shows that the person has been exposed).

GO TO aidsinfo.nih.gov.

Crypto in children living with or exposed to HIV

U.S. pediatric HIV treatment guidelines in August updated the section on cryptosporidiosis ("crypto" for short). No

major changes were made to the diagnosis and treatment of crypto in children living with HIV or those who were exposed to the virus in the womb. But minor changes were made to the information on epidemiology, clinical manifestations, and new diagnostic methodologies. There are also new resources listed for preventive measures. GO TO aidsinfo.nih.gov.

Chicago nurses mark 30 years of HIV care

Chicago Nurses in AIDS Care (CNAC) celebrates its 30th anniversary with a gala, Crimson and Pearls, on Saturday, December 7.

"CNAC is a wonderful organization for all people concerned with HIV to come together and share the depths of their experiences providing care and services to persons living with HIV," said board president Zyra Gordon-Smith.

The association invites all HIV health and service providers, allies, and community members to join in celebrating its milestone anniversary.

Crimson and Pearls starts with cocktails at 6 p.m. and dinner at 7 p.m., followed by commemorative reflection and remembrances. And yes, there will be dancing.

Proceeds support CNAC's mission to continue HIV education, advocacy, and health community networking through monthly programs and volunteer events. Additional proceeds will provide a nursing scholarship to attend the Assoication of Nurses in AIDS Care's national conference. TICKETS are \$100, available through Eventbrite at bit.ly/2klNDT4.



Board members Allison Halverson, Joan Swiatek, and Zyra Gordon-Smith at the ANAC booth for World AIDS Day 2018.

BRIFFLY

U=U: The third U

In an essay for the British Medical Journal, Tamás Bereczky of the European **AIDS Treatment Group** (EATG) notes that the U=U (Undetectable equals Untransmittable) message is hugely important, but not so helpful for those lacking access to care. Read his reminder of a third "U"universal access: bmi.com/ content/366/bmj.l5554.

Published in September, the essay includes suggestions to meet the need for diagnostics and antiviral drugs to promote the benefits of U=U, which means that people living with HIV who have undetectable viral load cannot transmit the virus to others.



Alexandra Billings gets Wicked on Broadway

Alexandra Billings is set to ioin the Broadway show Wicked as Madame Morrible in January, becoming the first openly transgender actress in the role. A veteran performer with roots in Chicago, Billings is also openly living with HIV. She is probably most known for her role as Davina on the Amazon series Transparent. Her last Broadway appearance was in the 2018 comedy The Nap. Read her heartfelt interview with POSITIVELY AWARE editor Jeff Berry in the May+June 2017 issue: positivelyaware.com/articles/ once-again-alexandra-billings.

BRIEFLY EXTRA BY JULIE TADDEO



"LET'S TALK MORE ABOUT THIS, HONEYS": VAN NESS DISCUSSES LIVING WITH HIV, U=U, AND MORE ON JIMMY KIMMEL

Jonathan Van Ness gives HIV stigma a makeover

Jonathan Van Ness, 32, hairdresser, television persona from Netflix's Queer Eye, and author of his recently released memoir, "Over the Top: A Raw Journey to Self Love," has added HIV activist to his lengthy resume. The Quincy, Illinois native has overcome a difficult past of sexual abuse, drug use, sex addiction, and depression to become who he is today.

In a recent op-ed in The New York Times, author and sociologist Celeste Watkins-Hayes of Northwestern University points out that Van Ness' story exposes a larger issue she has observed within her research on women living with HIV: the correlation between victims of sexual abuse and HIV. Hayes points out that assault victims do not typically acquire HIV from the incidents, but rather are more likely to engage in riskier sexual behavior later on in life. She explains how it can destroy one's perception of self and regard for safety. Van Ness' memoir recognizes and promotes the importance of love and self-acceptance. The story is "not going to be pretty," he explains, "but it's my truth and if I don't share it I won't be able to help others."

Since coming out, Van Ness has released a promotional video advocating for Planned Parenthood by encouraging people to get tested for STIs. Motivated to support the organization where he went to get tested seven years ago, he also highlights the importance of Title X, the federal grant program dedicated to providing accessible healthcare and regular STI screening. As a proud "member of the beautiful HIV-positive community," he hopes to combat stigma through education.

Van Ness was undetectable within two weeks after his diagnosis and starting treatment; he takes one pill a day, and continues to live an extraordinary life. He wants people to understand HIV is not what it used to be considered in the past; it is no longer a terminal illness, but a chronic manageable condition.

New effort targets HIV care disparities

The Merck Foundation has launched a \$7 million, fiveyear initiative aimed at improving access to care and health outcomes of people living with HIV in underserved and vulnerable communities in the southeastern U.S.

HIV Care Connect will be implemented in three sites: Care Resource in Miami. Florida: Medical Advocacy and Outreach in Montgomery, Alabama; and the University of Mississippi Medical Center in Jackson, Mississippi. Each location will receive a grant intended to link communitybased programs and promote long-term engagement in HIV care. The program will also encourage private and public partnerships to combat socially determined barriers of health.

The developers hope the initiative will identify plausible practices for improving access to HIV care. LEARN MORE about the program at msdresponsibility.com/accessto-health/key-initiatives/ hiv-care-connect.

Rugby's Gareth Thomas comes out-again

Having come out as gay in 2009, retired British rugby legend Gareth Thomas disclosed in September that he is living with HIV. He said he made the announcement to get in front of media reports that were being used to blackmail him or force him to disclose.

Thomas, 45, experienced depression and thoughts of suicide; he did not want the public to be aware of his status. He initially thought that suicide would be "the easier way out," but has come to realize the importance of confronting his fears. He



said that keeping the secret had been taking a toll on his wellbeing.

Thomas has since chosen to be transparent about living with HIV and said he will focus his efforts on HIV awareness and education to overcome stigma. It's important for someone living with HIV to have a strong support system, he said. He added that although he may be vulnerable, he is not weak.

HIV and heavy drinking

A new study released by Boston University School of Medicine (BUSM) shows a correlation between individuals with untreated HIV who drink heavily (three or more drinks a day for women; four or more a day for men) and harmful immune activity. The study examined three biomarkers which correspond to key immune functions: systemic inflammation (inflammation throughout the body), monocyte activation (fever response), and altered coagulation (blood clotting). Research indicates that raised levels of these responses are associated with an increased risk of

There were 350 participants, 71% of whom were male and the average age was 34. The study participants had little risk of chronic inflammatory diseases (diabetes, obesity, or kidney disease) associated with aging. The study relied

on self-reported alcohol use (collected at three points over two years), along with a blood-based marker called PEth (phosphatidylethanol).

Elevated levels of all three biomarkers were found in individuals with HIV who reported heavy drinking and had higher levels of PEth. It is important to note, however, that the results were observational and the relationship between systemic inflammation and monocyte activation were not linear. The researchers said further research is needed to verify causality. The study was published in PloS One at bit. ly/2m9UgZh.

New initiative for transgender community

Gilead recently established the TRANScend Community Impact Fund to improve the lives of transgender individuals, who acquire HIV at three times the national average.

In 2017, the company pledged \$100 million over 10 years to reduce HIV stigma and address inequalities in the U.S. South, and in 2018 awarded \$17 million in grants that helped fund programs for people living and aging with HIV.

The TRANScend initiative originated from an advisory panel made up of transgender people and leaders of organizations that provide services to people of trans experience. They stressed that they face multiple challenges including spousal abuse, stigma, and inadequate access to healthcare. Because many of these challenges intersect, it is hoped that the grants will help with more than just HIVrelated issues.

Gilead has pledged \$2 million for the initiative and is currently accepting applications from community groups across the U.S.



Second living kidney donation by PLWHIV

Karl Neumann had always considered becoming an organ donor. But the 52-year-old IT coordinator at Sentara Norfolk General Hospital in Virginia gave up hope when he was diagnosed with HIV 11 years ago.

The HIV Organ Policy Equity (HOPE) Act, passed in 2013, allows people living with HIV to donate their organs to recipients also living with HIV. As a result, **Neumann has** become the second successful kidney donor in the U.S. under the HOPE Act. (See "Where There's HOPE" in the January+February issue to read about the first donor, Nina Martinez.)

The procedure took place at Duke Health, the only facility in North Carolina—and only one of five facilities in the U.S. approved for HOPE Act transplants.

There have been more than 140 transplant procedures since 2014 involving organs from deceased donors who had HIV. According to the Organ Procurement and Transplantation Network, as of September 6, 2019 there were 220 people living with HIV who were in need of kidneys, and 16 were in need of a liver transplant.

It is a common and mistaken assumption that people living with HIV cannot be organ donors. Neumann hopes to end this misconception by bringing awareness to his story. If more people living with HIV become aware, they might decide to become donors themselves, increasing the viable options for patients awaiting transplants.

REGISTER through Donate Life America at registerme.org. Look for HOPE in Action studies at clinicaltrials.gov. GO TO hopkinsmedicine.org/transplant/living_donors. EMAIL hopeinaction@jhmi.edu.

Challenges accessing PrEP for HIV prevention in England

BY KIMBERLY LEVITT & LINDSAY TALLON

Access to PrEP is uneven and problematic, and not just in the United States. Although health care in the United Kingdom is administered under a socialized system known as the National Health Service (NHS), PrEP is not currently covered in England. This omission has become the subject of ongoing debate.

Bv 2016, the 5,164 HIV diagnoses in gay and bisexual men living in England represented an 18% decline compared to the 6,286 diagnoses in 2015. With successful integration of pre-exposure prophylaxis (PrEP), HIV infections in England will continue to decrease.

Public Health England (PHE) reports that by combining prevention strategies of condom use, HIV testing, and PrEP optimization, HIV transmission could be eliminated. However, access to PrEP in England has been an ongoing debate recently and improved access is dependent upon sustained efforts from National Health Service England (NHS). From 2012-2014 PHE funded the Pre-exposure Option for Reducing HIV in the UK: Immediate or Deferred (known as PROUD) that

enrolled 544 participants in an open-label randomized trial at 13 sexual health clinics throughout England. Participants were assigned to receive PrEP starting immediately at enrollment or after deferral of one year. Providing PrEP immediately was 86% effective in preventing HIV, which strongly supports the idea of adding PrEP to the standard of prevention care for those at risk. Despite these results, those most at risk remain unable to easily access this intervention in England.

NHS England has argued that it cannot legally commission PrEP because services that prevent the spread of HIV lie with local authorities. However, the High Court ruled that NHS England does have the legal power to commission PrEP. As a result, the HIV PrEP Impact Trial began as a

United Kingdom Drogheda Dublin Open for recruitment: 107 Paused: 28 Closed: 12 Selected: 6

new program within PHE and NHS England. In October 2017, the three-year trial aimed to enroll up to 10,000 participants who are interested in accessing PrEP. Two hundred level 3 GUM (genitourinary medicine) clinics are involved in the trial. The eligibility criteria for the trial includes the following: 16 years or older, cis- and transgender men who have sex with men (MSM), transgender women who are HIV negative and report sex without condoms in the past three months, HIV-negative partners of an HIV-positive person when the positive partner is not known to be virally suppressed and sex without condoms is anticipated, or heterosexual people at high risk.

In January 2018, more than 3,200 participants had enrolled across England. Will Nutland, founder of PrEPster, believes that placing cap numbers on clinics made it

difficult for eligible people to enroll. Plus, individuals with the highest levels of HIV and PrEP literacy are usually the ones who seek access to the trial. Nutland also stated that he does not want to see the trial end because if it does, the NHS could stop distributing PrEP altogether. One of the most visited sexual health clinics in London, 56 Dean Street in the city's Soho neighborhood, filled its allocation of 1,700 places in just weeks, and the Colchester Sexual Health clinic in East England also filled its allocation quickly. Therefore, NHS England allotted additional spaces and sites that are in demand. As of June 2019, the trial expected to have recruited just over 13,000 participants. 147 clinics are open to recruitment. of which 109 clinics are open to MSM recruitment. While there are still many sites open for recruitment, the sites are

Disparities here and abroad

THE U.S SAW a less substantial decrease in HIV diagnoses. According to Centers for Disease Control and Prevention (CDC), 26,570 gay and bisexual men were diagnosed with HIV in 2016, which represents only a 1% decline from the 26,950 diagnoses in 2015. Despite the decrease in diagnoses in both England and the U.S, accessibility to proper medication remains an issue in each country.

Findings suggest that there may be a correlation between access to PrEP and wealth distribution within the U.S. The CDC data shows that HIV diagnoses are not evenly distributed geographically. The South continues to have the leading rate of HIV diagnoses per 100, 000 people (16.8), followed by the Northeast (11.2), the West (10.2), and the Midwest (7.5). The South was not only reported to have the lowest median annual income, but over 50% of new HIV diagnoses occurred within the region, and only 30% of PrEP users reported to live there. —JULIE TADDEO

Acupuncture and long-term survivors

BY ELIZABETH SOMMERS, PhD, MPH, LAC

not evenly distributed geographically across England. The distribution of clinics poses an issue for people at risk for HIV who may require long journeys to one of the openly recruiting clinics. For example, there are no sites in or around Cambridge recruiting MSM, and sites are not open yet outside Birmingham.

The Impact Trial was intended to answer questions about the use of PrEP in England, and ultimately its goal was to ensure that those who want to access PrEP are able to do so without difficulty. However, many of those who are at highest risk for contracting HIV are still not able to access PrEP due to the constraints of the trial.

LEARN MORE about how to access PrEP in the U.K.: aidsmap.com/about-hiv/ how-get-prep-uk.

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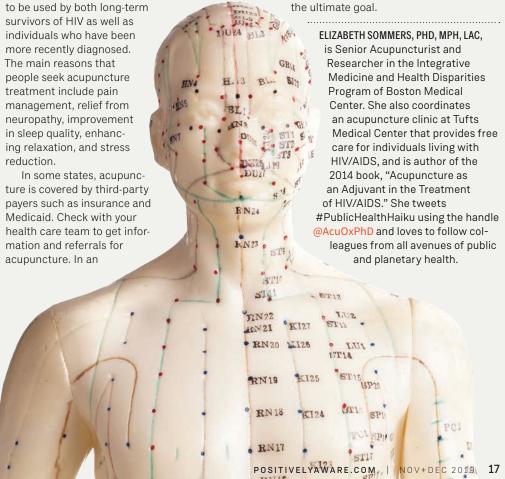
cupuncture has been used throughout the HIV epidemic to address physical symptoms and to promote relaxation. Before the advent of AZT and monotherapy, acupuncture was one of a few approaches that could offer symptom relief and palliative care. Monotherapy brought improved health outcomes for individuals diagnosed with HIV but was often associated with intense side effects. Acupuncture offered relief from a variety of digestive symptoms such as nausea, vomiting, loss of appetite, and an unpleasant change in taste.

Although acupuncture is not a cure for HIV, acupuncture treatment has helped improve quality of life for many people living with HIV. There were acupuncture treatment clinics in various cities in the U.S., including Chicken Soup Clinic in San Francisco and the AIDS Care Project in Boston. Individuals sought relief from pain, management of digestive side effects, alleviation of anxiety and depression, and improvements in sleep. Women have used acupuncture to address painful or absent menstrual periods. For individuals in recovery from substance use, acupuncture has been effective in reducing cravings and promoting recovery.

Today, acupuncture continues

attempt to improve access to acupuncture, some cities offer community acupuncture, which is a kind of group-style treatment. The People's Organization of Community Acupuncture (POCA) offers an online clinic finder: pocacoop.com/clinics.

Acupuncture can promote wellness and manage a variety of symptoms safely and effectively. Many individuals prefer to integrate acupuncture into their care because it is a form of drug-free treatment. Use of acupuncture in conjunction with HIV medication is also safe, and some studies indicate that acupuncture may be a factor in improving adherence to medication regimens. Optimizing the health and wellbeing of all people living with HIV is the ultimate goal.



THE FUTURE IS ALREADY

Technological advances in HIV treatment and prevention

BY MICHELLE SIMEK

"I'm always amazed by how modern medicine is advancing in treating HIV. And I'm very fortunate to live in an era in which I can be a person living with HIV long-term and still be able to live a long and healthy life."

-Josué E. Hernández

IV TREATMENT has certainly evolved since the early days of the epidemic. In the 1980s and '90s people living with HIV/AIDS (PLWHA) were taking multiple pills, two or three or even four times a day. These regimens came with complicated food restrictions and horrible side effects. Excruciating peripheral neuropathy. Dangerously elevated triglyceride levels. Uncontrollable diarrhea. Vomiting. Lipodystrophy that caused facial wasting and belly protrusions and "buffalo humps"—all of which took their toll physically and emotionally.

Once protease inhibitors (PIs) were approved in the mid- to late '90s, and Norvir (ritonavir) was approved as a PI booster at only 100 milligrams per day, many PLWHAs were able to scale down

their regimens to five pills per day. Many of the terrible side effects diminished or went away completely. In 2006, the FDA approved the first one-pill, once-a-day medication, Atripla, And Truvada—a combination of two medications (tenofovir DF and emtricitabine) in one that for years was used as the backbone in most regimens to treat HIV—was approved in 2012 for PrEP.

We've come a long way since the toxic monotherapy of AZT, and HIV treatment is much easier than it used to be, but... what if it could be even easier and there were more treatment options? Get ready, because monthly injections and implants are on the way along with some intriguing new prevention methods. All thanks to technology that almost seems like science fiction.

INJECTABLE HIV TREATMENT

Hit me with your best shot

IN 2019, there are currently 13 single-tablet regimens (STRs) in the U.S. market, of which six contain an integrase inhibitor. Each contains two to four HIV medications (the fourth being a booster such as ritonavir or cobicistat). STRs are much easier than taking 10 or 20 or even five pills daily. But many PLWHA (especially those who were diagnosed in the 1980s and '90s) experience "pill fatigue." Plain and simple, they are sick and tired of taking pills every day year after year and being told they would have to take them every day for the rest of their lives. Also, newly diagnosed and otherwise healthy PLWHAs have to adjust to the new routine of taking a daily medication, which can be a huge challenge. But a possible solution may be coming.

It's expected that the U.S. Food and Drug Administration (FDA) will approve the first longacting injectable form of HIV combination therapy before the end of 2019. "The first two drugs that are coming are injectable long-acting cabotegravir (an integrase inhibitor) and injectable long-acting rilpivirine (a non-nucleoside reverse transcriptase inhibitor)," said Dr. Judith S. Currier, UCLA Center for Clinical AIDS Research and Education (CARE). "I think this is a big deal and an important milestone in HIV therapy."

Once approved by the FDA, the drug will be given orally for a short time to make sure patients can tolerate the medication and that there are no serious side effects. If all goes well, patients would be switched to monthly injectable therapy. Shots would be given in the butt (a shot in

each cheek); patients would have to go to their doctor's office or clinic to receive the injections (no self injections at home). Patients (hopefully with help from their clinic or ASO) would have to remember—and be willing and able—to go to their medical provider monthly, which could be difficult for some, especially people living in rural areas or those who have competing priorities, like childcare, eldercare, complicated work schedules, mental health issues, or other physical problems.

"It is very exciting to have injectable treatment options so close to being available in the clinic," said Dr. Currier. "I suspect that the initial approval will be for people who are already suppressed and possibly for people who are starting treatment. There are many people who are suppressed who don't like taking pills for whom this will be a great option, but it will likely require visits to the clinic every month, for people who currently only come in twice a year. It is critical that we learn how to use long-acting injectable treatment for those who have not been suppressed. I have heard from many PLWHAs who have not been able to remain suppressed, that the daily pill-taking ritual is a psychological barrier to adherence—a daily reminder of HIV. If we can demonstrate that long-acting injectable treatment will overcome this barrier, it will be a major advance.

"Also, long-acting treatment with cabotegravir and raltegravir is currently being studied in ACTG 5359, the LATITUDE study," Currier added. "This study is designed for people who have not been successful in staying virally suppressed. ACTG sites around the United States are actively recruiting for this trial now. More information about the LATITUDE trial can be found at actgnetwork. org/study/a5359-latitude-study.

Currently, two injectable drugs are given monthly, but there is some emerging evidence that they may be able to be given every two months. Ultimately we hope that we can develop agents that will last even longer."

A few people from southern California living with HIV were asked for this article if they would switch to this new kind of treatment. Here's what they had to say:

"The news about the first HIV injectable medication sounds exciting-and, even convenient," said Josué E. Hernández, "But, my experience has been negative in trying new HIV medications when they first come out on the market. Some of the negative side effects I've had include getting a rash all over my body with one medication and getting blisters on my hands with another medication. As a result, I think I would rather wait and see how the general population reacts to the new HIV injectable medication before I consider giving it a try."

In a follow-up question that included information about the oral lead-in period, Hernández added, "I would be open to trying the pill form first to test for side effects. But I am not thrilled about going to my doctor or a pharmacy to get the injection. Because I've been on treatment and undetectable for nearly 11 years, I only see my doctor every six months. And I get my medication sent in the mail. Ideally, I would prefer to administer the injectable myself, like people who are living with diabetes."

"As someone living with HIV, I would not be willing to change my current daily pill regimen for this new process," said Dontá





Morrison. "Reason being is that [my body] has become accustomed to what I am on, and I do not want to risk shifting any of the positive strides I have made. Also, the thought of an injection is too extreme. What if something goes wrong? Unlike traditional medications, it won't flush out of the system as easily. For me, it feels too invasive. But I have also been living with the virus since 1999, and my thoughts on treatment may be a bit antiquated." Asked about an oral lead-in to the injectable, Morrison added, "That would make a huge difference. Yes... I'd be more willing to try."

"After nearly a decade of taking Atripla, I chose to transition to a two-pill, once-a-day regimen," said Carlos Cuauhtémoc Aguas-Pinzón. "As a treatment educator, I did some research and asked a few providers, including my own, to find the best fit for me. I've been on my current regimen— DTG, FTC/TAF [Tivicay plus Descovy]—for 18 months and am extremely pleased with how it's working. The pills are conveniently small and I can fit a couple doses in a discreet pill keychain. However, I've sometimes reached for my meds and realize I only

have one of the two pills. As far as an injectable, I've been waiting for it since it was mentioned at a conference several years ago. I kept my eye out for the trials but was not able to find one to enroll in. Now that it'll be available soon, I am very interested to talk to my provider about switching regimens. It's going to depend on copay, convenience, side effects, and frequency. I spoke with a couple of my treatment education clients about it, and both were enthusiastic about the possibility. We all concluded that 12 injections are better than 365 pills a they're on single tablet en ir regimens). I really hope that HIV medical clinics take note of the rates of viral suppression among their patients, especially those with

"I've had HIV since 1995, and I'm so damn tired and have been so damn tired of taking these damn pills, I'd try the shots!" said Sylvia Jones. "To hear about this-it's exciting for me."

inconsistent treatment

adherence."





IMPLANTS

Not just for cosmetic surgery anymore

RESEARCHERS ARE ALSO working on HIV treatment implants. These devices would be about the size of a matchstick that would slowly and consistently release HIV medication, but then be replaced after treatment has run out. Medication implants are curyear (730 pills for road Ination to use o ase sattwo was ge

as birth control (Nexplanon) for women, implanted in the upper arm, and as testosterone (hormone replacement therapy) for both men and women, implanted in the butt cheek. Again, these implants are removed and replaced when the medication has been completely dispensed, or if the patient wants it removed. Both insertion and removal need to be done in a clinic or doctor's office by a medical professional, and require a small incision. Researchers are also studying implants that would completely dissolve in the body once all the medication has been dispensed.

Looking ahead to an implant, it would contain a complete treatment regimen so patients would not have to take any pills. "Implant technology is continuing to advance, and this may be another option for the delivery of long-acting ART," said Dr. Currier. "As these studies are less further along, we hope to see more clinical studies of these agents coming soon. The benefit here would be that the implant could be removed if there was an adverse event. or if a change in treatment was needed."

MK-8591, an investigational nucleoside reverse transcriptase translocation inhibitor (NRTTI, a potential new HIV drug class) being developed by Merck, is one of the experimental drugs being studied as a possible implant. Data from a small Phase II study (in combination with other HIV medications) were presented in July at the International AIDS Society (IAS) Conference on HIV Science in Mexico City. Researchers reported that after 24 weeks, all study participants remained undetectable; research is ongoing.

We really don't know how long these implants will last in the body. PLWHA could potentially go two years without needing to remove or replace treatment implants. How amazing! But the entire care team—PLWHA. doctors, case managers, and others—would have to prepare to face a new set of potential adherence challenges. What if someone moves or becomes incarcerated? Or relapses? Or becomes homeless? HIV professionals will have to stay in close, continuous contact, and be ready, willing, and able to track them down before the implant expires. Implants can only last so long, and everyone including the patient—will have to plan ahead.



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11 think telemedicine holds great promise for managing monitoring for [people living with HIV/AIDS], especially those who live in rural areas without access to HIV specialists.'

WOMEN AND HIV PREVENTION

Girl Power

THANKS TO Truvada for PrEP, there's been a decline in HIV infections, particularly among white MSMs. Women, however, are taking PrEP at much lower rates than men. This is because of a variety of reasons: insufficient prevention education, reduced access, and less outreach to women vulnerable to HIV infection. amfAR reports that, in 2018, women accounted for 52% of all adults worldwide living with HIV. A womencentered HIV prevention modality is urgently needed. Enter vaginal rings.

NuvaRing is an FDA-approved method of birth control that is inserted into the vagina and replaced every 30 days. The patient can insert and replace the ring herself. NuvaRing releases two different hormones that prevent pregnancy, and gives women tremendous power to control their reproductive rights without the knowledge of their sexual partners. What if we take what we know about NuvaRing and use something akin to it to prevent HIV?

HIV activists around the world are hopeful that 2020 will finally be the year that the first vaginal ring for HIV prevention, containing dapivirine, an experimental non-nucleoside reverse transcriptase inhibitor, is approved for use by FDA. If—or, when—that happens, it has the potential to be a game changer. A dapivirine ring has been in development for years, but it wasn't until the 2019 Conference on Retroviruses and Opportunistic Infections (CROI) that encouraging data were seen (dapivirine has never been studied as an oral medication). Results from two Phase III studies-HOPE and ASPIRE-conducted in several African countries showed that the ring is safe and reduced HIV infection by 27-31%. Approximately 2,600 HIV-negative women in Malawi, Uganda, South Africa, and Zimbabwe took part in the studies. For reasons unknown (but quite possibly due to adherence), the ring's effectiveness was directly associated with the age of study participants. The ring was 0% effective for African women aged 18-21. But efficacy rates rose to 56% for women aged 22-26, and up to 51% for women 27 years and older. Further analysis of ASPIRE and HOPE studies was released at IAS 2019. Deeper analysis showed that women who used the ring regularly had a 65% lower risk of HIV. And efficacy may have as been high as 90% for women with total or near total adherence to the ring.

TELEMEDICINE

It's not dial-up

MANY (THOUGH NOT ALL) people living with HIV who are on treatment have access to their HIV doctors via the internet, especially if they receive their care at a large clinic (such as Kaiser Permanente or a university-based clinic). These clinics offer patient portals where patients can review lab results and other test results such as x-rays or biopsies, ask their doctors nonurgent questions, and request medication refills. It is a great option that certainly is better than waiting around for your doctor to call you back—when your cell phone battery has died, your voicemail is full, or you have no signal (we've all been there). What's the next step? Telemedicine!

Some general medicine clinics are using special software to conduct doctor visits online. This operates like Skype or Apple's FaceTime, but has a much higher level of security protection and is HIPAA compliant. Telemedicine doesn't replace an actual physical exam, but could be a great way to discuss results and address questions and concerns.

"I think telemedicine holds great promise for managing monitoring for PLWHA, especially those who live in rural areas without access to HIV specialists," said Dr. Currier. "The option for video visits is also becoming available at some sites. The willingness of insurance payers to reimburse for these services will be the key driver of whether this practice takes off."

Telemedicine also has the potential to assist incarcerated PLWHA with their HIV care. Another study presented at IAS 2019 focused on the use of telemedicine in Pennsylvania's Department of Corrections (PADOC). The Pennsylvania prison system recently changed its approach to HIV treatment.

PADOC had previously worked with an in-house infectious disease (ID) program. In 2015, they contracted with a university medical center to create an interdisciplinary team consisting of an ID doctor, nurse practitioner, and ID pharmacist. Using this new model, a retrospective study showed that out of the 227 patients who were involved, approximately 90% got their viral load down to undetectable, and most saw their T cells increase by an average of 40. The telemedicine team also worked with PADOC to help 28 incarcerated patients decrease their pill burden. This meant that 28 incarcerated PLWHA who were previously taking four pills a day to treat their HIV were switched to an STR.

Telemedicine can also be used to assist with PrEP prescriptions via a new platform called MISTR. Available in 44 states at last count. it is accessible on smartphones. tablets, and computers. MISTR allows users to have a video consultation with an HIV doctor (the out-of-pocket fee for potential PrEP patients is \$99), do needle-free lab work at home, and have their PrEP delivered free of charge. The program handles all of the paperwork necessary for patients to receive PrEP co-pay assistance, and also works with insurance plans. Given its name, MISTR's current focus is on MSM, but it plans to also launch a female-focused platform.

identify people who have been treated for an STI, and that can help lead to a discussion about the possible use of PrEP.'

ELECTRONIC HEALTH RECORDS

A potential prevention method

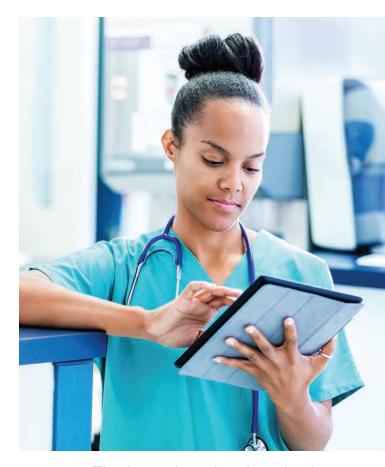
MOST MEDICAL CLINICS

and private practices have switched from paper charts to electronic health records (EHR). EHR is easy for all of your health care providers to access, and saves paper records from damage by fire, flood, earthquake, and other disasters while being more environmentally friendly. EHR can also be sent easily to a new doctor if you change providers or clinics. But are we using EHR to its full potential? Yet another study out of IAS 2019 doesn't think so.

A study conducted by Kaiser Permanente in northern California tried to predict HIV rates by reviewing the EHRs of approximately 3.7 million Kaiser members. Patients who were HIV-positive were excluded, as were straight men and MSM who had not been treated for STIs. The study was able

to predict HIV infections in 784 people. The next step for researchers will be to evaluate EHR-based risk prediction tools and measure their effect on PrEP prescriptions.

"As we work to expand PrEP to those at risk for HIV, finding ways to identify people at risk is critical," said Dr. Currier. "An electronic health record can help providers identify people who have been treated for an STI, and that can help lead to a discussion about the possible use of PrEP. Electronic health records are currently used to remind [health care] providers about the need for specific tests and health maintenance. While many providers complain about some of the burdens of EHR. the ability of these kinds of systems to help us improve care are of great value."



YOUR DATA

HIV surveillance and privacy

Data privacy—who has access to your personal information and how it is being used—is an issue in social media, and it's also drawing growing concern for people living with HIV. The Centers for Disease Control and Prevention (CDC) is examining data from people who are newly diagnosed, without their consent, on the genetic makeup of their HIV. While this data can be used to identify "clusters" of new cases, it raises concerns among advocates.

The Center for HIV Law and Policy (CHLP) in September issued a two-page factsheet, "Is Molecular HIV Surveillance Worth the Risk?" In a factsheet from the CDC, HIV molecular surveillance is described as "the collection, reporting, and analysis of HIV genetic sequences generated through HIV drug resistance testing." CDC said it uses the information to look for outbreaks. CHLP noted that the CDC has asked local and state health departments to gather community feedback by December. The center organized a webinar on the topic in October. While CDC says health departments do not report names, CHLP raises questions about potential problems such as using surveillance information in HIV criminalization. READ a blog post on this topic by CHLP staff attorney Jacob Schneider at bit.ly/2moMY45; the flyer can be found at bit.ly/2kroK8L. READ the CDC factsheet at bit.ly/2mpwrgj. GO TO hivlawandpolicy.org. —JULIE TADDEO

The future has already arrived

Technology is astonishing. Our smartphones are entire computers that we carry in our purses or back pockets. We can communicate with loved ones around the world with the push of a button. Breaking news isn't hours old—it's minutes or seconds. And technology is helping combat HIV/ AIDS with new potential treatment and prevention advances. Once approved, injectable and implantable treatments will provide more options for patients so that treatment can be customized to meet their individual needs. The addition of a female-controlled prevention tool (like a vaginal ring) will empower women while protecting them from HIV. More targeted use of EHR has the potential to identify those most vulnerable to acquiring HIV and help them access PrEP. All of this thanks to the targeted use of technology. No need to check the date—the future is already here. PA

MICHELLE SIMEK has worked in HIV/AIDS for more than 20 years. She currently works at the UCLA Center for Clinical AIDS Research and Education (CARE) and is a popular HIV/AIDS presenter, both locally and nationally. In her downtime, she is an avid reader and concert goer and proud mom of Baxter, her five-year-old rescue cat.

The United States Conference on AIDS (USCA) took place September 5–8 in Washington, D.C. The long-standing annual community-oriented event brought together people living with HIV and their allies as well as health care and service providers. USCA is organized by NMAC (formerly the National Minority AIDS Council), a Washington, D.C.-based organization that "leads with race to urgently fight for health equity and racial justice to end the HIV epidemic in America." Go to 2019usca.org.



Activists halt conference to protest CDC

He surely saw it coming. Dr. Robert Redfield, the Director of the Centers for Disease Control and Prevention (CDC) was speaking at the opening plenary. Protests are part of the DNA of the United States Conference on AIDS (USCA), and conference organizers have never shied from welcoming dissent from activists. In fact, they schedule time in their finely produced event for just such occasions.

Still, when a large group of diverse activists stormed the stage during the opening plenary on Thursday, their sheer number was impressive, as was their considerable list of grievances against the CDC and, in sometimes very direct and personal terms, against CDC Director Redfield himself.

God, I love a good protest. This one gets high marks. The speakers were passionate, concise, and withering in their takedowns of everything from the erasure of transgender women from epidemiological data to the ongoing controversy over Truvada pricing and patents to the quite troubling new policy of testing HIV genetics in a way that links

transmissions to individuals, known as "molecular HIV surveillance."

As the activists laid out their cases to a cheering crowd in the massive ballroom, plenary host Joy Reid of MSNBC and Director Redfield remained in their places on stage, joined by conference organizer Paul Kawata of NMAC, as if he were offering assurance and moral support to both the activists and his slightly stunned plenary guests.

Once the protest was complete, Reid assured the conference attendees that Redfield would be meeting with a select group of the activists to have a calmer conversation.

I joined them for that meeting, a group

of a dozen or so, and although we agreed the meeting would stay off the record, I can report that each of the major issues outlined during the protest were revisited with Redfield. Some items, such as the battle over patent royalties from Gilead's PrEP drug Truvada, are things Redfield cannot discuss due to litigation, which he has stated publicly.

Most reassuring to me was that, even after the drama of the protest, Redfield was receptive, and agreed to have future meetings with various activists to address their concerns in more detail.

Act up. Fight back. Fight AIDS.

WATCH VIDEO OF THE PROTEST: marksking. com/my-fabulous-disease/activists-haltu-s-conference-on-aids-to-protest-cdc

Reprinted with permission by Mark S. King from his blog, My Fabulous Disease, at marksking.com.

Don't call it PrEP

Lessons learned from D.C.'s PrEP for Women Initiative

COMPILED BY ENID VÁZQUEZ

he PrEP for Women Initiative is a public-private partnership between the Washington AIDS Partnership and the D.C. Department of Health's HIV/ AIDS, Hepatitis, STD, and TB Administration (HAHSTA). The initiative aims to increase uptake of PrEP (HIV prevention pill) among women of color through grantmaking which supports integration of PrEP into existing medical services; PrEP and sexual health outreach, education, and training in the community and for community-based organizations and health providers; and a social marketing campaign. The workshop featured a panel of representatives from three communitybased organizations funded by the initiative. Participants discussed their firsthand experiences building PrEP programs, including successes and challenges at the patient and organizational levels, and how those have informed their current work. Following is some of what they had to say.

Don't call it PrEPsay what?

In creating educational programs for women, it was better to begin with sexual health or other health concerns before easing into PrEP.

Telling women they needed PrEP was—in a nutshell stigmatizing, the presenters agreed. And so did people in the audience.

Ashlee Wimberly, the Washington AIDS Partnership (lead presenter):

The women ask, "Why are you pushing this on me?" PrEP is stigmatized. So you have to be careful about how you approach people. [Speaking in an upbeat voice] "PrEP is for everyone!"

Diane Jones, LICSW, Family and Medical Counseling Service, Washington, D.C.: So don't say PrEP, because it's [seen as] only for women who need this thing. It's stigmatizing. Now we don't

Rachel Browning, MPH. Planned Parenthood of Metropolitan Washington:

call it the PrEP talk.

We don't talk about statistics in a community setting [to help the women understand their vulnerabilities]. It's not helpful. It's stigmatizing. Let's not make it a statistics game. Let's have human interactions.

AW: How do we raise awareness that this is even available? How do we bring it up in discussions around sex so patients don't feel stigmatized?

DJ: We started with some invitation dinners and then threw in PrEP. They could have stayed for hours they're still talking about it. It naturally happens if you just set it up.

Don't assume that people have the basic information, the HIV 101, because there are a lot of misconceptions out there.

Our first event was a town hall meeting. We had a well-known local personality hosting. We had an expert in from Atlanta. We had gift baskets.

A woman in the audience asked, "How are you able to provide gifts? We can't with our funders." Jones said they found funders who would cover the costs.

AW: Our retreats included 10-minute chair massages. Listen, if you have one of these [holding up what looked like a lipstick but was actually a vibrator], you can have a conversation. [She flipped a switch and the audience heard a buzzing sound.]

RB: The one thing I wish we had was a patient advocate to come with us and speak

DJ: I think the patient advocate model is the best model.

Again, let's put the power of pleasure in the woman's hands. We don't have the luxury of being late on any innovation.

About the providers

AW: It's not enough just to educate about PrEP. Because if you educate women and they go to their doctor and their doctor says, "Oh, that's not for you," it doesn't work. We have to reach out to providers as well.

RB: Training staff was actually the biggest challenge. The fear of not being able to answer every question hurt them from hitting the ground running. They worried about oddball questions—like explaining the 2% side effects seen.

AW: I agree. Primary care providers think PrEP needs to be done by a specialist.

RB: Our key is "just do it." We've got training fatigue. We just had to rip off the Band-Aid. It takes a while. It takes services and training to get providers [knowledgeable about PrEP services]. It takes money. We now have a welloiled PrEP machine.

David Cornell, MBA, DNP, FNP, AAHIVS, Mary's Center:

Three years ago, when our PrEP program started, our providers knew nothing about it. Our staff knew nothing about it. Now, our CEO says, "If you're not going to provide PrEP, you're not going to be working here much longer."

AW: We need top-down pressure for PrEP in our organizations. If you're not there yet, find champions within your organization to advocate for it.

RB: We're doing everyone a disservice if we don't offer patients PrEP and PEP.

DJ: We were seeing hundreds of women, and I agree it's a disservice if we don't provide it.

A black woman from New York City in the audience said, "Providers say, 'Oh, you don't need it.' How did you get providers to that point?" [Other members of the audience said they experienced the same thing in their location.]

AW: Say "harm reduction." It's non-siloing as well—take things out of their separate categories. Connect sexual health with overall health.

DC: About 30% of our population is immigrant. How do you talk to them about PrEP when vou don't talk to them about sex? Then we saw a map of hot zones. Should we bring it up around birth control and prevention?

RB: There can be too many lavers. Be careful.

DC: We now send them to a PrEP navigator.

DJ: We started with treatment facilities. The providers were saying, "you don't need PrEP." So this year we funded Lunch & Learn. One nurse who attended got on PrEP, so don't assume who should be on it. [There was audible agreement from the audience.] Put it in everything you do. Everyone should be talking about PrEP.

Black and Latino queer men and pleasure

Choosing power over stigma BY ENID VÁZQUEZ



"There is a social death that happens every time I walk into a room. I feel like I have to prove myself."
—RICHARD HUTCHINSON, JR. YOUNG. BLACK. QUEER. BRILLIANT.

utchinson, from Atlanta, brought together a small group of young black and Latino queer men who, like him, worked in HIV services. They talked about the problems they saw in those places providing services, focusing on the treatment of young men who currently or previously engaged in sex work.

"Some of our community workers have to do survival sex to make ends meet. We want to end the shame around this," said Hutchinson. "Sex work is real work."

Cody López,
Founder and Director
of the Community
Cares Project in
Baltimore, said
young men are often
automatically labeled
homeless if they indicate that they have
engaged in sexual
services for resources.
This was part of the
stigma.

"This is not something they should be ashamed of doing," said López. "A lot of guys enjoy survival sex. They can make a lot of money."

Hutchinson noted that the situation is complicated, "We know about social determinants of health. Young black and Latino men—we know the vulnerability."

From the audience, nurse Brenice Duroseau, APRN, of Stamford Health in Connecticut, gently said she sees women engaging in sex work when they don't want to. "I don't address it as a choice," she told the panel.

"You're saying things a lot of people in the room are probably thinking," Hutchinson responded. "It comes back to the tone. We just want to be wholistic. addressing mind, body, and soul."

He noted the judgmental tone taken by some agency personnel: "Oh, we know what you do already." Or, "Why are you doing this?"

If individuals are instead treated with acceptance, in a sex-positive way, they can pour out their concerns, he said. "Then we can give them resources. There are psychological aspects to having sex and we should deal with that. If we judge them, they turn away and we've left them without resources."

HIV services, he finds, tend to address behaviors and not the whole situation.

"It's challenging," agreed JT Williams, from the LGBT Life Center in Norfolk, Virginia. "Know individuals in other agencies so you do a warm hand-off. 'Oh, this is my girl Jean I'm sending you to. She's going to treat you like a person.' "

"We're trying to destigmatize transactional sex," said López. "Just because someone trades something for sex, we shouldn't stigmatize them."

"We want to support that person to get what they need, if they're doing it in a way they don't want to do it," said a man in the audience.

Said Williams, "People say, 'We like y'all. You don't judge me. You don't make me feel bad.'"

Difficult services

There are other problems with HIV services, the panelists pointed out

Richard Hutchinson, Jr.: Getting people on PrEP and getting people to undetectable is the goal. But you can talk to people about PrEP until you're blue in the face, and if they don't feel their power or that they're valued, what's the point of it?

And collaboration never happens.

Cody López: Instead of giving money to the large ASOs [AIDS service organizations] to work with the community folks, just give it to the community folks. Not just a oneoff stipend. No, let us do the work with our people in our community.

What about people who are on the ground engaging people in the community and aren't concerned about getting people tested? We need to invest in those people.

Hutchinson: The community can do the work, but the community needs to build the skills they have.

JT Williams: We do all this work. But who's going to get the money?

What are you going to offer someone besides having them sit there for two or three hours and then telling them, "Okay, you need this and this and this." And then

You can burn your bridges by burning the community. The system really burns a lot of people. Saying "we're going to do this" but not following through.

When you burn people out instead of empowering them, you lose them.

Hutchinson: You want someone to engage you as a human being. We are not target populations. We are not targets. No, you are engaging me in a conversation. With targets, you are othering us.

López: We don't talk about breaking down the HIV system and starting over. We need to break down the system.

Williams: I would challenge you to hold your CBOs [community-based organizations] accountable. Who's on your board—are they representative of the people served?

You also need to empower your staff because your staff is part of the community. Like having to work Pride and then they can't enjoy it.

And they think all gay men know all gay men.

Hutchinson: We all deserve to be treated individually. That is traumatizing to that staff, instead of empowering that person to empower others in the community and bring them in.

We don't lead with HIV. Black gay and queer people want to talk about HIV because it's important. So people bring HIV up anyway.

López: How do you do this work when you come up positive? And then you have to navigate services.

An audience member asked about improving retention

Hutchinson: They're coming because they feel enriched by the conversation and they want to come away with something.

Williams: People who stop coming—we know about the stages of change. People can move from contemplation back to pre-contemplation. Understand their motivation.

Jorian Rivera: Send them a personal message. "Hey, thank you for coming. Hope to see you at our next event. This is the date."

We are all living with HIV, but a person living with HIV is living with it in a different

Other audience input

"Why are there 55 questions on an HIV test?"

"At our place, every last Tuesday is Taco Tuesday. We don't talk about anything. People get tired of hearing about HIV everywhere they go." (Audience members snap their fingers in agreement.)

"I've worked in organizations where we don't get funding to do anything if we don't do testing. Everyone doesn't appreciate you coming at them with a needle every time they come in your door."

He prefers the term "transactional sex" because not all sex work is based on survival needs.

Jorian Rivera, an HIV health navigator with Galaei in Philadelphia, asked, "Where is your mental capacity?" He was referring to psychological reasons for

engaging in sex work besides financial gain. He pointed out that sex is not just sexual. "It's also an image. Like burlesque."

Latinos who are undocumented are concerned about coming in for services, he said. "They take your information and can report it."

"We worked at organizations and that's why we know what needs to be changed," said Hutchinson. "We don't refer to anyone as a client. Everyone is a member. That means they are a stakeholder. CBOs (community-based organizations)—calling people a patient, you've already

established a power dvnamic.

"So let's be intentional about language. You are not just a client. You are not just a patient. You are a stakeholder. The dollars don't flow unless you come in here, so you have a stake," Hutchinson said.

"It's 2019," said López. "We've got to do better."

And, he added, hire transwomen of color. to which the audience signaled their approval with snaps of their fingers.

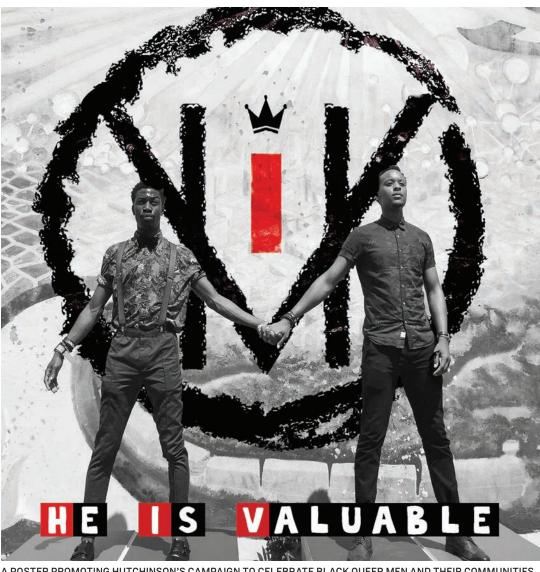
What the panelists see is a disconnect between service providers and young men seeking services. Too often, the youth are treated like a number instead of a person. The audience talked about all the boxes that need to be checked off for services-over and over.

Hutchinson said that as a provider, he understands the importance of collecting statistics. But it sometimes comes at the expense of the human touch.

"The tone is important. You want someone to engage you as a human being. 'Hey, how are you doing?' Not just hand them a bag of lube," said Hutchinson. "I can't tell you how just by me smiling at them and asking them how they are doing has changed the whole trajectory of that meeting. We can't just be focused on those numbers. We are not target populations. We are people first."

Added Rivera: "Use their name, have a conversation. Let them feel that they have the power to change their circumstances."

"We need to check our own biases," said Hutchinson. "If they check a box 'yes, I had sex for resources,' we have



A POSTER PROMOTING HUTCHINSON'S CAMPAIGN TO CELEBRATE BLACK QUEER MEN AND THEIR COMMUNITIES.

bias. We need to throw that out. People are being re-traumatized as they seek services."

Instead, said Hutchinson. "When someone knows they have worth and power, they can do anything. If you work with people just because you have funding to serve young black men, that's not empowering."

"Life is about people needing people," Williams said. "If you slept with 10 people, not 'Oh, my God!' No, you're a 'healthy sexual.' [Williams helped create the Healthysexual campaign.] 'Oh, you sucked 10 people. How did you like it? How can we help you do it better next time?' We wonder why people come back and test positive. I can tell you what happened. You looked at a list [at intake] instead of the person."

"The connotation around survival sex is that we have trouble talking about sex," he noted. "'Oh, no. First you're talking about sex and now you're selling sex?! We can't talk about that."

Said Hutchinson, "Our work is not about the science. Our work is about the people. To see that you are valuable and that you have the power to help yourself."

López's organization focuses on improving the socioeconomic status of LGBTQ individuals to improve their health. "We need access to higher education and

access to better job opportunities for young black queer men—for everyone. I really think a college education should be free for everyone."

Like López, Hutchinson founded his own organization. He describes his group, which he serves as executive director, as "a social movement that aims to identify, reinforce, and celebrate the value of Black Queer men and their communities." The name? He Is Valuable.

Richard Hutchinson, Jr. and Coronado "Cody López" Dyer are available as trainers on establishing collaborations. EMAIL heisvaluable1in2@ gmail.com and cdyer@ theccpbmore.org.

Overheard at USCA

"SOMETIMES YOUR authenticity is your activism. Being yourself can be a radical act."

-Flaine Welteroth author of More Than Enough: Claiming Space for Who You Are (No Matter What They Say)

"I BEGAN to foreclose on my life... I couldn't see past my 40th birthday."

IN A PEP PRESENTATION, an ER nurse in the audience said patients at her clinic are given a few days worth of prevention medication and some fail to follow up with a doctor to obtain

the rest of the 28-day regimen, and she wondered why. "I can answer that," said a young black man in the audience, Arturo Hill of the NovaSalud communitybased health organization in Falls Church, Virginia. "I had a friend who went to the ER recently for PEP. The nurses asked him demeaning questions because he's gay. He couldn't believe it. Many providers are not sensitive to the queer experience, so people may think it's going to be the same at the doctor's office."



USCA ON YOUTUBE

See presentations from USCA at bit.ly/2muE1Gc. There are several videos of the U=U plenary with inspiring personal stories and information.

Listen to beautiful music and a heartfelt story from America's Got Talent finalist tenor Branden James with husband, cellist James Clark.

"Letters poured in on Facebook and Twitter from kids all over the world," said James, who is living with HIV (his husband is not), about his journey to where he is today. "Some of those kids were from places like Russia and Egypt, who reached out to me in fear that if they told anyone who they really were, that they might end up in prison, or they might end up dead. Some letters were from others who'd been kicked out of their families all over the U.S., who were struggling with their sexuality. Parents began flooding my inbox, asking me how I can help them approach their kids with their sexuality. In 2014 I was here [in Washington, D.C.], appearing at the Cherry Blossom festival. And after my 90-second stint on local TV, a perfect stranger came up to me and he said, 'Branden, you are an agent of change. Keep telling your stories. Keep sharing your truth with us. It is a force for good.' I had an epiphany that day. And I realized the power I had. I understood for the first time that it was my calling to lead a life of authenticity and transparency. I realized that by simply offering a piece of my own story, I had the power to help potentially thousands of others."

What's Scruff got to do with it? Watch the video.

TWO SPIRIT CONVERSATION



sat next to David Herrera and Steven Barrios of the Montana Two Spirit Society during a lunch presentation at USCA. I took the opportunity to ask Herrera to tell us about his organization and about the nature of Two Spirit, and also explore the contradictory ideas that while Two Spirit people have a high social standing in Native cultures, they also experience discrimination from other Native people.

-ENID VÁZQUEZ

"We provide education about Two Spirit culture and increase understanding of two spirit ceremonies," said Herrera, "We help educate Two Spirit people and the larger community about a culture that was systematically eradicated by colonization. We work to reclaim our place in the sacred circle because without our Two Spirit people, that circle is not complete.

"Two Spirit individuals encompass both the masculine and the feminine and so were able to walk in both worlds. They historically had different roles, such as name givers, medicine people, or negotiators, depending on the tribe."

I asked about the people who say they feel afraid to come out as gay or Two Spirit in their Native communities.

"That's the influence of colonization." Herrera said. "Two Spirit people gay, lesbian, and transgender—were revered before the missionaries

came and the government started colonizing the land and moving tribes to reservations. They saw men dressing as women and women dressing as warriors and labeled it an abomination and a perversion. Families were separated and children were sent to boarding schools. They were forced to dress as the sex they were assigned at birth. Boys were forced to have their hair cut to reflect their gender and girls had to wear dresses."

THE MONTANA TWO SPIRIT **SOCIETY** celebrates its 25th annual Montana Two Spirit Gathering next year. In February, the Society will participate in the BAAITS Two-Spirit Powwow (organized by the Bay Area American Indian Two Spirits association), the largest Two Spirit powwow in the nation and in July, will take part in an indigenous HIV conference running alongside the International AIDS Conference in Oakland.



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Everyday moments in extraordinary lives

HAT MADE the autumnal equinox on Monday, September 23, different was that it was A Day with HIV. The aim of POSITIVELY AWARE's annual campaign is to capture in pictures 24 hours in the lives of people affected by HIV and its associated stigma.

Accompanied by the hashtag #adaywithhiv, hundreds of pictures from across the U.S. and 10 other countries were posted to social media. But the real impact often came from the personal stories behind those images.

"My diagnosis 35 years ago has enabled me to find my calling, leading, passion, the fire in my belly, which is education," posted Mark Grantham in Chattanooga, Tennessee. "I am grateful beyond words to say that I am not only surviving, I am thriving. Thirty-five years ago, I truly believed that my life was over; today, it's only beginning. As Elaine Stritch sang in Follies, 'I'm still here.' "

From Portland, Oregon, Carol's caption was poignant and succinct: "Even grandmas can have HIV."

The day coincided with personal events and milestones. "Today is also my mother's 64th birthday!" posted Adam from Beaumont, Texas. "Living another day with my diagnosis means having another day to be with her, and all my loved ones." Lilli Gonzalez snapped photos during her clinic visit at New York Presbyterian: "Getting my blood work done to keep up with my numbers and remain undetectable."

"Thanks to great medications I am able to be a father to an eight-month-old who is very active," posted Aaron Laxton from Saint Louis, Missouri. "HIV is the least interesting thing about my life."

Activist Bruce Richman posted a picture on his way to the airport to go to Toronto to speak about U=U. "I won't stop until everyone knows!" he posted. Giulio Maria Corbelli took a picture while waiting at Rome's Fiumicino Airport to attend a meeting in Amsterdam of the European Medicines Agency. "This is

an opportunity for people's voices to be heard by regulatory authorities," he said.

"If you are diagnosed with HIV don't be afraid, because this is not the ending of your life, but a beginning of new phase to be a better person," said Salina Shaari, of Kuala Lumpur, Malaysia.

Other pictures posted reflected the new reality that people living with HIV are often dealing with other conditions. "As a long-term HIV survivor of 23 years, at 47, I am now living with HIV and cancer," said Jasán Maurice Ward, of Schenectady, New York. "I was diagnosed with cancer in June, and am currently in recovery from chemotherapy and radiation. Through it all, I still wake up feeling ready to fly, rising higher each day, in order to keep fighting, inspiring other people, and living my best life!"

"I've always kept my beard trimmed for work, but a recent Type 2 diabetes diagnosis has left my face sunken," posted Robert Riester in Denver. "I have to embrace myself and rethink how I see myself."

Near the end of the day, Tami Haught of Nashua, Iowa summed up her experience: "The last five years, I have been doing what I call 'reclaiming miles,' events I thought I would not be able to experience after my diagnosis. I didn't think I would live long enough to see my son graduate from high school. And yet here I am today, rocking my eightmonth-old grandson to sleep."

IN ADDITION to the images posted on Facebook, Instagram, and Twitter, dozens of pictures were uploaded to the campaign's online gallery: adaywithhiv.com.









< 1:04 PM AMERSFOORT, THE NETHERLÁNDS Eliane Becks Nininahazwe: Picking up my medication at the pharmacy. A Day with HIV reminds me how lucky I am to have access to the treatment. It also reminds me how important is to be visible if we want to

end HIV stigma.

< 2:23 PM: WASHINGTON, D.C. Anthony Adero Olweny (right): Living with HIV has opened new opportunities and provided great lived experiences to be ourselves. I learn to be myself and love more. I appreciate life more and enjoy present moment positively. Jim and I reflect on what it means to be self advocates and also to be part of a thriving community of

< 4:15 PM: **NEW YORK, NEW YORK** Lilli Gonzalez: At my clinic at New York Presbyterian, getting my blood work done to keep up with my numbers and remain undetectable.

people living with HIV.

< 7:30 PM: SACRAMENTO. **CALIFORNIA** Arturo C. Jackson III: Celebrating love and 14 poz years together today! 39-year poz survivor.

Working at Philadelphia International Airport. "Dreams are not diagnosed."

8:10 AM: JACKSONVILLE,











9:15 AM: PORTLAND, OREGON > Carol: Even grandmas can have HIV.

9:30 AM: MINNEAPOLIS,

MINNESOTA >> Dale Stark: Mondays with HIV are like any other Monday—not enough weekend! Today we have more tools and resources than ever for education, prevention, treatment, and research. Additionally U=U and PrEP are game chang-ers in ending HIV. So, I guess Monday is really a day to cel-ebrate. Together, let's #endHIVstigma.



Robert Breining:

FLORIDA >>

Renee Burgess: With my daughters Myla, Michelle, and Micah getting some Dunkin' Donuts.

Mark S. King: Time to go speak to students at Johns Hopkins School of Nurs-ing about what my life with HIV is like. Behind me is a prized gift from another activist, a framed section of the 1988 "AIDS Wallpaper" art installation by General Idea. I am ready to face my 59th year on this earth—35 of them with HIV.

9:00 AM: GRANDVILLE, MICHIGAN >>

Kevin: In the waiting room at my therapist's office. Self-care is an important tool to achieve and maintain wellness.









<< 10:00 AM: PHILADELPHIA. PENNSYLVANIA

Waheedah Shabazz-EI: A Day with HIV looks bright when you're connected to your purpose and your community.

< 10:00 AM: TYLER, TEXAS

DeAnna Jackson: I acquired HIV in 2008, after the first pic was taken. Diagnosed in 2011, I almost had an AIDS diagnosis. With a CD4 count of 232, I was very sick. Now, in 2019 (the picture on the right), I'm a Ryan White medical case manager. HIV does not define who you are. I do not look like what I've been through, and you don't have to either! Love yourself despite what the world says!

<< 11:48 AM: GALLIPOLI, ITALY Damiano: Bella la vita.

< 11:52 AM: WASHINGTON, D.C. Michelle Anderson and Helen Zimba: Black women have the right to complete physical, mental, spiritual, political, social, and economic well-being. And until we achieve these rights, Helen and I will continue the fight to end reproductive oppression. If we end reproductive oppression for Black women, we end it for all women. Ending the struggle together!





<< 12:00 PM: NEW YORK, NEW YORK Bruce Richman: A Day with HIV for me is working in a car to the airport to fly to Toronto to talk about U=U. I won't stop until everyone knows!

< 12:00 PM: Los angeles, California

Mark Hermogeno: At the L.A. Mart checking out new product and learning stuff. Next month will be the 16th anniversary of my HIV diagnosis. I chose to start my own interior design company iust months after finding out my status because I learned life is an unexpected journey, and it's too short to just settle. I control my life; HIV does not.

12:03 PM: BERKELEY, CALIFORNIA > Branden James: Reflecting on a day with HIV.

12:05 PM: SAINT LOUIS, MISSOURI >>

Aaron M. Laxton: Thanks to great medications I am able to be a father to a eight-month-old who is very active. HIV is the least interesting thing about my life.

12:08 PM: NEW YORK, NEW YORK >>>

Stephen Addona: Noontime outreach, Washington Heights, NYC. CDC reports that within the Hispanic/Latino community, 85% of newly diagnosed cases of HIV are attributed to men who have sex with men.

12:37: BAMBERG, SOUTH CAROLINA >

Connie Johnson: Today, I went to the studio to record my first single, Soft Place. Music has always been a large part of my self-care regimen and healing journey. It soothes and heals in places nothing else can reach. It doesn't discriminate or judge.

12:40 PM: MACON, GEORGIA >>

Michael Leon: In my kitchen, checking email. October 27 I will celebrate my 30th year of living with AIDS. I decided back then to live as long as possible. It was not until I forgave myself and others, that I accepted my path.

12:40 PM: PORTLAND, OREGON >

Sam Wardwell: For the past three years, these two wonderful souls have been a big part of my life (I'm on the right). Born with and living with HIV for 23 years, I went from a scared country girl uncomfortable about my own status to a flourishing soul who feels comfortable enough to publicly announce my status, and identify as non-binary.

12:50 PM: SAN DIEGO, CALIFORNIA >>

Michael Lochner: My reason for living is this beautiful diva named Spirit. She keeps me active, she always knows when I need a kiss or a cuddle. Having been poz for 33 years, it's nice to have the ability to just relax and be me.

















<< 1:00 PM: SAN FRANCISCO, CALIFORNIA

Race Bannon: Well over 30 years HIV positive—and still thriving.

< 1:00 PM: Kuala Lumpur, Malaysia

Salina Shaari: If you are diagnosed with HIV don't be afraid, because this is not the ending of your life, but a beginning of new phase to be a better person. Fight against stigma and discrimination to prove that people living with HIV have a chance to be in the community.





<< 1:34 PM: NEW YORK, NEW YORK

Charles Sanchez:
Getting my regular
labs done with
phlebotomist
extraordinaire
Roosevelt. My fab
medical team helps
me stay healthy
and my viral load at
#undetectable! I've
been living with HIV
since 2003, and am
grateful to be living
and kicking ass!
#UequalsU

< 2:00 PM: HOUSTON, TEXAS

John Termine: What a wonderful day! Thirty-two years positive, and the fight continues!





<< 2:00 PM: WASHINGTON, D.C. Marnina Miller:

HIV hasn't controlled who I chose to date. It hasn't hindered me in my career, shortened my life expectancy, or any other weird rumor/stigmatizing thing you may hear. It has, however, made me live life without limits and given me the best damn chosen family ever!

< 2:00 PM: SAINT LAMBERT, QUEBEC, CANADA

Jennifer Vaughn:
Taking a cruise in the car with my husband (who doesn't have HIV). I take a pill a day, but other than that I don't feel, look, or live any differently than I did before I was diagnosed.

2:06 PM: NEW YORK, NEW YORK >

Tommy Young-Dennis: HIV positive and still doing my part to leave my work in the world. This photo was taken at the GLSEN headquarters right after meeting some of the national staff. It is my hope to use my work surrounding HIV advocacy to impact and educate the youth of tomorrow.

2:39 PM: PIETERMARITZBURG, SOUTH AFRICA >>

Wiseman T. Zondi: Decided to take a long walk, then come to campus because fresh air + music playing in my headphones = great way to feel good.

3:00 PM: FORT LAUDERDALE, FLORIDA >

Shane Bullock: Being diagnosed has only meant one thingstay healthy and take care of my body. Eight years later, I'm in the best shape of my life and healthier than I ever have been. This is on my daily bike ride to the gym.

3:45 PM: PHILADELPHIA, PENNSYLVANIA >>

Mark A. Davis: Weigh it, stamp it, face it! I carry placards as a suicide attempt survivor living with HIV 31 years. In 2003 I started Pink & Blues peer-run support group, a safe space to explore our dualities with complex lived experiences. Go to pinkandblues.info.

3:49 PM: LAS VEGAS, NEVADA >

Bryan Heitz: Surviving with HIV for 13 years. Appreciate living. In the photo, my knuckle tattoo is visible. It reads: We Are All HIV+. This same tattoo adorns the knuckles of Diamanda Gals, a fierce advocate, artist, musician, and warrior for people living with HIV/AIDS since the beginning. With her permission, I tattooed this as an homage and a reminder of the legions we have lost throughout the pandemic.

4:00 PM: INDIANAPOLIS, INDIANA >>

Art Jackson: At work at Brothers United Wellness Network.

















<4:15 PM: EDINBURG, TEXAS Janine Brignola: Positive mama, negative son! Thought it would be fitting to pose in my car after spending the better part of the last year driving across the South, with this kid right next to me, on a mission to learn about the challenges in southern states pertaining to HIV.

<4:33 PM: FORT MYERS, FLORIDA Marissa Gonzalez: Working to fight HIV stigma in our community is just one of the things that connects us. I'm surrounded by people I call friends! Don't assume who is living with HIV; can you tell who just by looking at this picture?

<< 4:40 PM: WARKWORTH, ONTARIO, CANADA Bob Leahy: Basset hound Ruby isn't my only dog, but she is the most sociable. Her love knows no bounds. HIV means nothing to her.

<5:28 PM: ARECIBO, PUERTO RICO Angel Luis Hernandez: This is La Poza del Obispo (Bishop's Pond) in the northwest part of Puerto Rico. This spot is my patio, my meditation place, my gym; my physical, occupational, respiratory, and psychological therapies. Taking care of myself is caring for all of you.





Deral Takushi: Being a tourist in our hometown, enjoying the beautiful views of the city and the company.

<- 7:30 PM: ROME, ITALY
Giulio Maria Corbelli:
Waiting at Fiumicino
Airport for the flight
to Amsterdam for
a meeting of the
European Medicines
Agency. This is an
opportunity for
people's voices to be
heard by regulatory
authorities.

< 8:08 PM: ATLANTA, GEORGIA Masonia Traylor: Stopping by the grocery store after school with my daughter while her brother volunteers after school at the recreation center.





8:30 PM: MILAN, ITALY > Raffaello della Penna: On the eve of a delightful performance.

8:36 PM: PLAINWELL, MICHIGAN >>

Debbie Sergi-Laws: My dad and I today after a rough day. Living with HIV/AIDS for over 30 years has taught me what it's like to love and grieve. I'm going to need help with this one. Hospice care has been called after failed lymphoma treatment. I love you, Dad—thanks for being the best!





9:16 PM: FREDERICKSBURG, VIRGINIA >

Jacob and Tabitha Brown: My wife Tabitha Brown, HIV positive for nine and a half years and myself 27 years HIV positive. We are a strong team together, and fight to live for one another.

10:30 PM: GRAND PRAIRIE, TEXAS >>

Evany Turk: My cousins and I watching a movie. This picture is very meaningful on this day because these particular cousins are living with HIV. Family support has been vital in all our journeys. From left: Delorise Holman-Wiley (from Missouri), me, and Joyce Hampton (from Arkansas).

10:47 PM: LOS ANGELES, CALIFORNIA >

Eugene Huffman aka liebeKunst: Surrounded by my art.

10:50 PM: SAN DIEGO, CALIFORNIA >>

Jacen Zhu: As Undetectable Man, I work on my personal fitness 3-4 times a week. Although I have super strength, going to the gym relieves my stress and anxiety. I love a late night workout before bedit's me time.

11:01 PM: DENVER. COLORADO >>> Robert Riester: I've always kept my beard trimmed for work, but a recent Type 2 diabetes diagnosis has left my face sunken. I have to embrace myself and rethink how I see myself.







Driving out stigma

'Dee' Conner and Deirdre Johnson hit the road to raise awareness in the South

avina Conner found inspiration in the pictures of A Day with HIV, POSITIVELY AWARE's anti-stigma campaign. Moved to share her own story, she submitted pictures several times over the years, making the cover of the magazine in 2015 and 2016. Known to many as "Dee," she has become a visible advocate and a powerful voice in the community. Conner spoke about her connection to A Day with HIV, and discussed her own efforts to confront stigma.

What inspired you to take part in A Day with HIV?

When I first saw A Day with HIV almost five years ago. the campaign made me smile. Seeing so many photos showing life as it is, and that people can be free from what others think. I cry every year looking at all the photos. The campaign shows that people diagnosed can still smile and be happy, whether it's with family, on vacation, at work, just taking a walk, or even riding their bike. It inspires people who are not open to see that they can live as well.

What has your personal journey been like?

I've been living with HIV for 22 years. I'd gone to get screened for cancer and got tested for STIs [sexually transmitted infections]. I was confused at first, then shocked by my HIV diagnosis. "Am I dying soon, how did this happen, what will I look like being sick, and what's going to happen to my daughter Sonja?"

My personal journey as a teenager and later after being diagnosed was ugly. I was basically homeless, selling drugs in the projects, getting

older people to rent me a motel room so I could sleep; I had been abused by a guy at 15 years old. I was in denial, suffered from depression, and became an alcoholic. I don't share much about becoming a sex worker after my diagnosis because it was something I was ashamed of. But as I grow over the years I know now that it's okay to share this because it was something that I went through, and my journey has made me a stronger person.



DAVINA "DEE" CONNER (LEFT) WITH DEIRDRE JOHNSON.

What as been your experience with stigma?

My daughter's grandfather wanted me to make sure I wiped the toilet after Lused it: he also didn't want me to drink from the cups in the kitchen cabinet, so I decided to just not go over to his house. I also have a good friend whose brother learned I have HIV, and he would not come over to her house whenever I was there. I think it was easier for me to just not go around too many people so I wouldn't have to deal with the stigma, so I worked a lot and took care of my family instead.

Talk about your recent road trip with Deirdre Johnson. What was the goal of Driving Out Stigma?

Our goal was to show people the impact of HIV, stigma, and depression among women of color and women of color who are of trans experience. We wanted to educate HIV-negative women of color about PrEP, and to educate women of color who are living with HIV about U=U [undetectable equals untransmittable]. When I shared my idea with Deirdre, she was ecstatic and wanted to be a part of it.

We started in Denver, and our first stop was in Dallas. In Houston, we set up a table in front of Out of the Closet, where we engaged people in conversations about stigma, PrEP, and U=U. We were invited to a community planning group meeting with members of the Houston Health Department, where they discussed their plans on Ending the Epidemic. We were offered a table at the New Orleans AIDS Walk, and invited to attend the Louisiana Integrated Prevention and Services meeting.

In Baton Rouge, we did a Straight Talk at The Kitchen Table meeting with 10 women at the home of Dr. Joyce Turner Keller. We had a frank conversation about how language matters when we speak of or about HIV. In Atlanta, we spoke to a Social Psychology class of 21 young men at Morehouse College. Our last event was a meet up with a group of women at a

café in Atlanta that Masonia Traylor put together for us.

I can't put into words how well the campaign went, and how I was touched by so many people. The amount of support we had was beautiful.

Conner's partner in Driving Out Stigma, Deirdre Johnson shared her own insights from the journey:

I learned a lot on this trip about myself, Davina and the world we live in. Stopping stigma is a duty we owe to ourselves, our community and each other. It starts with each one of us taking a hard look at how, what, and who we place judgment on, and realizing how we can make a change for the better. Eradicating stigma will be the key to us seeing an end to HIV. We must begin the dialogue of how to make that happen. PA

FOLLOW DEE AND DEIRDRE

on Facebook: PozitivelyDee. DeesDiscussion, and DeirdreSpeaks; and @DavinaConner on Twitter. #driveoutstigma and #drivingoutstigma.

DEEP AND SOUTHERN STRONG

Addressing HIV in the rural South

TEXT AND PHOTOS BY SEAN BLACK



rauma-informed care; the intersectionality of HIV, gender, and poverty; and the call to embrace People First Language were among the key takeaways for clinicians and care providers at this year's 7th Annual Rural HIV Research and Training Conference returning to host city Savannah, Georgia.

Healthcare can be overwhelming for anyone but for individuals living with HIV in rural communities, the added frustrations can result in not connecting to, or falling out of, care.

Linkage and retention are essential to Fayth M. Parks, PhD, who founded and first organized the conference seven years ago in memory of her late brother. Since then it has brought together some of the brightest and most passionate voices in HIV care, "You'd be hard pressed to find a more dedicated group of scholars and practitioners who share an authentic commitment to ending HIV in the American South," said Parks.

"Disrupting stigma and discrimination is tough," she added. "Grassroots effort

is essential. We must empower people at the community level; be it local healthcare providers, activists, advocates, allies, [or] people living with HIV (PLWH). As a psychologist, I believe that behavioral changes are and will remain an effective means for preventing the spread of the virus, and the diverse social impact on PLWH and their caregivers are all areas in which organized psychology must maintain a leadership role."

While working on her doctorate degree at the University of Illinois at Urbana-Champaign in 1989, Dr. Parks got an urgent call to come to Atlantic City; her older brother Ben had been hospitalized.

"During the long Amtrak train ride from Illinois to New Jersey, I had no idea that Ben was dying," she recounted. "At the local hospital, a few family members were gathered in the waiting room. The doctor explained my brother was seriously ill with pneumonia. He made no mention of immunosuppression because Ben's CD4-positive T cell levels were less than 200, therefore life threatening. He made no mention of the brain disease resembling Alzheimer's slowly destroying my brother's brilliant, creative mind. There was no mention of the AIDS virus, though I recall his hospital room was quarantined. The doctor asked me some personal questions about Ben's lifestyle. His questions seemed personal and oddly intrusive. I was uncomfortable. I wanted to protect my brother's privacy. Regrettably, Ben passed away a few days later. I felt confused, angry, and sad about Ben's death and the doctor's auestions."

After returning to Illinois to continue working on her degree, Parks was devastated about her only brother's passing but was resolved to moving forward

FACING PAGE, FROM LEFT: Warren A. O'Meara-Dates, Sande Bailey-Gwinn, Marcus D. McPherson, and Queen Hatcher-Johnson take part in a panel discussion. THIS PAGE, FROM LEFT: Mindi Spencer, PhD, associate professor, University of South Carolina. Stacy Smallwood, PhD, MPH, assistant professor of Community Health at Georgia Southern University. Fayth Parks with Betsy E. Smith, PhD, MPH, one of the recipients of the 2019 Rural HIV innovation Award.







with her life. It was during that time, in 1997, that the Champaign-Urbana Public Health District was looking for volunteers to join the African American HIV/AIDS Awareness Project for help with outreach activities, risk prevention/support services, and media/public relations. Dr. Parks joined the organization.

As a steering committee member, Dr. Parks contributed to such initiatives as an annual GospelFest (promoting AIDS advocacy in African American churches) and an initiative called Taking the Message to the Streets.

"On a Saturday morning during early spring, we walked the community's African American neighborhoods door to door to share information on HIV/AIDS and distribute condoms. At the time, African Americans made up 42% of all AIDS cases in Illinois with rates 15 times higher for African American women than for white women. So, I made a commitment to continue working on HIV/AIDS issues whenever possible. Sadly, over

30 years later, though there's progress, we're still fighting the epidemic."

Cherie D. Mitchell, MHS, Director of HIV/AIDS Programs of the Health Disparities Office at the American Psychological Association, returned for her second year, because the conference brings together diverse professionals to discuss unique challenges and innovative strategies across the lifespan when addressing HIV/AIDS in rural communities.

"We know the South accounts for more than half of new HIV diagnoses with many of these in rural areas, and people living with HIV experience disproportionately high rates of trauma and stressrelated disorders," she said. "Trauma, stemming from [situations like] Intimate Partner Violence can be both a risk factor for HIV and a consequence which decreases overall health and engagement in care. Trauma-informed care is key if we are going to address HIV across the care continuum and mental and behavioral health issues."

Mitchell pointed out that addressing disproportionately high levels of exposure to traumatic events and the resulting negative health and behavioral outcomes was a headlining topic of the conference.

Mindi Spencer, PhD, an associate professor at the University of South Carolina, reported on the opioid crisis in the South. "Now that we know about the intersection of HIV and the opioid epidemic, we have an opportunity to actually predict the communities which are at greatest risk for new cases of HIV," she said. "With this information, we can mobilize our public health efforts to better serve those communities and prevent future outbreaks. Just imagine if we could travel back in time and do the same thing in the 1980s and '90s." >>

Representing the Georgia Department of Public Health's Division of Health Protection/IDI-HIV was its medical advisor, Dr. Gregory S. Felzien, MD, AAHIVS, discussing "Getting to Zero." Citing CDC data from 2017, Felzien reported that, "in the South, 23% of new HIV diagnoses are

'When I think about what motivates me to do this work. I think about all the people who are rendered invisible, their stories unheard, because of the pervasiveness of HIV stigma.' -STACY W. SMALLWOOD, PHD, MPH



FROM LEFT: Queen Hatcher-Johnson; Sally Jue, MSW; Warren A. O'Meara-Dates; Marcus D. McPherson; and Sande Bailey-Gwinn.

in suburban and rural areas ... thus with 23% of new HIV diagnoses occurring outside urban centers, active participation from all communities is required whether they be urban, suburban or rural in order to remain diligent in providing high quality, accessible care, i.e. screening, treatment, prevention, etc., for patients in every community within Georgia. Equal access is vital to achieve the goal of reducing the number of new HIV diagnoses. The Rural HIV Research & Training Conference serves as an important platform for rural providers to come together to openly discuss real-world challenges and understand what is needed to provide accessible and current patient care."

Shifting between storytelling, the reporting of scientific data, oral care, IV substance abuse, and behavioral and mental health, the attendees were informed and updated on bedside manner. Providers' approach, if not genuine, can easily turn a patient away and language can not only be misunderstood but it can also be offensive and prejudicial, thus impeding the split-second window for patient-provider engagement.

Queen Hatcher-Johnson, a married woman of transgender experience offered an anecdotal tip that was simple and relatable. "There is no need for pronouns, just simply using a person's name is the best way to communicate with humans. Pronouns are interchangeable with identity."

Joining Hatcher-Johnson on the panel were fellow community leaders Warren A. O'Meara-Dates, BA, CPAT, Executive Producer, Start Talking Alabama and Special Projects Coordinator, HIV/AIDS Division, ADPH; Sande Bailey-Gwinn, Founder of Foundations for Living; and Marcus D. McPherson, MPPA.

People First Language places individuals as it literally states—the person first and the disability or disease second. Thus, it is "people living with HIV," not "HIV-positive people." Using People First Language is a key component of efforts to reduce stigma and discrimination.

"Doing this [HIV] work should be about respecting the person who comes into your office, clinic, or wherever you do this work," said McPherson. "This individual is someone who is trusting you to treat them as a fellow human being, not as

a patient, not a consumer... If you can look someone in their eye and see them as a person and can connect with them in that manner, you can then be able to provide quality care to that person."

The AIDS Institute (TAI) co-hosted the conference, collaborating with the Georgia Department of Public Health and Georgia Southern University's College of Education.

"As a person living with HIV, it's an amazing experience to work with many of my peers and care providers and researchers to curate a conference that holistically addresses HIV in the rural South," said TAI research coordinator Sean McIntosh. MPH. CPH. who is also an administrator

at the Florida Consortium for HIV/AIDS Research.

The closing keynote address was given by Jeanne White-Ginder, who recalled memories of her son-Ryan White-and his battle to overcome stigma, fighting for his right to go to public school in Indiana.

Balancing perspectives from both sides of care, presenter Dr. Stacy W. Smallwood, PhD, MPH, Associate Professor, Jiann-Ping Hsu College of Public Health at Georgia Southern University, shared with both charisma and compassion.

"When I think about what motivates me to do this work, I think about all the people who are rendered invisible, their stories unheard, because of the pervasiveness of HIV stigma. [It's] important to lift up the experiences of HIV in rural areas, as well as the people who work so hard to prevent new infections, treat those who have been diagnosed, and promote critical conversations in our communities. Until we are able to center the experiences of the most marginalized, we will never be able to make the impact that we seek." PA

Cross-generational collaboration

Coming together for HIV advocacy BY JEFF BERRY

"No one wants to be pushed off a ledge they helped to build."

Aquarius Gilmer, a striking young, black gay man wearing a bright lime green blazer, touched my shoulder as he delivered these powerful words. I struggled to keep my emotions in check as Gilmer, senior manager of Government Affairs and Advocacy at Southern

AIDS Coalition. spoke eloquently to the audience about the need to honor long-term survivors of HIV and the work done before us. as we pass the torch to a younger generation of HIV advocates.

I had the privilege of sitting on the panel "Fostering Cross-Generational

Collaboration in HIV Advocacy" with an amazing group of fellow HIV advocates that included Gilmer; Raniyah Copeland, CEO of Black AIDS Institute; and Guillermo Chacón, president of the Latino Commission on AIDS; and facilitated by the multi-talented Gabriel Maldonado, the young CEO of TruEvolution, Inc.

The session, as described in the program, was "designed to respond to areas of urgent, emergent, and unmet community needs," and convened "a diverse group of HIV/AIDS advocates from different generations."

MALDONADO POSED the following questions to the panelists:

Do you believe we can achieve meaningful outcomes in addressing health disparities and access to care, not in spite of, but with this administration [in the White House]?

How do we develop unified responses while still honoring the distinct and unique beliefs, approaches, priorities, and needs of different jurisdictions and communities?

Is there a role for communitybased organizations who do not choose to fully medicalize their operations, primary care, or outpatient services? Are they sustainable?

> What practices and approaches do we need to strengthen and replicate, and what practices or approaches we abandon?

Held on the first day of this year's **United States** Conference on

AIDS, people in the audience seemed eager to hear about how to facilitate discussions between generations to address the issues facing the HIV community under the current administration in the context of its Ending the Epidemic (EtE) plan. As a long-term survivor I reminded people that we have been here before. In the 1980s, in the midst of an epidemic, our president at the time (Reagan) wouldn't even mention the word AIDS, and yet we came together as a community and developed the tools and strategies we needed

Following the panel discussion, the room was divided into two groups, and participants shared their experiences while coming up with ideas and strategies for their own local EtE plans.

Key conclusions, taken from a follow-up report of the session, which was sponsored by Merck, are summarized helow:

INTERSECTIONAL ADVOCACY

is important-cross-generational, but also cross-cultural, cross-racial, etc.

We need to find common threads and move past prejudices

The HIV community should not marginalize long-term survivors

Be open to engaging and "walking down the path" with full knowledge that it may not work, but also allow room for the other party to grow/evolve

ADVOCACY IN THE current political climate and engagement with this administration is difficult, but not impossible

Utilize "Suspicious integrity" engage but continue to question motives and potential downstream consequences

Acknowledge the discomfort

and inherent tension of working with an administration that has engaged in behavior that "dehumanizes" members of the HIV community

We must remember that the HIV community already has power and resources

TAKING A LONG VIEW—and remembering previous victories—can empower us in these trying times

Look to our history, challenging administrations have come and gone. HIV advocates know how to work with hostile administrations

It is important now not to forget those who came before

ENDING THE EPIDEMIC will require the community to bridge rifts within itself and to build relationships with non-traditional partners

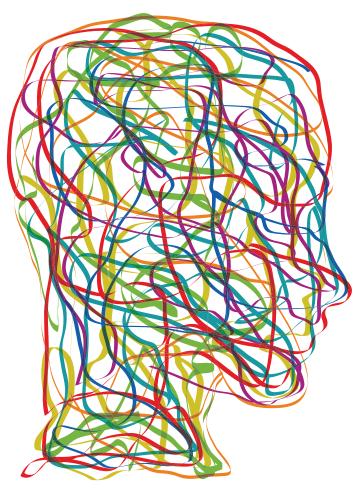
Introduce collaborations and coalitions of local organizations and institutions to share data, and reduce silos [separating issues] and redundant or contradictory efforts

Look to other disease approaches (HCV, syphilis, STIs) for successful strategies

Engage the media to lift up stories of people living with HIV

"We must ensure that any 'Ending the Epidemic Plan'[s]nationally and locally—are not only aspirational and theoretical, but that they are actionable and tangible," Maldonado told POSITIVELY AWARE in a subsequent email. "Grassroots leadership is essential to translating the needs on the ground in federal and state policies. Clinical and social service providers must hold the architects of the 'Ending the Epidemic Plan' accountable as we strive for innovation and culturally-responsive programs and services."

The report went on to say that, "The panel exhorted the attendees to realize the powers and resources already at their disposal in the historical record. The final presentations noted that while jurisdictions within and external to the EtE plans have distinct needs that will require unique strategies, they have much in common. There are strategies that all advocates can promote, such as: stakeholder engagement that involves non-traditional partners like homeless services, faith-based institutions, the justice system...methods for reporting that promote accountability; and speakers bureaus to allow [people living with HIV] to tell their own stories." PA



Mental health and self-care

Some things to think about when addressing your emotional and mental health

motional health can be just as important as physical health, especially when living with HIV. Recognizing emotional or mental health issues can be difficult; we might not even be aware of them ourselves. We can all use a reminder or tips on how to look after ourselves and our emotional health.

The following is taken from TEAM (Treatment Education Adherence Management), a quarterly education workshop conducted by TPAN, the nonprofit organization that publishes POSITIVELY AWARE. The TEAM program encourages people living with HIV to learn together. If knowledge is power, then learning together can become support.

As you are read through this article, consider if these descriptions are relevant to you now or were at any point throughout your diagnosis. Reflect and ask yourself questions. Think about what actions helped you to create positive change, or consider what you might be able to do to take control of current feelings.

Identifying grief and depression

Grief may be seen as a reaction or response to loss, it is part of the healing process.

Although usually focused on the emotional response to loss, it also has physical, cognitive, behavioral, social, cultural, spiritual, and philosophical dimensions. Consider what you might have grieved or are currently grieving after being diagnosed HIV positive.

There are five stages of grief, as outlined by Elisabeth Kubler-Ross: denial, anger, bargaining, depression and acceptance. Depression can be experienced in a variety of ways. A depressed mood or sadness is a normal temporary reaction to life events. If however symptoms intensify, or last many days or weeks, it may indicate a depressive disorder. Symptoms of depression can include:

FEELINGS:

- Sadness
- Hopelessness
- Guilt
- Moodiness
- Angry outbursts
- Loss of interest in friends, family, and favorite activities, including sex

THOUGHTS:

- Trouble concentrating
- Trouble making decisions
- Trouble remembering
- Thoughts of harming vourself
- Delusions or hallucinations can also occur in cases of severe depression

BEHAVIORS:

- Withdrawing from people
- Substance use disorder
- Missing work, school, or other commitments
- Attempts to harm yourself

PHYSICAL PROBLEMS:

- Tiredness or lack of energy
- Unexplained aches and pains
- Changes in appetite
- Weight loss
- Weight gain

- Changes in sleep—sleeping too little or too much
- Sexual problems

Understanding stigma and shame

Stigma is a set of negative and misconstrued beliefs that an individual, society or group of people have about someone, that sets the person apart from others. Examples of these beliefs can include: income level, mental illness, physical disability and HIV status. Shame can be seen as a painful emotional reaction to stigma, guilt or disgrace. It is best explained as a condition of how others (or ourselves) make us feel. Thoughts that we are somehow wrong, defective, inadequate, not good enough, or not strong enough. Feeling shame does not necessarily mean that you have done something wrong or "shameful." Consider how we see shame throughout our communities and in people around us. Reflect on how stigma affects people.

How mental health and physical health can intersect

Stress and depression are intertwined. When stress hormones are released, they trigger high blood pressure, quicker heart rate, increased glucose in the blood, and shut off blood from digestive organs and brain.

Depression and cardiovascular disease are interlinked, with research showing that some patients who suffer from a cardiovascular disease also have depression. Depression also predisposes a person to engage in risky habits such as smoking and excessive alcohol consumption, all of which are risk factors for heart disease. Individuals suffering from depression also suffer from irregular sleep patterns, which worsen the risk of cardiovascular complications and heart attack.

Methods of coping

There are many healthy ways to address our mental health. You should seek help and support if you feel like you need it, or when your mood begins to have a negative impact on your social life, work performance, and relationships. Options include individual therapy, recovery groups (AA, NA, Smart Recovery, and others), therapy groups, in-patient or out-patient programs, peer support groups, and talking to your physician. Another effective method of coping is self-care. Self-care is any activity that we intentionally engage in to take care of our mental, physical and emotional health. Consider the support you or another might seek after receiving a positive diagnosis, reflect on some things one might gain as a result. Possible self-care activities can include:

SENSORY

- Breathe in fresh air
- Snuggle under a cozy blanket
- Listen to running water
- Sit outdoors and listen to the night sounds
- Take a hot shower or warm bath
- Get a massage
- Cuddle with a pet
- Pay attention to your breathing
- Burn a scented candle
- Wiggle your bare feet in overgrown grass
- Stare up at the sky
- Lie down where the afternoon sun streams in through a window
- Listen to music

PLEASURE

- Take yourself out to eat
- Be a tourist in your own city
- Take up gardening
- Watch a movie
- Make art. Do a craft project
- Journal—write down your thoughts
- Walk your dogs
- Go for a photo walk

MENTAL/MASTERY

■ Try a new activity

- Clean out a junk drawer
- Take action (one small step) on something you've been avoiding
- Drive to a new place
- Make a list
- Immerse yourself in a crossword puzzle (or a jigsaw puzzle)
- Do a word search
- Read something on a topic you wouldn't normally

SPIRITUAL

- List five things you're grateful for
- Read poetry or inspiring quotes
- Attend church
- Light a candle
- Meditate
- Write in a journal
- Spend time in nature

EMOTIONAL

- Accept your feelings. They're all okay. Really.
- Write your feelings down
- Cry when you need to
- Laugh when you can
- Practice self-compassion

PHYSICAL

- Try yoga
- Go for a walk or run
- Dance
- Stretch
- Go for a bike ride
- Don't skip sleep to get things done
- Take a nap
- Eat a healthy meal

- Go on a lunch date with a good friend
- Call a friend
- Participate in a book club
- Join a support group

Self-care can also mean remembering that others go through similar experiences and difficulties. We're not alone! PA

SOURCES include depressiontoolkit.org and psychologytoday.com.

LEARN MORE about TEAM; contact Christina Joly, c.joly@tpan.com.



BILL RYDWELS (RIGHT) SHARING A WARM MOMENT AT TPAN'S 30TH ANNIVERSARY EVENT IN 2017.

The passing of a founder

Bill Rydwels, a founding member of TPAN, the organization that publishes POSITIVELY AWARE, passed away October 4. He was 87.

Bill was one of 16 gay men who first met in the living room of founder Chris Clason in June 1987, responding to a classified ad looking for people to share education and mutual support in the midst of the AIDS epidemic. He soon was serving on the first board of directors of the fledgling TPA Network (as TPAN was then known). Support groups met at various locations—a Chicago Park District fieldhouse, an alternative health center, the backroom of a

restaurant-and Bill was a constant presence. Through his 70s, he continued to lead a twice-weekly support group called Daytimers, for those looking for company and conversation during the day. It's a TPAN support group that continues to this day.

"Bill was one of the first people I met when I started attending TPAN support groups in 1990," said POSITIVELY AWARE Editor Jeff Berry. "Bill always had a big smile, an open heart, and a generous spirit. His strength and resilience over the years was, and will always be, an inspiration to others."

Godspeed, Bill.

SUDDENLY SUNDERED

HIV and the Foreign Service BY MICHAEL VARGA

"How soon can you get out of Canada?" asked the administrative officer at the U.S. Consulate in Toronto in October 1995 when I was informed that my application for disability retirement—due to my advanced HIV/AIDS—had been approved.

"What?" I asked.

"Now that you're officially retired, the State Department has liability issues with you remaining in Canada. I need to know how soon you can get out."

He was trying to be kind and not confrontational but nonetheless all I heard were those last two words; aet out.

This was the mid-1990s, before treatments became available that extended the lives of those of us with HIV. In 1995, after I pressed relentlessly for a life expectancy number, my doctor had told me that based on my lab numbers and what medications were available then. I could expect to last another eighteen months at most. Things were that grim, with HIV-positive individuals often moving from a first hospitalization to death in mere months.

What no one had prepared me for was the sundering from the Foreign Service when my disability application was approved. A cable had come from Washington on October 20, 1995—four months after I had filed for early retirement—informing the Consulate that my application had been approved. I was told that from that moment on I was no longer permitted in the Consulate building, that I should pack up all my personal belongings and leave the building as quickly as possible.

"You're no longer an employee. The U.S. government has liability issues with you now. You need to get out of Canada as quickly as you can. I don't mean to pressure you. I know you just learned that you're a retiree but the State Department wants me to cable them back when you're leaving Canada." I had no answer. That morning I had been working on a report about some trends at the Toronto Stock Exchange. There was work I still wanted to complete.

I had been HIV-positive ever since the test became available in 1985. The

Foreign Service requires a physical examination every two years to maintain worldwide availability to serve as a diplomat. In 1987, when I had my physical exam, an HIV test was conducted, and the Department was informed that I was positive.

I had no symptoms then, and, although there were no medications available to treat the disease, I continued to work like anyone else. I had assignments in Dubai, Damascus, and Casablanca. I was good at my job and was promoted rapidly. Still, as a gay man, I had to be careful about my sexuality. At that time, you could be fired for being gay. When my security clearance came up for review in 1991, the security officers told me they knew I was gay, but since I was "closeted," the only way they could renew my security clearance was by interviewing a family member about my sexuality.

I was confused.

"You're at risk for blackmail as a closeted gay man. If someone in your family knows about your sexuality, we can interview them and that removes the threat of potential blackmail." The whole blackmail question was a Catch-22. You couldn't be open about your sexuality or risk being fired. But they wanted you to be open (at least with someone in your family) so that you couldn't be blackmailed. That weekend, I went home and discussed this with my parents, to whom I wasn't officially out. They said they'd known that I was gay for a long time and had no issue with it. Diplomatic Security personnel interviewed them in the following weeks, and my security clearance was renewed.

I dodged that bullet, but this requirement to hide my sexuality took its toll as I struggled for balance between my working life and my personal life. I could not be open about any relationships, and I couldn't react when other diplomats made jokes about gays, which was often.

It was a very unwelcoming atmosphere to be gay in the Foreign Service in the 1980s and '90s.

PASSPORT

I am lucky to still be here in 2019. Given what the doctors told me back in Toronto, I had no expectation that new drugs would keep me alive this long. There is only gratitude for that turn of events. But remembering all of those HIVpositive people who never got the chance to grow old (I'm 63 now), I am driven with even more gusto to continue to be of service to others and to share my story.

The State Department was unprepared for how to handle those of us with HIV. In the early days of the epidemic, no one knew how bad it was going to get. So many young lives snuffed out before they had a chance to make a dent in our world. Today there are an estimated 1.1 million of us living in the United States with the virus, and more than 700,000 who died because of it.

I left Canada two weeks after I was told to get out. I had needed time to find a place to ship my things to in the U.S. and to figure out what it meant to be retired, looking my death in the eye. That was a lot to deal with at that time, and a little more compassion from the Department about how quickly an ex-employee could relieve them of their "liability issues" would have gone a long way to making my transition a less harrowing one. PA

MICHAEL VARGA is a playwright, actor, and fiction writer. His Peace Corps novel, Under Chad's Spell, is available on Amazon. Three of his plays have been produced, and his columns have appeared in many newspapers and journals. For other works, visit his website: michaelvarga.com.

This essay was first published on the website of The Gay & Lesbian Review (glreview.org).



We'd like to get to know you better; please take a few minutes to fill out the survey below. Tear out this page, fold, tape, and mail. You can also scan or take a picture of the page and email it to inbox@tpan.com—or go old school and fax it to 773-989-9494. Or, if you prefer, take the survey online at positivelyaware.com/2019survey. All responses are completely anonymous. Thank you for your help!

 I primarily read POSITIVELY AWARE: in print on a desktop or laptop computer on my smartphone, tablet, or other mobile device How do you get POSITIVELY AWARE? I have a subscription I pick it up at my doctor's office/clinic I pick it up at an HIV/AIDS service organization Other: 	6. I am receiving, or have received, treatment for (check all that apply): ☐ Alcoholism or substance use ☐ Arthritis ☐ Cancer ☐ Depression, anxiety, or other mental health conditions ☐ Diabetes ☐ Heart disease ☐ Hepatitis B or C ☐ High blood pressure ☐ STIs (sexually transmitted infections) ☐ None of the above		11. What is your race and/or ethnicity? (check all that apply): American Indian or Alaskan Native Asian Black or African American Latinx, Latino/a, or Hispanic Native Hawaiian or other Pacific Islander White I prefer not to answer I prefer to self-describe:
3. I read POSITIVELY AWARE because	☐ I prefer not to disclose ☐ Other:		☐ Less than \$15,000
(check all that are applicable):	Guner		□ \$15,000-\$34,999 □ \$35,000-\$49,999
☐ I work at an AIDS service organization	7. What is your age?		\$50,000-\$74,999
or community-based organization	Under 20	□ 50-64	□ \$75,000-\$99,999
☐ I am a healthcare provider	20-29	□ 65-74	■ \$100,000 or more
☐ I am incarcerated and need	3 0–39	☐ 75 and up	☐ I'd rather not say
current information	4 0-49	'	,
☐ I know/care for someone living			13. What is your HIV status?
with HIV	8. What is your gender identity?		☐ HIV positive
☐ Other:	☐ Female		☐ HIV negative
	☐ Male		I don't know
4. I would like to read more in	Non-binary/third gender		I prefer not to disclose
POSITIVELY AWARE about	I prefer not to say		
(check all that apply):	I prefer to self-describe:		14. I have been living with HIV for:
☐ The latest HIV-related			Less than 5 years
scientific/medical information			☐ 5-10 years
☐ HIV treatment and drug information	Transgender is an umbrella term that refers to people whose gender identity or expression differs from what is typically associated with the sex they were assigned at birth. Other identities considered to fall under this umbrella can include non-binary, gender fluid, and genderqueer—as well as many more.		☐ 11-20 years
☐ Stories about people living with HIV			☐ 21–30 years
☐ Information related to HIV and aging			☐ More than 30 years
☐ HIV advocacy and policy☐ HIV cure research			☐ I am not living with HIV
☐ Stories about TPAN, the publisher of POSITIVELY AWARE			15. How likely are you to share what you read in POSITIVELY AWARE with
☐ Other:	9. Do you ident	ify as transgender?	your health care provider?
	Yes		☐ Likely
5. I live in ZIP code:	☐ No		Somewhat likely
	☐ I prefer not to say ☐ I prefer to self-describe:		☐ Not at all
	· 		16. As someone living with HIV,
			my greatest concern is:
	10. What is you	sexual orientation?	
	Bisexual		
	Gay or Lesbia	n	
	☐ Straight/Heterosexual☐ I prefer not to say☐ I prefer to self-describe:		

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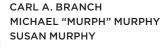


















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