

PA

POSITIVELY AWARE

HIV TREATMENT, PREVENTION, AND SUPPORT FROM **TPAN**
NOV+DEC 2018

A DAY WITH HIV

1:00 PM: BOULDERS BEACH, SOUTH AFRICA

CINDY PIVACIC: Checking out the penguins. HIV positive going on 14 years, diagnosed with AIDS in 2008, having acquired TB, meningitis, shingles, and pneumonia; I survived two strokes and cancer. More recently, unrelated to HIV, I had a massive heart attack in March 2018, and a double bypass to go with it, and I am still here. I'm 60 years old. Nothing should be allowed to impede your life, no matter what.



11:20 AM: ATLANTA, GEORGIA

DARRIYHAN EDMOND: 1,725 days living with HIV. Every night before bed I take my meds, almost choking myself trying to swallow that pill. There were times I used to break down but I've learned that crying will not change my status, so I wipe my face clean from the tears and replace that cry with a smile.



POSITIVELY AWARE

HIV TREATMENT, PREVENTION, AND SUPPORT FROM TPAN
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6:48 PM: QUINCY, ILLINOIS

TAMARA MAYFIELD DIETRICH:

I am doing POUND Rockout Workout fitness—it's a cardio workout inspired by drumming and it's totally changed my life. I started as a student doing this fitness class in 2016 and it's been awesome to watch my transformation. I've been teaching this class since December 2017. I still have my ups and downs, but it's a lot better than before.



A DAY

EVERYDAY MOMENTS



**10:19 AM:
KALAMAZOO, MICHIGAN**
LEVI BERKSHIRE: I am sitting at my desk at CARES. I am a non-medical case manager for people living with HIV/AIDS. I am also a person who is living with HIV. I took this picture to remind myself that this is what makes me happy and that I love helping other people living with HIV/AIDS.

WITH HIV

IN EXTRAORDINARY LIVES

ONE OF FOUR
SPECIAL EDITION
FOLDOUT COVERS

PA

POSITIVELY AWARE

HIV TREATMENT, PREVENTION, AND SUPPORT FROM **TPAN**
NOV+DEC 2018

10:33 PM: SAVANNAH, GEORGIA

KAMARIA LAFFREY: This Black Girl Magic isn't for show, doesn't come easy, and takes work to maintain. I'm learning to trust it along with my Creator and all that I am called to do. This is my power shift of empowerment.

A DAY WITH HIV

EVERYDAY MOMENTS IN EXTRAORDINARY LIVES

1:57 PM: WARSAW, POLAND

ANDREW ESPINOSA: Twenty-one years ago, while living in Poland, I found out I was living with HIV. I was able to stay here, start treatment in a clinical trial, and received incredible care from amazing doctors. I will always be grateful for the care, support, and love that I received here. I return annually to see my friends and doctors. Today was an especially beautiful day!





PA

POSITIVELY AWARE

HIV TREATMENT, PREVENTION, AND SUPPORT FROM T⁺PAN

NOV+DEC 2018

1:55 PM: MINNEAPOLIS, MINNESOTA

CREE GORDON: I have been HIV positive for 13 years. The last time I participated in A Day with HIV was in 2011. My opposites attract photo made such an impact on folks in my life and the people I came into contact through education opportunities and on social media, I did not think I could top it. Advancements in HIV have been made since then, so I thought I would update it. Treatment as Prevention (TasP) works to reduce HIV transmission. PrEP works to reduce HIV transmission.

A DAY
EVERYDAY MOMENTS

ONE OF FOUR SPECIAL EDITION FOLDOUT COVERS



WITH HIV
IN EXTRAORDINARY LIVES

FRONT COVER(S) BACKSTORY

ON SEPTEMBER 21, 2018, people across the U.S. and around the world captured a moment of their day for A Day with HIV. This issue features four different special edition foldout covers featuring photos from the magazine's annual anti-stigma campaign, now in its ninth year. A selection of photos appears on pages 33–39. View the online gallery at adaywithhiv.com. Also, search social media for the hashtag [#adaywithhiv](https://twitter.com/adaywithhiv).



1:00 PM: BOULDERS BEACH, SOUTH AFRICA

Cindy Pivacic: Checking out the penguins. HIV positive going on 14 years, diagnosed with AIDS in 2008, having acquired TB, meningitis, shingles, and pneumonia; I survived two strokes and cancer. More recently, unrelated to HIV, I had a massive heart attack in March 2018, and a double bypass to go with it, and I am still here. I'm 60 years old. Nothing should be allowed to impede your life, no matter what.

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Tamara Mayfield Dietrich: I am doing POUND Rockout Workout fitness—it's a cardio workout inspired by drumming and it's totally changed my life. I started as a student doing this fitness class in 2016 and it's been awesome to watch my transformation. I've been teaching this class since December 2017. I still have my ups and downs, but it's a lot better than before. I want to give a shout out to Design It, who designed my shirt, and to BW Photography.

10:19 AM: KALAMAZOO, MICHIGAN

Levi Berkshire: I am sitting at my desk at CARES. I am a non-medical case manager for people living with HIV/AIDS. I am also a person who is living with HIV. I took this picture to remind myself that this is what makes me happy and that I love helping other people living with HIV/AIDS.



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Kamaria Laffrey: This Black Girl Magic isn't for show, doesn't come easy, and takes work to maintain. I'm learning to trust it along with my Creator and all that I am called to do. This is my power shift of empowerment.

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Andrew Espinosa: Twenty-one years ago, while living in Poland, I found out I was living with HIV. I was able to stay here, start treatment in a clinical trial, and received incredible care from amazing doctors. I will always be grateful for the care, support, and love that I received here. I return annually to see my friends and doctors. Today was an especially beautiful day!



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Cree Gordon: I have been HIV positive for 13 years. The last time I participated in A Day with HIV was in 2011. My opposites attract photo made such an impact on folks in my life and the people I came into contact through education opportunities and on social media, I did not think I could top it. Advancements in HIV have been made since then, so I thought I would update it. Treatment as Prevention works to reduce HIV transmission. PrEP works to reduce HIV transmission. We can end HIV with help of TasP and PrEP; we just have to address the barriers of access, especially for Black, Latino, rural, and low-/no-income folks. This can happen. We can get to zero. Join me in ending HIV and the stigma attached to it.

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A WORLD POSITIVELY AWARE
OF HIV AND RELATED CONDITIONS.

SINCE 1989. PUBLISHED BY



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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.



TPAN STAFF
GATHER FOR
A DAY WITH HIV
2018.

Dear POSITIVELY AWARE Reader,

The current issue of POSITIVELY AWARE is a thought-provoking exploration of how communities of faith have grappled with HIV and how individual faith and spirituality have provided some with a path to strength and empowerment.

Faith means different things to different people. This month's POSITIVELY AWARE contributors highlight these different perspectives, creating a fascinating mosaic of how different views of faith and spirituality have confronted a common challenge.

Thank you for having faith in POSITIVELY AWARE. For almost 30 years, the magazine has been a leading educational and informational resource for people living with and affected by HIV. In fact, it 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. We remain committed to publishing the "go-to" magazine for what one needs to know to live the best, healthiest life possible.


Our current issue includes some inspiring stories of how communities and individuals of faith have mobilized to help others. If you are inspired and helped by POSITIVELY AWARE's mission and content, would you consider making a donation to help us bring important news and health information to people impacted by HIV across this country?

We invite you to be a part of this mission. Your support helps us reach people with HIV treatment education, inspirational stories of survivorship, and health information that can become a lifeline to readers who write to us every month. Every issue of POSITIVELY AWARE reaches 100,000 readers and nearly 20,000 website visitors. Most notably, POSITIVELY AWARE is free to anyone who is HIV positive or unable to pay.

Your donation has impact across the year. A \$30 tax-deductible contribution enables us to produce and deliver the magazine to a reader for a full year. A \$100 contribution will cover the costs of your subscription and the subscriptions of two other people who lack the means to contribute but rely on POSITIVELY AWARE as an important lifeline of HIV-focused information and stories. You can contribute by making a gift online at tpan.com/donate (fill out the donation form, click submit, and then select "POSITIVELY AWARE fund designation") or you can make a donation by phone or mail (designate "PA" in notes section of your check) using our address and contact information below.

Thank you for your support of POSITIVELY AWARE. Your own faith—in whatever form it takes—in our mission means a great deal to the countless individuals and families who open these pages to be inspired, informed, and feel connected.

In gratitude,



Jeff Berry
EDITOR, POSITIVELY AWARE



Christopher Clark
CHIEF EXECUTIVE OFFICER, TPAN

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ON THE COVER:
XX.

NOV+DEC 2018

VOLUME 28 NUMBER 7 positivelyaware.com @posaware



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POSITIVELYAWARE.COM

2018 NIH HIV cure workshop summary

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Religiously non-conforming

An Orthodox rabbi leads a
movement for trans inclusivity.



4:12 PM: LATHAM, NEW YORK

Mika DeRoo: I'm an HIV-negative ally. In an effort to support people living with and affected by HIV/AIDS, I've participated in 11 AIDS rides as a volunteer—10 since 2008 as part of BRAKING AIDS Ride. Since 2014, I've worked in Housing Works' Advocacy Department. I remember those who have died of AIDS. I'm proud to be of service in our collective work to end AIDS and to ensure those living with HIV can live their lives fully.

PHOTO: KYLE CAMERON

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.

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PA makes room at the U.S. Conference on AIDS

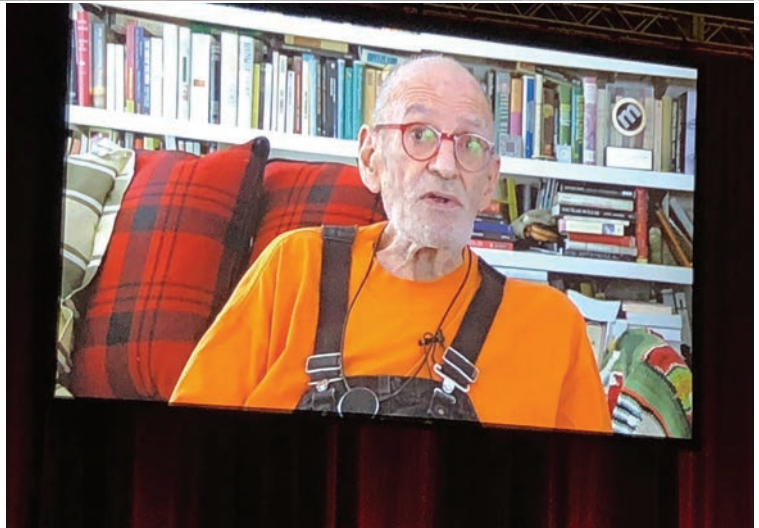
MORE THAN 3,000 advocates and activists gathered in September in Orlando for the U.S. Conference on AIDS, organized by NMAC (formerly the National Minority AIDS Council).

The four-day conference addressed issues such as PrEP and PEP, aging and long-term survivors, the opioid epidemic, and trauma-informed care.

PA editor-in-chief Jeff Berry and art director Rick Guasco attended the conference. Berry helped lead a discussion on the issues and needs of long-term survivors for The Reunion Project. Guasco was part of NMAC's cohort of attendees over age 50, and helped stage a rousing presentation called *The Survivor Monologues*.

The TPAN/POSITIVELY AWARE booth also made an impression. With a luxuriously ornate sofa and decorative chairs provided by Andee's Thrift Shop in Orlando, the booth was furnished more like a living room, creating an engaging conversation space that attracted conference goers.

PICTURED FROM TOP: THE OPENING PLENARY CLIMAXES WITH A CLACK OF FANS. A RECORDED ADDRESS BY THE ICONIC LARRY KRAMER. FRIENDS HANGING OUT IN PA'S "LIVING ROOM" IN THE EXHIBITION HALL.



PHOTOS: RICK GUASCO

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We accept submission of articles covering medical or personal aspects of HIV/AIDS, and reserve the right to edit or decline submitted articles. When published, the articles become the property of TPAN, POSITIVELY AWARE, and its assigns. You may use your actual name or a pseudonym for publication, but include your name, email address, and phone number with your story. Although POSITIVELY AWARE takes great care to ensure the accuracy of all the information it presents, POSITIVELY AWARE staff and volunteers, TPAN, and the institutions and personnel who provide us with information cannot be held responsible for any damages, direct or consequential, that arise from use of this material or due to errors contained herein. Opinions expressed in POSITIVELY AWARE are not necessarily those of staff or TPAN, its supporters and sponsors, or distributing agencies. Information, resources, and advertising in POSITIVELY AWARE do not constitute endorsement or recommendation of any medical treatment or product. TPAN recommends that all medical treatments or products be discussed thoroughly and frankly with a licensed and fully HIV-informed medical practitioner, preferably a personal physician. A model, photographer, or author's HIV status should not be assumed based on their appearance in POSITIVELY AWARE, association with TPAN, or contributions to this journal.



EDITOR'S NOTE
JEFF BERRY

You've got to have faith

The times in my life when I have been most afraid, I've been able to draw upon an inner strength, a voice within myself, to help guide me through the darkness.

I can remember sitting in the doctor's office when I was having my blood drawn for my HIV test. It was September 13th, 1989. I hadn't come that day to take the test, but here I was, sitting in a chair waiting to have my blood drawn. Suddenly I became very afraid, and a palpable fear fell over me. It was unexplainable, but nonetheless very real. It was a feeling of dread, of what was to come, of what the future held in store.

As the nurse began to draw my blood, an image popped into my head, of Jesus sitting next to me, holding my hand. Now, please understand, I'm not religious, by any stretch of the imagination. But at that moment a sense of peace washed over me, and a feeling as if everything was going to be all right. And it got me through that office visit.

I wrote those words in one of my first articles, "The Nebulous Spirit," as interim editor of POSITIVELY AWARE in the March+April 2005 issue. In the same article I also publicly disclosed for the first time that I am a survivor of childhood sexual abuse. We are in a very different time now than we were in 2005, and our belief and faith in the institutions that are the foundation of our democracy and our social structures are being tested and questioned. Which is not necessarily a bad thing.

This issue of POSITIVELY AWARE delves into the issues surrounding faith, spirituality and HIV, and highlights the very personal experiences of individuals who are on their own spiritual quest and journey while living with or working in HIV. As POSITIVELY AWARE contributor Michelle Simek states in her article "Amazing Grace or Highway to Hell?" on page 16, "for some in the HIV/AIDS community, their relationship to God, faith, and spirituality is complex and diverse, much like the epidemic itself."

Clark Hawley, who you first read about in the POSITIVELY AWARE Summer 2018 issue on HIV cure research "Brave New World," talks about how he found a philosophy that works for him, that doesn't

require him to make anyone else wrong. It turns out there are lots of groups out there that share the same goal of treating others as they would want to be treated.

In "Losing My Religion" on page 25, Rick Guasco relates the story of Joshua Stovall, who grew up in a religious upbringing, but it wasn't until he became HIV positive that he truly found his faith. And in "Religiously Non-Conforming" on page 27, we learn how a Jewish Orthodox rabbi is leading a movement for trans inclusivity.

Lastly, our annual A Day with HIV anti-stigma photo campaign, featured in this issue, is itself an expression of faith that shows us by coming together and sharing our stories of life in a world with HIV, we can begin to erase the stigma, fear and shame that can sometimes accompany it.

Faith can mean different things to different people, and it doesn't have to have anything to do with religion, but it is ultimately about trust or confidence in someone or something. Trust can sometimes be betrayed, so faith and forgiveness often go hand in hand. The thing that has been testing my faith the most these days is the seeming preponderance of "unforgiveability" in our world (for lack of a better—or real!—word). It seems we're losing the capacity to forgive because the transgressions or perpetrators seem, indeed, unforgiveable. But I try to remind myself that while I may not always be able to control some of the things that may be happening around me, I always have a choice in how I choose to perceive them.

And that's the truest test of faith.

Take care of yourself and each other.

@PAeditor

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BRIEFLY

ENID VÁZQUEZ @ENIDVAZQUEZPA

Two new HIV meds approved, Delstrigo and Pifeltro

THE HIV MEDICATION doravirine (DOR) was approved by the FDA in September in two separate formulations. Doravirine is now available as a single-tablet regimen (STR) in combination with 3TC and tenofovir DF, called Delstrigo. A doravirine-only version, available under the brand name Pifeltro, needs to be taken with other HIV medications. **Delstrigo and Pifeltro are each taken as one tablet once a day with or without food.** The new medications are intended for those who are just starting HIV treatment for the first time (treatment naïve), but promising Phase 3 switch study results were presented in October (see below). In clinical studies, the most common side effects (in 5% or more of people taking doravirine) were nausea, dizziness, headache, fatigue, diarrhea, abdominal pain, and abnormal dreams. Neuropsychiatric adverse events were reported by 24% of the 324 individuals taking Delstrigo in the DRIVE-AHEAD study. Of these, 12% experienced sleep disorders and disturbances and 9% experienced dizziness. Doravirine is a non-nucleoside reverse transcriptase inhibitor (NNRTI), like efavirenz (Sustiva, found in Atripla). For a review of the new medications, along with their pros and cons, see the inimitable Dr. Paul Sax's HIV and ID Observations blog ("Doravirine Sets a New Standard for NNRTIs—But What Role in HIV Treatment Today?") at blogs.jwatch.org/hiv-id-observations.



In the DRIVE-SHIFT switch study presented at IDWeek 2018 in San Francisco, the doravirine STR showed itself to be non-inferior to continuing on a stable HIV regimen.

The 670 participants all started out with undetectable viral load (under 40 copies) for at least six months. None had a history of treatment failure or any drug resistance to the medications in the new STR. For the first 24 weeks, only 447 had been switched to the doravirine tablet from day one (the immediate switch group). At 24 weeks, the remaining 223 participants were also switched (the delayed switch group). At the end of 48 weeks, more than 90% of each group maintained their undetectable viral load (less than 50 copies).

Search for the abstract online, "Switch to Doravirine/Lamivudine/Tenofovir Disoproxil Fumarate (DOR/3TC/TDF) Maintains Virologic Suppression Through 48 Weeks: Results of the DRIVE-SHIFT Trial (LB2)."



Harvoni and Eplclusa generics

THE HEPATITIS C (HCV) medications Harvoni and Eplclusa are coming out as generics. Gilead Sciences, Inc., manufacturer of both drugs, announced in September **the creation of a subsidiary company to produce the generics.** "We believe that introducing these authorized generics is the fastest way to lower list prices for our HCV cures without significant disruption to the healthcare system and our business, as a bridge to longer term solutions aimed at reducing patients' out-of-pocket

medication costs," according to a Gilead press release. "Starting in January, health insurers will have the choice of covering our branded medications or the authorized generics." The new subsidiary is Asegua Therapeutics. The list price for the new generics is \$24,000 for the most common course of treatment (8–12 weeks for Harvoni and 12 weeks for Eplclusa). Harvoni is the brand name for the combination of ledipasvir and sofosbuvir; Eplclusa is the brand name for the combination of sofosbuvir and velpatasvir.

Reducing death among drug users living with HIV

PEOPLE LIVING WITH HIV who inject drugs cut their risk of death in half with a counseling and treatment support intervention, according to an international study. A press release from NIH says, "They also were about twice as likely to have suppressed their HIV to undetectable levels after one year. The intervention consisted of psychosocial counseling along with guidance and support navigating the healthcare system."

"People living with HIV who inject drugs often encounter multiple obstacles to beginning and adhering to treatment for HIV infection and substance use," said Anthony S. Fauci, MD, director of the National Institute of Allergy and Infectious Diseases (NIAID), in the release. "This study demonstrates that **providing guidance and counseling can help such individuals overcome barriers** to starting and staying in care and treatment, leading to a significantly higher rate of HIV suppression and a much lower rate of death."

In the intervention, a systems navigator helped individuals

overcome such barriers as not knowing how to enroll in HIV medical care or trouble keeping appointments. Psychosocial counselors helped them overcome psychological obstacles they may have to starting and staying in treatment, such as lack of interest in therapy, stigma, or trouble with maintaining a medication routine.

"People who inject drugs and are living with HIV have potentially fatal co-occurring conditions, yet they and their at-risk partners often face different and confusing care delivery systems," said Nora D. Volkow, MD, in the release. She is director of the National Institute on Drug Abuse (NIDA), which co-funded the study with NIAID. "This study shows that integrated interventions, including help from systems navigators, can dramatically reduce mortality for both conditions."

HPTN 074 enrolled 502 men and women living with HIV from Indonesia, Ukraine, and Vietnam, along with 806 of their injection partners. The study was published September 1 in *The Lancet*.



Trans youth often hide their identity from health care providers

“MANY TRANSGENDER YOUTH lack access to transgender affirming care, which may put them at risk for HIV,” reported Celia B. Fisher, PhD, director of Fordham University’s Center of Ethics and Education, and colleagues in the August 2 issue of the journal *LGBT Health*. An internet survey of 228 trans youth ages 14–21 found that half had not disclosed their gender and sexual minority (GSM) identity to a primary care provider (PCP) due to concerns about a lack of acceptance. One-quarter did not disclose due to concerns that their parents would be notified. Another 25%, however, felt that their provider was helpful with GSM sexual health issues. “Transgender youth may not discuss their GSM identity or sexual health with PCPs because **they anticipate GSM stigma and fear being ‘outed’ to parents,**” the researchers concluded. “PCPs should receive transgender-inclusive training to adequately address youths’ sexual health needs and privacy concerns.”

Pediatricians group urges gender-affirming approach

THE AMERICAN ACADEMY of Pediatrics (AAP) in September issued its first policy statement on transgender children. “Despite increasing public awareness and some legal protections, children who identify as lesbian, gay, bisexual, transgender, or gender-diverse often lack adequate health care, including access to mental health resources,” the academy said in a press release. The policy statement “reviews the latest research and **provides recommendations that focus specifically on children who identify as transgender or gender-diverse,** a term used to describe people with gender behaviors, appearances, or identities that do not align with those culturally assigned to their birth sex.” The academy noted that its underlying theme is that, “Transgender and gender-diverse children face many challenges in life, but, like all children, they can grow into happy and healthy adults when supported and loved throughout their development.” Read the press release and the statement, published online September 17, at aap.org. According to its website, the AAP represents 67,000 pediatricians in the U.S.

PHOTO: @JUNO ROSENHAUS

Ending HIV

“ENDING HIV is Everyone’s Job,” the New York-based Latino Commission on AIDS declared for National Latinx AIDS Awareness Day, October 15. The commission said the theme focuses on the tools currently available to address HIV: “take the HIV test; consider PrEP as a prevention approach; stay adherent to HIV treatment to become virally suppressed or undetectable; and use condoms.”

“**New HIV diagnoses among Hispanics/Latinx have increased** while the incidence of new diagnoses have decreased or remained stable in the other ethnic groups,” the organization reported in a press release. “We see the impact of stigma, homophobia, and transphobia in accessing HIV testing, prevention, treatment, and care in our community.”

FOR MORE INFORMATION: cdc.gov/hiv/group/raciaethnic/hispaniLatinos/index.html

Erradicar el VIH

“ERRADICAR EL VIH” fue la declaración the Latino Commission on AIDS para el Día Nacional Latino para la Concientización del SIDA, el 15 de octubre. La organización notó que la tema enfoca en las herramientas disponible para trabajar con el VIH: “hacerse la prueba del VIH, considerar PrEP como un método de prevención, mantenerse recibiendo tratamiento de VIH para alcanzar la supresión viral y permanecer indetectable, así como usar condones.”

“**Los casos nuevos de VIH han aumentado entre los Hispanos/Latinx** mientras que la incidencia de nuevos casos disminuyó o permaneció estable en los otros grupos étnicos. Podemos ver así el impacto que el estigma, la homofobia y la transfobia tienen en la formación de barreras para el acceso hacia la prevención, tratamiento y cuidados del VIH, así como también sobre el acceso a pruebas de detección de VIH, prevención, tratamiento y cuidado médico en nuestra comunidad,” la comisión notó en un comunicado de prensa.

PARA MÁS INFORMACIÓN EN ESPAÑOL: cdc.gov/spanish/especialesCDC/VIHDiaLatino

Not just for women only

WHAT USED TO BE called “female condoms” have been **reclassified by the FDA as “internal condoms.”** According to the National Female Condom Coalition (NFCC), there are three important changes. The sexual health device is now:

- “Renamed as a ‘single-use internal condom,’ a change that de-genders the prevention tool and provides a more inclusive description of who is encouraged to use and benefit from it.
- “Transitioned from the regulatory Class III to a Class II, a move that will lessen the burden on manufacturers when seeking FDA approval for existing and newly developing versions of internal condoms.
- “Approved for both vaginal and anal intercourse, thus endorsing use of this tool for a wider spectrum of sexual activities.”

According to Sara Semelka of the AIDS Foundation of Chicago, which serves as the NFCC Secretariat, “We are thrilled to learn about these changes and so grateful for the tireless efforts of sexual health advocates across the globe who worked for years to demand greater access to this prevention method, which truly empowers people to take control of their health on their own terms.”

The condom reclassification was announced in September.



Greek HIV activist slain

LGBTQ activist and drag performer Zak Kostopoulos, 33, died in Athens on September 21 after a beating captured on video. According to a report from NBC News, the attackers claimed Kostopoulos was trying to rob their store while his friends say he was seeking shelter from a brawl outside. Kostopoulos raised HIV awareness through the organization Positive Voice. **More than 500 people attended a rally in his honor the day after he died.**

BROMMEL



Remembering a founding board member of TPAN

LAST YEAR, on September 28, **Bernard J. Brommel, PhD—Bernie to his friends**—attended TPAN’s 30th anniversary celebration, receiving an award for “A Legacy of Devotion” along with other founding members of the organization, including other long-term survivors of HIV like himself.

In 1987, TPAN founder Chris Clason had made a call out to Chicago for help in building TPA (as it was then called) and Bernie was one of those who answered the call. He served on the first board of directors and performed any number of services. There were no staff members then, so volunteers helped TPAN run as smoothly as possible, and assisted members in obtaining the information and support that they so desperately needed. At one point Bernie led a campaign to have memorial gifts made to TPA, especially after seeing the property of members go to families that had disowned them. He was then in his 50s, and survived to see the 30th anniversary of the organization he, along with others, helped build.

This year, on September 22, Bernie passed away at the age of 88, having entered hospice care a week earlier, after years of heart disease and regular kidney dialysis. “His final hours were peaceful,” baritone and music professor Carl Ratner, Bernie’s partner of more than 20 years, wrote in his announcement. Thanks to safer sex and U=U, Carl has remained HIV negative. Empowering people in their treatment decisions has been but one aspect of TPAN’s work.

Bernie was a professor emeritus of Northeastern Illinois University, in Chicago, where he taught for 28 years, in the Department of

Speech and Performing Arts (now the Department of Communication, Media and Theatre). There he was also a leader in many university functions. He was also a family therapist. He became the university’s first million-dollar donor, eventually donating a total of \$2.5 million. In a tribute from the school, Northeastern noted that it had in 2010 renamed the science building the Bernard J. Brommel Hall in honor of his support over the years, which included the establishment of 25 scholarships.

Gifts often keep on giving. Not five years ago, one of those scholarships went to a young gay man studying social work who was placed, coincidentally, at TPAN for his internship. That young man met Bernie at a school social function for the awardees, where he then heard stories about the early days of TPAN. Bernie was forever proud of Northeastern and helping students. He had asked that the school’s pennants and his cap and gown be placed on his casket.

Bernie grew up in poverty on an Iowa farm, milking cows before going to school. It was a hard life, with a difficult father, and it was also homophobic. He said he didn’t know the meaning of the word “gay” when he first heard it. He entered a long-term marriage and had six children before divorcing and becoming his true self. It wasn’t until after his mother died that he came out as a gay man.

He never stopped working to help others, even continuing to write and publish in his final years. Wrote longtime HIV activist Lori Cannon, founder of Open Hand Chicago (now Vital Bridges), then the only food pantry for people living with HIV, “RIP, Bernie. You done good.”

Rest in power as well.

Ride for AIDS Chicago

THIS YEAR, TPAN's Ride for AIDS Chicago (RFAC) recognized 15 years of community engagement and fundraising to support the life-saving services of TPAN and POSITIVELY AWARE. Over the weekend of September 7–8, more than 200 volunteer cyclists, crew, and supporters covered more than 200 miles in two days. Their stories reflect the many reasons and ways in which we all advocate for people living with and affected by HIV.

This year, two father-son teams inspired us all with their love for each other and their dedication to TPAN's mission.



▲ Dr. John Schneider, an HIV researcher and specialist in Chicago, rode the 200 miles with his 12-year-old son, Mahin, who was the youngest-ever participant in the Ride's 15-year history. They both were quickly embraced and supported by all the cyclists and volunteers. As he told *Windy City Times*, "I work in HIV and know firsthand what people living with HIV go through as well as those who are vulnerable to HIV. The outpouring of support for Mahin was incredible and not what I had expected."



▲ Steven Acosta (above, right) had participated in RFAC previously, and this year he and his father Orlando rode as a team. Steven shared his experience this summer with GoPride.com, saying, "There is someone close to me who died of AIDS many years ago...I ride for the community.... Doing 230 miles with my dad [is] an experience I will cherish my whole life."

A Day with HIV

EACH YEAR around September 21 (coinciding with the autumnal equinox) for A Day with HIV, some entries are prosaic, others poignant. This year, we wanted to give space to an entry for which there is not enough room in the ADWH pages, for the story it tells about treatment and resilience. See pages 33–39 for more photos from A Day with HIV.



10:17 AM: PORTLAND, OREGON

Anthony: When I first found out I was HIV positive I thought it would define me—but by “define,” I came to realize I really meant “stigmatize.” I felt like there would never be a part of me inseparable or irreducible from the virus itself. The thought of having it constantly preoccupied me. Each day when I swallowed that little greenish pill in the morning, I felt a pang of shame and sadness. Today, after living healthily with HIV for three years, the greenish pill still punctuates my days, but the feeling is one of propulsion and determination in place of despair, guilt, and self-loathing. How far I've come!

I happened to have an appointment scheduled with my HIV specialist at Prism Health today, so I took the opportunity to snap a selfie in celebration of taking control of my sexual health.

Speaking of health, specifically the medication and insurance end of it, I've attached an image of the receipt for the pill that I need once daily to stay alive.

The retail cost of a 30-day supply of these pills is \$3,467.99. For those like me who don't excel in arithmetic, that is approximately \$116 per day. It feels funny taking something that expensive every day, but I thank my lucky stars that my insurance completely covers this cost. There are also last-resort secondary insurance non-profits for people with HIV that exist to pick up the excess cost should one's insurance not cover it.

The precariousness of our government and the current administration means that some of this funding for HIV/AIDS research and for these non-profits is in jeopardy of disappearing. What would a person like me do then? I'm glad that is not our current reality. Anyway, fuck stigma and live your best life! Like my tattoo reminds me, I am still me.



'THE AIDS CHURCH':
HOLLYWOOD UNITED METHODIST
CHURCH IS KNOWN FOR ITS
AIDS AWARENESS RIBBON.

AMAZING GRACE OR HIGHWAY TO HELL?

God, spirituality, and HIV

BY MICHELLE SIMEK

WHEN YOU THINK OF HIV/AIDS AND GOD OR RELIGION, the following images may come to mind: “God Hates Fags” lining the streets at the local AIDS walk. A candlelight vigil in the church sanctuary on World AIDS Day. Members of a religious congregation figuratively (and literally) turning their collective backs on someone who has AIDS. Angry ministers loudly preaching “HIV is God’s punishment.” Magic Johnson pleading with African American churches to become more involved in the HIV/AIDS epidemic.

But none of these images tells the entire story, which is full of nuance and subtlety. For some in the HIV/AIDS community, their relationship to God, faith, and spirituality is complex and diverse, much like the epidemic itself. Several Southern Californian community members and faith-based service providers share their thoughts and their messages follow.

OCTAVIO VALLEJO, MD, MPH, CHES

Expressions of love

Octavio was born in Mexico and raised in the Catholic Church. He heard the anti-gay messages from the church but was always attracted to boys instead of girls, which was quite complicated for him. "At the age of six, when I dared to talk about my feelings and experiences in an act of confession, my soul was condemned to eternal fire by a priest who, far from listening to my cries for help, sunk me in the deepest and cruelest punishment when I learned from him that I was condemned for life and eternity." After that, he kept his sexual orientation to himself for many years.

In 1990, he was diagnosed with HIV but he avoided medical care for four years, an irony since he was a practicing physician at the time. In 1994 he was diagnosed with AIDS due to an opportunistic infection and a T-cell count less than 100. He went to see an HIV specialist but left in a panic after five minutes. Eventually he engaged in medical care and started treatment. Like many HIV-positive people in the 1990s he swallowed multiple pills per day and says he had to endure excessive diarrhea, constant nausea that made him hate the slightest smell of food, liver enzymes all over the place, unbearable pain because of neuropathy, and changes in his physical appearance that he says made him "look like Steven Spielberg's E.T." Ironically, his AIDS diagnosis made him restart a spiritual (but not a religious) practice. Today, his home is filled with images and icons of both the Virgin of Guadalupe and the Buddha.

Flash-forward to 2018, he now takes a single-tablet anti-HIV regimen with virtually no side effects. "These medical and treatment advances and the reunification with my spiritual life—not religious per se—gave me the opportunity to rescue the necessary values to survive with this disease: love myself, love others, love service, and the reunification with unconditional love. All these different expressions of love brought other things to my life: strength I did not know I had—a byproduct of my lived experiences—and the capacity to value life in its totality, and the perception to value what is really valuable in this life."

Octavio goes on to say that, "As a healthcare professional to all kinds of human beings [living] with HIV, spiritual life and the direct connection to my

Creator gave me the strength to encourage and help others. It gave me the certainty that I am an instrument of my Creator and that my God does not hate, on the contrary, He provides the purest compassion and love to whomever needs them. When you live with HIV or AIDS, you start to talk with your heart without trying hard and you are more real, you are more yourself.... And when you are genuine, humanity recognizes and values it."



ANDREA (FOURTH FROM LEFT) AT A FAMILY GATHERING

ANDREA DE LANGE

Being of service to others

Andrea is a self-proclaimed hippie from Southern California. She is a 55-year-old straight woman who was diagnosed with HIV in 1987 when she was only 22. Andrea was raised Jewish (Reformed). Her family honored the Sabbath every Friday and leaned towards Zionism. As a teenager, Andrea went to Jewish camp and lived in a kibbutz in Israel one summer. This being said, her family was not very religious. "The God thing was never an issue" and she never truly believed in God. Andrea now identifies as a spiritual atheist and culturally Jewish. "I'm proud of our heritage. I'm proud of the Jewish people." In terms of her atheism, "All you have to do is look at the Holocaust and ask how did God let that happen? The same with Rwanda and Cambodia."

However, she is a spiritual person, but

not in a religious way. Both she and her husband are vegetarians, which is "part of being spiritual. I don't do any special rituals and I tried meditation but it didn't stick." For Andrea, being spiritual equals being of service to others. "When you help others, you take your mind off your own stuff. Being of service is part of being a good person." She was "in the helping profession" even before her HIV diagnosis. "I'm the person who helps

little old ladies and strangers."

When first diagnosed, she went to the PLUS weekend seminars in Los Angeles, which were run by the now defunct LA Shanti. She first went as a participant but was then asked to return and to be on a panel, which she did several times. "Helping to heal others, heals yourself" was the mantra of the PLUS weekends, and Andrea took this to heart.

Nowadays, she volunteers twice a week with Holocaust survivors at Jewish Family Services. Andrea still identifies as Zionist but "feels empathy for Palestine. Forcing people out of their homes is bullshit." Volunteering at Jewish Family Services is "the best thing." The clients are "cool, loving people. If I go to my volunteer shift in a shit mood, they are so loving, giving and appreciative, my mood improves." She "feels affinity" with them. "They survived the Holocaust. I'm a survivor also. I've survived different things. I almost died five times so I feel a bond with them—as survivors." >>



JOE GREEN

Living the Red Ribbon Church

Joe is a 53-year-old out and proud gay man living with HIV and a resident of West Hollywood. His family creed is “God’s will is our command.” He is a very active member of the Hollywood United Methodist Church (HUMC, also known as “The Red Ribbon Church” or “The AIDS Church” due to the enormous red AIDS awareness ribbon on the steeple).

Originally from Wisconsin, Joe was raised Methodist and attended a Catholic university. But after college he was not involved with a church again until seven years ago. He was busy with “work, being single, and then being in relationships.” It was that red ribbon that attracted Joe to the church one eventful Sunday morning. He was considering a different open and affirming church but HUMC was closer so he ended up there. And never left. HUMC “reignited my spiritual journey.” The red ribbon in particular makes Joe feel “proud, as it is a clearly visible stance on HIV for all of Hollywood to see, and for the thousands of tourists who come to Hollywood each year.”

Joe worked at amfAR prior to testing positive for HIV in 1998. That job taught him a lot and provided a wealth of knowledge, “almost too much knowledge: the good, the bad, the ugly, and the worst

ugly” about HIV. He didn’t intend to tell his family but his mother found his Kaletra bottle in his fridge. (His family knows both his sexual orientation and HIV status but they don’t discuss it—“It’s no big deal.”). His mother died six years ago and although he misses her, he says it’s okay. “I outlived my mother, which was my prayer to God. When she passed, it was a relief. I thank God for that” (many PLWH have expressed fear of having their parents see them die). He does wish that she were still alive to meet his current partner, Josep. Josep and Joe recently received a special, private communion at HUMC, from their openly lesbian minister.

For a while, Joe had a very structured spiritual practice. “I would make myself get up at 5 am, seven days a week, to pray. Now I just pray nightly before bed.” He follows the teachings of John Wesley (the co-founder of the Methodist Church). Wesley organized small groups that stressed personal accountability, discipleship, and religious instruction. Or, as Joe puts it, “small groups of people getting together, being of service, and doing the Bible talk thing.” In addition to amfAR, Joe also worked at Easter Seals. Since 2004, he has volunteered as the Regional Disaster Duty Officer for the Red Cross of Los Angeles County, and is on call one week a month. He also feeds the homeless each Sunday, and is an At-Large Member of the Los Angeles County Commission on HIV. John Wesley would probably be proud.

JOSUÉ HERNÁNDEZ

Raising awareness, destroying stigma

Josué, now 31 years old, grew up in a conservative Jehovah’s Witness congregation on the border between Mexico and Texas. His parents both died of cancer. As Witnesses, they were not allowed to receive blood transfusions. Josué “cannot say with certainty” that the transfusions would have helped them live, “but, with my mom, blood transfusions were highly recommended” since she had cancer surgery. Even though his father was an elder in the church, Josué was “connected to spirituality but not to church” when he was growing up. At the age of 19, he left “a lot of things behind, like Jehovah’s Witness beliefs,” and moved to San Francisco. He received his HIV diagnosis two years later, at the age of 21. He “needed to wait 10 years before going public” with his diagnosis. “It took me 10 years to come to terms with my status, because there were other trauma and negative experiences that needed greater attention and prioritization before I could deal with my status.”



When Josué was ready to share his HIV status, he went public in a big way and wrote an article about his diagnosis for *A&U*, a national HIV/AIDS magazine. He "started this year [2018] by contacting friends and family to share my status before I'd make it public by releasing my article. Most of my friends' and family's responses were favorable, except [one] family member who told me that it was my fault for being HIV positive. This person said that I had decided to choose this 'gay lifestyle' and I was now suffering the consequences, by being HIV-positive." (Josué chooses not to reveal the identity of the family member as he is working on improving that relationship.) [They] also said that his "being HIV-positive was a sign that the end of times were close and that I was going to die in Armageddon. They were going to survive Armageddon and live in the new paradise that Jesus Christ promised, but I was going to die. The person added they were embarrassed to think of my parents in paradise, being asked about me and blaming them for not having done more to save me. This was very painful to hear. But, I felt prepared," he says, although "I had a nervous feeling in my gut" before the article came out. Now Josué does not speak with anyone from his former congregation, other than a couple of family members, which he says was what he expected.

Like others highlighted in this article, Josué also believes in helping people in need and works at Radiant Health Centers (formerly AIDS Services Foundation Orange County). There he pursues his "personal mission to raise awareness, destroy the stigma associated with [HIV], and empower those at risk by sharing my personal story in Orange County. At the same time, I'm taking advantage of this opportunity to make a stronger connection with friends and family members, including those that think that their religious beliefs are enough reason to cut me off from their lives." His job focuses on Latino MSM, who have among the highest infection rates in Orange County. He enjoys doing educational presentations on HIV and says it empowers him to be more open about his status, especially every time he says, "I am HIV positive."

Josué "believes that religion is not the same as spirituality. I can separate the two." Currently, he does not attend any particular church but does pray daily. "It is an everyday practice. I acknowledge that there is a God and I am thankful for what I have."



DONTÁ MORRISON, MA

Ministering in his truth

In addition to being the Program Manager of Youth Programs at APLA Health, Dontá is also a licensed minister at a Baptist church and he runs their youth group. Even when diagnosed with HIV, church has always been a large part of his life. "Spirituality is my base. Even when I don't go to church, I'm still connected to God."

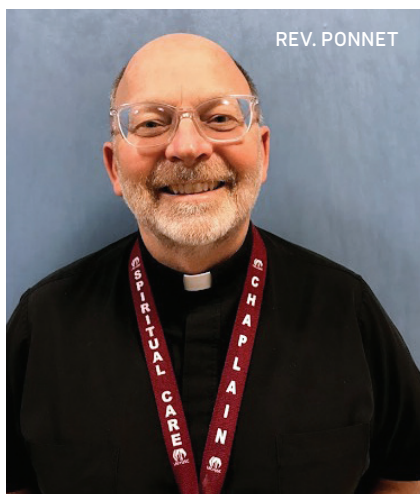
Dontá came out of the closet twice, the first time at 24. Then, at the age of 32, after years of "trying to please the church and not God," Dontá decided that he didn't want to be gay anymore, renounced homosexuality, and lived life as a straight man for five years. He wanted to "get in right with God. I hadn't tapped into God. I was living life to answer to the church." Interestingly, when he took a break from church, he got closer to God. "All I had was God" during that time. During those "straight" years, "he had a lot of girlfriends and almost got married." And yes, he did disclose his HIV status to his girlfriends. But his attraction to men returned. Dontá talked to his mother who asked, "Are you gay again?" Actually, he was still gay but had realized something important: he would not cheat on a man with another man but would cheat on a woman with another man. "I

had a forced attraction to women but a natural attraction to men." Finally, his mother understood his sexual orientation.

After his "second coming out," he returned to the church and was preaching as a Baptist minister across Los Angeles. But people started hearing that he was gay and the phone stopped ringing. "And it hurt." Also, everyone assumed that he was promiscuous and hypersexual. "Just because I'm gay, it doesn't mean I'm having sex. People assume that if you're gay, you gotta be a ho." Point of fact, Dontá was celibate at the time. Currently, Dontá is in a committed, long-term relationship and he and his partner attend church weekly.

At church and at APLA, Dontá sees himself in the youth he serves. He tells them things that he wishes he had heard as a teenager. "I had no idea what HIV was. I saw 'Philadelphia.' I thought it was only white boys in WeHo who got AIDS, like Tom Hanks in the movie. I thought I was going to be dead soon. I was angry at the church. They never talked about sex from a neutral perspective. They don't want to know [about HIV/AIDS]."

As this article goes to print, Dontá will already have been honored by his church, Church One in Long Beach, California, for his work with his youth group and he is working on his doctorate in Philosophy and Global Leadership. "Lots of people go to church but have no connection to God. I now live in my truth." >>



REV. PONNET

REV. CHRIS PONNET, MA, MDIV., BCC
An HIV/AIDS ministry

Father Chris has been a priest for the Los Angeles Archdiocese for 35 years. In 1986, then Cardinal Roger Mahony (controversial for both his liberal pro-immigrant stance and also for concealing pedophilia in his parishes) started the church's HIV/AIDS ministry when the "pandemic was experiencing tragic numbers." The HIV/AIDS and LGBTQ ministries were originally combined but have since separated. When the HIV/AIDS ministry first started, it consisted of many support groups for the infected and affected. Now the groups are "less needed and fewer attended" so they focus on one-on-one counseling and group education.

In the late 1980s, there were not many AIDS service organizations (ASOs) offering services in Spanish so the Spanish ministry began doing so (and still does). Also, the HIV/AIDS ministry has had a team in every AIDS Walk Los Angeles since it began. At first the team consisted of clients living with HIV and their families and loved ones. Now the teams are filled with students from Catholic high schools. Father Chris uses the AIDS Walk as an educational moment and makes sure that every team receives HIV/AIDS education. The team also prays as a group prior to the beginning of the walk.

Nowadays, the Ministry focuses on spiritual counseling, which Father Chris describes is "like regular counseling but with an emphasis on God." Anyone who is living with HIV can be counseled, not just Catholics. And there is no limit to the number of sessions. "Some come to hear that God doesn't hate them, and are

happy to hear it! Others need more time." The priest accepts both self-referrals and also referrals from local ASOs and HIV/AIDS clinics.

Much of Father Chris's work takes place in Los Angeles County+USC Medical Center (one of the largest hospitals in the United States, with over 600 beds). The social worker links patients who are HIV-positive with Father Chris and he performs spiritual counseling right at the hospital bedside. If the patient would like to see someone of a different faith, he will find someone else. Father Chris has a vast referral network of clergy in Southern California.

If he receives a report that a priest is talking about "hell and damnation" in terms of HIV/AIDS or LGBTQ issues, he can and will reach out to them to do an intervention. "Often it is an issue of ignorance. The pastor is just following what he was taught according to church doctrine." And he has been successful in changing some hearts and minds of conservative priests.

Lastly, Father Chris also does HIV/AIDS education in schools and parishes. While the doctrine of the Catholic Church does not allow him to pass out condoms, he knows and acknowledges that most people don't wait until marriage to become sexually active, so he encourages using protection.

RICHARD ZALDIVAR
Mentoring spirits with open hearts

Richard is Executive Director of The Wall/Las Memorias Project (TWLMP) and is considered a leader in the Los Angeles HIV/AIDS community. TWLMP started by erecting a memorial in East Los Angeles commemorating those who have died of complications from AIDS. The agency now offers services for people who are living with HIV and for those who are very vulnerable to HIV acquisition. Richard, a gay man who is HIV-negative, feels "spiritually called to do this work." In fact, spirituality is a core part of TWLMP's mission. The agency has a Faith Advisory Board that consists of clergy of many different religions. Also, TWLMP has been a past recipient of a faith-based HIV prevention grant. The agency has hosted and organized the annual "Conference on Latinos, Faith, Culture, HIV, and Mental Health" for the past 11 years.

According to Richard, "Everyone has to follow their own spiritual path. Some



ZALDIVAR

resist the God issue. It's either not for them, they haven't explored it, or they have had a bad past experience." With open hearts, TWLMP staff are "mentoring clients' spirits."

A practicing Catholic, Richard and his partner go to The Cathedral of Our Lady of the Angels every Sunday. When asked why he doesn't go to a gay specific and/or open and affirming church, Richard states, "I get to claim my space wherever I go. This is part of my spiritual journey." He noted that the LGBTQ community didn't always have representation in Congress and now there is the Congressional LGBT Equality Caucus. "We have had to fight for our space in the Democratic Party and everywhere else. For all marginalized communities in these turbulent times, it is okay to nurture a place where you can connect your spirit to your body and love that experience, and wait for things to happen from there." **PA**

MICHELLE SIMEK works at an HIV/AIDS clinic in Los Angeles, California. In 2006, she was given the annual "Social Service Provider Award" by the Los Angeles Women's HIV/AIDS Task Force. She is also an actor and writer. In her spare time, she goes to see rock bands, reads voraciously, and pets her cat, Baxter.



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SPIRITUALITY AND FAITH IN MY HIV JOURNEY

The line between religion and spirituality can be difficult to navigate

BY CLARK HAWLEY

My name is Clark Hawley, but in the HIV cure research world, my cells have a bit more notoriety as those of SCOPE patient 2512, living pincushion and reluctant poster boy for the cause.

I was born a spiritual being. For my younger years this characteristic expressed itself as an intense desire to know the answers to the questions of life. In the last few decades it expresses itself by having an internal sense of wonder, respect, and gratitude for the majesty of this life we all find ourselves in. Richard Rohr says it best for me in his podcast, *Utterly Humbled by Mystery*, "I believe in mystery and multiplicity."

A world-famous concert pianist once said, "There is a thin line between genius and insanity." The line between religion and spirituality is even thinner, and more complicated to navigate. Neither of these is a force for good in the world when their systems try to impose structures on others. Both are very powerful forces when they assist people to find themselves, know themselves and express themselves. This is my story as a spiritual being having a human experience with HIV.

Establishing themselves as places of danger for LGBTQ+ people and especially folks living with HIV, many, many churches have aligned themselves with a philosophy of fear and exclusion, basing their decisions on tradition, dogma, or the interpretation of documents thousands of years old by people looking outside themselves for answers. This is not all churches, religions, traditions, and congregations; however, their members seemed to make the news and get elected. I myself was a conservative fundamentalist evangelical with a wife, minivan, and two kids who believed all five points of Calvinism. I had all the right answers for myself and everyone else in the WORLD (in my mind at the time), but I was miserable. I gained weight until I topped at 340 pounds. Once every third telephone pole seemed to call at me to drive into it, I got help from a psychologist. In all my miserable "rightness," a dear friend asked me a simple question, and it was this, "Clark, what if God doesn't care so much what you do with your genitals? Do you think He/She would really mind so much if you were happy?" I tried to respond, and he stopped me. "It's a question. Just think about it." I did, and started my journey from religion to spirituality.

God (whomever He/She/It is) doesn't mind.

At 35 years old I discovered what my 12-step friends call a higher power that was bigger than a guy in the sky with lightning bolts in one hand to smite those he dislikes and a bag of jewels in the other that he distributes to those

that please him. I simply let go of 12 apostles, 10 commandments, and four spiritual laws and embraced myself. Instead, I made four agreements with myself, with a little wisdom from Don Miguel Ruiz.

Finding a group of people

so I would be supported and encouraged in living my journey, no matter what path it would take, should have been a challenge, but my friend, who taught me the magic words, “What if,” asked me if I wanted to go to his “Center” on Sunday. I found a philosophy that works for me, that does not require me to make anyone else wrong. There are groups of folks (it turns out there are hundreds of thousands of folks and hundreds of congregations) whose goal is to treat each other as they wish to be treated. Not in one church or path or spiritual philosophy, but many differing ones, including Centers for Spiritual Living, Unity, Unitarian Universalists, Agape International Spiritual Communities, and many others that are listed on the International New Thought Alliance website. These formalized groups of fellow men and women simply have no place in their philosophy for guilt over being gay. It simply is not an issue. They think you are made the way you are. There is no guilt for having HIV; you experience what you experience.

There are also mainline denominations that have come to a similar conclusion. They have focused on the expressions of love in their texts rather than judgement. A fairly comprehensive list of these can be found at gaychurch.org.

Even within affirming churches, there can be vast differences in receptiveness and celebration of their LGBTQ+ members and members who are HIV-positive. One of the most celebrative and expansive individual congregations on earth is Glide United Methodist in San Francisco, yet because of their radical inclusiveness, they are currently in conflict with their parent organization. Since my ex-wife attends a United Methodist church in ultra-conservative California congressional district 22, I personally have long been aware of the variation in belief and practice in *that* denomination.

Group spirituality and spiritual organizations are not for everyone, and I believe that one's own spiritual journey is enough. Spirit, God/s, the Goddess/-es, the Universe, the Creative Impulse, whatever you want to call it, is actually big enough to support every individual without a group effort at all. You, alone, are able to find your spiritual expression without judgement from anyone. Yet, if

you are built to have community support, it is helpful to have a couple of tools to find the community for you that considers you to be what you are—a wonderful expression of stardust and energy on earth, rather than an anathema.

I was fortunate to have that. On the day I was told about my HIV status, what was truly puzzling them was that the “number” of the positive test was like nothing they had ever seen. When a person is tested, what is normally found is a viral count of around 150,000 to 200,000. In the very rarest of cases, the count can be as low as 2,000. No one I encountered had ever seen a number less than 1,000. The number on the test result from the vial with *my* name on it was 212.

This result, I was later informed, was the earliest detected, lowest viral count positive test in the history of all mankind and modern science, coming in at four times lower than any previously encountered positive reading then known.

As I sat in the Civic Center BART station waiting to get on the train home, I was texted by a spiritual mentor to see where I was, and to care for me. After answering her, I checked my phone for any other messages. There were none, except for an automated app update notice from AVG. It read this exactly: ANTIVIRUS: You're fully protected!

Perhaps there is no such thing as coincidence, perhaps there is just one life being lived. AVG is not intended to be a prophecy app, yet it didn't say, “You are negative,” it said, “You're fully protected.” As odd as the timing of this was, it has proven to be accurate. I was in the fray, but fully protected by doctors, researchers, experts, social workers, and a cornucopia of folks willing to devote their time, prayers, thoughts, intentions, and positive energies on my behalf.

Once again I found myself in this place of wonder. The place of mystery and multiplicity, knowing that faith means just that—faith—not a surety of outcomes or answers.


There had been some success in giving monkeys with a low viral load ART therapy, then having them clear SIV (the monkey equivalent of HIV). My virus count was so low that my doctor put me on maximum ART therapy, to see if my body might react the same way. I went 32 months on ART, with an undetectable viral count, not knowing if the virus was controlled or cured. Instead of getting judgement, pity, or shame from folks in my spiritual community, I got messages like this from dozens of dynamic leaders:

“There is only One activity ever taking place. It is that of God. You are one with this Power, this Creativity, this Intelligence. You are that which is greater than an outcome, a diagnosis, a medication. You are the Presence and Perfection of the Allness of the Divine. Therefore you are at ease, and not about Dis-Ease. Your life ahead is healthy—mentally, emotionally, physically, sexually, spiritually, financially. You are a conscious being and your relationship to the Universe reflects your acceptance of your Oneness. Any fear or doubt you may be experiencing is just your “awareness” needing to know more. You are bigger and on a higher plane than any diagnosis—EVER! Power, Peace, Beauty, Light, Love and Joy are your qualities of Life—ALWAYS! This is your truth because you are One with the ever-present, Infinite Nature of Spirit. The Law of Life is working through you with perfection, grace, ease, and completion. You trust all that is manifesting and let good be your Reality. All is well. All is well. All is well.

And so it is!”

—DR. REV. KEITH COX

Though I would never expect anyone to interpret these things that encouraged me as scientific fact, even entertaining the possibility that there may be something “bigger” has helped my attitude and encouraged me to give what I can to my fellows.

What if there is an originating creative force? If so, when he/she/it began to create, then the only substance available was itself. So every doctor, researcher, patient, medication, and being is an individualized expression of it, made of the same stuff as stardust. 

CLARK HAWLEY holds a bachelor's degree in Philosophy (with a concentration in Religious Studies) from California State University Bakersfield, a valid California K-12 teacher's credential, a master's degree in Educational Administration and Supervision, and a California administrative certificate. He is also the father of two adult boys, and is celebrating five years with the love of his life, Josh.

READ ABOUT Clark's journey as an HIV cure research participant in the Summer 2018 special issue of **POSITIVELY AWARE**.





LOSING MY RELIGION

He lost his church, but Joshua Stovall found his faith

BY RICK GUASCO

PHOTOGRAPHY BY DARREN CALHOUN

Growing up in his father's church, Joshua Stovall had a religious upbringing. But it wasn't until he became HIV-positive that he discovered the real meaning of faith.

"Being the pastor's son had its perks and trials," the 36-year-old says. Among the congregation of the Pentecostal Church of God in Christ on Chicago's South Side, the pastor's family was at the top of the social ladder, and many of the parishioners sought status by associating themselves with and insinuating themselves into the family.

"I loved the hands that were there to help raise us. Our family never really lacked for anything," he says. "But sometimes the hands that helped were the same hands that hurt."

Stovall was first sexually molested at the age of four by one of the members of his father's church. The molestations continued over the years committed by other youth, deacons, church elders, and ministers. Some of them would confess to Stovall's father, whose main priority, according to Stovall, was to prevent it from becoming gossip.

"I had a warped sense of spirituality and what 'God meant,'" Stovall says. "On the one hand, I was being reared to godliness, but on the other hand I was being opened to sexuality at a very young age. The spiritual and the sexual intermingled all the time. I was confused by what it meant to be Christian."

According to Stovall, many of the people around him at church engaged in sex with each other, while claiming to be religious. Sex was tacitly accepted as long as it was kept secret—and as long as it was heterosexual.

"Around eighth grade I knew I liked boys," he says, "but being gay was not acceptable, so I liked boys secretly."

HE SOON CAME ACROSS a book, E. Lynn Harris' *The Invisible Life*, a 1991 coming-of-age novel about a

young gay African American man's realization and self-acceptance. "He was such a great writer, I could see myself in the book," Stovall says. "It was like a movie was playing in my mind. That was my Eureka! moment. The molestations didn't [make me gay]—I was seeing myself in that book.

"From that point I was curious about what gay was and what it meant," he says. "I saw how people in church would talk about them. I knew I didn't want my mom and dad to look at me and think of me in the same way that they looked at other people, so I didn't tell anyone."

Keeping his secret took its toll. "I would take safety pins and stick them into my fingers," he says. "I was a cutter, I was inflicting pain on myself. To me, it wasn't cutting; I was trying to release the pain. But not only did it not release the pain, it caused a lot of self-hatred because I couldn't get it out of me. I prayed, I fasted. I started hating myself.

"I felt God hated me," he adds. "You look for spiritual guidance from your pastor, priest or elder; you feel that God feels that way about you. Their dogma is that God hates gay people. How could He say He loved me so much, and then make me this way? Why can't He remove this thing that so many other people hate? I felt rejected by God. I felt He was mocking my life. I wanted to know what kind of God would make me who I was to tell me He hates me. You can deal with your father not loving you, but for your God, who made you, that He hates you, where do you go after that?"

STOVALL FOUND HIMSELF at the corner of Belmont Avenue and Halsted Street in Chicago's predominantly gay Boystown neighborhood, which has for decades attracted LGBTQ youth, particularly those who are homeless or transient. He would wander the street, aimless, looking for a hookup and acceptance.

"I was 16, 17 years old," he says, "I'd meet a guy, sleep with him. I couldn't go home, so even if he wasn't my type I'd stay with him to have a place to stay and something to eat. If we liked each other enough to do it again the next day, fine; otherwise, I'd find someone else to do it with."



'When a pastor serves up God's word, you have to pick out the pastor's own beliefs to get to the meat of what God is saying to you. I read my Bible on my own.'

Stovall eventually found a place of his own on the city's South Side, but it wasn't long afterward that he took ill with flu-like symptoms. A public health department case manager had been trying to contact him, and he had been avoiding her. But his symptoms convinced him to get tested for HIV. She delivered the test result in person.

He could hardly walk down the stairs to let her in. He recalls bracing himself for the news: "Lord, they say you won't put on us more than we can bear. If that's the case, strengthen my shoulders."

LEARNING THAT HE WAS HIV-positive was actually a release of the burden of rejection he had been carrying. He says the "old" him died, and that he experienced a rebirth. Stovall even gave himself a new name—London Benton.

He called many of his friends and acquaintances with the news; rather than

offering words of comfort to him, he was consoling them, reassuring his friends that he would be alright but to pray for him. The following Sunday, he returned to his father's church to tell the congregation.

"I was taking the power away from them that they had had over me," he says. However, the church members responded by turning their backs on him. During the service, at the point when congregants shake hands with each other, they intentionally passed over Stovall, shaking hands instead with the people around him. He was shunned outside the church as well. "The same people that molested me, the same people I had had sex with, they would cross the street to avoid me because they don't want anyone from our congregation to see me with them," he said.

Not long afterward, he left the church altogether. His older brother became pastor after their father died in 1998, and runs the church much the same way it always has been. When Stovall suggested having an event to observe World AIDS Day, his brother killed the idea, saying he didn't want his church "looking like gay pride."

"RIGHT NOW, I don't go to any church," he says. "I don't need it to have a relationship with God. I'd rather my experience with God be a loving one, and not worry about who's judging me for being gay or having HIV. I have a greater faith in God now. When a pastor serves up God's word, you have to pick out the pastor's own beliefs to get to the meat of what God is saying to you. I read my Bible on my own.

"God's truth is that He loves you," he adds. "The Bible is supposed to be a book of love, about the relationship between God and humanity. People think that God is in control. God is not always in control. God has given us free will, for us to do either good or evil. Bad things do happen, but the lesson is what will you take from that and teach the next person. He is a free will God that loves all people." **PA**



RELIGIOUSLY NON-CONFORMING

An Orthodox rabbi leads a movement for trans inclusivity



This past summer, Rabbi Mike Moskowitz became the first Orthodox rabbi to serve at the world's largest LGBTQ synagogue, Congregation Beit Simchat Torah, in Manhattan, where he is the Scholar-in-Residence in Trans and Queer Jewish Studies. Rabbi Moskowitz has long supported the LGBTQ community and trans inclusiveness in particular. At the time of his appointment, he spoke about his journey in supporting the LGBTQ community on the podcast Unorthodox, created by Tablet magazine. A lightly edited transcript of his interview with Unorthodox hosts Stephanie Butnick and Liel Leibovitz follows here.

Liel Leibovitz: So here's the thing. When someone imagines the rabbi they might meet in the world's largest LGBTQ synagogue, they don't imagine a dude looking like you, with a black hat and a beard. They don't imagine a traditional Orthodox rabbi. Tell us about the path that got you here.

Rabbi Mike Moskowitz: The path here was actually a very traditional rabbinic trajectory. I was a rabbi of Columbia University, with Aish New York. I was the rabbi of the Old Broadway Synagogue, which is an Orthodox synagogue, right by JTS [the conservative Jewish Theological Seminary]. And I had

transgender congregants and a trans student at Columbia that was really struggling. And as a rabbi of a synagogue in Harlem, it's a pretty diverse and progressive space, all things considered.

As I started to meet more trans-folks and started to create a space that was trans inclusive, >>

I recognized that I was in a unique position to try to provide some scaffolding to support the trans Jewish experience, so people shouldn't have to choose between a gender identity and a religious identity.

Leibovitz: As you embarked on that mission, I imagine that there were some people in your community who looked at your work and said, "Why are you doing this?" It's highly, if I may, unorthodox. Did you face a lot of struggle going through that?

Rabbi Moskowitz: Internally I did not find any sort of struggle. There was a kind of an invitation to be a light in the darkness where other people weren't. So personally I found a level of clarity and comfort in knowing that I felt like I was doing the right thing. But from the outside there's still tremendous opposition daily, in the emails, on Facebook posts—

Leibovitz: Saying what?

Rabbi Moskowitz: Saying that these things are actually mutually exclusive. You can't be an orthodox rabbi and be supportive of the LGBTQ community. I wrote an article about marching with Pride that I really feel when so many marginalized segments of society are being targeted, that we as Jews have a responsibility to stand up, because we're also targeted as a minority. So the idea that somehow we can be passive or apathetic here—like you *have* to choose sides. It's either about standing up for those who are the most vulnerable or recognizing that it's probably just a matter of time before we don't have the privilege and the entitlement and the agency to do something about it.

Leibovitz: How do you respond to someone who goes on Facebook and just angrily rants at you, "But you know being gay is not allowed

in the Torah. It's *halakhically* bad." [*Halakha* is Jewish law.] How do you square that? Because you see a lot of people in the Orthodox community who are very sensitive to these issues, but you really took a leadership stand on it.

Rabbi Moskowitz: Gender identity and sexual identity are very different. I think it's very easy to hate things that you don't know and it's really easy to kind of mush all this stuff you haven't been exposed to into one little space. So I think the first thing is to try to create space for dialogue, to try to recognize that the struggles of a gender identity are actually very different, both culturally and socially and also in Jewish law, as one of sexual identity. I deeply believe in the autonomy of each person's relationship with God, that it should be the result of our unique life experiences. If we can't create a safe space for people to be authentic and genuine about who they are in that relationship with God, then what is religion? It's not about me in intimacy with God. So the Torah says what the Torah says and everybody gets to figure out what that means for them as an individual. I think that there's a lot that we as Jews can learn from the trans world about being present in the moment, in the most authentic space and embracing a certain amount of fluidity in our relationship with God.

Stephanie Butnick: I'm curious. Given the sort of rigid differentiation between men and women in ultra-Orthodox spaces, how *do* LGBTQ issues arise in that world?

Rabbi Moskowitz: Within the gender space many people find it very affirming. For the trans experience to exist, there needs to be differences between men and women, or else there's no space to transition. So when one walks into an Orthodox synagogue you have to make a choice right away. What

side of the *mechitza* [a partition used to separate men and women] do you want to sit on? Because there's so much gender-based spiritual practice for people who find that type of spiritual practice affirming, the challenge becomes one of providing the invitation and the resources to help the individual navigate all of those gendered choices in Orthodox synagogue, about being counted in a minyan [the minimum number of participants required, 10 men, for traditional Jewish public prayer], getting an Aliyah [immigrating to Israel], chevra kadisha [traditional performance of rites for the deceased] issues. There are all sorts of gender-based spiritual practices that make it a little bit more nuanced. Whereas in a more egalitarian space, in that area you don't have to make a choice but you also don't get the affirmation.

Butnick: It's interesting. When you call it affirming, I would imagine it can be very intense and frightening for someone for whom gender identity is sort of a question at a certain moment, to have to choose a side.

Rabbi Moskowitz: One of the things that is really complicated in the way in which *Halakha* creates a binary around male and female in certain kinds of halakhic spaces—doesn't necessarily resonate with people who adopt a gender non-conforming identity. And then it's complicated. Ideally a *tri-chitza*, right? [Leibovitz laughs, Rabbi Moskowitz is making a word play on *mechitza* basically referring to three genders] allows for those who don't feel like they fit in the binary. I often speak about borrowing language from the queer community. That I was assigned secular, and then identified as ultra-Orthodox, and now I'm some version of religious non-conforming, and that kind of space to be able to be recognized in present tense where I am in a relationship

It's either about standing up for those who are the most vulnerable or recognizing that it's probably just a matter of time before we don't have the privilege and the entitlement and the agency to do something about it.



with God allows for it to be much more alive and also conscious and deliberate. If every Jew would be as aware of their religious identity the way in which trans folks are about their gender identity, there'd be no apathy, there'd be no assimilation. It would just be a constant recognition.

Leibovitz: We would be on fire.

Rabbi Moskowitz: That's what we're looking for.

Leibovitz: You wrote a piece for *Tablet* that I found very moving about the importance of accepting people's choice of their own names and why that actually resonates sort of spiritually as well as civically.

Rabbi Moskowitz: In the Jewish tradition we believe that names are very powerful. That emanates from the power of speech. God said, "Let there be light," and there was. So this world was created through letters and we find this throughout the tradition. You can look at the article. There's a way in which transfolks in having to distill who they are in terms of an identity, especially if there's been a shift into a name, is often the most immediate point of entry in a conversation that either allows for a person to be rejected or accepted. And so when a person speaks about their pronouns and their name, it's *not* simple in the mind of a trans person. That's one of the reasons why I co-authored it with a transman, is to have it in that first person experience that "hello, my name is" is much more of an exposed experience where there's a posture of vulnerability and fragility for a trans person. So I think one of the things that's really important as an ally is to listen to that voice about the experiences that we have. "Hi. Are you Rabbi Moskowitz or are you Mike?" The stakes there aren't actually very high for me. I don't care. But

for a trans person, it represents so much more of the way they're being seen.

Butnick: How does that play out within a Jewish context?

Rabbi Moskowitz: Some people choose a Jewish name or a Hebrew name. We have it within the tradition as something being very powerful. We have it deep within our tradition that if a person, God forbid, is sick, we add a name. Moses changes [Hosea's] name [to "Joshua"] in anticipation of an event. The Torah says that we can no longer call Abraham "Abram." We have to say the new name and not the old name. We find the struggle, it's literally in the struggle with the angel, that Jacob gets a name change from the individual to the communal [he becomes "Israel"] and the mystics that tell us that it was that moment where he went back for the *pacham katan*—the smallest, the most vulnerable, the most marginalized. So I think it's in this space of struggle where we try to create new space to uncover the divine will and it's in that place of the progressiveness of *Halakha*, which is the language of *halocho*, which means "to go" [also "to walk" or "the way to walk"], which is where the Talmud says God exists—in this exile. It's in that place with God to explore and to expand in these new spaces. As the world continues to move, how can we allow the Torah to speak in present tense? In the Jewish tradition, a name really reflects the embodiment of being able to be present as one's fuller self.

Butnick: It seems like there is space even within religious Judaism for transfolk, for a questioning. It actually works well within the structure.

Rabbi Moskowitz: I think if we want for there to be space for Jews, then there needs to be space for trans Jews. Because one of those is a choice. Religion, and a religious identity, is an absolute choice of showing up and being present in that relationship with God. Gender identity, sexual identity, those aren't action items. Those are just identities. They just are. So if we force a person to choose, they will walk away from religion. So if we believe that God is everywhere all the time—"HaShem [an expression for God, meaning "The Name," as Jews are not allowed to utter the name of God] is here. *HaShem* is there." So then what are we doing? We're just speaking to the reality that God is everywhere. And for each person there's the responsibility to ask the exact same question, "What does God want from me right now in this moment being who I am?" I don't think it gets more religious than that. **PA**

GET MORE

Rabbi Mike Moskowitz:
rabbimikemoskowitz.com

The Unorthodox podcast:
tabletmag.com

Congregation Beit Simchat Torah sponsors **Talk to Me About HIV**, a program designed for rabbis, cantors, chaplains and other institutional leaders at Jewish congregations, schools and community centers throughout New York City. The education and outreach program aims to break the silence and stigma around HIV/AIDS. Visit talktomeabouthiv.org. CBST also provides onsite HIV testing once a month as well as a weekly supportive social gathering for adults aging with HIV/AIDS.



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Today is **A Day with HIV**

HOW DO YOU MAKE THE POINT that everyone is affected by HIV and the stigma that surrounds it? By inviting people everywhere to capture a moment of their lives, all within the same 24-hour period, and calling it **A Day with HIV**.

Since 2010, POSITIVELY AWARE has designated a day in September, around the autumnal equinox, as the date for its annual anti-stigma campaign. Over 250 people across the U.S.—with a number of others from nine other countries including Australia, Brazil, Canada, the Philippines, Poland, and the United Kingdom—answered the call, taking a snapshot of their day on September 21.

Participants posted their pictures on social media, along with a caption detailing the time, location, and what inspired them to take the photo, accompanied by the hashtag #daywithhiv. Photo submissions were also uploaded to the campaign's website adaywithhiv.com, creating an online gallery of the day.

"Enjoying the end of summer sun before the fall winds blow," says Katie Willingham. "Even in rural Alabama HIV is a reality, so get tested and know your status!"

For some, HIV is just one of a number of health conditions they are living with. In addition to testing HIV positive in 2004, Cindy Pivacic has survived two strokes, cancer, and a massive heart attack, in contrast to the scenic tranquility of her picture taken among the penguins at Boulders Beach, South Africa: "Nothing should be allowed to impede your life," she says, "no matter what."

Fitness is often key for many people who manage life with HIV, and a number of photos submitted were taken at the gym. Phillip Shipton started his day in Sydney, Australia with an 8 a.m. workout, while Eliane Becks Nininahazwe hit the gym in

Amsterdam that afternoon. Tamara Mayfield Dietrich led a POUND Rockout fitness class outdoors in Quincy, Illinois.

A good many photos were submitted by people active one way or another in the fight against HIV—activists, advocates, case managers, counselors, and researchers. Ronald Shannon and Demetrius Smith took a moment from their work at the Urban Coalition for HIV/AIDS Prevention Services in Washington, D.C. After a lunch meeting, Michael Louella at Seattle's Fred Hutchinson Cancer Research Center remembered to take his picture. In between clients, Yomi, an HIV counselor in Manila, in the Philippines, paused for a moment of reflection. As blogger Mark S. King says in the caption of his photo, "Activism is joy. Activism is life."

For others, A Day with HIV was the opportunity to do something different. Informed that her photo was among the seven chosen for the four foldout covers of the issue, Kamaria Laffrey expressed the personal significance of the picture she had taken: "That pic was so out of my comfort zone, but I'm learning to embrace my body on a newer level now. Loving myself, at least learning to, is not a one-time event, but a process. Thank you so much for seeing me." —RICK GUASCO

THE FOLLOWING SIX PAGES feature a selection of the more than 250 photos taken on A Day with HIV. Captions have been edited for clarity and space; complete captions and the online gallery are at adaywithhiv.com.



**< 10:20 AM:
CHICAGO, ILLINOIS**
Rae Lewis-Thornton: At 56 years old, I'm more comfortable than ever in my skin. I've lived with HIV for 35 years and I know my life is a living example that each day with HIV can be a life well lived. Each and every day I embrace the life that I have and I do everything that must be done to thrive in spite of HIV! I know that Grace abides even where shame resides and it's that Grace which has given me my power in the face of HIV/AIDS.



**< 11:17 AM:
MANILA, THE PHILIPPINES**
Yomi: As an HIV counselor, I trained for three years at one of the largest treatment facilities in the Philippines. Every session with a client leaves me thinking. Ultimately, you are also a client, in need of care and attention. You will be just a little different, because you are on the frontline, assuring them that there is still life after becoming HIV positive. There is hope as long as you help yourself to stand up again.



**< 11:30 AM:
WASHINGTON, D.C.**
Ronald Shannon and Demetrius Smith: On A Day with HIV, the Urban Coalition for HIV/AIDS Prevention Services (UCHAPS) is excited to take part in eliminating stigma and celebrating the lives of those living with HIV!

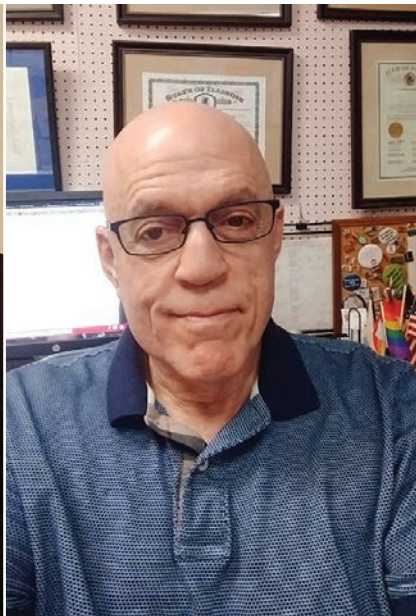
7:13 AM >

ARECIBO, PUERTO RICO
Angel L. Hernández: Getting my hands dirty in my garden. There is nothing more rewarding than volunteer work as a peer educator and coordinator of relief efforts in the aftermath of Hurricane Maria.



8:00 AM >>

BALTIMORE, MARYLAND
Mark S. King: Using my voice as a long-term survivor since 1985 through my writing. It gives me such purpose and meaning. Activism is joy. Activism is life.



8:30 AM >>>

CHICAGO, ILLINOIS
Greg Harris: Getting ready for a day of conference calls with legislative colleagues about transforming Illinois' hospital and healthcare system.



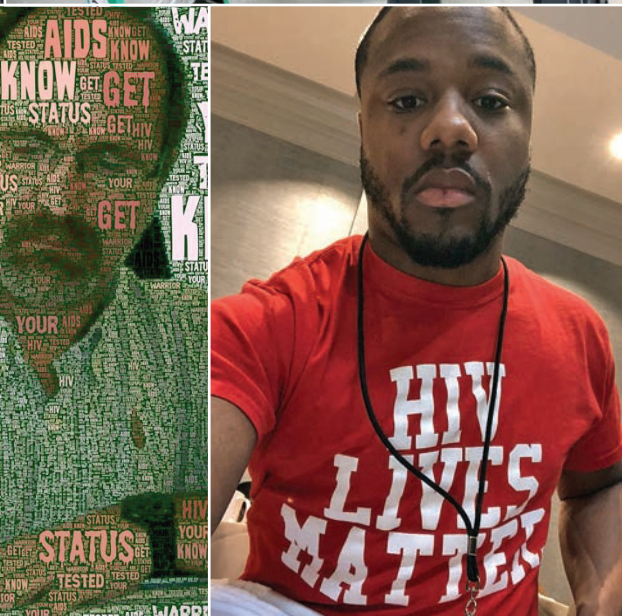
10:00 AM >

BROOKLYN, NEW YORK
Bruce Richman: Walking down the East River to the new U=U office, feeling fine and ready to fight HIV stigma by sharing the news.



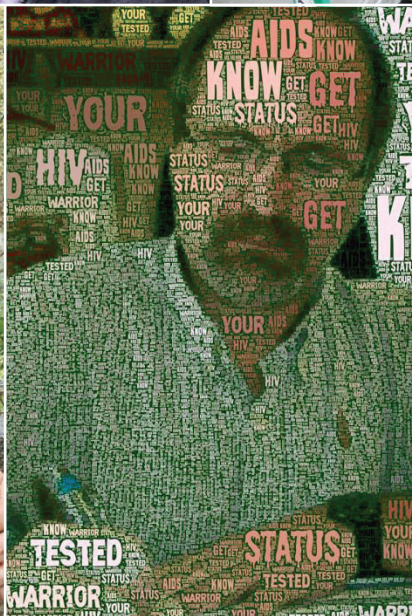
10:00 AM >>

LEYDEN, MASSACHUSETTS
Teo Drake: I balance the emotional labor of HIV/AIDS activism with the solitude of working in my woodshop.



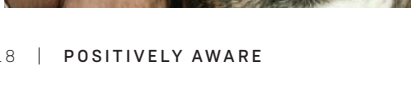
10:05 AM >

NASHVILLE, TENNESSEE
Brady Dale Morris: Gabby Gayle came into my life less than a month before I received my AIDS diagnosis. For almost a decade now, she's been by my side as I went through AIDS, addiction, alcoholism, suicide attempts, and pancreatic cancer. Not once has she ever judged me; she's only shown me what it means to truly love unconditionally.



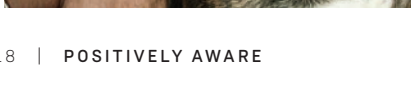
11:02 AM >>

WASHINGTON, D.C.
Craig A. Fowler: 23-year long-term survivor.



11:02 AM >>>

WASHINGTON, D.C.
Toraje Heyward: At the Advocates for Youth Urban Retreat!





<<< 11:30 AM
CHICAGO HEIGHTS, ILLINOIS
Gina Collins: Taking care of my health at the dentist office. It's also the day after the 13th anniversary of my HIV diagnosis.

<< 11:34 AM
NEW YORK, NEW YORK
POZ Magazine: Opening a box of the newest issue of POZ featuring Charles Sanchez (aka Merce) on the cover!

< 12:00 PM
TUSCUMBIA, ALABAMA
Katie Willingham: Enjoying the end of summer sun before the fall winds blow. Even in rural Alabama HIV is a reality, so get tested and know your status!



<< 12:00 PM
HOUSTON, TEXAS
Eunice and Calvin Marshall: Married for 34 years, both have been living with HIV for 12 years. Photographed here at Legacy Community Health. "We are loving and enjoying life as a couple living with HIV."

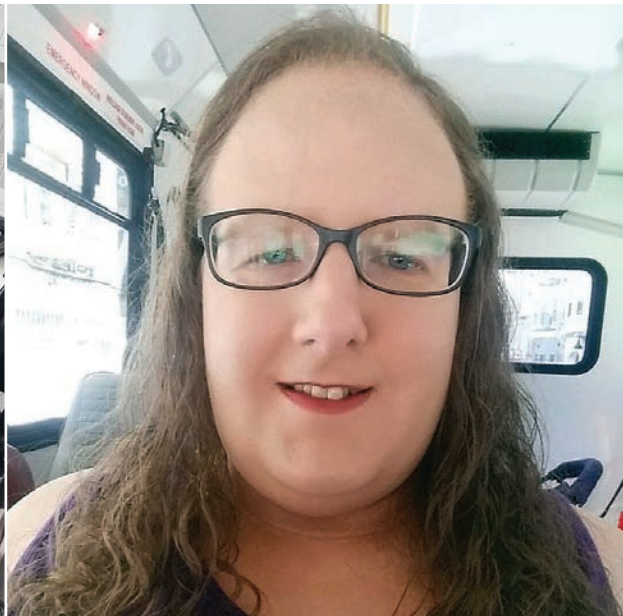
< 12:27 PM
PHILADELPHIA, PENNSYLVANIA
Reverend Andrena Ingram: Thirty years in, I am still getting used to new norms and living life on life's terms. Though I am no longer a minister with a building, I minister on my terms: be it in a waiting room at cardiology or in a Lyft. I have fallen in love with the art of makeup, and am getting closer to my ancestors through drumming lessons.



<< 1:05 PM
SEATTLE, WASHINGTON
Michael Louella: After a lunch meeting discussing a new website, a poster on acceptability of cell and gene therapy approaches to an HIV cure, and the defeatHIV community engagement budget, I remembered today is A Day with HIV! I snapped this pic in my office at Fred Hutch.

< 1:17 PM
AMSTERDAM, THE NETHERLANDS
Eliane Becks
Nininahazwe: Being in control of my HIV by doing sports to keep in shape and stay healthy. I am in charge, not HIV.

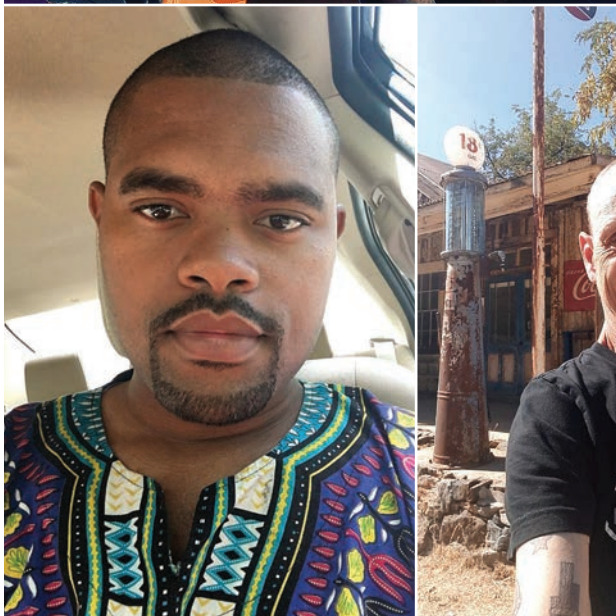
1:36 PM >
NEW YORK, NEW YORK
Lilibeth Gonzales:
At my desk at GMHC, getting my Pussy Packs and condoms ready to go out and talk to people about the tools we have. If I can keep one person from contracting HIV, that's one less statistic!



1:45 PM >>
SAN FRANCISCO, CALIFORNIA
Bobbee Trans Mooremon: Seven years ago today I was raped while looking at a room for rent at a friend of a friend's apartment. PrEP wasn't around back then and I was not aware of PEP so I contracted HIV from my rapist. Since I had been celibate for a year and a half, and had negative HIV tests within that time, they were pretty certain I contracted HIV from my rapist. September 21 is always a difficult day for me.



2:00 PM >
ATLANTIC CITY, NEW JERSEY
Leanza Cornett:
Proud to wear my Red Ribbon shoes in the Miss America Parade on the boardwalk.



2:27 PM >>
KAILUA KONA, HAWAII
Kekoa Kealoha:
Battling stigma requires daily visibility, honesty, and transparency. It requires strength, persistence, and compassion. No matter who you are, what you believe, or what your status is, every day is a day with HIV.

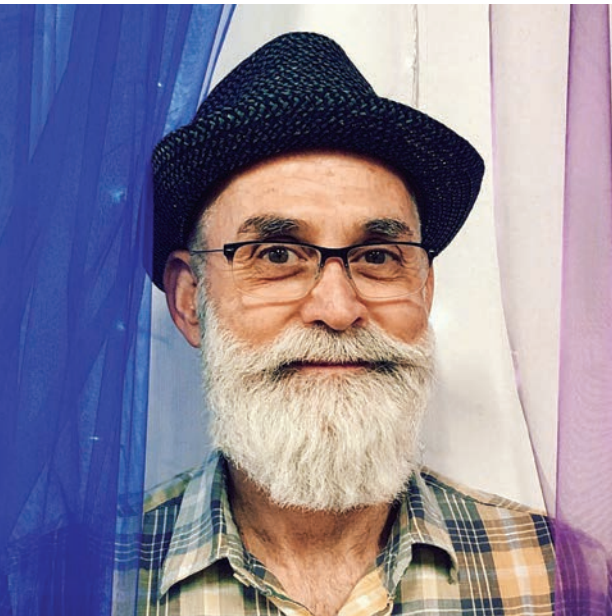


2:40 PM >
TAMPA, FLORIDA
Kahlil Hall, Outreach Coordinator: No matter what I have been through, I still look good. Stay woke about your status and live your Best Life.



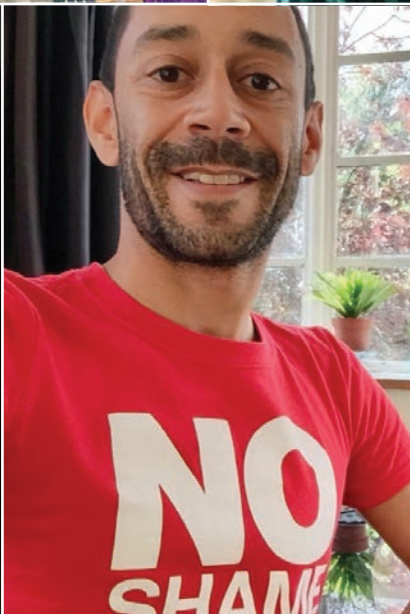
3:00 PM >>
SAN FRANCISCO, CALIFORNIA
Jason Bennett:
Spending the weekend with Shanti at Catherine's House.

3:00 PM >>>
SAN FRANCISCO, CALIFORNIA
Steve Ibarra:
HIV positive 18 years and thriving to build community one person at a time. A reverend ordained in June 2018, I am the messenger of the positive spirit of our lives.



<< 3:04 PM
STOCKTON, CALIFORNIA
Efrén Solanas:
 I intend to spend this day expanding acceptance and strengthening the health and happiness of all LGBTQ+ folk of all ages. I am at the San Joaquin Pride Center.

< 3:06 PM
COBOURG, CANADA
Bob Leahy:
 Shopping at Walmart. If it seems mundane, that's what life with HIV can be in 2018, thanks to advances in treatment.



<<< 3:30 PM
BUFFALO, NEW YORK
Donna: I am just getting home from teaching elementary students, which I've been doing for about 22 years. I don't let HIV and stigma control my life or my story.

<< 3:30 PM
LONDON, UNITED KINGDOM
Ant Babaje: I am president of the Middlesex University Public Health Society. We'll be talking to our new students about PrEP and U=U at the Freshers Fair next week.

< 4:30 PM:
WASHINGTON, D.C.
Jennifer Vaughan:
 Still humming with excitement, relief, and gratitude after having the opportunity to share my HIV/AIDS story at the 11th annual ADAP Conference in Washington, D.C. I spoke to a room full of strangers for 30 minutes yesterday.



<< 5:31 PM
MIAMI, FLORIDA
Alecia M. Tramel:
 Hanging around my homegirl's house watching TV after running errands and doctor's appointment.

< 6:00 PM
IN THE SWAPS, LOUISIANA
Sian Green: A mother's job never ends. Spending time with my children, while eating funnel cakes and stuffed snowballs dripped with condensed milk, is everything. Reflecting on the greatness in our lives.

6:40 PM >

SEATTLE, WASHINGTON

TJ: Tomorrow (Sept. 22) is my 49th birthday, and four months post-op from a quadruple bypass from HIV complications. Not going to slow me down. My partner, friends, and family keep me safe and sane 24 hours a day.



6:40 PM >>

ATLANTA, GEORGIA

Wanona Thomas: Enjoying dinner with one of my children.



7:00 PM >

TALLAHASSEE, FLORIDA

Paula Kiger (second from left): Tallahassee's Neighborhood Medical Center held a Happy Hour focused on STD prevention. As a parent of young adults, a friend of mid-lifers re-entering the dating world and an ally to LGBTQIA people, I appreciate how they educate, inform, and support.



7:04 PM >>

OLATHE, KANSAS

Kalvin Pugh: In the gym, like in life, I'm not where I want to be, but I've begun to understand that it's not about being perfect or the end goal. The journey is where the beauty truly lies. I live with HIV loudly because there are so many who cannot.



7:09 PM >

ROCK HILL, SOUTH CAROLINA

Michael Bivens: My hubby took me out of my comfort zone to a food truck fair downtown. After not dying from AIDS in my 33 years of living with HIV, every day not in the hospital is a great day. Getting to spend the day advocating and then going home to my husband and dog is an awesome day.



7:30 PM >>

BURLINGTON, NORTH CAROLINA

Billy Willis (second from right): Planning the grand opening of our co-op. Some of us are artists and tradesmen, all of us are young and ambitious professionals.





<< 8:00 PM
WASHINGTON, D.C.
Wanda Brendle-Moss: At the ADAP Advocacy annual awards dinner listening to Josh Robbins remind us it's A Day with HIV.



< 9:07 PM
WEST NEW YORK, NEW JERSEY
Xio Mora-Lopez: Expressing my "inner unicorn" and winding down after a day of paperwork.



<< 9:25 PM
NORTH CANTON, OHIO
Bob A. Mohr: All packed and ready for the North Coast 24-Hour Ultra! My fifth 24-hour race, hoping to hit 100 miles for the first time. Running has kept me healthy physically and mentally since being diagnosed almost seven years ago!



<<< 10:13 PM
WASHINGTON, D.C.
Tez Anderson with Hanna Tessema: In D.C. for the ADAP Advocacy Association Conference to pick up an award for Best Social Media Campaign.



<< 10:20 PM
SALT LAKE CITY, UTAH
Brian Rodriguez: There is still plenty of education to be taught. I live in a community where I am able to be open, honest, and free about my status. More support me than turn me away.



< 11:38 PM
RICHMOND, VIRGINIA
Rob R and Danny Y: Arguing over who is the best Golden Girl while falling asleep the night before Richmond Pride.

AGENDA FOR SURVIVAL

The Reunion Project seeks to build an HIV research agenda for long-term survivors

BY DAVID FAWCETT, PhD, LCSW

Seventy percent of people living with HIV will be over age 50 by the year 2020. This stunning statistic highlights the myriad complications facing long-term survivors and people affected by HIV as they age. For those who lived through the dark, early days of the epidemic, there are long-standing issues related to a life disrupted: grief and loss, trauma, higher risk of depression and substance misuse, and in many cases, disability. And for many of those whose lives were saved by anti-retroviral therapy, there is ambiguous loss and the work of reclaiming an unanticipated life. While HIV is now a manageable condition and the urgency of earlier decades has faded, thousands of long-term survivors continue to experience ongoing personal consequences related to the overwhelming devastation in certain communities in the 1980s and 1990s, as well as the impact of stigma up to the present day.

Since 2015, The Reunion Project (TRP) has addressed these needs by providing weekend gatherings around the country aimed at helping long-term survivors connect and talk about their common experiences. Several workshops at USCA 2018, facilitated by advisory board members of TRP, presented an overview of its history along with plans for future activities derived from a roundtable held earlier this year. Yet, perhaps most meaningful to the long-term survivors who were present was the rare opportunity to give voice to their experiences and feelings as survivors, witnessed by those who share similar experiences. Like TRP weekend workshops themselves, this format created a safe container in which people shared not only struggles but their strategies for physical and emotional resilience, as well.

TRP summits are funded by grants and guided by a board that includes prominent advocates, such as Jeff Berry (of Test Positive Aware Network, and editor-in-chief of POSITIVELY AWARE), Matt Sharp (independent consultant), Jeff Taylor (HIV+Aging Research Project-Palm Springs), Chris Bartlett (William Way Center), Waheedah Shabazz-El (PWN-USA), Louis Spraggins (independent consultant), and Greg Cassin (Shanti Project). These weekend workshops, held in cities around the country, are designed to recognize common experiences of long-term survivors—stigma, pain, loss, and trauma—and to build resilience and self-determination among those affected by the magnitude of the epidemic. TRP summits are “an opportunity to gather together to share our stories of survival while honoring our past and acknowledging our

resilience, both individually and as a community,” states board member Jeff Berry. While the emphasis of TRP summits has been on those living with HIV for many years, it is recognized that the definition of who is a long-term survivor is not as important as the process of coming together to heal. It is the individual who self-identifies as a long-term survivor.

Despite the extraordinary physical and emotional impact of HIV on long-term survivors, these consequences remain largely hidden and out of the public consciousness. At another plenary at USCA 2018, Ron Stall, Ph.D., M.P.H., an investigator of Multicenter AIDS Cohort Study (MACS)—a longitudinal analysis of thousands of gay and bisexual men—announced research findings indicating that the prevalence of post-traumatic symptoms among long-term survivors is actually higher than the “shellshock” experienced by soldiers in World War I. TRP workshops address these symptoms. Jeff Berry notes: “There is a yearning . . . to be seen and heard. Many feel that they have been left behind, and yet they have gone about their daily lives all these years despite having survived multiple losses and trauma, financial hardships brought on by the disability trap, psychosocial issues including survivor conflict, isolation, and PTSD-like symptoms, and the onset of multiple comorbidities at an earlier age than many of their HIV-negative peers.”

In recognition of these significant unmet needs, in March 2018 TRP convened a National Roundtable Forum including a diverse group of more than 50 advocates with the goal of coming to a consensus regarding a Coalition of

Survivorship, as well as to begin a process to build a sustainable and powerful movement. In advance of the meeting, the committee gathered research papers and fact sheets and devised four overarching themes to organize the discussion: research, programs, community building, and advocacy. Eight roundtable participants were asked to lead discussions on key issues faced by long-term survivors: isolation, stigma, and shame; services for women and LGBT seniors; resources for people of trans experience living with HIV; research on older adults with HIV; employment; and programs such as NMAC’s “HIV 50+ Strong and Healthy” and the HIV & Aging Working Group of the San Francisco Department of Aging and Adult Services.

Recommendations

Recommendations for each of the four areas were made following facilitated discussions among the attendees:

RESEARCH: More studies are needed on disparities across communities, technology transfer, and research methodologies and compensation, along with research about lived experience, communities, aging, and co-morbidities. Standout issues for research include the South (the epicenter of HIV in the United States), women, the long-term impact of anti-retroviral therapies, trauma and other mental health concerns, “early aging,” and inflammation.

PROGRAMS: There is a need for more goal-oriented, system-based programs (such as navigation and employment) along with those that are individual/community-based (e.g., addressing isolation and well-being) and that promote state-of-the-art technology, rapid dissemination, and replicability. There is a need for programs that are community-based and created through expanding partnerships and stakeholder engagement, including those focused on access and accessibility, awareness, skills and support, and competence, with priority needed for programs addressing mental health and well-being, employment, and economic justice.

COMMUNITY BUILDING:

Recommendations included social and community organizing, broadening networks across demographic groups

(including inter-generational), and expanding partnerships with a focus on bringing long-term survivors together both formally and informally. The need

for safe spaces was noted, along with efforts to build a long-term survivor community, reach long-term survivors in rural areas, and foster a better understanding of the role and power of networks of people living with HIV, including an analysis of power and privilege within the wider long-term survivor community. Additionally, it was noted there should be efforts to integrate best practices with aging service communities and to engage youth and those who acquired HIV perinatally.

ADVOCACY: Advocacy was recognized as the means by which these goals will be accomplished, while never losing sight of

'THERE IS A YEARNING... TO BE SEEN AND HEARD.'

Many feel that they have been left behind, and yet they have gone about their daily lives all these years despite having survived multiple losses and trauma...'

medications; dementia and other cognitive issues; job training; needs of women, especially women of color; and needs of trans people, including binary and non-binary individuals. Other fundamental concerns included the meaningful involvement of people living with HIV/AIDS; reauthorization of the Older Americans Act; and protecting Social Security, Medicaid, and Medicare.

Summary

Upcoming TRP workshops will be held in Washington, D.C., and New Orleans, with other efforts directed toward the role it can play in giving voice

the need for self-care and community-care among advocates. The following critical issues were identified: housing; mental health; long-term consequences of

to long-term survivors and raising awareness about both the opportunities and challenges faced by survivors going forward. While HIV has taken a tremendous toll on several generations of men and women around the world, it is the actions and voices of long-term survivors themselves that will be the source of healing. Says Jeff Berry, "The collective strength and wisdom of these hidden survivors can help guide future generations as they age with HIV." **PA**

DAVID FAWCETT, PhD, LCSW, is a substance abuse expert, certified sex therapist and clinical hypnotherapist in private practice in Ft. Lauderdale, Florida. He is the author of *Lust, Men and Meth: A Gay Man's Guide to Sex and Recovery.*

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