P+A
POSITIVELY AWARE
HIV TREATMENT, PREVENTION, AND SUPPORT FROM **TPAN**
NOVEMBER+DECEMBER 2017

3:00 PM:

ATLANTA, GEORGIA
Shyronn Jones:
Homework time for
my kindergartener.

A DAY WITH HIV

EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

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BORN THIS WAY
A STRAIGHT MAN NAVIGATES STIGMA

OUTDATED ORDERS
HIV CRIMINALIZATION IN THE U.S. MILITARY

SOCIAL SCIENCE
GOING BEYOND THE CLINICAL

NEWS FROM WASHINGTON, D.C.
USCA 2017

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PLUS
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6:00 PM: MIAMI, FLORIDA
Alessandro Pino, Andre Ampudia, Matthew Phelps, Andres Sosa, Yoel Moreno, Nicholas Ferrera, Alejandro Suarez of Latinos Salud: HIV doesn't discriminate; good thing pizza doesn't either!

A DAY WITH HIV
EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

POSITIVELY AWARE
JOURNALISM. INTEGRITY. HOPE.

EDITOR-IN-CHIEF **JEFF BERRY**
@PAeditor
"I think one key to my survival has been the love of family and friends."

ASSOCIATE EDITOR **ENID VÁZQUEZ**
@enidvazquezpa
"If only sexual harassment would end."

CREATIVE DIRECTOR **RICK GUASCO**
@rickguasco
"A Day with HIV isn't all smiles and happy people, but it is an opportunity to share personal moments that serve as a reminder that we're all affected by stigma."

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A WORLD POSITIVELY AWARE
OF HIV AND RELATED CONDITIONS.

SINCE 1989. PUBLISHED BY

TPAN 30 YEARS

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TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals 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.

TO OUR READERS

AUTUMN 2017

Dear POSITIVELY AWARE Reader,

POSITIVELY AWARE (PA), the leading educational and informational resource for over 25 years for people living with and affected by HIV, is the most widely read HIV treatment journal in the U.S. produced by a not-for-profit organization, Test Positive Aware Network (TPAN). Having recently received the most current issue of the magazine, you can see the value that this publication brings to those living with and affected by HIV.

POSITIVELY AWARE is one of the most informative and consumer-friendly HIV journals available. Keeping current on the latest research, clinical data, and HIV and HCV medications, as well as lifestyle and advocacy news, is important to those living with and affected by HIV. POSITIVELY AWARE is the "go-to" publication for what one needs to know to live the best, healthiest life possible.

Can we count on your financial support in helping us to produce and distribute POSITIVELY AWARE to people living with HIV? The generous gifts of readers like you have supported our efforts to provide HIV-related treatment and wellness information to over 100,000 readers with each issue, as well as to nearly 20,000 visitors to our website each month. Your donation, in any amount, will help us provide POSITIVELY AWARE to those who need it most. A $30 contribution will cover the expenses necessary to produce and deliver the magazine to you for one year. A $100 contribution will cover the costs of your subscription and the subscriptions of two other people who can't afford it, but who definitely benefit from the critical information contained within the pages of POSITIVELY AWARE.

You can donate online at **www.tpan.com/donate**, fill out the form, submit, and then select "POSITIVELY AWARE fund designation" to earmark your donation for the magazine.

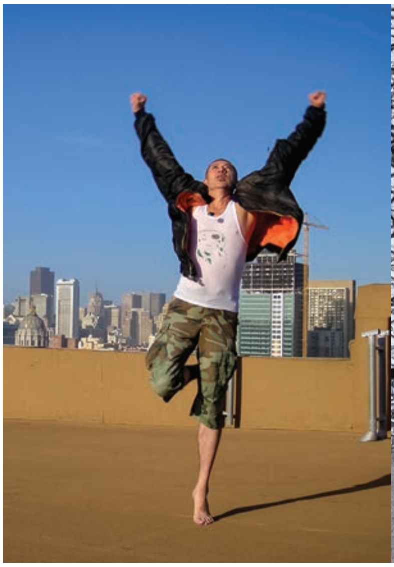
Thank you for reading and supporting POSITIVELY AWARE. You are truly making a difference in the lives of those living with and affected by HIV and AIDS.

Jeff Berry
Editor, POSITIVELY AWARE

Patti Capouch
CEO, TPAN

If you enjoy reading **POSITIVELY AWARE** and want to help support it, go to www.tpan.com/donate

24 HOURS. 11 COUNTRIES. 5 CONTINENTS. 3 FOLDOUT COVERS.



This issue of POSITIVELY AWARE features three versions of a foldout cover of photos selected from A Day with HIV, the magazine's annual anti-stigma campaign that captures 24 hours in the lives of people affected by HIV. (See pages 31–37.)

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NOV+DEC 2017

VOLUME **27** NUMBER **6**

EVERY ISSUE

FEATURES

CONFERENCE UPDATE

USCA 2017

HIGHLIGHTS FROM THE UNITED STATES CONFERENCE ON AIDS

< 8:34 PM: LONG BEACH, CALIFORNIA
Michael Buitron: The group hug at the end of Support Positive, a newly diagnosed drop-in group I've been doing at The LGBTQ Center Long Beach for six years. Two new participants today, along with new disclosures in a room full of non-judgmental, supportive peers.

MORE PICTURES FROM A DAY WITH HIV BEGIN ON PAGE 32 >>

JOIN THE CONVERSATION

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All letters, email, online posts, etc. are treated as letters to the editor unless otherwise instructed. We reserve the right to edit for length, style, or clarity. Let us know if you prefer not to have your name or city mentioned.

SUBSCRIPTIONS AND BULK ORDERS

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Elite controllers

On behalf of the Elite Controller community, I'm writing to thank you for noting our existence in your article "Towards An HIV Cure" (September+October 2017), and for suggesting that we, as a collective, do have a role in advancing the "field of HIV cure research."

More often than not, our contributions to that effort are relegated to the pages of scholarly journal articles with infrequent mention in the mainstream press or publications like POSITIVELY AWARE.

Given the field's intense interest in a minority of cases (about 17) called "post-treatment controllers," continued support of clinical studies focused upon elite controllers (around 500 individuals) is paramount to understanding the human response to the virus in the absence of medications.

Our individual contributions in the form of donations of blood and tissue samples to these important research studies shall continue in the hope of shedding light on how best to improve the lives of non-controllers in whatever form, for that is our personal and collective aim.

Congratulations on TPAN's 30th anniversary!

—**LOREEN WILLENBERG**
SACRAMENTO, CALIFORNIA

LOUISIANA LAW

I read with interest your article by Michelle Simek ("Undetectable Equals Untransmittable," September + October 2017). Very informative.

But, she includes this incomplete message about Louisiana's HIV laws:

But what about the naysayers? Those who don't believe in U=U or have concerns? Some were contacted and declined to comment. However, Gina Brown, an activist from New Orleans who is living with HIV, says,

"In the beginning I had some reservations about this message. I wasn't really sure how it worked. To me it was almost too good to be true. I didn't want to give PLHIV the wrong information or information that could get them into trouble. (Louisiana is a state that criminalizes HIV.)

It would be more accurate to report, Louisiana is a state that criminalizes the intentional exposure of another person to HIV/AIDS through sexual contact. But, despite the language in the statute, Louisiana courts have found that neither the intent to transmit HIV nor actual transmission is required.

This link provides an overview of HIV-Specific Criminal Laws in Louisiana and what a person living with HIV can be criminalized for: hivlawandpolicy.org/states/louisiana.

—**ROBERT JOHANNESSEN**
COMMUNICATIONS DIRECTOR,
BUREAU OF MEDIA AND
COMMUNICATIONS, LOUISIANA
DEPARTMENT OF HEALTH

PA at USCA 2017

Staff from POSITIVELY AWARE and TPAN, the non-profit HIV/AIDS services organization that publishes the magazine, attended NMAC's U.S. Conference on AIDS 2017 this past September. Our booth was turned into a "social media living room," complete with a living room rug, illuminated couch, throw pillows, and other assorted pieces. The items were provided by Miss Pixie's Furnishings & What Not, a popular Washington, D.C. vintage shop.

FROM LEFT: PA Advertising Manager Lorraine Hayes, TPAN Development Director Merrill Kenna, TPAN CEO Patti Capouch, PA Editor-in-Chief Jeff Berry, PA Creative Director Rick Guasco, and TPAN Manager of Case Management José López.

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EDITOR'S NOTE
JEFF BERRY

@PAeditor

Surviving with style

"My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style."
—Maya Angelou

I **remember as a young child** wanting to be "popular." Being popular meant you were part of the "in" crowd, had lots of friends, and were the life of the party. Everyone wanted to be with you; near you… they even wanted to *be* you.

I recall at one point fantasizing that if I were on crutches, then I would be popular. I guess I thought that everyone would want to sign my cast, provide comfort and consolation, and hold doors open for me. I must have pushed to the back of my mind the unsettling fact that I would have to break a bone to get there, and all that came along with it—the pain, the rehabilitation, the scar.

I tried my hardest to fit in, but I was always a bit different from an early age—soft-spoken, shy, and let's just say, not the athletic type. When all the other boys were playing football or tag at recess, I would be playing wall ball with the girls.

Eventually I would be bullied at school on a regular basis. They called me Fairy Berry (I hated that); would snap their towels at me in the gym locker room; add to that the onset of puberty and the raging hormones that came with it, having sex regularly by sixth grade with the boy who lived down the road, and then the sexual abuse by my father, and it's a wonder I even survived.

I attempted various ways of coping over the years, but nothing seemed to completely wipe away the internalized feelings of shame and unworthiness that lie deep inside. That feeling that was inevitably still there when I came down from the high, the feeling I was never quite able to drown out no matter how much sex I had…and I had a lot.

In 1989 just a few weeks before my 31st birthday, I received the devastating news, "you're HIV-positive." I had finally found my crutch, and the scars that came with it, but somehow it didn't make me popular.

Fast-forward almost 30 years later, and time has given me, at least I hope, some perspective. I find that I'm much more empathetic and forgiving (at least part of the time!), because I've been there. I see my own life reflected back to me when I hear other peoples' stories of pain and trauma. I've come to realize that each of us is on our own path to survival and resilience; we just may be at different time points on the journey. Just as those who have led the way in front of me have picked me up and helped me along, I too try to offer a hand to those on the path behind me.

> I've come to realize that each of us is on our own path to survival and resilience; we just may be at different time points on the journey.

Recently I was able to indulge myself in an old passion of mine—deejaying. I was honored to be able to spin at Club Metro here in Chicago in late August for Chuck Renslow's memorial and the last White Party. I worked for Chuck (who was an early champion of gay rights in Chicago starting in the 1950s and the founder of International Mr. Leather) for about five or six years as a DJ in the late '80s and early '90s. Going back to my first love—music—after all these years later was scary, but ultimately fulfilling. When I was initially asked back in July I immediately jumped at the opportunity and said yes. But then doubt started to creep in when I realized I would not be using any of my old vinyl or turntables, and would have to do everything digitally using a computer. I practiced, practiced, practiced, had a blast, and people seemed to have fun and were dancing (the ultimate litmus test for a DJ). The point is, if you have a chance to follow your passion, go for it. You only go around once (and I'm not talking records on a turntable!).

I think one key to my survival has been the love of family and friends. I was lucky; I realize not everyone gets that (but you can choose your own family if you need to). My mom made me believe I could do anything. And Dad, in his own way that somehow got twisted up along the way, loved me too.

So I'm not just surviving, but thriving, as Ms. Angelou so eloquently put it. Passion? Check. Compassion? I'd like to think so. Humor? A must. And style? I leave that up to you to decide.

Take care of yourself, and each other.

PHOTO: JOHN GRESS

BRIEFLY

ENID VÁZQUEZ @ENIDVAZQUEZPA

How to make a baby

Undetectable viral load makes having a baby safe

IN THE LATEST BATTLE over reproductive rights for people living with HIV, activists demanded that the CDC clarify the safety of conception between a man living with HIV and his HIV-negative female partner. The reality is that simply being undetectable on anti-HIV medication is enough for a man to prevent transmission to the woman.

Instead, the CDC in June issued guidance saying that sperm washing technology can now be used. This was an update from a 1990 CDC report in which sperm washing was *not* recommended.

Sperm washing, however, is a costly and burdensome way to make a baby when all you need to do is have sex—as long as the man is on HIV therapy and has undetectable viral load.

Under activist pressure, the agency published an erratum notice on August 18. The statement clarifies that HIV treatment alone can prevent transmission. Like the June guidance on conception for couples where the male is living with HIV and the woman isn't, the August report pointed to perinatal guidelines from the National Institutes of Health (NIH), which recommend that men living with HIV who want to father a child should have undetectable viral load under HIV therapy before attempting conception.

Also under activist pressure, the August notice goes further in adding data from three studies of thousands of mixed status couples having condomless sex. No HIV transmissions were found among uninfected partners when the HIV-positive partner had undetectable viral load while on antiretroviral therapy.

According to the erratum notice in *Morbidity and Mortality Weekly Report* (MMWR):

The risk for male-to-female sexual transmission of HIV in the absence of any prevention measures is estimated to be approximately 8 per 10,000 episodes of condomless intercourse.

Mixed HIV-status couples attempting conception can also reduce the risk for sexually transmitting HIV by decreasing the frequency of sexual contact and limiting condomless intercourse to the time of ovulation.

In addition, data is added that suggests a risk of 0.32% per 10,000 acts of condomless sex. There's also discussion about HIV genetic material found in the semen of men with undetectable viral load (which may or may not be infectious). Also, the use of PrEP, intrauterine insemination, or *in vitro* fertilization, and any combination thereof, can be used to further reduce the risk of transmission. Unfortunately, the wording of the June *MMWR* guidance made it sound as if multiple prevention strategies are necessary, rather than just one.

The differences matter because many doctors are not knowledgeable about conception for people living with HIV. With misleading or incomplete information, providers might make patients go through unnecessary, and costly, hoops to achieve their dream of having a child.

Shannon Weber, MSW, director of the HIVE at the University of California San Francisco, told TheBodyPro.com that "the lack of information and clear guidance on TasP [treatment as prevention] and PrEP as stand-alone options" was disappointing, whether it was the male or the female partner who was living with HIV. HIVE is the nation's leader in promoting reproductive rights for people living with HIV, including gay men.

JD Davids, Director of Partnerships for TheBody.com, said in a statement, "The vast majority of those on effective treatment have suppressed the virus, meaning they're not at risk of sexual or perinatal transmission of HIV. And a daily pill of anti-HIV medication taken by HIV-negative people virtually eliminates their own HIV risk.

"We were, frankly, shocked and appalled to see a CDC guidance rife with outdated and misleading information that implied otherwise. Today, CDC has not only corrected these errors but released an updated analysis that shows respect for both the strength of the data and for people with HIV themselves.

"Now, they need to bring all their materials and activities into concordance with the simple truths of HIV today, which is preventable and treatable in ways unimaginable decades ago. People with HIV, and the public at large, desperately need this information, as stigma, misinformation, and discrimination remain abysmally high."

ISTOCKPHOTO

Donations to support HIV Hurricane Relief Effort needed

In the wake of Hurricanes Harvey and Irma (and subsequently Maria), the HIV Hurricane Relief Effort was created to provide grants to support organizations serving the needs of people living with and affected by HIV in Florida, Louisiana, Texas, Puerto Rico, and the U.S. Virgin Islands.

AIDS United established the HIV Hurricane Relief Effort as part of the **rapid response arm of the new Southern HIV Impact Fund**, a collaborative effort coordinated by Funders Concerned About AIDS with generous support from Gilead Sciences, Ford Foundation, Elton John AIDS Foundation, and ViiV Healthcare. Gilead Sciences made an additional $1 million available to the Fund to support immediate assistance to areas affected by the storms, and Johnson & Johnson made a major contribution as well.

The demand for help will soon outstrip current available funds. Organizations, businesses, and individuals can make donations to the HIV Hurricane Relief effort at aidsunited.org/Donate/Donate-to-the-HIV-Hurricane-Relief-Effort.aspx.

Aetna lawsuit over privacy violation

The AIDS Law Project of Pennsylvania, along with the Legal Action Center (New York City) and the Philadelphia law firm of Berger & Montague, filed a federal class action lawsuit against the insurance company Aetna for **sending patients letters in which information on HIV medications was clearly visible through a large clear window on the envelope.** They first issued a cease-and-desist letter to the insurer to prevent more letters from being mailed.

Ironically, the 52-year-old man listed as the lead plaintiff does not have HIV, but is taking an HIV medication to prevent infection (a strategy called PrEP). Nevertheless, clearly visible through the envelope is information about obtaining HIV medications. His sister, who lives with him, learned he was taking an HIV medication because of the breach of confidentiality.

The letter was sent to 12,000 customers in at least 23 states.

"For 40 years, HIV-related public health messages have been geared toward assuring people that it's safe to come forward to get confidential HIV treatment, and now our clients come forward for HIV-related healthcare and Aetna fails to provide confidentiality," said Ronda B. Goldfein, executive director the AIDS Law Project of Pennsylvania, in a press release.

Goldfein told TheBody.com that family members, roommates, and neighbors have learned of people's HIV-positive status as a result of the letters.

According to the media release, one Florida couple has already moved from their home because of embarrassment over their invasion of privacy. Other people are being shunned. "After four

HIV nutrition advocate Lark Lands battling metastatic cancer

HIV activists and treatment advocates (including myself) have established **a GoFundMe page for a longtime friend of the HIV community, Lark Lands**.

Since the start of the epidemic, she has served people living with HIV by providing nutritional and supplement advice that's helped keep them alive and healthy, when established medical providers couldn't help with the symptoms patients were experiencing. When the people she helped couldn't afford to pay for her consultation (which was the vast majority of the time), she simply provided her support for free.

Now Lands is battling metastatic cancer that has spread to her lungs, but has no financial means to pay for her therapy or medical equipment, such as a portable oxygen machine that would make a huge difference in her ability to get around. She would need it to get on a plane for a cancer study found by fellow activists.

LARKIN VIA FACEBOOK

"Lark is a very private person who was reluctant to allow us to establish this GoFundMe page, soliciting funds for her," the group writes. "But we argued that *she had given the HIV community so much for so many years that she needed to now let us do something for her.*

"And Lark needs our help. Most of what Lark did working with people living with HIV and with the AIDS orphans project she cofounded in South Africa was done on her own, without a salary and largely uncompensated through much of 30 years. As a result she has no savings or retirement fund or investments to cash in. She still works as a medical editor, basically living hand-to-mouth every month. Thus, *she doesn't have the financial resources to deal with what she is facing*."

Go to gofundme.com/helplarklands. See also an article by Nelson Vergel on TheBody: thebody.com/content/80338/please-help-lark-lands-an-old-friend-of-the-hiv-co.html.

BRIEFLY

decades, HIV and AIDS still cause stigma, leading to discrimination in employment, housing, education, and health care, and even violence," the report notes.

Those affected by the privacy breach can contact the project at 215-587-9377 or find more information at aidslawpa.org.

Hep C medication Olysio to be discontinued?

Janssen Sciences pharmaceutical company announced that **it will not pursue development of its investigational hepatitis C treatment JNJ-4178**. As such, it is withdrawing from the hep C treatment field. In a press release, Janssen reported that, "This decision was made in light of the increasing availability of a number of highly effective therapies addressing the medical need in hepatitis C." Instead, the company will focus on therapy for hepatitis B, "where a high unmet medical need still exists." Hep C treatment advocates expect that the company's hep C medication Olysio (simeprevir) will be discontinued.

'Recovery Rising'

My favorite blogger, William L. White, has a new book out, *Recovery Rising: A Retrospective of Addiction Treatment and Recovery Advocacy*. "I have worked in the arenas of addiction treatment, recovery research, and recovery advocacy for nearly half a century and been blessed with opportunities to work with some of the leading policy makers, research scientists, clinicians, and recovery advocates of my generation," White said in his blog. "At this late stage of my life, it seemed a worthy effort to try to pass on some of the hard-earned lessons I have drawn from this work. Such was the inspiration for turning decades of professional journaling into a book of stories that highlight, through my own experiences, some of the major milestones in the modern history of addiction treatment and recovery." A portion of the proceeds from each book will be donated to grassroots recovery advocacy. Ask your local independent bookstore to order a copy for you. Other books by White include Slaying the Dragon and Pathways from the Culture of Addiction to the Culture of Recovery. His earlier book, *The Culture of Addiction and the Culture of Recovery*, was instrumental in my understanding of addiction.

Criminalization reform passes in California

Knowingly exposing a sex partner to HIV will no longer be a felony in the state of California. Governor Jerry Brown has signed a reform bill into law that reduces it to a misdemeanor.

Senate Bill 239 **amends a decades-old law, reducing prison time from up to eight months to no more than six months if convicted**, the same penalty for intentionally transmitting any other disease.

"HIV should be treated like all other serious infectious diseases, and that's what SB-239 does," said state senator Scott Wiener (D-San Francisco), co-author of the bill. "We are going to end new HIV infections, and we will do so not by threatening people with state prison time, but rather by getting people to test and providing them access to care."

Supporters of the reform charged that the old law criminalized HIV, creating an atmosphere of fear and distrust that discouraged people from getting tested. HIV was the only communicable disease for which intentional exposure was a felony under California law.

"The passage of SB-239 marks tremendous progress for Californians living with HIV. Laws that criminalize HIV positive status are not based on science—they are based solely on hysteria and fear—and essentially create an underclass of people diagnosed with a disease, placing us at risk for discrimination and even violence," said Naina Khanna, executive director of Positive Women's Network (PWN-USA).

The reform bill goes into effect January 1, 2018. It will also apply to people living with HIV who donate blood without informing the blood bank of their status. —RICK GUASCO

Descovy in pediatrics

The Descovy (FTC/TAF) package insert was updated to include 24 week data in children. "**Use of Descovy in pediatric patients weighing at least 25 kg [55 pounds] is supported by adequate and well-controlled studies** of [Genvoya] in adults [and by a study of children ages 6 to less than 12 who weighed at least 25 kg]." Descovy can now be used in that population. Previously, it was approved for use in patients age 12 and up weighing at least 35 kg (77 pounds).

Norvir oral solution

The package insert for Norvir oral solution was updated in October to include feeding tube information. "Because Norvir oral solution contains ethanol and propylene glycol," the FDA reported in a press release, "**it is not recommended for use with polyurethane feeding tubes** due to potential incompatibility. Feeding tubes that are compatible with ethanol and propylene glycol, such as silicone and polyvinyl chloride (PVC) feeding tubes, can be used for administration of Norvir oral solution. Follow instructions for use of the feeding tube to administer the medicine."

CDC: Undetectable means effectively no transmission risk

The CDC issued its **strongest statement to date** on the lack of HIV transmission when people living with the virus have undetectable viral load. For National Gay Men's HIV/AIDS Awareness Day, on September 27, the CDC said that "people who take ART [HIV therapy] daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner." This means you too, straight boys and bi boys.

HIV research in the era of PrEP

Treatment Action Group (TAG) reported that, "The effectiveness of pre-exposure prophylaxis (PrEP) with the antiretroviral drug combination TDF/FTC (Truvada) **raises questions regarding the design and conduct of trials** of other candidate biomedical HIV prevention interventions, such as vaccines, passive immunization and alternative forms of PrEP." Read the group's white paper on this topic at treatmentactiongroup.org.

Nurse assaulted by police who protected a patient

An internal affairs investigation found that **two Salt Lake City police officers violated guidelines on arrests, ethics, and officer conduct**, and other rules, when arresting a hospital nurse for refusing to take a blood sample from an unconscious patient. As both she and a hospital supervisor had explained, such an action was against hospital procedure, as well as state and federal law. A blood draw was not allowed without a patient's consent unless there was a warrant or an arrest. According to reports, the patient had been struck by a vehicle driven by someone fleeing from the police.

Detective Jeff Payne and Lt. James Tracy were put on administrative leave. Payne also lost his part-time job as a paramedic. The FBI announced that it was looking into whether Payne violated federal laws. The State of Utah is also investigating.

In a press release from National Nurses United, co-president Jean Ross, RN, said, "The first job of a registered nurse is always to protect and advocate for her patient, period. As the videos and news accounts make clear, there is no excuse for this assault, or her arrest, which sends a chilling message about the safety of nurses and the rights of patients." The association announced that it was sponsoring a campaign to help stop "the growing epidemic of hospital workplace violence."

Everyone living with HIV should be checked for pain

New guidelines recommend screening everyone living with HIV for pain. The guidelines were released in September by the HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA). **Patients should be asked how much bodily pain they have experienced in the past week** or if they've had bodily pain that has lasted more than three months. A list of resources for physicians is provided. The guidelines state that opioids should not be used as a first-line treatment. Instead, physicians should turn to a multidisciplinary approach using non-drug options ranging from yoga to physical therapy.

HIVMA PAIN GUIDELNES AT A GLANCE

All people living with HIV should be screened for chronic pain, which affects 39 to 85% of people with HIV.

Those who have chronic pain should be treated using a multidisciplinary approach focused on non-drug options ranging from yoga to physical therapy, note the guidelines. Opioids should never be a first-line treatment.

Almost half of all chronic pain in people with HIV is neuropathic (nerve) pain, which researchers believe is due to **inflammation caused by the infection of the central or peripheral nervous system**. Non-neuropathic pain typically is musculoskeletal, such as low-back pain and osteoarthritis in the joints.

Born this way

HIV-positive since birth, Nestor Rogel navigates stigma in a gay, HIV-positive world

BY **ENID VÁZQUEZ** PHOTOGRAPHY BY **LOUIS CARR**

“I have to explain—even defend—my sexuality,” said Nestor Rogel, 27. Born with HIV in 1990, he finds accessing services, and clinical care, uncomfortable, and even discriminatory, as a straight man.

One doctor insisted on an anal swab for gonorrhea because he didn’t believe Rogel was straight. Nor did he believe that Rogel had never had anal sex. Rogel was extremely uncomfortable with the entire encounter, including the dismissal of his sexuality.

When filling out medical paperwork and putting down “HIV-positive,” providers have said, “Oh, you’re gay.” This despite the fact that they know he was born HIV-positive.

Rogel is open about having HIV and about being born with it. “I have this tattoo on my arm that reads ‘HIV+’ in big, bold letters,” he said, “so I get some interesting encounters in my day-to-day life.” People, including medical providers, often still don’t believe he’s straight. “Maybe because the virus is supposed to make me gay,” he jokes with a laugh.

Rogel first realized how left out he was as a straight male when he sought social services at the age of 18. His mother had died and he wanted to strike out on his own. He found housing services and other assistance closed off to him because they were created specifically for men who have sex with men (MSM). Although such services exclude him, he understands the need for serving gay men living with HIV.

“I know that HIV was once called GRID [gay-related immune disorder]. And because I have HIV, people assume automatically that I’m gay,” said Rogel. “I am often labeled as gay because I’m HIV-positive, or a drug user when people learn I’m straight.”

He only knows three other straight men living with the virus—and one of them lives in Thailand. “HIV providers focus heavily on ‘target populations,’ ” he said, such as young gay black men, and “we’re not a targeted population, so it’s not something that people want to focus on. We’re so few, so we’re forgotten.”

One difficulty arises when he searches for support from other people living with HIV.

In Los Angeles, where he lives, Rogel looked for events where he can talk with other people also living with the virus, but these events were inevitably gay-centric. He found himself having to explain that he is not gay, particularly when being cruised. “In a lot of ways ... you feel sexually harassed. Having people staring at you, you know?” he says.

The men making him uncomfortable were older. One man who was interested in having sex with him taunted him to “stop being straight.”

It’s a problem that also affects young gay men looking for HIV services. Dazon Dixon Diallo, Executive Director of Sister Love in Atlanta, when interviewed for a separate article, reported that young gay men would rather reach out to her organization because they felt preyed upon by older men at other HIV service organizations.

Although Rogel is comfortable around gay men and the gay community, like many, he’s uncomfortable fending off unwanted advances.

“I go to these events just to know other people living with HIV, but you know, guys can be very aggressive when they flirt,” he said. “I tell my sisters [who are HIV-negative] I sympathize with them. I realize this is what I have to deal with when I go to events like this. But women have to deal with different straight guys every day of their lives.”

Yet educational or social events may be the only places where he can meet other positive people, or the only services he can access. Many services are provided directly by LGBTQ organizations.

He finds that HIV-positive women, however, often identify as heterosexual, and that may be one way to open up positive communities to more straight men. “I think some services and spaces could be opened to all people living with HIV instead of just gay people living with HIV,” Rogel said. Some of this, he noted, could start with branding (advertising, logos, etc.).

“Sometimes the focus on key populations takes away the humanity of HIV,” Rogel said. “That it is a human condition. This is a human disease.”


HIV+

WHAT IS GENVOYA®?

GENVOYA is a 1-pill, once-a-day prescription medicine used to treat HIV-1 in people 12 years and older who weigh at least 77 pounds. It can either be used in people who are starting HIV-1 treatment and have never taken HIV-1 medicines before, or people who are replacing their current HIV-1 medicines and whose healthcare provider determines they meet certain requirements. These include having an undetectable viral load (less than 50 copies/mL) for 6 months or more on their current HIV-1 treatment. GENVOYA combines 4 medicines into 1 pill taken once a day with food. GENVOYA is a complete HIV-1 treatment and should not be used with other HIV-1 medicines.

GENVOYA does not cure HIV-1 infection or AIDS.

To control HIV-1 infection and decrease HIV-related illnesses, you must keep taking GENVOYA. Ask your healthcare provider if you have questions about how to reduce the risk of passing HIV-1 to others. Always practice safer sex and use condoms to lower the chance of sexual contact with body fluids. Never reuse or share needles or other items that have body fluids on them.

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about GENVOYA?

GENVOYA may cause serious side effects:

- **Worsening of hepatitis B (HBV) infection.** GENVOYA is not approved to treat HBV. If you have both HIV-1 and HBV and stop taking GENVOYA, your HBV may suddenly get worse. Do not stop taking GENVOYA without first talking to your healthcare provider, as they will need to monitor your health.

Who should not take GENVOYA?

Do not take GENVOYA if you take:

- **Certain prescription medicines for other conditions.** It is important to ask your healthcare provider or pharmacist about medicines that should not be taken with GENVOYA. Do not start a new medicine without telling your healthcare provider.
- **The herbal supplement** St. John's wort.
- **Any other medicines to treat HIV-1 infection.**

What are the other possible side effects of GENVOYA?

Serious side effects of GENVOYA may also include:

- **Changes in your immune system.** Your immune system may get stronger and begin to fight infections. Tell your healthcare provider if you have any new symptoms after you start taking GENVOYA.
- **Kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys. If you develop new or worse kidney problems, they may tell you to stop taking GENVOYA.
- **Too much lactic acid in your blood (lactic acidosis),** which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- **Severe liver problems,** which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of GENVOYA is nausea. Tell your healthcare provider if you have any side effects that bother you or don't go away.

What should I tell my healthcare provider before taking GENVOYA?

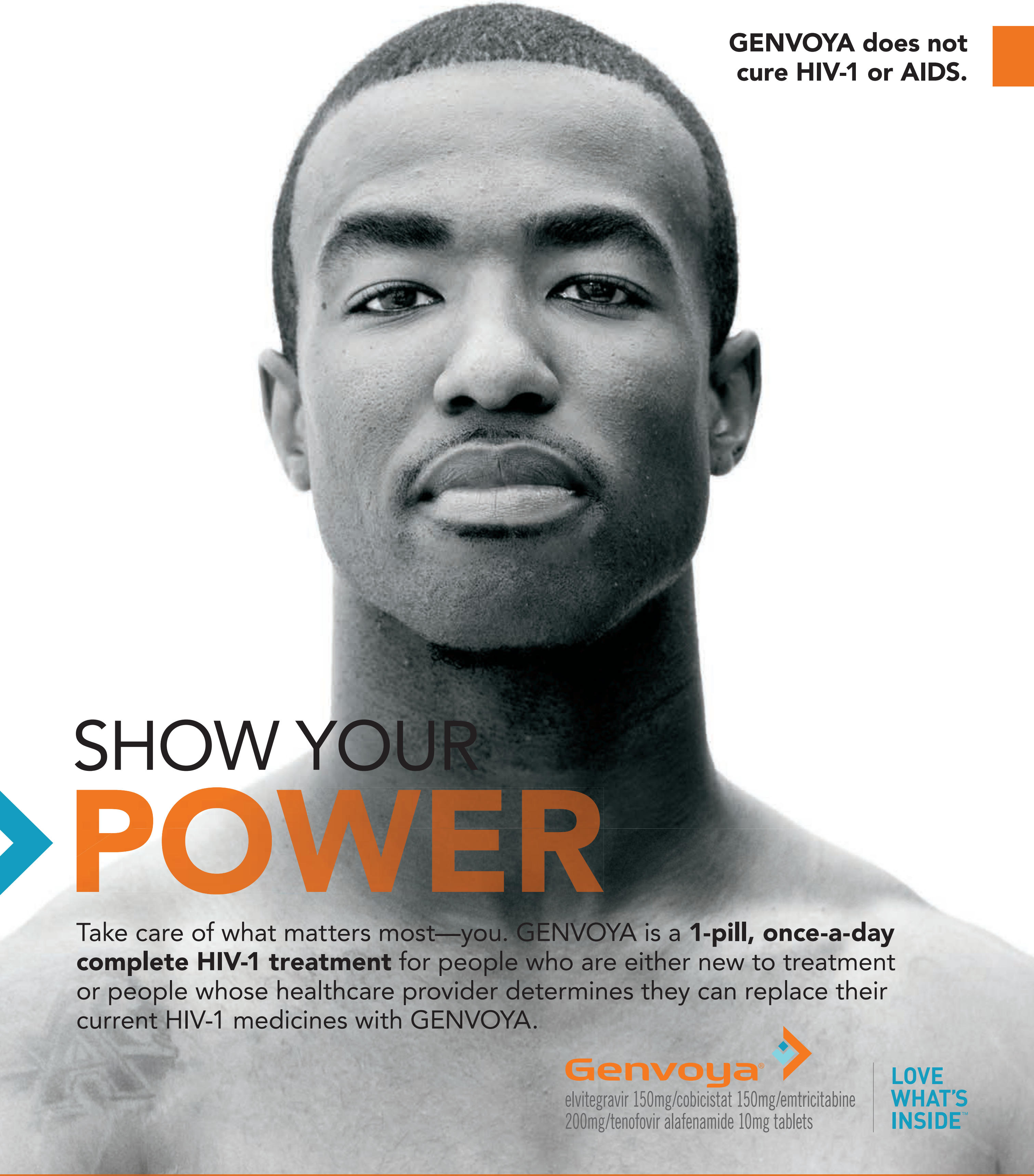
- **All your health problems.** Be sure to tell your healthcare provider if you have or have had any kidney or liver problems, including hepatitis virus infection.
- **All the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. Other medicines may affect how GENVOYA works. Keep a list of all your medicines and show it to your healthcare provider and pharmacist. Ask your healthcare provider if it is safe to take GENVOYA with all of your other medicines.
- **If you take antacids.** Take antacids at least 2 hours before or after you take GENVOYA.
- **If you are pregnant** or plan to become pregnant. It is not known if GENVOYA can harm your unborn baby. Tell your healthcare provider if you become pregnant while taking GENVOYA.
- **If you are breastfeeding** (nursing) or plan to breastfeed. Do not breastfeed. HIV-1 can be passed to the baby in breast milk.

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

Please see Important Facts about GENVOYA, including important warnings, on the following page.

Ask your healthcare provider if GENVOYA is right for you.

GENVOYA.com



Genvoya®

elvitegravir 150mg/cobicistat 150mg/emtricitabine
200mg/tenofovir alafenamide 10mg tablets

(jen-VOY-uh)

IMPORTANT FACTS

This is only a brief summary of important information about GENVOYA® and does not replace talking to your healthcare provider about your condition and your treatment.

MOST IMPORTANT INFORMATION ABOUT GENVOYA

GENVOYA may cause serious side effects, including:

- **Worsening of hepatitis B (HBV) infection.** GENVOYA is not approved to treat HBV. If you have both HIV-1 and HBV, your HBV may suddenly get worse if you stop taking GENVOYA. Do not stop taking GENVOYA without first talking to your healthcare provider, as they will need to check your health regularly for several months.

ABOUT GENVOYA

- GENVOYA is a prescription medicine used to treat HIV-1 in people 12 years of age and older who weigh at least 77 pounds and have never taken HIV-1 medicines before. GENVOYA can also be used to replace current HIV-1 medicines for some people who have an undetectable viral load (less than 50 copies/mL of virus in their blood), and have been on the same HIV-1 medicines for at least 6 months and have never failed HIV-1 treatment, and whose healthcare provider determines that they meet certain other requirements.
- **GENVOYA does not cure HIV-1 or AIDS**. Ask your healthcare provider about how to prevent passing HIV-1 to others.

Do NOT take GENVOYA if you:

- Take a medicine that contains: alfuzosin (Uroxatral®), carbamazepine (Carbatrol®, Epitol®, Equetro®, Tegretol®, Tegretol-XR®, Teril®), cisapride (Propulsid®, Propulsid Quicksolv®), dihydroergotamine (D.H.E. 45®, Migranal®), ergotamine (Cafergot®, Migergot®, Ergostat®, Medihaler Ergotamine®, Wigraine®, Wigrettes®), lovastatin (Advicor®, Altoprev®, Mevacor®), lurasidone (Latuda®), methylergonovine (Ergotrate®, Methergine®), midazolam (when taken by mouth), phenobarbital (Luminal®), phenytoin (Dilantin®, Phenytek®), pimozide (Orap®), rifampin (Rifadin®, Rifamate®, Rifater®, Rimactane®), sildenafil when used for lung problems (Revatio®), simvastatin (Simcor®, Vytorin®, Zocor®), or triazolam (Halcion®).
- Take the herbal supplement St. John's wort.
- Take any other HIV-1 medicines at the same time.

GET MORE INFORMATION

- This is only a brief summary of important information about GENVOYA. Talk to your healthcare provider or pharmacist to learn more.
- Go to GENVOYA.com or call 1-800-GILEAD-5
- If you need help paying for your medicine, visit GENVOYA.com for program information.

POSSIBLE SIDE EFFECTS OF GENVOYA

GENVOYA can cause serious side effects, including:

- Those in the "Most Important Information About GENVOYA" section.
- Changes in your immune system.
- New or worse kidney problems, including kidney failure.
- Too much lactic acid in your blood (lactic acidosis), which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- Severe liver problems, which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of GENVOYA is nausea.

These are not all the possible side effects of GENVOYA. Tell your healthcare provider right away if you have any new symptoms while taking GENVOYA.

Your healthcare provider will need to do tests to monitor your health before and during treatment with GENVOYA.

BEFORE TAKING GENVOYA

Tell your healthcare provider if you:

- Have or have had any kidney or liver problems, including hepatitis infection.
- Have any other medical condition.
- Are pregnant or plan to become pregnant.
- Are breastfeeding (nursing) or plan to breastfeed. Do not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.

Tell your healthcare provider about all the medicines you take:

- Keep a list that includes all prescription and over-the-counter medicines, vitamins, and herbal supplements, and show it to your healthcare provider and pharmacist.
- Ask your healthcare provider or pharmacist about medicines that should not be taken with GENVOYA.

HOW TO TAKE GENVOYA

- GENVOYA is a complete one pill, once a day HIV-1 medicine.
- Take GENVOYA with food.

GILEAD

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OUTDATED ORDERS

How service members living with HIV are subjected to criminalization

BY JOSEPH DARIUS JAAFARI

Zachary remembers the exact date he was diagnosed with HIV while serving in the armed forces. He remembers exactly the situation that got him there—a bad relationship with a cheating partner—and he remembers feeling completely numb for days. The one thing he doesn't remember that well is signing an order that would eventually result in him being charged with felony assault and a military court martial because of his HIV status.

"I was so out of it after being diagnosed, I didn't know what exactly was being said to me. I was in a daze," said Zachary, which is not his real name; he was granted anonymity because of fears of retaliation.

Zachary said he lived in a haze—an almost zombie-like trance where nothing made sense for days on end. The feeling is not lost on other service members interviewed for this story who were diagnosed with HIV while serving. That state of shock lasted for days with many, and, for some, a few weeks.

It's during that time period immediately after diagnosis that the military makes their best efforts to get HIV-positive service members access to medication and therapy, but it is also the time when important documents are presented and signed off by military members. Included in that list of documents is a safe sex order that requires soldiers to verbally express their status to doctors or dentists, avoid certain types of sexual contact, and to always wear a condom—even during oral sex.

But science and the progress of HIV medication, prevention, and transmission isn't behind the military's safe sex orders, which if violated can result in military charges of felony assault and a court martial for failure to abide by an order. >>

Despite national trends, HIV in the military has actually gone up since 2011, according to the Defense Health Agency's Medical Surveillance Report published in 2015.

ISTOCKPHOTO

>> A FEAR OF TEARS

HIV has become less of a problematic disease as doctors and health departments in high-risk urban cities across the country have pushed for the marketing and daily usage of pre-exposure prophylaxis, or PrEP—the medical protocol that reduces exposure to HIV by up to 99 percent. Since 2012, there have only been a few cases of someone on the treatment actually contracting the virus.

And medical advances in the treatment of those living with HIV has proven to be 100 percent effective in not transmitting the virus if the person infected is at an undetectable level—the level in which the virus can't be traced in their blood stream.

But despite those national trends, HIV in the military has actually gone up since 2011, according to the Defense Health Agency's Medical Surveillance Report published in 2015.

The military began testing and tracking HIV service members 30 years ago. In 1986, roughly five years after the HIV and AIDS epidemic began, the military tested during enlistment and barred anyone who tested positive. By the time the AIDS crisis began to lessen in the mid-1990s, the Army and Navy started testing more regularly. Service members are now tested every two years after enlistment as well as before deployment.

But the Centers for Disease Control (CDC) suggest testing for HIV among men who have sex with men—or other high-risk populations—every three months. And based on who you speak with, military personnel should be one of those populations with greater vulnerability to HIV.

"The military, depending on how you look at it, could be seen as high risk for contracting HIV," says Matt Rose, policy and advocacy manager with NMAC (formerly known as the National Minority AIDS Council) in Washington, D.C, referring to exposure on the battle field to blood or in medical situations where open wounds could come in contact with others.

Brian Ledford, a former Marine who was diagnosed with HIV in 2010, says that the two-year testing period provided a false sense of security. "I was dumb and should've known better, but I just thought, you know, I'm already getting tested so it'll be fine," Ledford said.

Ledford's mentality was echoed by former Army Cpt. Josh Seefried, the founder of the LGBTQ military group OutServe. In a phone interview, Seefried said OutServe warned military health leaders that HIV was a problem within the armed forces a decade ago.

"People have this mindset that since you're tested and you're in the military, it must be okay to have unprotected sex," he says. "That obviously leads to a higher infection rate."

Ledford is a shining case study of the policy's missteps. He tested positive before his deployment out of San Diego. He says because the Navy offered routine tests, he never bothered to get tested independently, despite being sexually active.

Ledford said he remembers being taken back to San Diego for "legal reasons," and after he was told about his status he was kept locked alone in a barracks hall on base for a week.

"I was left completely alone, I had no one to talk to. It was awful," he said, and added that he thought his handlers didn't know what to do with him after being diagnosed.

The treatment Ledford experienced doesn't sound unusual to other soldiers who tested HIV-positive while serving in the military.

"In general, we don't have a lot of good education awareness within the military on being HIV-positive," said Matt Thorne, the current executive director of OutServe-SLDN. (SLDN—Servicemembers Legal Defense Network—provided services to gay and lesbian military personnel and veterans, and later merged with OutServe.) "People are looking back and they're reflecting on those initial horrors. But the truth of the matter is that it's not a death disease anymore."

Peter Perkowski, OutServe-SLDN's legal director, said the education surrounding HIV in the military is shocking.

"It's pretty mind-boggling some of the things people still think," he said, remembering a case where he witnessed someone consoling a friend who was diagnosed with HIV, and then later saying they were afraid to be infected by the friend's tears. "That was just—*insane*."

SCIENCE NOT IN COMMAND

In 2016, Zachary invited a friend over on base who he met off a gay sex hookup website.

"I honestly thought we were going to watch a movie and that be that," he said. But anyone who can read between the lines could easily interpret and give a nod to this encounter as a "Netflix and Chill" situation (code for more than just watching a movie).

Nonetheless, Zachary made his intentions and his status clear—he knew that much, that he had to disclose his status to everyone. But it was via online.

"I've never hid my status among people. It's everywhere on my Facebook and [other social media sites]," he said. "And it says right there on [the website we met on] that I'm positive."

Zachary had sex with a condom that night. But even if he hadn't, he already had an undetectable status at that point, making transmission a near impossibility.

Months after the movie night, Zachary found himself being questioned by military officials, saying he was accused of violating his safe sex order for not verbally expressing his status and was being charged with assault and could face discharge.

Charging HIV-positive service members with assault is not a new course of action for the military. A handful of cases has been brought before court martial that made their way into the national press. In all the cases, including Zachary's, there have been no instances of HIV being transmitted from one person to the other. "Assault" refers to exposure to the virus, whether it was transmitted or not.

In 2012, former Army Lieut. Col. Kenneth Pinkela was charged under Uniform Code of Military Justice rules with aggravated sexual assault and served time in prison for exposing a younger soldier to the virus, despite medical testimony saying it was impossible for Pinkela to transmit the virus because of his undetectable status and that anal sex had never happened.

In 2014, Air Force Sgt. David Gutierrez was also charged with aggravated assault for exposing multiple people to HIV, though the prosecution admitted that no transmission had actually happened. Both were also charged with violating their safe sex orders.

Safe sex orders have been used since the 1990's, when HIV ran rampant across gay communities and information on how the virus was transmitted was still widely misunderstood. At the time the orders were first drafted in 1994, the military knew primarily two things: HIV was transmittable by bodily fluids, and it was happening predominantly among gay men.

The original orders forbade the sharing of toothbrushes or razors, and stated that service members who test positive should reconsider children because of the transmission of the virus from mother to child.

But we've known for decades now that HIV's transmission via the bloodstream needs to be direct. The nick of a razor or a dirty toothbrush can't do that (although the CDC recommends not sharing these items due to the potential for blood contamination). Research also shows that women who are HIV-positive can, indeed, have HIV-negative children so long as proper medication is used.

Despite the medical advances and general understandings we've gathered over the past thirty years, only one military branch—the Navy—has updated its safe sex orders. The other branches of the military still use the 1994 form. The Navy and Marine guidelines, though, still suggest avoiding childbirth.

"It's your right to procreate," says Catherine Hanssens, executive director of the Center for HIV Law and Policy, in New York City. "To effectively say to someone that because you're HIV-positive, even if you inform your partner, you shouldn't conceive a child raises constitutional issues."

When asked earlier this year why the current safe sex orders continue to list off risks that can't transmit the virus, Department of Defense officials responded that, "It is true that the risk is negligible if... the HIV-infected partner has an undetectable HIV viral load. However, it cannot be said that the risk is truly zero percent."

The orders also require those diagnosed to tell sexual partners and medical personnel of their status before contact with any body fluids, including saliva.

If someone does not follow any one of the guidelines outlined in the order, they can be punished under the Uniform Code of Military Justice (UCMJ) and face jail time or a discharge, or both.

Only one military branch—the Navy—has updated its safe sex orders. The other branches of the military still use the 1994 form. The Navy and Marine guidelines, though, still suggest avoiding childbirth.

Earlier this year, officials at the Department of Defense emailed a statement to this reporter that "the Army does not use [safe sex orders] to support adverse action punishable under UCMJ."

Perkowski, OutServe-SLDN's legal director, scoffed at the Department of Defense's comment.

"That's preposterous," he said, "having just finished a court martial involving a UCMJ felony charge arising from a safe sex order."

In the past six months, Perkowski has been involved in at least two cases where a soldier has been either put into a court martial or has gone through the process of being separated (discharged) for failing to abide by their safe sex order. The Center for HIV Law and Policy has also seen a number of cases in the military rising from a failure to abide by a safe sex order dating back to 2008.

A NATIONAL PROBLEM

It's unclear how many service members have been punished for not abiding by their safe sex orders, but the criminalization of HIV is not unique to the military. Thirty-two states have similar laws that punish and imprison people who have HIV, even if no transmission occurred.

Between January and July 2017, the Center for HIV Law and Policy counted 24 news reports of people being charged with various criminal charges for exposing HIV to a victim via biting. Bites from people with HIV are considered a "negligible" risk factor for transmission, according to the CDC.

This year, California Rep. Barbara Lee and Florida Rep. Ileana Ros-Lehtinen again introduced a bill that would end criminalization of HIV. The bill has been reintroduced every year since 2011 without passing.

Rep. Lee also spoke on the issue recently at a Global Citizen event in New York and said in a statement that, "HIV criminalization laws are based on bias, not science. Instead of making our communities healthier, these laws breed fear, discrimination, distrust, and hatred. Our laws should not perpetuate prejudice against anyone, particularly against those living with diseases like HIV."

The U.S. is second only to Russia in HIV prosecutions, with at least 104 cases brought forward between 2013 and 2015, primarily in America's heartland states, according to a report released by the HIV Justice Network.

And the length of time for those prosecuted for an HIV-related crime is significantly harsh, with prison times stretching into years. The current tide of criminalization might see a swell of interest since the recent re-emergence of news on college wrestler Michael Johnson, aka "Tiger Mandingo." Johnson was originally sentenced in 2015 to 30.5 years in prison for knowingly transmitting or exposing HIV to five sexual partners and is now pleading no contest in order to see freedom within the next two years, *BuzzFeed* reported.

"When you think of it, the sentence does not fit the crime. People have murdered and been sentenced for less time in prison," says Joel Goldman, the executive director for the Elizabeth Taylor AIDS Foundation. "We really need the public to be aware. There's so much more that needs to be done, and what is effective is really just telling the story of HIV criminalization."

PrEP FOR A FEW

Travis Hernandez, a former sergeant in the Army, has been on the drug Truvada for about two years now. While stationed at Fort Bragg, he started using the once-a-day blue pill when he learned that the drug could prevent HIV transmission by nearly 100 percent.

He didn't learn about the drug from any military health officials, though. He got the information from a casual sex partner.

"A guy I was in the Army with and having sex with told me about it, and I was sexually active so it made sense for me to try it," Hernandez said, also saying he didn't have any problems getting the drug while enlisted.

But that's not everyone's story.

The military gives access to Truvada, which is the drug used for PrEP, through its healthcare provider TriCare, but only for certain individuals. Different military branches have their own set of rules for who can get access to the drug.

BLACKWATERIMAGES/ISTOCKPHOTO

"The military likes to set their own rules, even if it doesn't always make sense," says NMAC's Matthew Rose. "The Army thinks they know what's best for the Army, and Marines think they know what's best for the Marines. But they all have different medical requirements that shouldn't have any dissimilarities."

Emails between NMAC and Military Health officials that were obtained by this reporter confirmed that there are different protocols for prescribing Truvada between the service branches and its members without any specific reason.

"Navy pilots, for example, can take Truvada while on the flight line, but Air Force pilots cannot while they are on the flight line," says Seefried, from OutServe. "These military branches have different chains of command, so they have different policies that all agree on nothing. It's just disjointed, and not grounded in science."

Military Health said in a statement that they are conducting studies on the effectiveness of PrEP in certain situations, such as while on flight status or sea duty, and are also looking into barriers service members face with access to care across the military branches. Among those barriers, officials pointed out that not every military hospital has infectious disease specialists who would be in charge of prescribing the drug.

Truvada does not require a prescription from an infectious disease doctor, though. And the different policies, Seefried says, show the lack of scientific competence within the Department of Defense and the policies it creates.

According to a source inside Military Health familiar with the problem, what happens on the research and medical arm of the military doesn't necessarily inform the policy arm of the military.

Advocates point to the 2014 Gutierrez case, where the court's judges ruled that military members could not be charged with aggravated felony assault if a person is undetectable and the risk of contracting the disease is negligible.

"It's very interesting that you have all these medical experts serving in the military and know about this, and yet the people who came to the conclusion that the risk was insignificant was a court of law—a bunch of judges," said Allison Nichol, a senior legal and policy advisor for the Sero Project, an HIV non-profit. "It's pretty astonishing."

Despite the Gutierrez ruling, a lower felony assault charge can still be executed against service members if those who test positive don't properly disclose, as instructed on their safe sex orders. The assault charge assumes that if someone does not know of the other person's status, full consent of a sexual act can't be confirmed.

Which is exactly what got Zachary into the position he was in a few months ago when facing court martial for his assault charge—despite his undetectable status—and was found guilty for not abiding by his safe sex order.

The loss is proof for lawyers who work on behalf of service members living with HIV that the military still has miles to go when it comes to equal treatment for HIV-positive and gay service members.

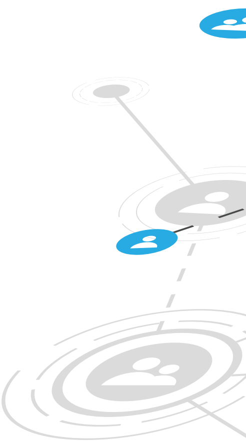
"The military for people with HIV is not safe right now, and it's because of these safe sex orders," said Perkowski. "There's this combination of knee-jerk application of rules and regulations along with LGBT bias and HIV bias which is based on a lack of understanding of HIV science."

Despite the experience of the court martial, Zachary still loves the armed forces.

"I don't want to leave [my job]. I get to travel the world, do great things and help people," he said. "I just think there needs to be a change."

JOSEPH DARIUS JAAFARI is a writer and documentary filmmaker based out of Brooklyn, NY. His work on military and veteran health can be seen in *VICE*, *The Atlantic*, *Rolling Stone*, and *Quartz*. He is also a guest lecturer on military and sex at the University of Chicago's School of Professional Psychology in Washington, D.C. He can be reached via his website josephdariusjaafari.com or Twitter @josephjaafari.

SOCIAL SCIENCE IN HIV CURE RESEARCH



Three studies go beyond clinical work

BY **AMY K. JOHNSON, GEORGE GREENE,** AND **JIM PICKETT**

INTEREST IN HIV CURE RESEARCH is growing exponentially, and we've seen an increase in funding available for HIV cure research in the past five years. The majority of research is in the clinical science sphere—with approximately 100 clinical trials being conducted globally (go to treatmentactiongroup.org/cure/trials).

Early and ongoing engagement of stakeholders, such as people living with HIV, is critical to navigating complex ethical issues as well as ensuring acceptable implementation strategies should there be an opportunity to scale up cure activities.

HIV cure can be thought of in two distinct ways:

1. eradication, or sterilizing, cure in which HIV is completely eliminated from the body; and
2. remission, in which some HIV remains but is undetected in the blood without ongoing medication

A cure for HIV would get rid of the need for ongoing medication, stop onward transmission, and would halt viral progression. The promise of a cure is exciting and has the potential to positively impact the health and wellbeing of many as well as reduce the global economic impact of lifelong treatment. Most, if not all, of the current trials are in the very early "proof-of-concept" stages.

This important work will contribute greatly to the cure field, but honestly won't offer much, if any, clinical benefit to participants—yet participation could pose a number of risks.

The potential benefit of finding a cure for HIV is great, and highlights the need for people living with HIV to look at every aspect of the research agenda. Clinical cure trials may involve significant risk to participants, requiring close external monitoring, ongoing examination of risk-benefit ratios, careful informed consent procedures, and mechanisms for reporting findings as trials progress.

All clinical cure trials should have a well-planned community engagement strategy, inclusive of ongoing monitoring and feedback mechanisms. Research designs and methods should be reviewed by community representatives and advocates, allowing time for discussion, feedback, and revision as needed.

The possibility of being cured of HIV is a strong incentive to participate in cure research activities. Research involvement, however, may pose significant short- and long-term risks with very little promise of study participants being cured (at this stage of research).

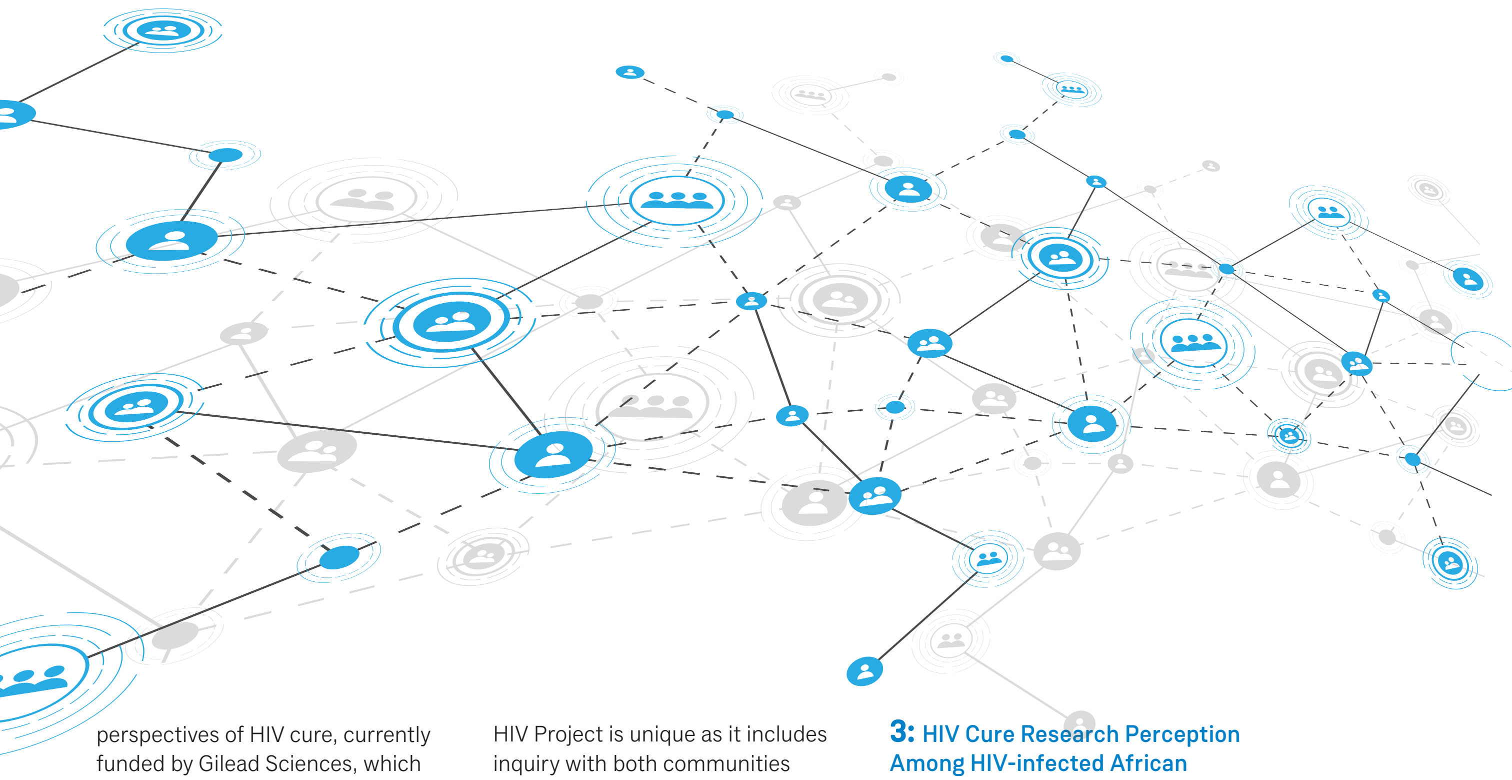
One example under investigation is analytic treatment interruption, in which HIV-positive participants stop taking antiretrovirals (ARVs) and are monitored over time for sustained viral suppression.

Ongoing dialogue needs to occur between the scientific community and communities impacted by HIV about how to determine and communicate the risks and potential benefits of participating in cure research.

Jim Pickett, Sr. Director of Prevention Advocacy and Gay Men's Health at AIDS Foundation of Chicago and Key Personnel on a community-based cure research project, affirms the need for people living with HIV to be front and center in cure research. "Having worked most of my career in advocacy for new HIV prevention strategies like PrEP and microbicides, I am delighted to be working on HIV cure research as well," said Pickett. "Frankly, when I found out I was HIV-positive in 1995, I had no expectation I would be here at age 51, and I certainly could not have conceived of such a robust cure agenda. That said, we collectively need to step up our game in terms of socio-behavioral research. Humans are messy and complex—and cure research is anything but easy and straightforward."

Developing a cure for HIV requires a combination of innovative clinical techniques and interventions, as well as the collaboration of multiple sectors and key stakeholders.

To that end there are three studies focused on community



ISTOCKPHOTO

perspectives of HIV cure, currently funded by Gilead Sciences, which aim to explore social and behavioral implications of HIV cure research.

1: Chicago Unites in Research to End HIV (CURE HIV)

CURE HIV is a partnership among the AIDS Foundation of Chicago, Northwestern University, and Lurie Children's Hospital of Chicago. The project's long-term goals are to increase the acceptability and willingness to engage in future HIV cure research and therapy among four key populations: young gay men and other men who have sex with men, men of color who have sex with men, and women of color, inclusive of transgender women. The CURE HIV project also aims to increase scientists' ability to engage in ethical and acceptable HIV cure research with highly impacted communities. To achieve these goals, it seeks to engage communities disproportionately affected by HIV in mixed methods research, using focus groups and surveys, to assess understanding of, and interest in, HIV cure research. Using findings from this formative research, the study team will develop a curriculum to educate and train community liaisons and cure researchers to increase and sustain dialogue about research. Finally, the CURE HIV Project will host community events to enhance education on HIV cure research to both facilitate community involvement and disseminate accurate information. The CURE HIV Project is unique as it includes inquiry with both communities most impacted by HIV and cure scientists themselves.

2: Women's Willingness to Participate in HIV Cure Research and Principles of Stakeholder Engagement

Data that are currently available on participation in cure trials underrepresent women living with HIV. To address those limitations, a partnership between Project Inform, the University of North Carolina Gillings School of Global Public Health, The Forum for Collaborative Research, NMAC, and the Women's Research Initiative on HIV/AIDS, led by principal investigator David Evans (of Project Inform), will be conducting in-depth interviews, focus groups, and online surveys to determine the characteristics of a hypothetical cure that would be most or least appealing to women living with HIV, and how they feel about the types of cure-oriented research likely to move forward in the near future, with all of its attendant risks, benefits, and burdens. A second aim of the research collaboration is to define some of the factors that might distinguish the best community participatory practices for HIV cure science. For example, effective community engagement has not only improved the conduct of clinical trials for PrEP, but also the dissemination of research results to the community and the wider public.

3: HIV Cure Research Perception Among HIV-infected African American MSM, and Affected Communities in the Deep American South: A Multi-Level Mixed Methods Perspective

Principal investigator Dr. DeMarc Hickson at My Brother's Keeper in Mississippi will focus on adding the perspectives and experiences of African American and black men who have sex with men from the South to the HIV cure research agenda. This community research will use focus groups and surveys to gather data from community participants. We know little about the knowledge and beliefs that black men in the South have about cure research, yet the South experiences much of the U.S. HIV epidemic and would be a crucial intervention point should a cure be viable.

Summary

These three projects funded by Gilead Sciences represent some of the social science involvement in cure research and an inventory of current social science research on HIV cure is being undertaken. As cure research advances, expanding the role of systematic collaboration of multiple sectors ensures that the approaches tested will be acceptable for scale-up and implementation. PA

REFERENCES AVAILABLE AT
POSITIVELYAWARE.COM

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That's why starting and staying on HIV-1 treatment is so important.

WHAT IS DESCOVY®?

DESCOVY is a prescription medicine that is used together with other HIV-1 medicines to treat HIV-1 in people 12 years and older. DESCOVY is not for use to help reduce the risk of getting HIV-1 infection. DESCOVY combines 2 medicines into 1 pill taken once a day. Because DESCOVY by itself is not a complete treatment for HIV-1, it must be used together with other HIV-1 medicines.

DESCOVY does not cure HIV-1 infection or AIDS.

To control HIV-1 infection and decrease HIV-related illnesses, you must keep taking DESCOVY. Ask your healthcare provider if you have questions about how to reduce the risk of passing HIV-1 to others. Always practice safer sex and use condoms to lower the chance of sexual contact with body fluids. Never reuse or share needles or other items that have body fluids on them.

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about DESCOVY?

DESCOVY may cause serious side effects:

- **Worsening of hepatitis B (HBV) infection.** DESCOVY is not approved to treat HBV. If you have both HIV-1 and HBV and stop taking DESCOVY, your HBV may suddenly get worse. Do not stop taking DESCOVY without first talking to your healthcare provider, as they will need to monitor your health.

What are the other possible side effects of DESCOVY?

Serious side effects of DESCOVY may also include:

- **Changes in your immune system.** Your immune system may get stronger and begin to fight infections. Tell your healthcare provider if you have any new symptoms after you start taking DESCOVY.
- **Kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys. Your healthcare provider may tell you to stop taking DESCOVY if you develop new or worse kidney problems.
- **Too much lactic acid in your blood (lactic acidosis),** which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- **Severe liver problems,** which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.
- **Bone problems,** such as bone pain, softening, or thinning, which may lead to fractures. Your healthcare provider may do tests to check your bones.

The most common side effect of DESCOVY is nausea. Tell your healthcare provider if you have any side effects that bother you or don't go away.

What should I tell my healthcare provider before taking DESCOVY?

- **All your health problems.** Be sure to tell your healthcare provider if you have or have had any kidney, bone, or liver problems, including hepatitis virus infection.
- **All the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. Other medicines may affect how DESCOVY works. Keep a list of all your medicines and show it to your healthcare provider and pharmacist. Ask your healthcare provider if it is safe to take DESCOVY with all of your other medicines.
- **If you are pregnant** or plan to become pregnant. It is not known if DESCOVY can harm your unborn baby. Tell your healthcare provider if you become pregnant while taking DESCOVY.
- **If you are breastfeeding** (nursing) or plan to breastfeed. Do not breastfeed. HIV-1 can be passed to the baby in breast milk.

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

Please see Important Facts about DESCOVY, including important warnings, on the following page.

Ask your healthcare provider if an HIV-1 treatment that contains DESCOVY® is right for you.

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IMPORTANT FACTS

This is only a brief summary of important information about DESCOVY® and does not replace talking to your healthcare provider about your condition and your treatment.

MOST IMPORTANT INFORMATION ABOUT DESCOVY

DESCOVY may cause serious side effects, including:

- **Worsening of hepatitis B (HBV) infection.** DESCOVY is not approved to treat HBV. If you have both HIV-1 and HBV, your HBV may suddenly get worse if you stop taking DESCOVY. Do not stop taking DESCOVY without first talking to your healthcare provider, as they will need to check your health regularly for several months.

ABOUT DESCOVY

- DESCOVY is a prescription medicine that is used together with other HIV-1 medicines to treat HIV-1 in people 12 years of age and older. DESCOVY is **not** for use to help reduce the risk of getting HIV-1 infection.
- **DESCOVY does not cure HIV-1 or AIDS**. Ask your healthcare provider about how to prevent passing HIV-1 to others.

BEFORE TAKING DESCOVY

Tell your healthcare provider if you:

- Have or had any kidney, bone, or liver problems, including hepatitis infection.
- Have any other medical condition.
- Are pregnant or plan to become pregnant.
- Are breastfeeding (nursing) or plan to breastfeed. Do not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.

Tell your healthcare provider about all the medicines you take:

- Keep a list that includes all prescription and over-the-counter medicines, vitamins, and herbal supplements, and show it to your healthcare provider and pharmacist.
- Ask your healthcare provider or pharmacist about medicines that should not be taken with DESCOVY.

HOW TO TAKE DESCOVY

- DESCOVY is a one pill, once a day HIV-1 medicine that is taken with other HIV-1 medicines.
- Take DESCOVY with or without food.

POSSIBLE SIDE EFFECTS OF DESCOVY

DESCOVY can cause serious side effects, including:

- Those in the “Most Important Information About DESCOVY” section.
- Changes in your immune system.
- New or worse kidney problems, including kidney failure.
- Too much lactic acid in your blood (lactic acidosis), which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- Severe liver problems, which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark “tea-colored” urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.
- Bone problems.

The most common side effect of DESCOVY is nausea.

These are not all the possible side effects of DESCOVY. Tell your healthcare provider right away if you have any new symptoms while taking DESCOVY.

Your healthcare provider will need to do tests to monitor your health before and during treatment with DESCOVY.

GET MORE INFORMATION

- This is only a brief summary of important information about DESCOVY. Talk to your healthcare provider or pharmacist to learn more.
- Go to DESCOVY.com or call 1-800-GILEAD-5
- If you need help paying for your medicine, visit DESCOVY.com for program information.

GILEAD

2:50 PM: PASADENA, CALIFORNIA
Carlos: I just so happened to have my meds delivered at work! Woot!

3:00 PM: SOUTHWEST WASHINGTON STATE
Maggie: I want to post something upbeat for A Day with HIV but for me, I feel loneliness and fear… In the small pockets of time when I get to connect with my positive community, I feel love and acceptance, but those times are so few and far between."

11:11 AM: NEW ORLEANS, LOUISIANA
Eryck Dillard: Though I'm not living with HIV, I can relate because this is my community. A day has never gone by that I haven't fought for my brothers, sisters, and gender non-conforming persons who are living with HIV.

Behind the smiles on A Day with HIV

Now in its eighth year, POSITIVELY AWARE's anti-stigma campaign has become an annual opportunity to post pictures while sharing personal stories of resilience, perseverance, and support in the face of HIV.

The message behind A Day with HIV is simple—we're all affected by HIV and the stigma sometimes associated with it. To make its point, the campaign captures a single 24-hour period—September 22, this year—by inviting people to photograph a moment of their day. Participants are asked to include the time and location along with a caption explaining what inspired them to take their picture. While uploaded to the campaign's website (adaywithhiv.com), many other pictures were posted on social media with the hashtag #adaywithhiv.

For Melissa Baker, it was a mother's love as her daughter walked to school. "Watching how the sun shines on her," she wrote. "Just another day for me living with HIV, and her without it."

In Pasadena, California, Carlos was excited to have his HIV meds delivered to him.

This year's event was marked by the participation of a number of advocates and activists from various HIV service organizations and other groups, such as the HIV Vaccine Trials Network in Seattle; the Terrence Higgins Trust in England; Hope and Health in Orlando; and the Frannie Peabody Center in Portland, Maine. Evany Turk submitted a photo taken during a meeting of a women's leadership training: "We are a group of women living with HIV, and allies, who are trying to improve the landscape for other women living with HIV in the Dallas-Fort Worth area."

Ten other countries, in addition to the United States, were represented this year. An HIV counselor in Manila, capital of the Philippines, submitted his photo after a long day. An HIV long-term survivor from South Africa posted a photo with his dog. Felipe, a young man, posted on Instagram a picture of himself, facing the mountains in Brazil.

Some photos took a creative approach. Michael Buitron portrayed the group hug at the end of The LGBT Center of Long Beach's newly-diagnosed group by photographing the circle formed by members' feet. Damone Thomas offered a painterly picture of himself preparing for work as an HIV counselor. Some of the staff at Latinos Salud in Miami recreated Leonardo da Vinci's *The Last Supper*—with pizza.

"Humor has always gotten me through the hard parts of living with HIV," said Josh Robbins, of Knoxville, Tennessee, who has shared his own life with HIV on his blog, *I'm Still Josh*, as he mugged for the camera.

But A Day with HIV isn't always about smiles and happy people. Some of the photos submitted serve as reminders of the stigma some people face.

"I live in a small community in southwest Washington State, where the stigma is so heavy," wrote Maggie in her caption. "I spend most of my days feeling isolated. I want to post something upbeat for A Day with HIV but for me, I feel loneliness and fear… In the small pockets of time when I get to connect with my positive community, I feel love and acceptance, but those times are so few and far between."

But A Day with HIV is also a day for hope. As Maggie added, "I took this picture holding the hand of my granddaughter on our way to the park. I believe that she won't know a world that has a stigma attached to HIV." —RICK GUASCO

The following six pages offer a selection of some of the more than 200 photos taken and shared on A Day with HIV. More can be found at adaywithhiv.com.

A Day with HIV has been nominated for a POZ Award in the "Best Performing and Visual Arts" category. Cast your vote by Dec. 1 at poz.com/article/poz-awards-2017-arts.

7:22 AM >
MECHANICSVILLE, VIRGINIA
Melissa Baker: Watching how the sun shines on her. Just another day for me living with HIV and her without it.

8:10 AM >>
AMERSFOORT, THE NETHERLANDS
Eliane Becks Nininahazwe: On my way to Den Haag [The Hague] to get my visa so that I can travel to Burundi, where I will provide HIV education to the indigenous Batwa people.

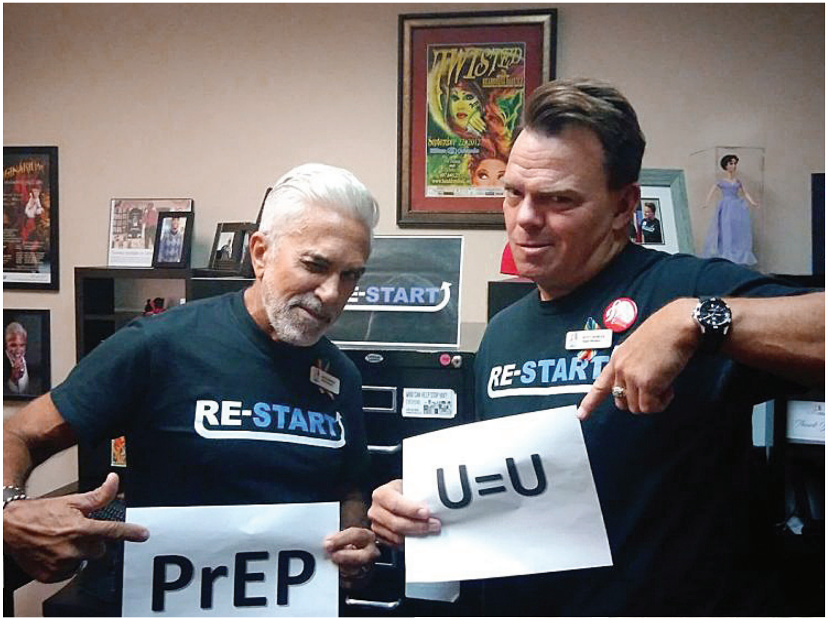
8:10 AM >>>
SAN FRANCISCO, CALIFORNIA
Hank Trout: As a writer and editor-at-large at *A&U: America's AIDS Magazine*, I give voice to the unexpected consequences and challenges as well as the joys of being a long-term HIV/AIDS survivor.

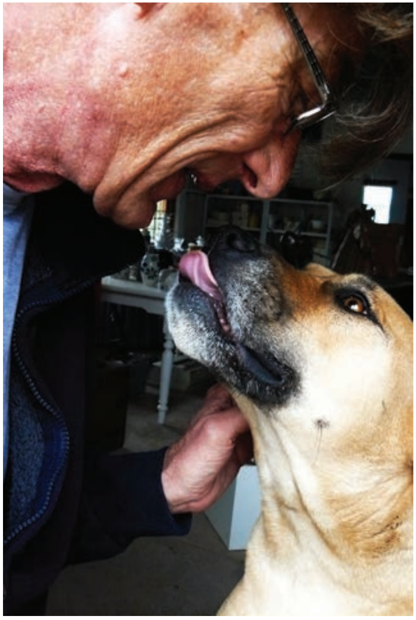
8:50 AM >
ORLANDO, FLORIDA
Steve Addona: I'm the guy with the silver hair. Next to me is my co-facilitator of RE-START, Scott Bowles. We are peer specialists at Hope and Help, Central Florida's oldest and largest HIV organization.

9:30 AM >>
PETERSBURG, VIRGINIA
Michelle Anderson-Morrison: Simply because I can overcome the negative connotations of what HIV looks like and what I can do when I decide to live beyond my diagnosis and societal standards of beauty.

9:27 AM >
RICHMOND, SOUTH AFRICA
Michael Drysdale: With the love of my life, Fronsie. As a 22-year long-term survivor, I have no partner. Fronsie is my angel—without her unquestioning love, I would not survive.

9:27 AM >>
BALTIMORE, MARYLAND
Mark S. King: My dear friend Edwin J. Bernard, an HIV criminalization reform advocate, visited me from England. I am grateful that HIV activism has brought me such wonderful friends.





<< 10:00 AM
MAXTON, NORTH CAROLINA
Billy Eugene Willis III: Got my passport! I'll be an honorary Youth Ambassador to Honduras with Youth Across Borders out of Ohio, but today I'm just a North Carolina millennial on his way to work.

< 10:00 AM
BOSTON, MASSACHUSETTS
AIDS Clinical Trials Group: Clinicians take part in a brainstorming session at Brigham and Women's Hospital in Boston. From left: Jon Li, MD; Davey Smith, MD (via video conference from San Diego); Cheryl Keenan, RN; and Paul Sax, MD.

<< 10:15 AM
RIDGELAND, MISSISSIPPI
Marcus McPherson: A day with HIV involves not letting HIV stop me from helping others, and working hard to change the statistics regarding HIV diagnosis rates among communities of color.

< 10:30 AM
KNOXVILLE, TENNESSEE
Milo: Your fear of stigma is part of the illness.

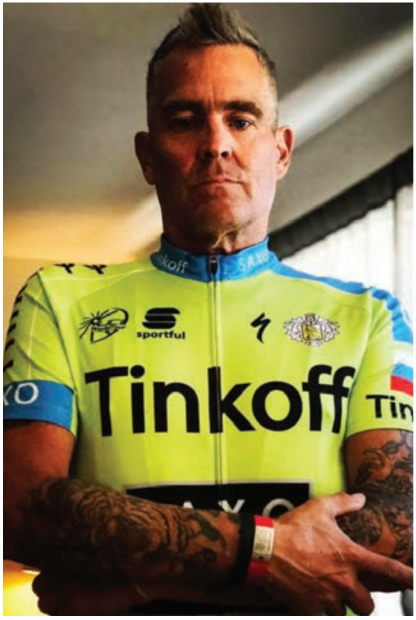
<< 11:00 AM
HANOI, VIETNAM
Joe Tucker, MD: Celebrating the fantastic five finalists in the Hanoi Medical University's "Meaning of Recovery" crowdsourcing contest.

< 11:05 AM
CRAWFORD, COLORADO
Laurie Priddy: Calling congressional offices to save the ACA. My heart is breaking that we are still fighting for accessible healthcare. We must all ACT UP and fight back!

12:38 PM >
LOS ANGELES, CALIFORNIA
Damone Thomas: As an HIV counselor, a typical day with HIV is preparing the testing lab and being equipped with information for clients: how they can reduce their risks without shame or discrimination in an effort to lower the transmission of HIV and other STIs, and if they are positive, to get them linked to treatment and care immediately.

1:15 PM >
DALLAS, TEXAS
Evany Turk (center, in pink): HIV Women's Leadership Training sponsored by Gilead. We are a group of women living with HIV, and allies, who are trying to improve the landscape for other women living with HIV in the Dallas-Fort Worth area.

1:00 PM >
DEERFIELD BEACH, FLORIDA
Zee Strong: Stronger than stigma. More powerful than HIV.

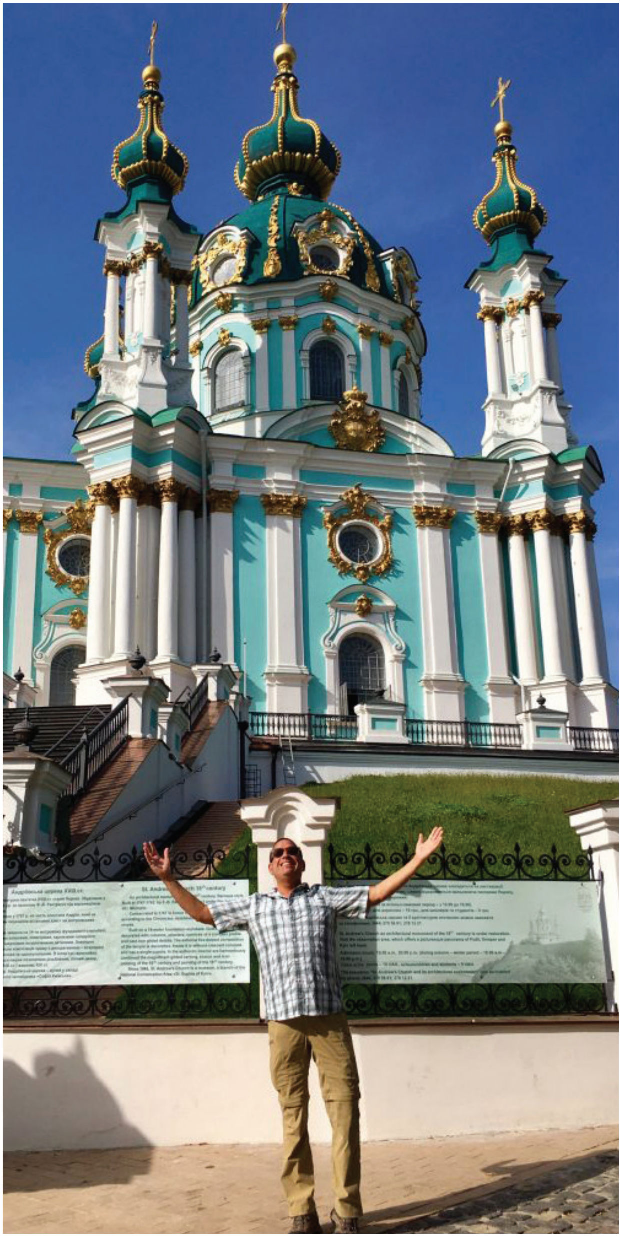


1:00 PM >>
WASHINGTON, D.C.
Masonia Traylor: A Day with HIV for me means being in spaces using MY VOICE, to talk about my body and my life for the #InOurVoice panel on Black women and the Reproductive Justice Framework.

3:00 PM >>>
SEATTLE, WASHINGTON
Anthony Adero Olweny: Being a peer navigator living with HIV, living with HIV is almost like a day-to-day testimony that HIV treatment works.

<< **2:00 PM**
BELO HORIZONTE, BRAZIL
Felipe: On the edge of a high cliff. Never be afraid to live! Live every second with no fear!

< **2:00 PM**
LONDON, ENGLAND
Ian Green: As CEO of the Terrence Higgins Trust, and someone living with HIV, I am participating in #ADayWithHIV. My friend Bu is one of the office dogs.



<< **2:06 PM**
SEATTLE, WASHINGTON
S Wakefield: I was fortunate to be involved with gay men's health before we had HIV. The relationships established at TPAN have sustained me with the "committed to living" motto over my desk each day. To those who have shared this journey, U=unbelievably wonderful.

< **2:25 PM**
KIEV, UKRAINE
Andrew at St. Andrew's in Kiev! Here for the 2017 European AIDS Treatment Group (EATG) General Assembly during the group's 25th anniversary. I was fortunate to find the EATG 20 years ago, right after I found out that I was living with HIV; being involved with the group saved my life.

<< **5:42 PM**
PHILADELPHIA, PENNSYLVANIA
Andrena Ingram: A lot has happened in a year. I had a pacemaker/defibrillator implanted and am currently living with a heart performance percentage of 20%. My church closed its doors due to financial issues, and I am currently adjusting to living a new normal. I just came from a morning of hanging out with a friend. Am lying down and contemplating the future possibility of a mechanical heart. They don't do heart transplants on persons with HIV.

4:47 PM >
PORTLAND, MAINE
Frannie Peabody Center: By providing compassionate services and advocating for our clients every day, we are working towards a world free from stigma.

5:34 PM >>
BROOKLYN, NEW YORK
Karina Fomicheva: Implementing healthy choices to my diet; I just got a blender, so there are also tropical mix smoothies (mango and strawberries). Wishing everyone Shana Tova (I am Jewish; it's the Jewish New Year this week). The weather is beautiful; I love sitting on my fire escape during a warm moment like this.

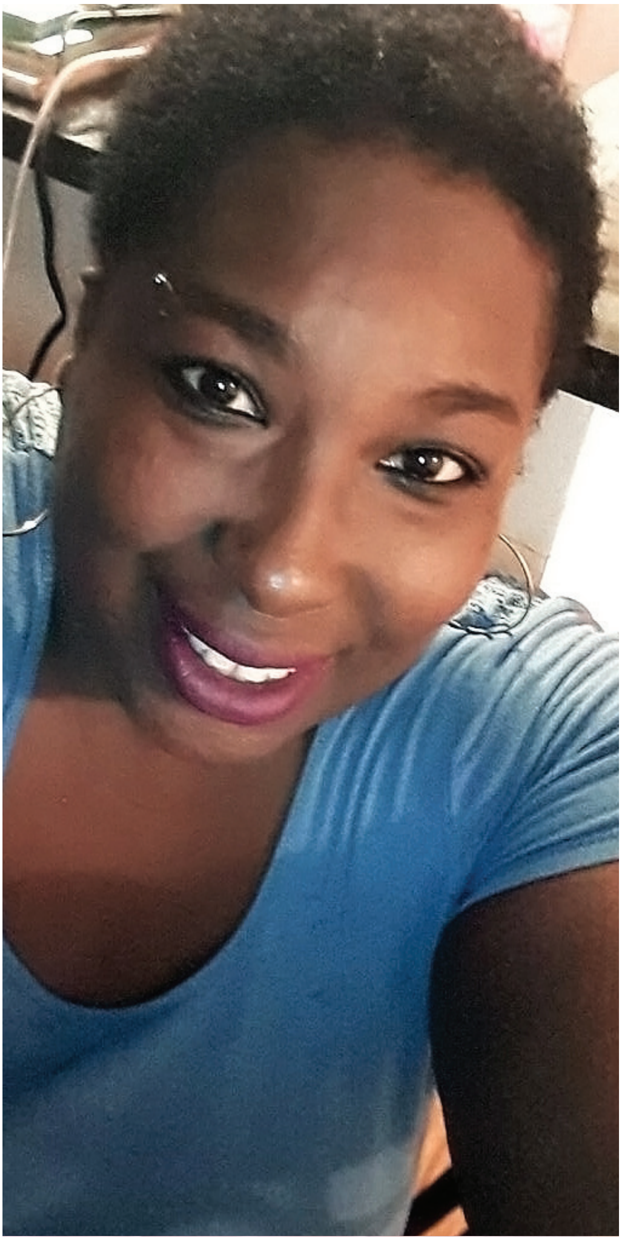
5:35 PM >
MANILA, THE PHILIPPINES
"Yomi": After a long counseling session with a client, the day is finally over. Living with HIV does not stop with your diagnosis, especially if you want to make a difference, like helping at a treatment facility. Give hope to those who are newly diagnosed.

6:25 PM >>
PHILADELPHIA, PENNSYLVANIA
Matthew Dunn: Making sure everything is ready for the pre-launch of my new nonprofit @theScarletRibbonProject in time for Philly's annual AIDS Walk.

6:36 PM >
LAS VEGAS, NEVADA
Deral Takushi: Enjoying the golden hour and feeling amazing.

7:00 PM >>
CARLINVILLE, ILLINOIS
Joshua Damm: Every day is a battle, but just looking at my tattoo reminds me that I'm not fighting alone. And I refulse to let others fight this battle alone.

7:15 PM >>>
NASHVILLE, TENNESSEE
Josh Robbins: Humor has always gotten me through the hard parts of living with HIV. #stayPositive



<< 7:35 PM
KINGS MOUNTAIN, NORTH CAROLINA
Juan: 10,220 days living with HIV = 28 years. Diagnosed in 1989 at age 23 in Mexico City. After I was diagnosed, I dropped out of college because I was told I should go home to die. But I was one of the lucky ones to survive. Now I am undetectable, healthy and love to share my story.

< 8:01 PM
STATEN ISLAND, NEW YORK
Sharell: Still able to smile while living with HIV. I have a very supportive family and great friends. I take my medication Odefsey once a day.

<< 8:28 PM
NEW YORK, NEW YORK
Charles Sanchez: At a rehearsal studio in Manhattan, after a day of meetings and rehearsals for season 2 of my HIV-positive musical comedy web series [Merce], I take a moment to reflect on how full my life is. Full of creativity, friends, family, music, laughter, and joy. HIV wasn't invited to my party, but since she's here, I make that bitch dance!

<< 9:01 PM
PETERBOROUGH, ONTARIO, CANADA
Brittany Cameron: Today we finally received our "U=U" t-shirts for tomorrow's Peterborough Pride parade.

< 9:47 PM
NEW YORK, NEW YORK
Robert Suttle: To fight HIV stigma and the isolation it causes, I like to get out day or night and connect with other social communities or networks of people living with HIV.

A NIGHT IN HONOR OF HOPE AND COMMUNITY

Founders and friends gather together in unity and celebration

BY **ENID VÁZQUEZ**
PHOTOS BY **ERIC CLARKE** AND **JOHN GRESS**

Oh, what a night.

It was 30 years ago on June 19, 1987 that a group of gay men joined Chris Clason in his living room to found Test Positive Aware Network (TPAN), an HIV service organization, and the publisher of POSITIVELY AWARE.

Chris had searched for support following his HIV diagnosis and told there was none unless he had AIDS. Together the men formed a group in which they would support one another: with information, with compassion, with laughter.

Thirty years. On September 28, TPAN celebrated its survival and three decades of service. Early founders and "angels" spoke and received awards for their "Legacy of Devotion."

"Tonight, we also honor all those who came after the founders for their dedication and their activism in the fight against AIDS," said activist Peter Staley, a founder of ACT UP (AIDS Coalition to Unleash Power), also formed in 1987, a thousand miles away in New York City. ACT UP/Chicago started a year later. Early TPAN member Bill McMillian was a part of that ACT UP group. He had never met Staley—but had been arrested with him. They finally spoke together on this night.

Founding member Bill Rydwels said, "We started with 19 people and we ended up within two months with over *200* people." Like the other members, his doctor told him he had 18 to 24 months to live.

Other doctors refused to accept that. Daniel S. Berger, MD, Medical Director of NorthStar Medical Center in Chicago, spoke about being a clinician just out of medical school and pushing the boundaries in search of anything that would help his patients survive—nutritional support, psychologists for emotional support, creating clinical trials looking at potential new remedies, advocating that the voice of patients be included in their care.

Dr. Neel French, who received a legacy award for his early involvement with TPAN, also spoke about those often horrifying early days and what TPAN meant for patients. Doctors were a frequent part of TPAN's meetings, answering questions to the best of current knowledge. Sometimes, they had to go past what was


FOUNDERS, FRIENDS, AND ANGELS HONORED. FROM LEFT: LISA CONGLETON, NEEL FRENCH, HANNAH HEDRICK, BERNIE J. BROMMEL, MARY PAT BROWN, CHARLIE MORRIS, BILL RYDWELS, BOB HULTZ, AND ED HARRISON


PETER STALEY


TPAN BOARD MEMBER AND FORMER CLIENT CARL BRANCH GIVES A TEARFUL SPEECH

known to examine the cutting edge, before it became established practice. Members also brought back information not yet widely known.

Board members and support group members spoke briefly but powerfully about the importance of TPAN's support. One broke down and cried.

In his brief comments, Dr. Berger said, "Who would have predicted that we'd be here 30 years later for a celebration?"

Later he said, "During the event, it was really special to run into people who traveled back to Chicago for the evening, some of whom I haven't seen in years. There were many moments seeing tears in people's eyes."

But, he said, it's also important to "celebrate our achievements and be joyous about our success."

As music pumped up the energy—DJ Marc "Moose" Moder played a list of songs from 1987—Denise Ward videotaped the members of her women's support group dancing together, saying, "This is my family!" Event volunteer Bruno Mondello, now a chef, said, "I was part of TPAN 20s [a support group]. Now I'm in my 40s." (He's 49.) A patient at NorthStar, Mondello said, "Dr. Berger saved my life—over and over."

Carol Mendelson, co-founder of Family AIDS Support Network (FASN), which operated through TPAN, was able to attend, joined by her husband, Ken. The Mendelsons lost their son, artist Steven (Steve), in 1995. FASN has an unpublished manuscript with dozens of stories from families who lost a loved one. Co-founder Betty Stern's story about her son Robert was published in the July 2003 issue of POSITIVELY AWARE. Said Bernie Brommel, "How many hundreds or thousands did these two mothers with dying sons help?"

Unable to attend the celebration were members of Chris Clason's family, whose support has never wavered. Chris died on December 26, 1991, at the age of 38.

Three years ago, for POSITIVELY AWARE's 25th anniversary, niece Jill Stover Martinez said, "We are over-the-top proud of him."

Sadly, her mom, Chris's sister Phyllis Stover, the oldest of his siblings and his close confidant, passed away earlier this year. Back in 2014, Phyllis told POSITIVELY AWARE, "At that time there wasn't much information about AIDS or what you could do about it. He got information wherever he could. He had people over to his living room and it grew from there. Heterosexual couples came to his apartment because one or both were infected and there was just no place to go for information. It truly was a calling, but it was necessary, too, for himself and for everyone he knew who was in the same situation. Maybe it was just a little match flicker, but it was better than total darkness. Wouldn't he be amazed at the computer revolution?"

TPAN CEO Patti Capouch told the audience that just earlier that day, the agency received a call from a young man who had moved away to a small town in the South and missed the agency's support and education. He talked about the lifesaving effect it had on him, and how he and his new—and HIV-negative—partner planned to move back to Chicago. The crushing stigma, she reminded everyone, is far from over.

"A lot of work remains in the post-PrEP era," said Dr. Berger, "bridging the gap to those who still don't have access to treatment, education, and support, the censorship and prejudice we still endure, and the long-term effects HIV is having on aging."

Founding member Bernie Brommel talked about supporting early members, many rejected by their families, and about the "angels" who joined the group in support through their grief. He read a note from Oprah Winfrey, who was unable to attend. Her second employee after she arrived in Chicago, her right-hand man, was Bill Rizzo, the first board president of TPAN. She rushed to his hospital bedside during every major illness.

"Bill Rizzo was a founding member of TPA, just as he was a beloved member of my original team," Oprah Winfrey wrote. "Rizzo brought to TPA the same spirit and mission as he did for the Oprah Show—bringing hope amid despair, advocating truth against rumors, promoting education in the face of ignorance, inspiring courage and compassion in place of fear.

"A dark shadow fell over the late '80s, and TPA was one of the first guiding lights. At a time when doctors, airlines, restaurants, and even families of young men who tested positive were closing their doors, TPA opened their doors and their arms. When so many said, 'Go away,' TPA said 'Come on in.' Today, the world now sees HIV and AIDS more clearly all due to the courage of individuals such as Bill Rizzo and groups such as TPA who turned a light on for us all in 1987."

In his comments, Peter Staley said, "As the plague years showed us, activism is about plowing through pessimism. So we are fighting back again, pushing back against hate, against Trumpism, and determined to write the final chapter of the AIDS crisis. We will never give up until a cure and a vaccine are found. We will never let the memories of those we lost fade away before the work they started is complete. We will continue to fight in their name.

Go to positivelyaware.com to read Peter Staley's and Bernie Brommel's entire comments, and to watch the short documentary *TPAN: 30 Years of Hope.*

"Make no mistake. History is being written again, and we will be part of it."

"It's very important to me that TPA exists and I'm very secure in the fact that it will continue to exist. TPA just happened to be the right seed in the right earth at the right time to take off and grow. It was a matter of timing, of developing awareness and creating something that served a lot of people and that continues to serve a lot of people. It will not be the same for generations after us. The situation is not going to be the same for people tomorrow that it was two years ago. It will be better and it will be worse. Just try to maintain the flexibility to handle whatever is coming up. I think death and dying is an important issue, but I think health and living is a very important issue; both deserve equal focus, if not a little extra on health and living issues."

—CHRIS CLASON, TPAN FOUNDER

TPAN CEO PATTI CAPOUCH WITH PETER STALEY

CHRISTIE'S STEVE ZICK

JEFF BERRY AND ENID VÁZQUEZ

ILLINOIS STATE REPRESENTATIVE GREG HARRIS AND JOHN PELLER, CEO OF THE AIDS FOUNDATION OF CHICAGO

TPAN 30—A LEGACY OF DEVOTION AWARD RECIPIENTS

Founders, friends, and staff
Jeff Berry
Bernard J. Brommel
Mary Pat Brown
Lori Cannon
Lisa Congleton
Dr. Neel French
Ed Harrison
Hannah Hedrick
Bob Hultz
Jill Stover Martinez (niece of Chris Clason, on behalf of his family)
Alice McGee
Charlie Morris
Bill Rydwels
Father Mike Shanahan
Enid Vázquez
Steve Wakefield

TPAN 30 YEARS

PA
POSITIVELY AWARE
JOURNALISM. INTEGRITY. HOPE.

30 years in, we are still committed to

EMPOWERING individuals to navigate their lives by providing tools, resources, and support; **ADAPTING** to the changing needs of the community; **SUPPORTING** sex-positive environments by affirming sexuality as an integral part of being human; **INCLUDING** everyone by embracing differences and creating community; **EXCELLING** in delivering quality programs, advocacy, and ending stigma; and **RESPECTING** others through honest, open, and supportive communication.

SPECIAL THANKS TO THE SPONSORS OF TPAN: 30 YEARS OF HOPE

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WINDY CITY TIMES

HIV CURE RESEARCH STRATEGY FOR WOMEN— WHERE ARE WE?

BY **DANIELLE CAMPBELL**, **JULIE PATTERSON**, **DAVID EVANS**, **PEDRO GOICOCHEA**, **MOISÉS AGOSTO**, **DAWN AVERITT**, **CATALINA RAMIREZ**, AND **KARINE DUBÉ**

ISTOCKPHOTO

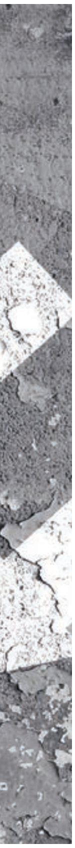
THE FOLLOWING REPORT is taken from a session presentation summary at this year's U.S. Conference on AIDS (USCA), a community-based event organized by NMAC, that was held in September in Washington, D.C.

The need for a cure is critical, but will the search for HIV cure strategies include women? Women are drastically under-represented in HIV cure research studies. A review of 159 studies showed that only 18% of HIV cure study participants were women. Women have a high willingness to participate in research, although they are in general less willing than men to take risks related to HIV cure research interventions. Research is in the works to better understand the differences in willingness, but studies outside of the HIV cure arena suggest that if structural barriers to participation are diminished, and more effort is made to establish trusting relationships between investigators and participants, more women will participate.

Currently, there is no cure for HIV. Only one person has been cured: Timothy Ray Brown, after receiving two bone marrow transplants that simultaneously rid his body of HIV-infected cells and gave him new cells that are resistant to HIV. Scientists are trying to replicate his cure. The transplant of stem cells is a central HIV cure strategy being investigated, particularly to eliminate nearly all traces of the virus from a person's body (e.g., an eradicating, or sterilizing, cure). Other methods include the early administration of antiretroviral treatment, combined with a variety of strategies that make HIV more visible to infection-fighting immune cells, improving the immune system's ability to detect and eliminate infected cells, and possibly rendering immune cells impervious to HIV infection.

Scientists suspect that there are gender-based differences that affect how these investigational interventions might work inside the body. For example, two studies have suggested that the presence of female hormones and hormone receptors on immune cells might make it more difficult to flush HIV out of hiding. In addition, cis-gender women who have female chromosomes are genetically primed for stronger immune responses to infection and to vaccines. They might, perhaps, have an advantage if vaccines or other approaches to prime the immune system's response to HIV are used.

While studies of all diseases have traditionally lagged far behind in terms of participation by women, HIV has more recently had a better track record in terms of prevention and treatment trials, and improvements in recruitment and retention guided in part by the efforts of the Women's Interagency HIV Study (WIHS), which is an NIH-funded cohort (or group) that studies the impact and progression of HIV infection among women in the United States. It is the largest



and longest-running HIV cohort focused on women. In total, 4,982 women at nine sites have participated in the cohort to date. The WIHS cohort is also uniquely diverse in that it is reflective of the U.S. epidemic among women. The WIHS cohort is a great platform to advance HIV cure-related research in the United States. WIHS participants volunteer in studies that measure the HIV reservoir in the blood, genital tract, and other tissues; that study the role of sex hormones on HIV reservoirs; and that examine the relationship with ART pharmacology.

The WIHS cohort has been creative in overcoming challenges to women's participation in HIV cure research. For example, if women are asked to come in fasting for a lab test, the study site provides a substantive meal after the procedure. Providing mileage reimbursements, metro vouchers, and taxi rides is critically important, since transportation issues are a main deterrent to participation in research. Other strategies to improve sex equity in HIV cure-related research include addressing eligibility criteria, adapting recruitment strategies, and engaging community members as early as possible in the process. For this reason, WIHS could serve not only as a model for successful recruitment and retention of women living with HIV into research, but also as a source of participants who might be inspired to participate in HIV cure-oriented research.

Including women in HIV cure research means:

Thinking about what they need: different types of recruitment strategies and study coordination which may benefit from partnerships with different organizations or advocacy groups

Listening to what they want: information and a chance to participate, fair reimbursement and compensation, assistance with logistical barriers

Designing studies that reflect them: re-thinking eligibility criteria to balance participant risk with exclusions that disproportionally affect women

Prioritizing their involvement: a few women or a single study is not enough; we need to advocate for representation of all women, including transwomen

MORE RESOURCES

Women and HIV cure-related research

The Well Project/Women's HIV/AIDS Research Initiative
The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls.
thewellproject.org/womens-research-initiative

Treatment Action Group
A great resource for articles, reports, and other information related to HIV cure research efforts. Advocacy resources: treatmentactiongroup.org/CURE/advocacy. **Media monitor** which tracks cure research related news, places stories in context and addresses inaccuracies: treatmentactiongroup.org/cure/media-monitor. A listing of clinical trials and observational studies related to the research effort to cure HIV infection: treatmentactiongroup.org/cure/trials

AVAC
AVAC's work includes a range of activities aimed at addressing ethical issues, including community involvement in research, standards of prevention and care in trials, and community engagement and research literacy outside the context of a specific clinical trial or intervention.
avac.org/prevention-option/cure

HIV Cure Research Glossary
This glossary is designed for the media and laypersons interested in understanding the issues involved in HIV cure-related research.
projectinform.org/pdf/HIVCureGlossary.pdf

CUREiculum
A suite of tools that provides simple, accessible information on HIV cure research, organizing into a systematic format for ongoing or issue-specific learning.
avac.org/cureiculum

Social and Ethical Aspects of HIV Cure Research (searcHIV)
A multi-site, multi-disciplinary working group focusing on investigating the biosocial implications of HIV cure research.
searchiv.web.unc.edu

Women's Interagency HIV Study (WIHS)
A large, comprehensive prospective cohort study designed to investigate the progression of HIV disease in women.
statepi.jhsph.edu/wihs/wordpress/

CAN WE TALK ABOUT... DIARRHEA?

"It's a neglected co-morbidity," said Josh during an interview at the 2017 United States Conference on AIDS (USCA) when talking about HIV-associated diarrhea. "Doctors say to just take an Imodium or bananas and rice, and sometimes on top of nausea."

That's coming from renowned blogger Josh Robbins, whose blog, *I'm Still Josh*, recounts his daily life with HIV and provides information to people newly diagnosed and living with HIV on living better, healthier lives. He's also a paid spokesperson for Napo Pharmaceuticals, which markets Mytesi, the first-in-class and only drug on the market specifically for non-infectious HIV-associated diarrhea for those on anti-retroviral therapy (ART).

Napo Pharmaceuticals reported that a recent survey of 271 gastroenterologists found that their patients living with HIV reported diarrhea more often than any other gastrointestinal (GI) complaint.

According to a recent press release, "Mytesi is the only antidiarrheal studied in and U.S. FDA-approved for the symptomatic relief of noninfectious diarrhea in adults living with HIV/AIDS on antiretroviral therapy (ART). Mytesi is a prescription treatment for diarrhea that works differently, by acting locally in the GI tract to normalize the flow of water. Mytesi does not have drug-drug interactions with ART and has side effects that are similar to placebo."

For Josh, all that really boils down to is improving the quality of life for people living with HIV.

"I think having somebody pretty cool talk about something that is not so cool is important." —JEFF BERRY

The lotus in spite of the swamp

BY **JOURDAN BARNES**, 2017 USCA SOCIAL MEDIA FELLOW

Bold, resilient, elegant, resourceful, triumphant, and vibrant are all words I think of when I imagine the lotus flower. To the world the lotus flower symbolizes a number of characteristics, like strength and endurance. However, we rarely focus on the swampy environment it emerges from—hot, muddy, muted, crowded, and grimy—or the many factors that should work against its growth, yet surprisingly encourage it. In spite of the difficult environment, the lotus flourishes.

My experience attending USCA (United States Conference on AIDS) was one of the most educational experiences I've had in a while, but not in the way I had expected before my arrival. Similar to the lotus's swamp, I found navigating the conference confusing and difficult; yet I emerged from the experience both with better skills and a supportive, family-like network.

Unwarranted environments have been the cause of all major movements. It is during times of dysfunction and disorganization when people find themselves having to be more organized and functional than ever before.

I didn't clearly understand that notion until I reflected upon this year's USCA. The theme was "Family Reunion," but surprisingly enough, a lot of queer people did not feel a part of the conference "family." For example, a trans man interrupted the Gilead plenary because he wasn't included in the statistics shown in the presentation. He also stated that he saw no imagery that represented him at the entire conference.

There was a woman who felt that the conference registration fee alone was too high for someone living with HIV to afford, then to add hotel and travel would be too much. She felt that the conference was designed only for a group of people that she wasn't a part of. However that may be, the underlying complaint about the conference being unorganized, and important populations being underrepresented, encouraged people to speak out and unify. This USCA created union.

Before we can talk about health care access, stigma, PrEP (pre-exposure prophylaxis), and ending the HIV/AIDS pandemic, we must first have support, a family. As I reflected upon all the sessions I attended and one-on-one interviews I conducted, I noticed that even amid the disagreement, each group of people—Black women, Latino gay men, trans men, trans women—all bonded.

I hate to admit it, but it seems as if the most passion and best work emerge from disagreement. There would be no USCA if someone had not gotten fed up with the environment that people infected and affected by HIV/AIDS experience. Despite being underrepresented, these groups of people rose to the occasion and shone and let their voices be heard. It was so beautiful to see USCA support, foster, and respect their plight. Surprisingly, the seemingly biased and weighted environment may have created a positive movement that I think everyone leaving USCA feels. No matter the demographic, there's a sense that everyone knows there's work to be done, and now is the time to do it.

Working as a social media fellow through NMAC this week has opened my eyes to see what I wasn't seeing before because of the uncomfortable, unfamiliar environment we were subjected to. Initially I was extremely critical of the Social Media Fellowship program because of seemingly missed opportunities and lack of support. Think: no reliable place where we could recharge the very devices we were relying upon to report on the conference. But that exact environment created a group of 11 close friends in a matter of days. I was forced to depend on my intergenerational peers for help, assistance, and knowledge. We exchanged wisdom with one another, based on our cultural and professional backgrounds, in ways that I had never experienced with a group of people before.

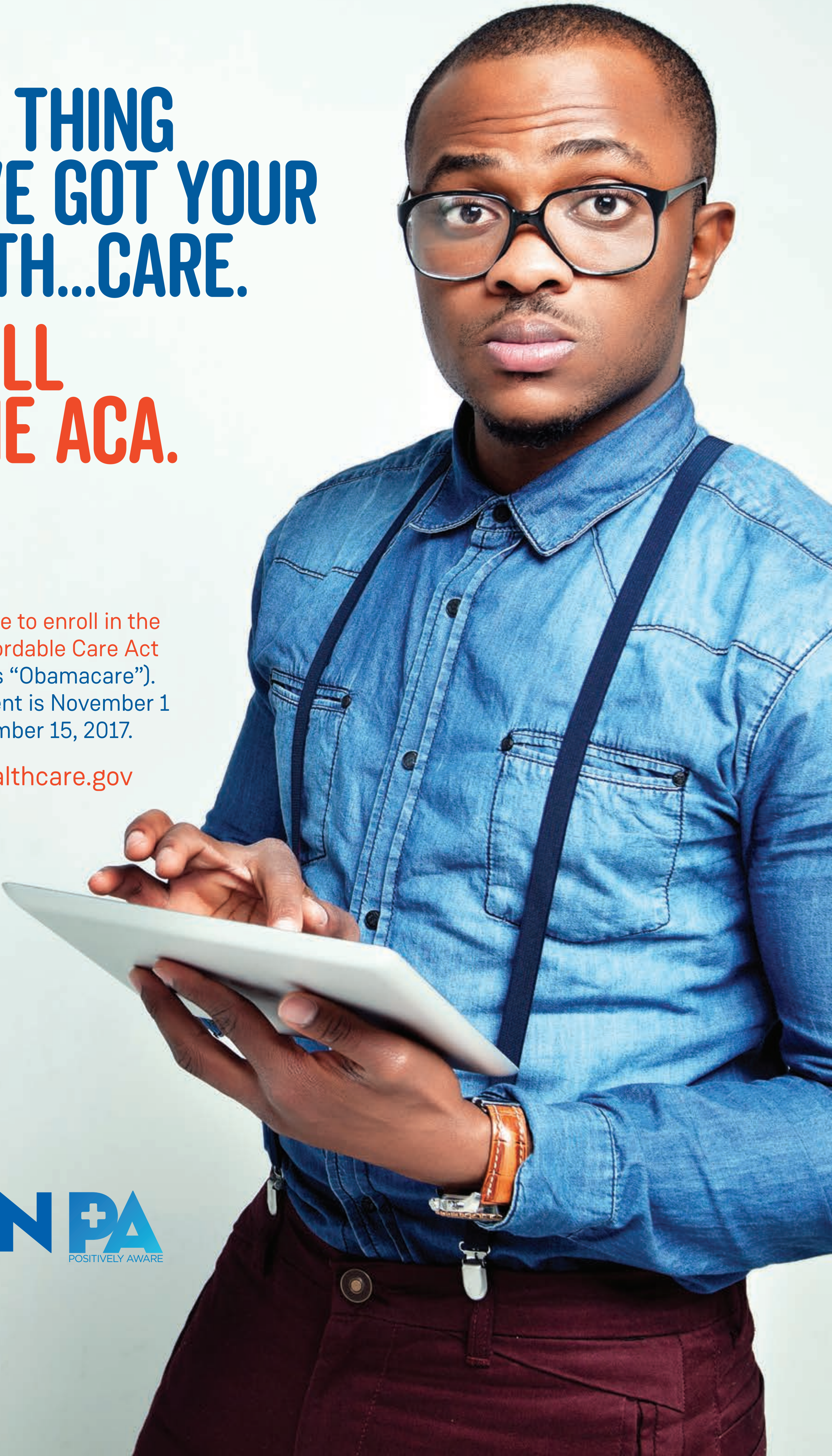
ALABAMA CONGRESSWOMAN TERRI SEWELL WITH BARNES AS THEY DISCUSS PROMISING LEGISLATION.

PHOTO: KYLE POMPEY

Even more importantly, we bonded beyond the work of HIV/AIDS. We became a family, and that would not have occurred in a more structured and organized fellowship. I honestly wouldn't trade the experience for the world. That type of peer support and unspoken bond is needed to end the HIV/AIDS pandemic. Sharing unconditional love, support, and balance will provide me with the fuel to fight for health care, advocate for PrEP, and combat stigma—and that's all because I know my family has my back.

So despite our challenging environment, we embodied boldness, resilience, elegance, the sprit to be triumphant, and vibrancy, just as the lotus would in spite of the swamp. In spite of the HIV/AIDS pandemic, everyone in this fight can rise. In spite of not being represented in the world, we can join together to form a union that will be as loud as loud can be. In spite of an unorganized situation, we built family and guidance and fostered togetherness. In spite of not having the structure for success, we made it work for us.

JOURDAN BARNES works as a community-engagement specialist with the Louisiana Office of Public Health and STD/HIV Program.

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