

COVID-19 AND LATINX

STORIES OF WOMEN
REMAKING THEIR LIVES

THE SAN FRANCISCO
PRINCIPLES

BREAKING THE CYCLE
OF ADDICTION

POSITIVELY AWARE

HONORING THIRTY YEARS PUBLISHED BY TPN
NOV+DEC 2020

9:30 AM: DECATUR, GEORGIA

DEVIN MIDDLETON: A day with HIV is another day for me to bloom. To grow. To bask in the light and plant my own seeds into this world.

A DAY

EVERYDAY MOMENTS IN EXTRA



4:10 PM: LAS VEGAS, NEVADA

Davina Conner: Not letting today's issues get me down. Working from my mom's house today; she took this picture.
A SPECIAL SECTION OF PHOTOS TAKEN ON A DAY WITH HIV BEGINS ON **PAGE 40**

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NOV+DEC 2020

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A DAY WITH HIV 2020

24 HOURS IN THE LIVES OF PEOPLE AFFECTED BY HIV

'You know what? It's time for me to live for me. I can't live for how people want me to be.'

—Tiommi Luckett, PAGE 27

FRONT COVER(S) BACKSTORY

ONE ISSUE, THREE COVERS. POSITIVELY AWARE's annual anti-stigma campaign portrays 24 hours in the lives of people affected by HIV. On September 22, 2020, people across the U.S. and from 11 other countries captured a moment of their day, posting their pictures and sharing their stories with the hashtag #adaywithhiv. In addition to a selection of photos appearing on pages 40–46, there are three different versions of the foldout cover for this issue, shown below. An online gallery is also on view at adaywithhiv.com.

JOIN IN THE CONVERSATION

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< 5:34 PM: SEATTLE, WASHINGTON

TJ Elston: Letting go of all the shame and negativity of the 21 years of living with HIV, and starting to celebrate me. Sept. 22 is my 51st birthday, and my one-year anniversary of marrying my husband, James (on the right).



<< 12:45 PM: SAN FRANCISCO, CALIFORNIA

Bobbee Trans Mooremon: Nothing but Glittery Purple Unicorn Magic.

< 4:47 PM: PHOENIX, ARIZONA

Jacundo Ramos: Three years ago I had no idea that HIV would help me shed my old skin and help me grow into someone new. Three years later I am stronger, happier, kinder, and more levelheaded than I ever would've imagined. Meet yourself where you are, and understand that the way you are feeling right now is valid. Remember that your story is a radical act of healing.



<< 9:30 AM: DECATUR, GEORGIA

Devin Middleton: A day with HIV is another day for me to bloom. To grow. To bask in the light and plant my own seeds into this world.

< 2:54 PM: NEW YORK, NEW YORK

Dana Diamond: I fight stigma by telling my story. Ready for a day of work at Exponents, a community-based organization, where I'm fortunate to work as the director of health services. Educating all about HIV and assisting HIV+ people to take care of their health. Also, preventing overdose by training and distributing Narcan kits. This helps me also stay in a positive environment by doing what I love and taking care of my health.



EDITOR'S NOTE

JEFF BERRY
@PAeditor

Make your monthly recurring PA Impact Member contribution today, or a one-time donation, and help make a difference in the lives of those living with and affected by HIV. You may help save a life.

positivelyaware.com/impact

Finding your voice

A funny thing happened during the pandemic—I lost my voice. Not my ability to speak, mind you, rather the ability to speak through my writing.

According to Wikipedia, “writer’s block is a condition, primarily associated with writing, in which an author loses the ability to produce new work or experiences a creative slowdown. This loss of ability to write and produce new work is not a result of commitment problems or the lack of writing skills. The condition ranges from difficulty in coming up with original ideas to being unable to produce a work for years. Writer’s block is not solely measured by time passing without writing. It is measured by time passing without productivity in the task at hand.”

“Time passing without productivity in the task at hand.” I can definitely relate. In that respect, I imagine many of us are experiencing writer’s block. Over the last nine months I’ve spoken with countless people who are going through the same thing in their work or their lives. Whether it’s the inability to meet deadlines, or everything seeming like it’s a struggle, or how projects seem to take much longer to complete than they used to or are just plain overwhelming—the block is not just for writers anymore.

When I came on as editor of POSITIVELY AWARE in 2005, I always tried to speak from the heart, especially in my editorials. That’s when it seemed, at least to me, that my writing would most connect with other people, when something I revealed about myself was something they could relate to in their own life, or was similar to what they were going through.

I was unafraid in my writing, but for some reason, I now feel paralyzed.

COVID-19 has taken so much from us. It has taken lives: As of this writing over 250,000 have died in the U.S. by some estimates, with more than one million deaths globally. It has taken our livelihoods: 22 million people have lost their jobs, and according to a recent Pew survey, about half of those are still without a job—and one in four adults have had trouble paying their bills.

The disproportionate impact of the virus on people of color and marginalized communities is devastating. The cruelest irony: While some of us here in the U.S. stock up our cupboards and closets with food staples, the United Nations warns of a looming food crisis, stating that the pandemic could have a devastating impact on global hunger and poverty—more people

could potentially die from the economic impact of COVID-19 than the virus itself.

According to a new report in JAMA as reported by CNN, “a second mental health wave will bring further challenges, such as increased deaths from suicide and drug overdoses, and will have a disproportionate effect on the same groups that the first wave did: Black and Hispanic people, older adults, lower socio-economic groups and health care workers.”

The daily assaults on our freedom and liberties, from the administration itself, threaten the very fabric of our lives. The deaths of George Floyd, Breonna Taylor, Ahmaud Arbery, and so many others have led to nationwide racial justice demonstrations and calls for true change. The majority of people in this country support the Black Lives Matter movement. Meanwhile, white supremacist groups who have felt emboldened by the current administration were caught plotting to kidnap and kill the governor of Michigan.

I could go on and on, but after a while you become desensitized to the violence and injustice, and just want to shut it all off. But that doesn’t work either.

So what do we do?

We speak up. We use our voice. We say, no more. For those of us who may be in places of power we are obliged to use our privilege to speak up for those who have no voice, but also recognize that we need to lift up other voices and let them speak for themselves. My story is my story, but it may not reflect your experience. Your story has meaning. It has value. It has the ability to lift us all up, as well as perhaps help that one person right now who can relate to what you are saying, and needs to hear exactly what you have to say at this particular moment in time, to begin to find their own voice.

So don’t hesitate, don’t hold back. Make your voice heard. Bang the drum slowly—and loudly. We need you. And don’t forget to wear a mask, practice physical distancing, and wash your hands frequently.

Take care of yourself, and each other.

My story is my story, but it may not reflect your experience. Your story has meaning. It has value.



You can make an **impact**

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LIVE LIFE POSITIVELY AWARE.

FOR 30 YEARS, PUBLISHED BY



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



“POSITIVELY AWARE saved my life.” We've heard that from readers more than once over the years, but each time it affirms for me that the work we are doing makes a difference.

When you support POSITIVELY AWARE (PA) as an **Impact Member**, you help TPAN deliver critical HIV health news, treatment information, peer stories, and inspirational profiles to people affected by HIV. With every issue, we serve more than 100,000 readers—including long-term survivors of HIV, individuals living in isolation who turn to PA as their confidential, go-to health resource, and care providers working to better serve our HIV-affected communities.

We asked readers in a recent survey what their concerns were. One reader told us: **“Misinformation. There is still so much stigma. And I believe that trustworthy resources regarding HIV/AIDS, such as POSITIVELY AWARE, are a great resource to share with others.”**

Our readers consistently tell us that they turn to PA to help make sound, informed decisions about their health. **“The more I learn, the better equipped I am to teach,”** one health educator said.

Readers also tell us that PA uplifts and inspires. **“I am an HIV advocate and love to read POSITIVELY AWARE!”** said another.

Because of subscribing members and supporters like you, we tackle important issues and help HIV-affected individuals on the path of life. Many readers express concern about aging well with HIV. One asked, **“How am I going to survive financially in retirement? I did not plan on living this long.”**

When you subscribe and donate as a PA Impact Member, you are an integral part of our mission. You help make sure that PA reaches more readers who need us and PA's trusted resource of accurate, up-to-date treatment information and important news for people living with HIV/AIDS as well as our advocates. Every issue, PA arrives in mailboxes, non-profit and health care settings, and readers' hands around the country and the world, reaching some of our most isolated peers and community members. Most notably, **POSITIVELY AWARE is free to anyone who is HIV positive or unable to pay. This is our mission.**

Go to our website at www.positivelyaware.com/impact, use the enclosed envelope, or contact us (see below) to make a monthly recurring gift of \$5 or more to become a PA Impact Member. Your support not only carries membership benefits for you, it helps us uplift all communities affected by HIV. Impact Member includes:

- **FREE annual subscription** to PA's mailed print edition (6 issues per year, mailed discreetly to you)
- **PA's annual HIV Drug Guide.** Your handbook to the medications prescribed for HIV, along with the latest HIV treatment news
- **PA Update.** Our bi-monthly email news update, alerting you to latest issues and stories
- **Invitation to the annual PA Online Update:** a virtual update from experts and PA contributors
- **Invitation to our PA30 Celebration:** an online experience celebrating our 30th anniversary.

Make your monthly recurring PA Impact Member contribution today, or a one-time donation, and help make a difference in the lives of those living with and affected by HIV. You may help save a life.

In gratitude,

Jeff Berry
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BRIEFLY

Generic Truvada now available in U.S.

A generic version of the medication Truvada, which is used for both HIV treatment and PrEP, is now—finally—available in the U.S.

The generic medication from Teva Pharmaceuticals USA was actually approved by the U.S. Food and Drug Administration (FDA) in 2017, but the Gilead Sciences patent on Truvada prevented its availability as a generic.

Then Gilead announced it was relinquishing its Truvada patent a year early, in 2020. Gilead made an agreement with Teva, allowing the generic version of tenofovir disoproxil fumarate plus emtricitabine (TDF/FTC) to be made commercially available this year.

Teva reported that the generic Truvada tablets “are expected to be available through retailers and wholesalers at a Wholesale Acquisition Cost (WAC) of \$48.51.”

A bottle of 30 tablets (a month’s supply) would be \$1,455.30. This compares to \$1,755.30 for the wholesale acquisition cost for Truvada and the average wholesale price (AWP) for Truvada of \$2,210.74 per month, according to Eric Farmer, PharmD, at Indiana University Health LifeCare Clinic, and pharmacist for the Positively Aware HIV Drug Guide. Different clinics and hospital systems negotiate with pharmaceuticals based on the WAC and AWP prices. Patients will not

pay those prices, unless paying entirely out-of-pocket (in the absence of insurance or other financial assistance). “The price won’t change too much until other generic manufacturers or formulations become available to increase competition in the market,” said Dr. Farmer.

According to Teva’s announcement, “Actual costs to individual patients and providers are anticipated to be lower than WAC because WAC does not account for additional rebates and discounts that may apply. Savings on out-of-pocket costs may vary depending on the patient’s insurance payer and eligibility for participation in the assistance program.”

Teva also made available a generic form of Atripla, but that single-tablet regimen is no longer recommended for first-time HIV therapy. The Teva wholesale acquisition cost is \$78.86 per tablet, or \$2,365.80 for a bottle of 30. Atripla’s AWP, according to the PA drug guide, is \$3,583.65/month.

GO TO [TevaHIVgenerics.com](https://www.positivelyaware.com/hiv-drug-guide). Our HIV Drug Guide is at [positivelyaware.com/hiv-drug-guide](https://www.positivelyaware.com/hiv-drug-guide).

Pricing for generic Truvada and Atripla

There’s more than one way to skin a price cut. For the new generic of Truvada, the devil may be in the co-pay.

In a message to fellow pharmacy staff at the pharmacies of Indiana University Health, Matthew Reed, CPhT, laid out some reasons **why going generic may end up costing more.**

“Truvada and Atripla’s current copay card (from Gilead) does not have a monthly cap on the amount of assistance (there is an annual cap of \$7,200 and \$6,000 respectively),” wrote Reed, a certified pharmacy technician and Patient Care Coordinator. “A patient with a high deductible plan will typically have a cost of about \$1,600 and \$2,400 per month when their plan resets until the deductible is met. With no monthly cap on assistance, the patient is typically able to continue therapy without any out-of-pocket expense.”

“The new generics being released,” Reed continued, “also have copay assistance programs setup for patients, but the programs have a monthly cap. The copay card for generic Truvada will pay a maximum of \$600 per month. The copay card for generic Atripla will pay a maximum of \$750 per month. Since the generic versions are similarly priced to the brand, a patient with a high deductible plan may have an out-of-pocket expense greater than \$800 per month until their deductible is met even after the copay assistance card. In today’s insurance environment, these programs

may be viewed as grossly insufficient for keeping a patient on therapy. It can be especially difficult for a patient that always had a \$0 copay to be told they must suddenly pay a much larger copay for a generic version. Unfortunately, patients often do not learn of this change until requesting a refill giving them little time to financially plan for such a large change.”

“In talking about generic releases of brand specialty medications, cost and copay assistance offered is a major concern” Reed said. “This is a great example of how a change to generic may cost the patient with commercial insurance much more than what they paid for the brand name.”

Generic Truvada cost sharing

A reminder: the U.S. Preventative Services Task Force (USPSTF) made a recommendation in June 2019 limiting a patient’s cost-sharing expense for PrEP that is slated to start in 2021. **Private insurance plans that are not grandfathered in must cover PrEP** without cost-sharing payments, such as co-pays, from patients. Health Affairs has more information: [healthaffairs.org/doi/10.1377/hblog20190613.596797/full](https://www.healthaffairs.org/doi/10.1377/hblog20190613.596797/full).

New cure potential

A research group looking into HIV cure reported a new way that it may happen.

Cure research has long looked at elite controllers, people living with HIV who continue to have undetectable viral load without

treatment. Cure research also looks at the HIV reservoir, places in the body where the virus hides. Once HIV treatment dominates the virus, HIV may lie dormant in these sites ready to continue battling against the body. Ready to rumble, so to speak.

Now, a group reports new information on reservoir sites. Elite controllers appear to have HIV in areas of these sites different from people who have controlled the virus long-term using medication. The team said this different configuration points to the importance of the quality of reservoir sites, not just the quantity of the virus there.

Understanding how HIV functions in elite controllers raises hopes of helping to control the virus in others.

Chenyang Jiang, of the Raygon Institute of Massachusetts General Hospital, MIT, and Harvard, and colleagues published their study in the August 26 issue of *Nature*, but their highly technical report was told in a more accessible story format the same day by *The New York Times*. READ “A Woman May Have Been Cured of H.I.V. without Medical Treatment” at [nytimes.com/2020/08/26/health/hiv-cure.html](https://www.nytimes.com/2020/08/26/health/hiv-cure.html).

Islatravir continues to show promise

Merck & Co. reported that **96-week results of its investigational drug islatravir are “consistent” with promising data seen at 48 weeks**. Islatravir belongs to a new HIV drug class that has not yet hit the market: nucleoside reverse transcriptase translocation inhibitors (NRTTIs). The company also reported good early results for a new once-a-week oral HIV compound.

Islatravir was given with doravirine, a drug that is already available under the brand name Pifeltro. The two meds were given at the same



Dovato shows promise for rapid start

“Rapid start” HIV therapy has become the standard of care. Also called “test and treat,” it means putting people on HIV treatment within two weeks after diagnosis. But for rapid start, not all HIV drugs are equal.

A recently reported study showed that the HIV medication Dovato (dolutegravir/lamivudine) may be effective for rapid initiation.

Individuals were put on Dovato within 14 days of their diagnosis, and before test results for hepatitis B, renal function, and drug resistance were back.

All people who are newly diagnosed should be tested for hepatitis B and C. They should also know their hep B status before starting some HIV drugs that can also treat hepatitis B, as lamivudine does. Otherwise, they may experience a flare-up of their hep B when stopping or switching their HIV treatment.

The STAT study found that for **the five individuals who had hepatitis B at baseline, all had undetectable viral load** (less than 50) at the six-month mark. They had been successfully switched to other HIV therapy. HIV treatment needs to include two medications that work against hepatitis B for those who are co-infected with HBV and HIV.

For the participants in the clinical trial with available data, 92% (102) had undetectable viral load. ViiV Healthcare reported its findings at ACTHIV 2020 (the American Conference for the Treatment of HIV), held virtually in August. The study is continuing out to 48 weeks.

time as a once-daily regimen. For the first 24 weeks, study participants also took 3TC (brand name Epivir) before the regimen was simplified from three drugs to two.

The islatravir regimen was compared to Delstrigo, a single-tablet regimen containing doravirine plus lamivudine and tenofovir DF.

All participants were taking HIV medication for the first time (treatment-naïve).

Islatravir will move forward in research at a 0.75 mg dose for the 90 participants taking it. The three islatravir groups had an average of 81.1% of participants who had an undetectable viral load (fewer than 50 copies). This compared to 80.6% for the 31 individuals taking Delstrigo. The average for the islatravir groups was dragged down by the discontinuation rate among those receiving the highest test dose, 2.25 mg.

A new oral HIV compound, MK-8507, is moving forward into Phase 2 study in combination with islatravir. The two-drug regimen will be taken once weekly. MK-8507 is a non-nucleoside reverse transcriptase inhibitor (NNRTI).

The drug studies were presented as oral and poster presentations at the virtual 2020 International Congress on Drug Therapy in HIV Infection, in Glasgow (HIV Glasgow 2020) in October.

U=U: Spread the word

“For ART [antiretroviral therapy], the science is strong and clear; the data show that the **effectiveness of ART with viral suppression is estimated to be 100% for preventing sexual transmission of HIV**. In other words, for persons taking ART as prescribed and achieving and maintaining viral suppression, there is effectively no risk of transmitting HIV through sex.” So wrote Eugene McCray, MD, director of the Division of HIV/AIDS Prevention of

the National Center for HIV/AIDS, Viral Hepatitis, STD & TB Prevention, at the Centers for Disease Control and Prevention (CDC). Dr. McCray reached out to health departments and community organizations in a July letter, after CDC updated its web page on “Effectiveness of Prevention Strategies to Reduce the Risk of Acquiring or Transmitting HIV.” The page is full of research information, walking you through the scientific evidence. “I am writing to encourage you to continue your work to spread the word about the power of viral suppression to improve the health of people with HIV and to prevent the sexual transmission of HIV,” Dr. McCray wrote. “This information is important and has the power to change lives.” GO TO bit.ly/EffectivenessofPreventionStrategies.

PrEP on vacation

How’s this for innovative use of PrEP? Give people the HIV prevention pill before they go on vacation. Although one pill a day keeps the HIV away, that’s not always so easy to do. So, a group of researchers put 54 men who have sex with men (MSM) on the prevention pill before the guys went on vacation. Of these, 48 completed a three-month visit afterwards. Three-quarters of the men reported having condomless sex during the vacation—something they had done previously—and a third reported having recreational drug use. The research team called the strategy “Epi-PrEP,” for episodic use. The majority of the men, however, continued to use PrEP after their vacation—and 94% of them had prevention drug levels consistent with daily use. “Many participants felt the experience of initiating PrEP while on vacation could be a means for transition to long-term PrEP use,” the team noted in its conclusions.

One of the men acquired HIV after stopping PrEP following his vacation. James E. Egan, MPH, PhD, and colleagues published their findings in the August 15 issue of *JAIDS*.

My Fabulous Disease wins GLAAD award

Blogger Mark S. King received the 2020 GLAAD Media Award for Outstanding Blog for *My Fabulous Disease*. The blog’s introduction: “I’m an HIV-positive gay man in recovery from drug addiction. What’s not to love?”

“I accept this honor with great humility and a lot of sashaying around my living room,” King wrote. “Meaning more sashaying than usual.

“I have been living with HIV for more than 35 years. Long-term survivors are the wounded elders of our tribe. We are the storytellers of an epic tale of courage and humanity. I am so gratified to know that GLAAD has been listening,” King posted on July 30, the day of the awards.

King also received the LGBT Journalist of the Year 2020 award from the Association of LGBTQ Journalists (NLGJA). The association also recognized him with the Excellence in Blogging Award for 2014, 2017, and again this year.

GLAAD was founded in 1985 in response to inflammatory coverage of HIV and AIDS.

Damn you, COVID-19, for making the fabulous Mark S. King’s moment virtual. How great the tall, handsome redhead would have looked sashaying in the aisles.

Gilead privacy lawsuit

“An Alabama man was mortified when an envelope for him with the return address HIV Prevention Team in bold red lettering turned up in his workplace mailroom,” reported the newsletter of the AIDS Law Project of Pennsylvania. “An Indiana

man, who is so protective of his confidentiality that he fills his HIV-related prescriptions at a different pharmacy chain from where he gets his other medications, was shocked to receive the same mailing.”

As a result of the incidents, the two men are being represented by the law project and the law firms of Berger Montague PC and Langer Grogan & Diver PC in a class action lawsuit against Gilead, the sender of the envelopes.

The two men had signed up for the company’s Advancing Access Program, which offers discounts for Gilead’s PrEP medications. It appears that the envelopes were meant for providers, not people in the program.

Opioid agonists in lock-up during COVID

A survey of opioid agonist treatment (OAT) programs for incarcerated individuals found that half had challenges maintaining their staff under the COVID-19 crisis. On the other hand, most—more than 80%—saw early release given to OAT participants.

A research team from Johns Hopkins University used an online survey in May of 19 institutions that were providing maintenance treatment with methadone or buprenorphine around the time COVID-19 hit the U.S. Sixteen (84%) responded: 12 jails and four prisons.

A report on the



PAUL STALBAUM (ABOVE, IN WHITE T-SHIRT)

‘Poz Cruise’ founder Paul Stalbaum dies

Paul Stalbaum, the travel agency owner who founded a yearly cruise voyage specifically for people living with HIV, died in August after years of struggling with cancer.

The HIV Cruise Retreat, better known as “The Poz Cruise,” provided education and entertainment, but more importantly, the chance to create community with people around the country. Paul negotiated the best prices he could for the cruise and also made sure that scholarships were available to help people attend it.

Paul has a special place in my heart for being one of the few people to reach out to *Briefly*, wanting to let people all over the country hear about the cruise. I never met Paul, but he was just loving in all his communications and wanted to make the world a better place. Happy heavenly travels, Paul.

survey results in *Addiction Treatment Forum* called the downsizing “a matter of concern, because OAT is known to reduce mortality and improve treatment outcomes.” The article quoted the study team itself as noting that, “**By threatening access to life-saving medications, the COVID-19 pandemic poses an additional threat** to an already vulnerable and highly marginalized population.” The team also noted that jails and prisons are “at the epicenter of the [COVID-19] pandemic in the United States.”

The study by Sachini Bandara, PhD, and colleagues was published online August 27 ahead of print in the *Journal of Addiction Medicine*. **READ the *Addiction Treatment Forum* report at**

atforum.com/2020/09/covid-19-threatens-incarcerated-loss-oat-treatment. See also “Five Ways the Criminal Justice System Could Slow the Pandemic” from the Prison Policy Initiative at **prisonpolicy.org/blog/2020/03/27/slowpandemic**.

Mental health and substance use

“People with substance use disorders often have long histories of unmitigated mental illness and trauma. With very little access to the same treatment and support than their white counterparts, **Black and brown people with substance use disorders are especially vulnerable** to cycling in and out of correctional facilities and

emergency rooms,” reported the Latino Commission on AIDS as the agency presented a webinar, “Mental Health and Substance Use: Realities and Challenges During Uncertain Times,” June 11 on its YouTube channel. The presentation includes an overview of challenges seen by the Substance Abuse and Mental Health Services Administration (SAMHSA), and a presentation from the Harm Reduction Coalition. **GO TO bit.ly/LatinoAIDSwebinar2020-06-11**.

National Latinx AIDS Awareness Day

“Ending HIV is at your fingertips” was the theme of this year’s National Latinx AIDS Awareness Day. **The theme “focuses on the tools already**

available to address the HIV pandemic as we are dealing with another one,” organizers reported. “While we continue maintaining social distance and following preventive measures to respond to the COVID-19 pandemic, we ask everyone to do their part in the fight against HIV: take the HIV test, learn about HIV and risk factors, consider using PrEP and condoms as prevention approaches, and stay adherent to HIV treatment to become virally suppressed or undetectable.... We see the impact of stigma, homophobia, transphobia, and xenophobia as major barriers in accessing HIV testing, prevention, treatment, and care in our community.” In 2018, more than one in four new HIV diagnoses (27%) occurred in Latinx, although they represent only 18% of the national population. **GO TO nlaad.org**.

AIDS.gov is now HIV.gov

“The U.S. Department of Health and Human Services [HHS] today officially changed the name of AIDS.gov, the federal government’s leading source for information about HIV, to **HIV.gov**,” the agency reported June 5. “The announcement coincides with the 36th anniversary of the Centers for Disease Control and Prevention’s first report of the initial cases of what would become known as AIDS. **The name change reflects major scientific advances** that have transformed an almost universally fatal disease to a condition that, if diagnosed and treated early and continuously, can be controlled and prevented from progressing to AIDS. In fact, there are more people living with HIV in the United States now than people living with AIDS.” **GO TO hhs.gov/about/news/2017/06/05/more-name-change-aidsgov-becomes-hivgov.html** to read the announcement.

‘When Dogs Heal’

Healing takes more than medicine. Sometimes it takes love. Read true tales of exquisite connection in the new book, *When Dogs Heal: Powerful Stories of People Living with HIV and the Dogs That Saved Them*. A portion of the proceeds goes to Fred Says, a Chicago-based organization that raises money for teens living with HIV. **Due out early next year**, look for pre-sales of the book on World AIDS Day (December 1) at **whendogsheal.org**.

SAMUS STARBODY AND ZEUS



Remembering Lark Lands

Lark Lands, who wrote about alternative therapies for people with HIV/AIDS, died of cancer on November 2019, but was remembered by her friends and colleagues in the community with **an online memorial celebration of her life on her birthday**, September 5. Over the decades, many attributed their survival directly to her advice and counsel. She wrote regularly for *POZ* magazine for many years, and served as its science editor, and her work also appeared in *POSITIVELY AWARE*.

Lark had Type I diabetes, also known as “childhood diabetes.” Her parents were told she would die by age 12. She laughed at having beaten that prediction. But her serious condition left her with a strong drive to learn about metabolic processes and anything that could help her survive and be healthy. Then AIDS came along and she turned her knowledge and skills to helping the HIV community. At the time, there were no medications. Lark spoke with individuals and at community meetings about the things that

could be done to ease symptoms of disease and strengthen the body. Although she devoted her life work to the HIV community, she rarely received compensation. Later, when HIV medications became available, she turned her attention to dealing with the side effects of treatment as well. Later in life, she founded a project in South Africa to help orphans and impoverished families. Lark continued to tend to her health and once told me that she could swallow a handful of supplements with one glass of water. Her vitality was unbelievable.

“For decades my friend Lark Lands was the person I called with every question and fear I had about my HIV/AIDS diagnosis. ... Any time, day or night her phone rang from longtime friends with HIV or a complete stranger who had been given her number,” said Gregg Cassin, said Gregg Cassin of Shanti Project in San Francisco, and co-founder of AIDS, Medicine, and Miracles.

Rest in power, Lark Lands.



What do you give a long-term survivor turning 60 who wasn't supposed to make it to 30?

Mark S. King's

60TH BIRTHDAY BASH!

VIRTUALLY HAPPENING
**WEDNESDAY,
DECEMBER 16**

A CELEBRATION OF
LONG-TERM SURVIVORS OF HIV
BENEFITING
THE REUNION PROJECT



WHAT IS DELSTRIGO?

DELSTRIGO is a complete, one-pill prescription HIV medicine used to treat HIV-1 infection in adults who have not received HIV-1 medicines in the past, or to replace their current HIV-1 medicines for people whose healthcare provider determines that they meet certain requirements. HIV-1 is the virus that causes Acquired Immune Deficiency Syndrome (AIDS).

IMPORTANT SAFETY INFORMATION

Worsening of hepatitis B virus infection (HBV).

If you have both Human Immunodeficiency Virus-1 (HIV-1) and HBV and stop taking DELSTRIGO, your HBV may suddenly get worse. Do not stop taking DELSTRIGO without first talking to your doctor, as they will need to monitor your health. Your doctor should test you for HBV infection before you start treatment with DELSTRIGO.

Do not take DELSTRIGO if you are currently taking any of the following medicines:

- carbamazepine
- oxcarbazepine
- phenobarbital
- phenytoin
- enzalutamide
- rifampin
- rifapentine
- mitotane
- St. John's wort

Ask your doctor or pharmacist if you are not sure if your medicine is one that is listed above. If you have taken any of the medicines in the past 4 weeks, talk to your doctor or pharmacist before starting DELSTRIGO.

Do not take DELSTRIGO if you have ever had an allergic reaction to lamivudine.

New or worse kidney problems, including kidney failure, can happen while you are taking DELSTRIGO. Your doctor should do blood and urine tests to check your kidneys. If you develop new or worse kidney problems, your doctor may tell you to stop taking DELSTRIGO.

Some people who take DELSTRIGO experience bone problems such as pain, softening, or thinning of the bone. Tell your doctor if you have any of the following symptoms during treatment with DELSTRIGO: bone pain that does not go away or worsening bone pain; pain in your arms, legs, hands or feet; broken bones; or muscle pain or weakness.

Changes in your immune system (Immune Reconstitution Syndrome) can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your doctor right away if you start having new symptoms after starting your HIV-1 medicine.

The most common side effects of DELSTRIGO include: dizziness, nausea, and abnormal dreams.

These are not all the possible side effects of DELSTRIGO. For more information, ask your doctor or pharmacist.

Please see additional Important Safety Information on next page.



Learn more at
delstrigo.com



Delstrigo[™]
doravirine/lamivudine/
tenofovir disoproxil fumarate
100 mg/300 mg/300 mg tablets

**YOU ALREADY THINK
OUTSIDE THE BOX,**

**SO THINK DIFFERENTLY ABOUT
YOUR HIV TREATMENT.**

HIV-positive model

GETTING TO UNDETECTABLE IS IMPORTANT— it means the level of HIV in your blood is so low, lab tests can't even see it. But there's still more to consider, like drug-drug interactions and side effects. Ask your healthcare provider about DELSTRIGO, a once-daily treatment option for HIV-1. After all, you write your own story and undetectable is just the beginning.

IMPORTANT SAFETY INFORMATION (CONT'D)

Before starting DELSTRIGO, tell your doctor about all your medical conditions, including if you have hepatitis B virus infection; kidney problems; bone problems, including a history of bone fractures; are pregnant or plan to become pregnant; or are breastfeeding or plan to breastfeed. It is not known if DELSTRIGO can harm your unborn baby. Do not breastfeed if you take DELSTRIGO. Women with HIV should not breastfeed because their babies could be infected with HIV through their breast milk.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Some medicines interact with DELSTRIGO.

Keep a list of your medicines to show your doctor and pharmacist. Tell your doctor if you have taken rifabutin in the past 4 weeks. **Do not start taking a new medicine without telling your doctor.** Your doctor can tell you if it is safe to take DELSTRIGO with those other medicines.

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

Please read the adjacent Patient Product Information for DELSTRIGO and discuss it with your doctor.

Having trouble paying for your Merck medicine? Merck may be able to help. Visit merckhelps.com.



Patient Information
DELSTRIGO™ (del-STREE-go)
(doravirine, lamivudine, and tenofovir
disoproxil fumarate) tablets

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

DELSTRIGO can cause serious side effects, including:

Worsening of hepatitis B virus infection (HBV).

If you have Human Immunodeficiency Virus-1 (HIV-1) and HBV infection, your HBV infection may get worse (flare-up) if you stop taking DELSTRIGO. A "flare-up" is when your HBV infection suddenly returns in a worse way than before. Your doctor will test you for HBV infection before you start treatment with DELSTRIGO.

- Do not run out of DELSTRIGO. Refill your prescription or talk to your doctor before your DELSTRIGO is all gone.
- **Do not stop taking DELSTRIGO without first talking to your doctor.** If you stop taking DELSTRIGO, your doctor will need to check your health often and do blood tests regularly for several months to check your liver. Tell your doctor about any new or unusual symptoms you may have after you stop taking DELSTRIGO.

For more information about side effects, see **"What are the possible side effects of DELSTRIGO?"**

What is DELSTRIGO?

DELSTRIGO is a prescription medicine that is used without other HIV-1 medicines to treat HIV-1 infection in adults:

- who have not received HIV-1 medicines in the past, or
- to replace their current HIV-1 medicines for people whose healthcare provider determines that they meet certain requirements.

HIV-1 is the virus that causes Acquired Immune Deficiency Syndrome (AIDS).

DELSTRIGO contains the prescription medicines doravirine, lamivudine and tenofovir disoproxil fumarate.

It is not known if DELSTRIGO is safe and effective in children under 18 years of age.

Who should not take DELSTRIGO?

Do not take DELSTRIGO if you take any of the following medicines:

- | | |
|-----------------|-------------------|
| • carbamazepine | • rifampin |
| • oxcarbazepine | • rifapentine |
| • phenobarbital | • mitotane |
| • phenytoin | • St. John's wort |
| • enzalutamide | |

Ask your doctor or pharmacist if you are not sure if your medicine is one that is listed above. If you have taken any of the medicines in the past 4 weeks, talk to your doctor or pharmacist before starting treatment with DELSTRIGO.

Do not take DELSTRIGO if you have ever had an allergic reaction to lamivudine.

What should I tell my doctor before treatment with DELSTRIGO?

Before treatment with DELSTRIGO, tell your doctor about all of your medical conditions, including if you:

- have hepatitis B virus infection
- have kidney problems
- have bone problems, including a history of bone fractures
- are pregnant or plan to become pregnant. It is not known if DELSTRIGO can harm your unborn baby. Tell your doctor if you become pregnant during treatment with DELSTRIGO.

Pregnancy Registry: There is a pregnancy registry for people who take DELSTRIGO during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk to your doctor about how you can take part in this registry.

- are breastfeeding or plan to breastfeed. Do not breastfeed if you take DELSTRIGO.
 - You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.
 - Two of the medicines in DELSTRIGO (lamivudine and tenofovir) can pass into your breast milk. It is not known if doravirine can pass into your breast milk.
 - Talk with your doctor about the best way to feed your baby.

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

• Some medicines interact with DELSTRIGO. Keep a list of your medicines to show your doctor and pharmacist.

- Tell your doctor if you have taken rifabutin in the past 4 weeks.
- You can ask your doctor or pharmacist for a list of medicines that interact with DELSTRIGO.
- **Do not start taking a new medicine without telling your doctor.** Your doctor can tell you if it is safe to take DELSTRIGO with other medicines.

How should I take DELSTRIGO?

- Take DELSTRIGO every day exactly as your doctor tells you to take it.
- Take DELSTRIGO 1 time each day, at about the same time every day.
- DELSTRIGO is usually taken by itself (without other HIV-1 medicines).
- If you take the medicine rifabutin during treatment with DELSTRIGO, your doctor will also prescribe an additional dose of doravirine for you. You may not have enough doravirine in your blood if you take rifabutin during treatment with DELSTRIGO. Carefully follow your doctor's instructions about when to take doravirine and how much to take. This is usually 1 tablet of doravirine about 12 hours after your last dose of DELSTRIGO.
- Take DELSTRIGO with or without food.
- Do not change your dose or stop taking DELSTRIGO without talking to your doctor. Stay under a doctor's care when taking DELSTRIGO.
- It is important that you do not miss or skip doses of DELSTRIGO.
- If you miss a dose of DELSTRIGO, take it as soon as you remember. If it is almost time for your next dose, skip the missed dose and take the next dose at your regular time. Do not take 2 doses of DELSTRIGO at the same time.
- If you have any questions, call your doctor or pharmacist.
- If you take too much DELSTRIGO, call your doctor or go to the nearest hospital emergency room right away.
- When your DELSTRIGO supply starts to run low, get more from your doctor or pharmacy. This is very important because the amount of virus in your blood may increase if the medicine is stopped for even a short time. The virus may develop resistance to DELSTRIGO and become harder to treat.

What are the possible side effects of DELSTRIGO?

DELSTRIGO may cause serious side effects, including:

• **See "What is the most important information I should know about DELSTRIGO?"**

• **New or worse kidney problems, including kidney failure.** Your doctor should do blood and urine tests to check your kidneys before you start and during treatment with DELSTRIGO. Your doctor may tell you to stop taking DELSTRIGO if you develop new or worse kidney problems.

• **Bone problems** can happen in some people who take DELSTRIGO. Bone problems include bone pain, softening or thinning (which may lead to fractures). Your doctor may need to do tests to check your bones.

Tell your doctor if you have any of the following symptoms during treatment with DELSTRIGO: bone pain that does not go away or worsening bone pain, pain in your arms, legs, hands or feet, broken (fractured) bones or muscle pain or weakness. These may be symptoms of a bone or kidney problem.

• **Changes in your immune system (Immune Reconstitution Syndrome)** can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your doctor right away if you start having any new symptoms after starting your HIV-1 medicine.

The most common side effects of DELSTRIGO include dizziness, nausea, and abnormal dreams.

These are not all the possible side effects of DELSTRIGO.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store DELSTRIGO?

- Store DELSTRIGO tablets at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep DELSTRIGO in the original bottle.
- Do not take the tablets out of the bottle to store in another container, such as a pill box.
- Keep the bottle tightly closed to protect DELSTRIGO from moisture.
- The DELSTRIGO bottle contains desiccants to help keep your medicine dry (protect it from moisture). Keep the desiccants in the bottle. **Do not eat the desiccants.**

Keep DELSTRIGO and all medicines out of the reach of children.

General information about the safe and effective use of DELSTRIGO.

Medicines are sometimes prescribed for purposes other than those listed in the Patient Information leaflet. Do not use DELSTRIGO for a condition for which it was not prescribed. Do not give DELSTRIGO to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or doctor for information about DELSTRIGO that is written for healthcare professionals.

What are the ingredients in DELSTRIGO?

Active ingredients: doravirine, lamivudine, and tenofovir disoproxil fumarate.

Inactive ingredients: colloidal silicon dioxide, croscarmellose sodium, hypromellose acetate succinate, magnesium stearate, microcrystalline cellulose, and sodium stearyl fumarate. The tablet film coating contains hypromellose, iron oxide yellow, lactose monohydrate, titanium dioxide, and triacetin. The coated tablets are polished with carnauba wax.

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BREAKING THE CYCLE

Finding a way out
of addiction
—with a road map
BY JEFF BERRY

“I love what I do; it’s crazy as hell. All my family and friends are like, *Aaahhh, we don’t know what she does.*”

She is Neva Chauppette, PsyD, a licensed psychologist in California, and what she’s *done* is treat over 1,500 patients with HIV who have multiple co-occurring conditions such as addiction, a history of trauma, or other psychiatric diagnoses. She’s gritty, brassy, and doesn’t hold back on telling you exactly what she thinks—and in the most simple and sometimes graphic terms.

“Normally what I consider to be my area of expertise is addiction in its multiple forms: Food, gambling, pot, porn, pills, sex...the whole gamut!”

Chauppette says addiction was on the rise among the general population as well as in people living with HIV (PLHIV), even before COVID-19. “In Los Angeles, methamphetamine remains the nightmare drug of choice for many of my HIV-positive patients. It is also the drug that has brought many of my patients to the world of HIV due to the hypersexuality and wild abandonment associated with the drug’s use.”

“I was talking with someone last night who had come home from not the bathhouse, because those are closed, but the underground

bathhouse. And I said, where have you been, I’ve been looking for you for two days. ‘I was doing quarantine.’ Meaning, you know, party and play [PNP], but mostly with meth. *Quaran-tina* is just their word play with PNP plus the quarantine.”

Another form of addiction burdening our community is sex addiction, she says. “This is a more difficult form of addiction to treat as we possess the ‘drug’ 24/7—it is free, and often does not even require other human contact. Your hand can be a form of addiction—meaning masturbation.”

Chauppette says that you can’t really work in addiction competently unless you understand other co-occurring disorders, “especially PTSD, bi-polarity, ADHD, some schizophrenia, and some personality disorders.”

“Historically, mental health folks like me don’t interact with the treating psychiatrist of the patient that we share, which is insane to me. So when my patients have their video Zoom conference call with their psychiatrist, I’m usually on that call. Because I’m going to be able to articulate what is really going on, easier and quicker, so that that

ticking clock that we know has to be done in 20 minutes can actually be used with some efficacy. And most of my patients are happy to have me on the phone, because they’re embarrassed about some of the stuff they did; you know, all the guilt and shame. I just cut to the chase, tell them what I’m going to say before I say it, so we have a prep call, before I get on the phone with the doc and them. So they can trust me. I’ve got the facts, I’m not going to blindside them.”

She works closely with their HIV docs, and is sometimes on those calls as well. “Usually, before COVID, I would meet them there and go in with them to see their HIV provider. Because a lot of them get in there and get anxious. They don’t want to disappoint the provider. They don’t want to say, ‘Look, I slipped again, and had a PNP event, and I’m thinking maybe I should get checked for everything, STD-wise.’ Or, ‘My partner wants to go on PEP. He’s out in the waiting room; can you help him get on PEP today, because we hooked up last night?’

“So it’s a lot of what I call *therapy-plus case management* that I do. And I try to do integrated work...I think it’s unethical to work as a solo provider without talking to the major players who are also treating

this patient. It's more work, but I get better outcomes.

"My patients are burdened with significant addiction—multiple entities in an obsessive-compulsive way—and they also have concurrent psych [issues], or they're chronic relapsers, and no one can figure it out. 'What the hell, he seems to be trying, authentically, to stop using, or slow his roll, but he just can't get it.' We'll then try to figure out what co-occurring psych is going on, because it's almost always there...missed, over and over and over again. And then I determine whether or not I think at this level of severity of addiction whether or not they should go into an inpatient setting, to just put some geography between the body and the mind and the dealer and the hookups and the cell phone. Referrals come from different directions. Drug treatment programs out here will sometimes call me. They'll hire me and say, 'We've got a chronic relapse. We love this woman—or this guy, whoever it is—but we've done everything we know to do. Can you take a look at what we're missing?' And usually it's major psych.

"I've seen thousands of patients with serious psych, usually multiple psych. ADHD, PTSD, bipolar disorder are the common three. And then of course HIV and hep C, which in my world is the least of the problems. Many of them got to the world of HIV behind undiagnosed and untreated psych. And when I say psych, I mean, addiction is a psychiatric disorder. Addiction can run solo by itself, but almost always there is an additional co-occurring psychiatric disorder, like the ones I've mentioned."

It's possible you can have all three, says Chauppette, but it's treatable. "You just have to have a provider who gets you, gets your community. One of the blessings I have is that I'm part of the LGBTQ community, so I'm already in the door so to speak, and I know the culture. Even though I'm not male, I've seen so many gay male patients that I feel like I know it pretty well. So yes, it sounds overwhelming when you hear it, but a good provider can navigate it when he or she is really skilled and cross-trained, and willing to do the case management piece of talking to the doctors, the psychiatrists, the therapist if there is one, the case manager, and most importantly the HIV doc as well."

Chauppette employs the "stages

of change" model when talking and working with patients, "to find out where they really are, as opposed to where I would like them to be." According to Elizabeth Hartney, BSc, MSc, MD, PhD, the "stages of change" or "transtheoretical" model is a way of describing the process by which people overcome addiction, and "provides a useful way of understanding the process of change and gives a structure to how changes in addictive behaviors can be encouraged and managed." There are variations on the model but it is essentially made up of four stages: Precontemplation, contemplation, preparation, and action. (Maintenance and relapse are also sometimes included as additional stages.)

Chauppette says she finds the evidence-based treatment that is appropriate for the level of change where her patients are at, and meets them there to develop a rapport and to try to minimize "wreckage accumulation," while she tries helping them "move further down the chain of behavior change."

"One of the mistakes we make as providers, I think, is that we overshoot readiness. Patient readiness is usually much less, no matter the problem—HIV, hep C, addiction, bipolar disorder. They're usually not at the place yet where they are ready to see a psychiatrist, who of course is gay-friendly, HIV-knowledgeable, understands addiction—which we think is yes, yes, and yes, but is usually no, no, and no, that they have training in that area. So the stages of change model is kind of like a navigator for me... and I teach it to my patients. They like to use it. I'll ask, what stage of change do you think you're in for the nicotine dependence? And they'll say, 'Oh, I'm in pre-contemplation,' which means *don't talk to me about it, I don't want to hear about it, I'm gonna smoke on my deathbed*. All the tools that I use, I try to teach them how they can use them...it gives them a roadmap, because they feel lost most of the time.

"If a patient is in the precontemplation or contemplation stage of change, one of the evidence-based treatments recommended is harm reduction. For example, a patient might not be ready or willing to use condoms even in a high-risk setting or discontinue drug or alcohol use, so we discuss PrEP and PEP as an urgent priority to keep the HIV-negative [person] just that—negative. Behavior change is a slow

process that takes significant time, attention, and a lot of trial and error. I refer to my clients as patients as I want them to understand that we will both need to be patient in our work together. I am also a proponent of addiction medication. I have seen my patient's chances of success increase significantly when we add to their recovery program MAT (medication-assisted therapy). Some examples are Suboxone, Vivitrol, and Campral. When a patient is in early recovery from addiction, and especially when it co-occurs with other major psychiatric disorders, the addition of MAT offers them a brain-based form of support."

As a self-identified member of the LGBTQ community, Chauppette says that early in her career she felt a loyalty to her "brothers and sisters to help them in our fight to live dignified, authentic lives." While completing her doctorate in Los Angeles, the HIV epidemic raged.

"I knew I always wanted to work with the diseases of our time—HIV, HCV, addiction. My brothers were dying horrible deaths, many alone, afraid, dealing with dying and death. For some, their own internalized homophobia was being fueled by ignorant and shame-based statements like 'HIV is a message from God that your sexual orientation is the reason you have HIV and are suffering.' 'Leading a gay lifestyle is immoral.' So, during my doctoral work I started treating HIV-positive heterosexual and gay/bisexual men, and trans women. For most, if not all my patients, even before their HIV-positive status, psychological suffering had been enormous and was now simply devastating."

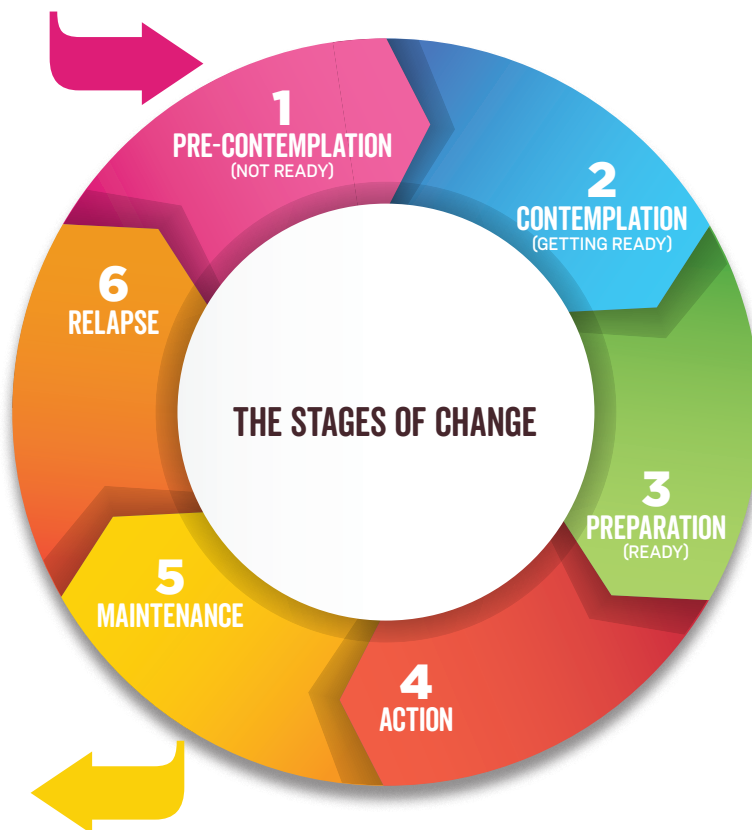
The LGBTQ community is exhausted but still fighting, says Chauppette. "Our heavily fought for gains are again in jeopardy. There is a push to move us back into the closet or require us to just settle for being 'tolerated.' We are not having it ever again, so we soldier on. We are indeed strong given the minority stressors we have and continue to face daily. Using addictive objects like drugs, food, pornography, chemsex, [and others] for attachment and coping is clearly dysfunctional and I hope as a community we can find other ways of coping that do not fulfill society's expectations of us (i.e., to be self-destructive, hypersexual, irresponsible, etc.)."

For her trans patients, their journey is even more painful, she says.

They are more heavily judged, and as they like to remind her, they reside in the “caboose of the LGBT train.”

“My transgender patients face sexual and physical violence, murder, verbal and non-verbal disrespect, housing and work discrimination, and mental and physical health ignorance and insensitivity. It is just awful.” She implores us to treat our transgender community members with kindness, support, guidance, and respect. “My transgender patients of color face even more challenges given their desire to live authentically atop the culture mandates from their ‘hood.” She says she works closely with them to help them live authentically and dignified. “I help them see that the rudeness and lack of sensitivity from others should be addressed, but not in an aggressive manner. I teach them not to be ‘played’ and not to be messy even when the messenger is a mess. It is beneath them to become messy too. We practice ways to respond that permits them an option when they feel disrespected, and how to get their needs met without alienating others. As Michelle Obama says, ‘When they go low, we go high.’”

“**There are** many things we can do!” exclaims Chauppette when asked what we can do as a society to address mental health and addiction. “First, we must educate ourselves about mental illness and know that addiction is a mental illness. We need to understand that there is a genetic load [the presence of unfavorable genetic material in the genes of a population] for many mental illnesses and certainly for addiction. Addiction rarely occurs without the presence of other psychiatric illnesses. Understand... that addiction and other psychiatric disorders should not be shamed or judged. I tell my patients there is no shame in either, except knowing [that] you might or do have them and not get help. That choice may be based in shame and as a result you will stay sick and your life will not be yours. We need to stop using terms like *addict*, *crazy*, *hype*, and *junkie* so that people who need help cannot be turned away from seeking help. Seeking help is a sign of strength, not weakness. For those of us who are out about our addiction or mental health history, I commend you. Remember, people cannot shame us if we do not have shame ourselves. I would like to respectfully request that as members of the LGBTQ community we recognize



that during our struggle we might have gone too far with PNP. Often it is a reaction to our own internalized homophobia, our rage as to why we are viewed as “less than,” and a derailment from our psychic pain. Leading authentic lives is the goal, but that should not include self-destruction.”

If you know someone who is struggling with addiction or mental health issues, there are lots of dos and don'ts, says Chauppette. “Do not be harsh with them. Talk to them from your heart and your head. Recognize that they are sick, not ‘bad.’ Recognize they are lost and that you must earn their respect by giving them respect, and not pushing them to do things that they are not ready to do.” She encourages her patients to Google search celebrities with addiction, bipolar disorder, or ADD/ADHD, to help them see that they are not alone, and that even very successful people can have these burdens.

“Teach them the drug or object of over-attachment is not the problem. Transference of addiction is the norm. That what they are attached to is fulfilling a need. I always teach patients that there is function in dysfunction! That means there are underlying psychological needs [being] addressed, albeit in a dysfunctional way, by using the form of addiction they are burdened with. Help them understand that they are not bad human beings but that the illnesses they are likely burdened

with can make them engage in self-defeating behaviors.”

Chauppette says to let them know who can help them if and when they wish to take a time-out, or get a knowledgeable professional to help. “Do not have rescue fantasies or a need to be needed. If you like drama, you will likely be unable to help them. Be patient with strong boundaries. Speak truth and explore resistance. Do not enable. Do offer a more realistic option instead of abandoning them. For example, if someone you care for is in withdrawal, instead of giving them more alcohol or drugs or money for either, call paramedics instead. Do not be fearful of their anger. Remember, if you are healthy yourself you will not enable them.”

As for the pandemic, Chauppette says, “I’m not seeing much COVID in my HIV-positive patients. Most of them, their immune system is probably stronger than it’s ever been, because of the meds.

“Honestly, I don’t worry about HIV anymore, in terms of lethality. It’s the easiest to treat—to me addiction is the hardest to treat, and co-occurring mental illness is second in terms of difficulty to treat. HIV, you just need to swallow the pills, for the most part, right? Been there, done that; it’s old news to them. The only thing they complain about is, ‘It doesn’t give me anything, doc.’ I say no, it’s just keeping you alive. Hello? It’s keeping you alive, and do you want to stay alive?” PA



'As someone who has experienced intimate partner violence, I know as a Black trans woman I'm blessed to have my own space. I'm able to set boundaries for myself. That's not the case for everybody.'

TIOMMI JENAE LUCKETT

Addressing partner violence and trauma in the time of COVID-19

Survivors and advocates face new problems,
and develop new forms of support

BY OLIVIA G. FORD

Arkansas-based advocate Tiommi Jenae Luckett said it best, and bluntly, in a recent conversation: “Under the auspices of COVID, every bad thing that could happen has happened.”

At the time of this writing, the world just crested one million known deaths from COVID-19—a pandemic to which the United States’ federal response has been so counterproductive that the nation quickly rose to lead the world in case numbers and fatalities. The disease has catalyzed months of relative confinement to homes, massive job losses, disparity in education systems, isolation from loved ones, few to no social outlets—a total upending of societal norms, which many experience alongside their rage at the current administration’s denial, grief for those who have lost their lives, and fear of potentially being next.

We are also facing the most contentious and consequential presidential election of our lifetimes, as uprisings nationwide bring attention to state violence and murder of Black people—and face brutal repression by authorities. Then there is climate change, culprit for this season’s historically devastating fires in the western U.S. and catastrophic storms and flooding in the southeast.

The link between crises and the uptick in rates of domestic violence is well documented; COVID-19 follows that model, and brings its own unprecedented challenges.

“[Addressing intimate partner violence] is complex all the time; add COVID to it and it makes it infinitely more difficult,” said Katy Davis, PhD, of the Women’s HIV Program (WHP) at the University of California, San Francisco. “People can’t get any kind of breather from each other, because they’re all stuck at home.”

Initial drops in calls to domestic violence services (which have remained largely open, if modified, during the pandemic) and police reports turned out to be a negative sign: Victims were often unable to reach out for help because those

abusing them were constantly present. Some reports indicate that instances of physical violence that were reported were more severe: strangulations, stabbings, burns.

But abuse is not limited to physical violence, or visible injury. Violence can take numerous forms, including threats; emotional or economic abuse; isolation; canceling health insurance or withholding medications; claiming a partner has COVID-19 in order to restrict contact with their children; or exerting power by blocking use of prevention tools like soap or hand sanitizer.

“COVID-19 has given abusive individuals additional tactics and excuses for maintaining control,” said Ashley Slye, who works at the intersections of HIV and domestic violence as the Positively Safe program manager at the National Network to End Domestic Violence (NNEDV). Globally, UN Women—the United Nations entity charged with promoting gender equity and empowerment—has sounded the alarm about a “shadow pandemic” of violence against women and girls mounting amidst this worldwide crisis.

Intimate partner violence (IPV) is already a concern of stunning proportions among women with HIV. Groundbreaking studies in 2012 revealed what many advocates and providers in the community knew anecdotally: that *most* women with HIV had experienced some form of violence or trauma. Women with HIV were twice as likely as the general population of women to experience IPV, five times more likely to endure sexual abuse, and five times more likely to have PTSD (post-traumatic stress disorder, commonly associated with survivors of war) as a result of these and numerous other forms of traumatic disruption to their lives. These conditions were found to negatively affect women’s physical health, as well as their mental well-being and quality of life.

These findings spurred a raft of advocacy up to the federal level to address this epidemic of violence, and promote healing in medical and service settings through trauma-informed care. This approach strives to recognize and address, in every area of service delivery (including the physical environment of the

center, and all staff on the premises), the profound impact of trauma not just on health outcomes, but on individuals’ ability to access care at all.

Positive Women’s Network–USA (PWN) has been a longtime leader in this movement, spearheading the annual National Day of Action to End Violence Against Women with HIV on October 23. Early in the pandemic, PWN assembled a resource page on their website addressing the “crisis within a crisis” of IPV, HIV, and COVID-19.

Luckett, a PWN staff member, shared recollections of the initial days of lockdown: “When COVID first hit, it was a scramble to try to find resources for these women”—places where someone leaving a violent situation could be safe not only from abuse and COVID-19, but also from the trauma of discrimination.

A May 2020 piece on TheBody.com on PWN’s early pandemic response related a story of a member of transgender experience who left an abusive partner, only to end up in a shelter run by a Christian organization. They required her to hide her gender identity and present as the sex she was assigned at birth in order to stay there.

“As someone who has experienced intimate partner violence, I know as a Black trans woman I’m blessed to have my own space,” said Luckett. “I’m able to set boundaries for myself. That’s not the case for everybody.”

For Angie Espinoza, unfair housing, limited social services, employment insecurity, and lack of child care all interact to compound risk for domestic violence under COVID-19 conditions.

“Many of our clients are paying anywhere from \$500 to \$1,000 [per month] for a single room that may have two adults and three-plus kids,” explained Espinoza, who coordinates domestic and intimate partner violence services at Queens, New York’s Voces Latinas, which empowers and trains immigrant Latinas to address HIV and violence in their communities. “There is no space for privacy, and [it] puts more people at risk for abuse.”

Many individuals may be coping with crisis, and their own trauma, by increasing substance use—which can heighten violence risk. “Usually, the partners would be ‘bread-winners’ and so the clients had some time away from the abuse,” Espinoza went on in our email conversation. “But without work, families are stuck together in confined spaces. Partners are abusing more of substances such

AUTHOR’S CONTENT WARNING: VIOLENCE, ISOLATION, SYSTEMIC OPPRESSION. IF YOU ARE FEELING THREATENED RIGHT NOW, IN THE U.S. YOU CAN CALL THE NATIONAL DOMESTIC VIOLENCE HOTLINE: 800-799-SAFE (800-799-7233); OR TTY, 800-787-3224, OR CALL 911 IF IT IS SAFE TO DO SO. YOU CAN ALSO SEARCH FOR A SAFE SPACE, DOMESTICSHELTERS.ORG.

as alcohol, which impacts not only clients but their children.”



Dramatic scale-up of telehealth engagements has been made possible in part by relaxed federal regulations around distance appointments. For those isolated by not just COVID-19 but also an abusive partner controlling contact with loved ones, a telehealth visit with a provider may be their sole contact with the outside world. It’s also an opportunity for abuse to be witnessed and assessed.

But an abusive partner may monitor a survivor’s devices and messages, or appointments themselves, making it impossible to engage honestly. Davis shared an anecdote from a WHP provider: “[They] talked about doing a Zoom [video] meeting with a patient who we know is in an abusive relationship, and seeing her partner open the door every few minutes to check in on what’s going on, in a really creepy and disturbing way.”

WHP providers exercise caution with what is said on these visits, and follow clients’ lead as to whether they can speak freely. In many cases,

agency and fearing for their safety, she conceded: “If the only solution we provided was ‘you need to get away from that partner,’ we wouldn’t be engaged with our patients.”

One solution, said Davis, is “really trying to listen to the patient, while at the same time providing education, and talking to them about how they deserve to be in a healthy relationship, they deserve to be treated with respect and kindness—and trying to model that in our relationship with them.”



This depth of engagement is key to a trauma-informed approach to care: Providers and clients know one another well, and there is a level of trust. WHP and Voces Latinas both employ trauma-informed practices—Davis directs the trauma-informed care initiative at WHP, also a key source of research on women, HIV, and trauma. That foundation has helped these organizations prepare clients for the dizzying pivot to telehealth and virtual community engagement—which included bridging a massive digital divide.

When Voces Latinas’ staff shifted to conducting their domestic violence and women with HIV support and education groups online, they knew their clients would need help getting the necessary equipment. “It is so important for them to still stay connected to those groups, to continue to hear the message,” said Nathaly Rubio-Torio, LMSW, the organization’s executive director. COVID-19 relief funds were a lifeline. “We applied them towards basic needs like food and rent assistance, but we also designated some funds toward technology,” she explained. Her staff spoke to each client about their specific digital needs, whether it was a phone with video capability, an internet connection at home, or support exploring Zoom.

“Even these ear pieces,” Rubio-Torio said, gesturing to the headphones she and I were both wearing during our own video conversation, “is something we don’t even think about, that they need in order to even participate in a group.” They were able to purchase or provide what clients needed—including numerous sets of ear buds. For clients in close

Many individuals may be coping with crisis, and their own trauma,

partner interference may make video meetings impossible.

Such conditions complicate safety planning for survivors. But many survivors may not consider leaving—in part because they have no other access to some resource their partner provides. “For trans people in abusive relationships who have lost their jobs during the pandemic, they are now more dependent on their abusers than ever,” said Arianna Lint of Arianna’s Center, which serves a largely undocumented population of Latinx people of trans experience in South Florida. “Without an income, many are trapped in violent relationships.”

In one recent instance at WHP’s clinic, Davis related, a woman’s abusive partner was her caregiver. “She couldn’t care for herself; she needed him there to help her get through her day-to-day medications,” Davis explained. When police removed him from the client’s home, relief soon turned to panic, and she took steps for him to be able to return to the apartment.

While Davis noted that these kinds of cases are hardest, with the tension between respecting a client’s



‘[Addressing intimate partner violence] is complex all the time; add COVID to it and it makes it infinitely more difficult. People can’t get any kind of breather from each other, because they’re all stuck at home.’

KATY DAVIS, PHD

quarters with concerns about privacy, or their household knowing what groups they participate in, ear pieces provide some relief.

“Whether they’re cooking, or taking care of the kids, they have their group in their ear”—even if a woman is only able to listen, or speak up quietly on a rare occasion. “That’s been extremely helpful,” said Rubio-Torio, “that avoids isolation.”

At WHP, in San Francisco, the staff engaged in a comparable ongoing process to assess clients’ barriers to staying connected, technological or otherwise, and support them in managing those obstacles. Clients and staff at WHP are accustomed to a high level of contact with the program—through appointments with providers or social workers and educational groups, but also social activities planned by the patient leadership team, or sharing a meal. Virtually all those traditional points of contact have dissolved due to COVID-19.

WHP staff have maintained a weekly online education group on Wednesday mornings—a time when the clinic would normally be teeming with community members

enjoying the weekly breakfast and other activities. “People can tune into Zoom, sort of a replacement for being able to come in and hang out,” Davis explained. But it’s not the same as in-person engagement—which WHP made very easy for clients to tap into. “We were cultivating a really strong community,” said Davis. “Now all of a sudden, we are discouraging people from coming in—which was our major mode of connecting with people.”

Though Florida’s Arianna’s Center provides and refers to virtual services, Lint also lamented the suspension of in-person support. “It gives case managers an opportunity to assess the clients’ situations,” she said. “Our clients develop trusted relationships with their trans peer navigators and the pandemic has, to some extent, denied them this support.”

On the other side of the coin, WHP providers have found that for some clients—particularly young women—the pandemic approach to care and services is a better fit for their lifestyle. They may have struggled to make their clinic visits in the past, but a therapist or provider calling *them* for their appointment

‘Our clients develop trusted relationships with their trans peer navigators and the pandemic has, to some extent, denied them this support.’

ARIANNA LINT



“To improve our support, domestic violence organizations are likely going to have to change how we respond to survivors,” Slye concluded. “If we are telling survivors to call the police, are we being mindful that this may not be a safe option for them? Have we talked through all the options before we get to that recommendation? Are there other things that we can be doing as a community to support survivors?”

“[How are we] addressing the systems and how they have harmed survivors—and really, have they actually helped us end domestic violence?”



In the U.S., while the COVID-19 pandemic continues to rage, businesses and services are going through their paces of reopening—for better or worse. But the crisis and its fallout are far from over.

The need for providers to hone their awareness of abuse that may be taking place in their clients’ homes is unlikely to dissipate. One place to begin is a guide for telehealth providers working with clients experiencing abuse during COVID-19, published

by increasing substance use—which can heighten violence risk.

means they don’t have to travel or even remember they had an appointment scheduled. “They’re actually getting a service they weren’t getting before, because we were asking them to come in, and that wasn’t really feasible for them,” Davis said. “There has been increased access.”



Criminalization and racism are persistent forms of trauma that have been amplified in this era. Similar to HIV, generations of racial inequity and repression have led to conditions in which Black, indigenous, and other people of color become sicker and die more often from COVID-19 than their white counterparts. And reports are showing that Black people are more frequently targeted and criminalized for alleged violations of safety measures such as social distancing.

“That ties into the [Trump] administration ... in their lack of response regarding COVID and their *immediate* response to deploying the military against Black and Brown bodies,” said PWN’s Lockett, speaking of violence against participants in recent anti-racist uprisings. “As a Black person, I can’t help but see the

anti-Blackness of it all being amplified because of COVID.”

Immigration status can become a tool of control by an abusive individual, who may threaten to call Immigration and Customs Enforcement (ICE) on a partner who is undocumented, and can also be a deterrent from reporting violence to police, for fear of detention.

For Black people and immigrants experiencing violence in their homes, the police may be the last people they want to involve. “We’ve seen time and time again that police intervention can lead to unwarranted incarceration and death for people of color, particularly Black people,” said Slye of NNEDV. According to Slye, many involved in the domestic violence response are grappling with its connection to a criminal legal system deeply rooted in violence against Black and Brown people.

The Violence Against Women Act, co-authored by current presidential candidate Joe Biden, was passed as part of the 1994 crime bill, Slye reminded. Funding for domestic violence response has been delivered through fight-crime initiatives and administered through the Department of Justice.

by the LEAP (Look to End Abuse Permanently) Program and accessible online alongside numerous trauma-informed anti-violence resources for professionals at leapsf.org.

As a result of the drastic measures required during stay-at-home orders, many service providers may have additional useful tools in their toolbox of keeping clients engaged in care and support—and new insights into clients’ needs.

“It’s transforming the way we’re going to provide services,” said Rubio-Torio of Voces Latinas. “Now, not everyone will need to leave their home, their kids, their family life to come in and get a service here.”

Davis agreed: “Even if and when things go back to normal ... we will be much more open to doing things virtually for patients who clearly prefer or need that,” she said. “That has been one real benefit: [to see that] we *weren’t* actually reaching everyone the way we were doing things before.” [PA](#)

Stories of women remaking a life

Overcoming trauma and stigma to live free
COMPILED BY ENID VÁZQUEZ

I was at a national community meeting when I heard Celeste Watkins-Hayes, PhD, of Northwestern University, read from her latest book, *Remaking a Life: How Women Living with HIV/AIDS Confront Inequality*. Through the stories of the women she interviewed, Dr. Watkins-Hayes shows how trauma transmuted to power by linking socioeconomic problems with medical advances, political empowerment, and human resiliency. In August, ViiV Healthcare invited Dr. Watkins-Hayes to lead a webinar with women based on the stories in her book. Although Dr. Watkins-Hayes wrote about Black women, it's a universal story of moving from stigma to personal—and political—power.

STORIES HAVE BEEN EDITED FROM BOTH THE BOOK AND THE WEBINAR.

DAWN'S STORY

Injuries of inequality

Dawn's story was read by Chicago native Evany Turk, now national field organizer for the Positive Women's Network-USA.

"If it wasn't for HIV, I'd probably be dead."

Dawn grew up in a Black working-class neighborhood on Chicago's West Side in the 1970s and '80s. Racial and economic residential segregation and lack of investment by government and private business limited upward mobility for residents, especially young adults.

When the sexual trauma of Dawn's childhood collided with the structural blows and deteriorating safety net afflicting her community, the effects were combustible.

Dawn moved in for a few weeks with the person she most idolized, her 19-year-old stepsister Jackie. Jackie used intravenous drugs and dated the neighborhood dealers who maintained her supply. Dawn followed suit, and her addiction grew. Her habits became a source of deep disappointment and sadness for her parents, who knew nothing about the molestation that was at

the root of Dawn's pain. Their lack of awareness fueled Dawn's sense of anger and betrayal, and she continued to distance herself. After exhausting all of her invitations to sleep on the couches of various family members and friends, Dawn ended up on the streets.

"My village wasn't safe," she said through tears.

After her HIV diagnosis, she entered a home for women living with the virus and addiction, this time staying [at a housing facility] for two full years to become strong enough to make it in the world without numbing herself with drugs. She began systematically gathering the tools she would need to change her life's course.

"I realized that doing drugs was killing my body more than HIV. I decided that I wasn't ready to die. I didn't want HIV to take me out. So, I had to stop getting high."

Dawn's personal story has also led her to political work. Since leaving St. Mary's, Dawn has been a prominent voice in the HIV community and a trusted leader. She has traveled the country speaking about HIV prevention, met with public officials to advocate for increased funding for AIDS programs and services, and served on the boards of





prominent national and local AIDS organizations.

"The only risky behavior I do now is telling a politician what I really think of him."

DR. CELESTE WATKINS-HAYES ON DAWN'S STORY

Rising intracommunity violence, a growing drug epidemic, declining funding for healthcare and other community services, and a precipitous rise in mass incarceration that warehoused many friends, family members, and neighbors made the barrier between life and death increasingly porous for young people like Dawn.

The environmental and personal turmoil in Dawn's life was occurring precisely when the AIDS epidemic was gaining an early and strong foothold in vulnerable communities, quietly taking up residence in neighborhoods and networks, and weaving itself into the epidemiological fabric.

"If it wasn't for HIV, I'd probably be dead." In Dawn's assertion, she is reflecting on the chokehold that was slowly but steadily killing her. Addiction, with its roots in Dawn's history of childhood sexual abuse, was shaping every aspect of her life, from her tools of economic survival to her residential choices to how she formulated, sustained, or damaged relationships with friends, family, and intimate partners. Dawn's broader environment, lacking many opportunities and resources, also posed obstacles that she addressed through a variety of coping and survival strategies that were destroying her health.

TANYA'S STORY

When systems fail and women's burdens are too heavy

Tanya's story was read by Kimberly Smith, MD. A longtime HIV specialist in Chicago, Dr. Smith is now head of Research and Development for ViiV Healthcare.

Forty-year-old Tanya is a mother of four children. She lives in Phoenix House, an apartment building for people living with HIV, that has suffered for years under the weight of poor institutional staffing and meager funding...

Tanya's story reflects what can happen when a breakdown in the safety net meets a client facing multiple barriers.

Tanya's world effectively came to a halt with the incarceration of her

child....Tanya's challenges did not stop there. Diagnosed bipolar at 16, she had been struggling ever since with her mental health. HIV prevalence is much higher among women suffering from mental illness; the mental instability and debilitating stigma make them vulnerable to drug addiction and high-risk sexual experiences.

After waiting an hour and a half past her appointment time, Tanya was finally called in to see the doctor. "Your numbers," he said with deep concern, "aren't so good. Stress will wreak havoc on your immune system. You have to find ways to deal with what is going on without sacrificing your health."

It is a nebulous term for some: social determinants. But as Tanya's story demonstrates, poverty, family crises, unaddressed mental health issues, a broken and inefficient criminal justice system, and weak social support networks can be devastating to health. These issues, which confront significant numbers of people living with HIV, can severely undercut even the most promising of medical advances and scientific discoveries.

Dr. Smith on Tanya's story

This story recalls so many patients I saw. So many women have families and the family came first. It led to disease progression. There's the saying that 'you can't take care of anyone else if you can't take care of yourself.'

The doctor in the story—those were also my words to my patients.

Now I'm with a health company—to change the tons of pills needed. But even if we had the best treatment in the world, people need to address stigma and make HIV a smaller part of their life instead of dominating it.

Dr. Watkins-Hayes asked Dr. Smith about the role of institutions.

The social safety net doesn't have enough for the meds of the folks who come in. And that's just the folks who even make it there.

You have to start with people where they are. I think peers are so important at the beginning, in dealing with that self-stigma.

One thing that stands out was that hour and a half that you fall behind. My patients really appreciated that one of those crisis times might be theirs. Institutions are not devoted to spending the real time often needed. >>

At the nexus of body and soul

An HIV doctor seeks solutions beyond medicine

INTERVIEW BY ENID VÁZQUEZ

While listening to Celeste Watkins-Hayes, PhD, read from her new book at a ViiV Healthcare community summit, it was so interesting to me that Kimberly Smith, MD, was now Head of Research and Development for the company. I had heard Dr. Smith tell similar stories when she was an HIV specialist at Rush University Medical Center in Chicago. Although corporations are under pressure to do things that make them look good—like giving money—ViiV has gone beyond funding medical presentations. Dr. Smith is perfectly poised to do something Dr. Watkins-Hayes advocates: speak truth to power.

I spent 20 years taking care of patients in Chicago and got to experience through them many ways of navigating challenges. One of the really interesting things that Celeste captured in [her book] *Remaking A Life* was the experience of women and how they were always challenged by everything else going on in their lives. I can't tell you how many times I had patients who weren't able to focus on their own care because they were so busy focusing on some trauma that was happening in the life of their child or their husband, or someone else. So I'm very happy that she's out there telling the stories.

I always talked to my patients about the fact that they could not manage to care for anybody else if they weren't there. You have to focus on your own care. So I find ways to have them see that as the highest priority. A lot of them did. Lots of folks got it together, took all their meds, and dealt with all that drama too. But then it was a challenge for others.

I remember there was one patient in particular who stands out to me because when I met her, she was extremely ill. I met her and her daughter, who was around 18 at the time. Her daughter literally brought her back to life. When you treat MAC—*mycobacterium avium* complex, that in itself often requires three different medications. Then you had three or four different medicines for HIV. Her daughter made a routine for her.

She lined up all her pills. Made sure she took every one of her meds. She just completely got it together and got back to being independent. And she was so proud of what her daughter had done. They were so close, for an extended period of time. It was really something to be a part of that relationship between the two of them.

Then her daughter, after all that, she could go on with her life. And she did.

She and her partner had a child, she went on to college. She did all of that. Then my patient stopped taking her meds. She just went back to, "I don't want to deal with this. I don't want to take medicine anymore." Ultimately, she ended up dying. The daughter felt ... almost mad at her mom. "We went through all of this. Got everything back. We got you back to independence."

There are so many stories, so many families and relationships. That's one thing as a provider that I felt: being a part of their lives in a way that was profound. There's nothing like it as far as being able to affect people's lives in a positive way—hopefully.

ENID VÁZQUEZ: It's interesting that this story tells what you saw, that medicine is only going to take you so far.

KIMBERLY SMITH, MD: That's right.

The question we asked through the webinar was, if you could magically create something, what does everybody need? One of my responses was safe spaces. That people can be safe in whatever way they came to be. Some of it is physically safe, from violence, from danger and risk, and protected from this sort of angst and all of that.

It's also spaces where you can actually be you. Some of that is for transwomen—transwomen and transmen—to be able to be who you are. And that I think it's so important for people, living with HIV or not, to be able to have a place where they feel like they can be themselves and not be judged, and not be discriminated against.

You mentioned in the webinar dealing with stigma so that HIV could be just a part of someone's life and not dominate it.

In general, that's the philosophy. What can we do? Pharmaceutical companies



KIMBERLY SMITH, MD

can do a lot of things to make better medicines, and we are doing that. But we're also trying to find ways to address stigma. And find ways to have people feel comfortable—or to feel more comfortable—in their skin.

One of the things that we've been doing is anti-stigma campaigns. One of the new campaigns is called *Being Seen*, and is focused on Black MSM [men who have sex with men]. Our Positive Action group is doing that. It's basically interviewing different Black MSM from all parts of society, including actors, directors, and artists. They're telling stories about how they are impacted by the visual of Black MSM in different settings. Someone, for example, told the story in one of the first podcasts about how the first time he got ahold of an E. Lynn Harris book was the first time he actually saw the feelings that he had represented on paper.

The way I describe it, particularly for the women that I took care of, is that the stereotypes about women living with HIV, that they had to be drug users or that they were quite unquote promiscuous—I would remind people that the overwhelming majority of my patients got HIV from their husbands or



their long-term boyfriends.

You don't know what a person's story is. The notion that you ascribe something negative to people is just always so problematic to me. It got to the point that when I had fellows or students presenting cases to me and they would describe somebody with HIV and talk about how they got it—that was the least relevant part. What matters is, how are they taking care of themselves now? How are we going to take care of them? How are we going to help them through whatever they're going through at that moment?

Better medicine is really important. Simpler medicine is really important. But it's not just that. People need to have the other parts of their lives coming together well, too, in order to allow them to be able to consistently stick to their medicines, and not be traumatized by their

medicines, actually. We heard from people in clinical trials for long-acting therapy that one of the biggest benefits was not having to take a pill every day, which was a daily reminder of living with HIV. When you think about it, something happened to them that was likely traumatic. They received their HIV diagnosis. There's so much self-stigma that people blame themselves. So, taking a pill every day is a reminder. How do you get past that?

Long-acting therapy, that's one way. But people have to be able to get past that trauma to live out their lives. And then they won't see taking medicine as a negative thing.

So why is a pharmaceutical company doing something to sponsor these types of podcasts? Because we recognize that there's so much more to living with HIV and helping people thrive than making medicine. It's about having people be able to live their lives in a positive way, to be themselves. Address that stigma, and it empowers people to be able to take on what they need to take on to control this disease. **PA**

VIEW some of the community outreach at [Viivhealthcare.com/en-us](https://viivhealthcare.com/en-us)

TIOMMI LUCKETT'S STORY

Claiming space in HIV activism

Activist Tiommi Lockett read her story. She is now the Communications & Training Assistant of the Positive Women's Network-USA.

Diagnosed HIV-positive in September 2012, I was fortunate to receive treatment, and within six months had an undetectable viral load. A few years later, a nurse in my doctor's office asked if I would be interested in speaking at an event in Washington, D.C., on Medicaid expansion in my home state of Arkansas. I said yes, but had no idea what was in store for me. A couple of months after my visit to Washington, I was asked to speak at other venues on behalf of transgender rights. From there, I attended the HIV Is Not a Crime Training Academy, a gathering of activists, legislators, lawyers, people living with HIV, and other experts to discuss and plan ways to reform and modernize laws that criminalize HIV.

My work in the HIV and transgender communities continued to grow. I serve as a blogger and advisory board member for various HIV and transgender organizations and held a seat on the Arkansas Ryan White HIV planning group. I did it to get my words out there. People related. Women relate to what I am saying. It started to break down the differences in our lived experiences, and it brought me closer to a community of people that I trust.

I always put up a façade that I was happy. Then I said, "You know what? It's time for me to live for me. I can't live for how people want me to be."

Lockett also talked about being invited to speak at the White House with a coalition of women in 2016; she wrote about the experience, "From the Big House to the White House," for The Well Project's blog, "A Girl Like Me."

Webinar discussion

EVANY TURK: Eventually, you get tired of being tired. Tired of the stigma, tired of the denial. That's when you turn it around. That's when I gained purpose.

You learn about it. You learn about treatment, and that you can't transmit it [if you have undetectable viral load]. That made me less afraid of the stigma and allowed me to live my life. I'm going to do the things in my life that I want to do. I'm going to do the things in my life that I love to do.

TIOMMI LUCKETT: I really thought I was alone. When I saw that others experienced these traumatic experiences—that it was common—I was angry.

Social media—that was my community. That was my promise to my Higher Power, that I would help others.

This work is so much bigger than me. It encompasses all of us. I got tired of talking about me. What's next?

There's no more weight holding me down about being trans or being diagnosed with HIV. I'm a whole person. HIV is just a part of who I am.

Activist Gina Brown, based in New Orleans, co-facilitated the session. She asked, "If we had a magic salve, what would you put in it?"

CELESTE WATKINS-HAYES: The first thing I would add is protection from sexual trauma. I was surprised at the number of women who experienced sexual trauma, which is where 'I'm not worthy' comes from. [Dr. Watkins-Hayes and her research team interviewed more than 100 women over 10 years. Sixty percent of them had experienced childhood sexual abuse.]

One of the things I wanted to highlight is people getting involved in the political system in a way that helps all of us—the willingness to speak truth to power.

EVANY TURK: One of most important things is you don't have to know anything but your story, what you've been through. What do you need? You don't have to disclose.

The more someone shows up, the more comfortable they get.

KIMBERLY SMITH: I would add the need for safe spaces. I mean, clinics that are safe. I mean housing that is safe.

The reality is that you can't get the services you need—the counseling, the health care, and everything else—if you are not in a safe space.

From Remaking a Life

The extraordinary conversion of HIV/AIDS from an inevitable death sentence to a manageable chronic illness in well-resourced countries like the United States is not only one of the most noteworthy medical achievements of the past 35 years, it is also a significant social achievement. ... Perhaps one of the most important but underrecognized outcomes of this mobilization was the emergence of the extensive HIV safety net of human service providers and other entities who would prove vital for individuals confronting difficult circumstances by offering four things:

- Access to health care
- Modest economic assistance
- Extensive social support, and
- A path to political and civic engagements

COVID-19's impact on Latinx communities

The pandemic is hitting Latinx people harder; HIV researchers say it's time to create policy changes

BY ENID VÁZQUEZ



Like the HIV epidemic, the COVID-19 pandemic shows what happens to people who are socially and economically disadvantaged—greater risk of disease and death.

Already understanding how these disparities are harmful to health, two groups of HIV researchers working together documented the greater COVID-19 risks for two vulnerable groups—Black and Latinx people.

The researchers say they want more than just statistics to show to government officials and other policymakers. They want policymakers to work towards ending the inequities in the first place.

Study on COVID-19 and Latinx

CARLOS E. RODRÍGUEZ-DÍAZ, PHD, MPH, is a community health scientist with the Milken Institute School of Public Health, George Washington University, focusing on action research on the social determinants of health. He is lead author of the first nationwide analysis of COVID-19 cases and deaths in the Latinx population, “Risk for COVID-19 infection and death among Latinos in the United States: Examining heterogeneity

in transmission dynamics,” published July 23 online in *Annals of Epidemiology*. He discussed his study during an August 5 webinar organized by the Latino Commission on AIDS in collaboration with other agencies. Note: Dr.

Rodríguez-Díaz used “Latinos” for the sake of simplicity, while recognizing the many ways that people identify.

“The attention to the Latino community has been part of the discussion of the pandemic since very early, because, unfortunately, there were disparities in our Latino communities that the pandemic is just highlighting.

“For those of you engaged in work with Latino

communities, you understand this. But do not underestimate the importance of the discussion that we’re framing that discussion, because the issue of health disparities is not obvious for the overall population of the United States. Crowded housing. Chronic medical conditions. Environmental racism.”



“**THE PURPOSE** of our research was not only to highlight structural drivers of the pandemic among Latinos in the United States, but to make sure that we come up with findings that are useful to make changes and have a positive impact on the health of our communities.

“We have a great opportunity to respond to the emergency and change the negative impact that the pandemic is having among Latinos, but also to make changes that can have a durable impact on Latino communities.”



“**OUR STUDY** was in part developed because of our historic involvement in health disparities. Many of us have worked in the HIV field for decades. And the knowledge that we have gained in health disparities and HIV in

Policy and political needs

JEFFREY CROWLEY, MPH, Georgetown University Law, is an expert on HIV/AIDS. He spoke to policy needs.

- Address health care not just through the health system, but through housing, employment and working conditions, and other structural factors.
- Use contact tracing together with other responses such as education.

SHORT TERM: Protect against occupational exposure, such as the Defense Production Act, used by the White House to order meatpackers to return to work. Protect testing and health care access. Address food insecurity. Collect information based on gender and other factors.

LONG TERM: Address health care access and coverage. All states need to expand Medicaid. This will not help many

documented immigrants, who are barred from accessing Medicaid for their first five years in the U.S. COVID-19 shows the public health reason that everyone needs coverage. Address housing instability. Extend paid sick leave. Support families to support communities. Address systemic racism and deal with issues of distrust.

“If only this study could tell us some things and then we can say it’ll be taken care of,” said Crowley. “We’ve provided the data. This is what we need to do. And I think there are a lot of reasons why policymakers want to say, ‘Oh, we’re responsible for everybody. We don’t have time to go down and do this for this group, this for that group.’ But from what we’ve seen, we can’t just trust that by giving data about disparity impact on Latinos that policymakers will respond appropriately. We need to make that happen.”

the Latino communities was very transferrable and useful these days.”

The study was modeled on one published a month earlier examining the impact of COVID-19 on Black communities. Dr. Rodríguez-Díaz pointed to differences between Latinx groups.

“We know that not all Latinos in the U.S. share one unique story. We have people who speak different languages, Spanish or English for the most part. They are geographically located in different places. They have experienced migration in different ways. So, all those elements were considered in the way we approached the data.”



THE STUDY looked at county-level data through May 11, when some states began to relax stay-at-home policies. Counties considered “Latino” were those with a Latinx population greater than 17.8%, which is the percentage of the Latinx population in the country as a whole. Latinx make up the largest racial and ethnic minority group in the U.S. Puerto Rico, which does not have counties, was added as one county. Fourteen percent of all counties (443 out of 2,700) were predominantly Latinx. The Latinx counties had a Latinx percentage ranging from 22.9% to 47.9%.

Nationally, COVID-19 diagnosis rates were greater in Latinx counties: 90.9 vs. 82.0 per 100,000 persons.

Predominantly Latinx counties were more likely to

- Have people who were younger (on average, under 35)
- Have a greater number of individuals without health insurance
- Have a greater number of persons per room in a household
- Have fewer monolingual English-speaking Latinx
- Have a greater proportion of monolingual Spanish-speaking or bilingual individuals

These differences were statistically significant. Dr.

Rodríguez-Díaz said this was no surprise: “It’s a profile we see very often.”



BECAUSE SO MANY early COVID-19 cases in the U.S. occurred in the Northeast, the study looked specifically at different regions to make comparisons.

It found that in the Midwest and the Northeast (specifically New York, New Jersey, and Connecticut), the rates of COVID-19 cases were highest in the counties with greater Latinx populations.

“This means that Latinos were disproportionately affected early,” said Dr. Rodríguez-Díaz.

In the South, however, no greater risk was found.

For counties across the country with more Latinx people, the COVID-19 rates were higher with

- A greater proportion of Spanish-monolingual people
- Lower unemployment rates
- More heart disease deaths
- Less social distancing, and
- More days passed since the first reported case



“WE KNOW, unfortunately, that for monolingual Spanish speakers to have access to prevention information and to engage properly with the healthcare system is much more difficult. We also found more COVID cases among those with lower unemployment rates, and this is interesting. ... Consider this as we move forward to deaths. What we are seeing here is that the cases are more common among Latinos that are working, who couldn’t stay at home to prevent infections.”



IN TERMS of deaths from COVID-19, the numbers were greater in

- Latinx counties in the Midwest
- Latinx counties with
 - crowded living conditions
 - elevated air pollution
 - higher rate of

employment

- age (younger than 35)

“What we know about crowded housing in the Latino community is that we often have households with multiple families because it’s part of the experience of migration. It’s part of some cultural practices. People have different explanations, but we have documented this in the past. With crowded living, you have multifamily housing. So people are coming in and out for work, but there’s also less space for distancing.

“Air pollution has been associated with respiratory conditions that are exacerbated when the person is infected. Air pollution has often been documented where communities of color live. There are different reasons for that. In some cases,

it’s because communities of color, including Latinos, are living in metropolitan areas where you have more air pollution because of transportation and other industries. In rural areas, it has to do with industries that are there, as in the case of Texas, or other parts of the states where you have refineries and other industries that are constantly polluting the air. This compares with other trends in environmental justice and how communities of color are disproportionately affected by environmental pollution.”

The employment findings were consistent, he said, with U.S. reports that most Latinos couldn’t stay home.

“They had to go out and work because they are front-line workers and they are working in industry, some of which were considered

Study on Black people and COVID-19

GREGORIO A. MILLET, MPH, of the Public Policy Office of amfAR (Foundation for AIDS Research), was lead author of the study that inspired the Latinx report from Dr. Rodríguez-Díaz. Before joining amfAR in 2014, Millet, an epidemiologist, was senior policy advisor of the White House Office of National AIDS Policy. “Assessing differential impacts of COVID-19 on Black communities” by Millet and colleagues was published online May 14 in the *Annals of Epidemiology*.

Millet said that the information presented by Dr. Rodríguez-Díaz “has really not been part of the national conversation in the media.”

According to Millet, the study he led found that, “Black counties were only 22% of all counties, but 52% of COVID diagnoses and 58% of deaths.

“One of the things that did not make it into the media as much, though, was just as Carlos had mentioned beforehand when we looked at primarily Latino counties—that underlying health conditions did not explain the disparities that we were seeing in COVID-19 cases or deaths. What we found was that health care access, the number of people in shared housing, and unemployment were all associated with COVID-19 diagnoses in our paper for Black Americans, and it was a lot of the same things that we saw in the COVID-19 paper for Latinx populations.

“When you look at the maps that we have for Black Americans, you can see underlying health conditions are elevated for heart disease as well as diabetes, which is associated with COVID-19 in the southern U.S. This is where 55% of Black Americans live.

“But that’s not really the big story. The big story is the social determinants of health within those same counties. So it’s poverty. It’s unemployment. It’s lack of health insurance. Those are the main issues that are driving not only COVID-19, but also HIV in these counties that are primarily counties where Black Americans live. And it’s exactly the same story that’s happening in the Latinx counties.”

essential, like the meatpacking and multiprocessing industries.



ACCORDING TO the study's conclusion, "COVID-19 risks and deaths among Latino populations differ by region. Structural factors place Latino populations and particularly monolingual Spanish speakers at elevated risk for COVID-19 acquisition."

"We have demonstrated that not all Latinos are equal. But again, there are many assumptions and there are several discourses in our country that make it harder to communicate challenges in our communities. I hope that this study serves to document challenges and the nuances in the experiences of the Latino communities in the U.S. Because we also know that we need policy changes, but the policy response cannot be the same for all counties, all communities, and assuming that all communities of color

or other communities are equally affected by the implementation of certain policies.

"We are okay with people working and feeling productive, and getting an income. However, we need to provide the best conditions possible to prevent infection at work."



Action research

DR. RODRÍGUEZ-DÍAZ urged partnerships between health departments and community-based organizations, as well as greater media visibility for those groups. Asked about "next steps," he replied, "We will probably have enough data, perhaps better data, soon. I am now trying to look at what we can do with these findings

Latinx account for

33%

(1 in 3) of all confirmed COVID-19 cases in the U.S. in which ethnicity/race is known.

SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION, JUNE 11, 2020

to actually change the conditions that affect our communities. To take a closer look at those issues so we can move faster to solutions. To do

more action research. Work with communities that are already doing something and evaluate what is working. Use some implementation science to expand good practices very fast.

"That's what we need," he continued. "Otherwise we will keep describing problems that we know are affecting our communities."

"I completely agree with you," said Gregorio A. Millet, MPH, of the Public Policy Office of amfAR (Foundation for AIDS Research):

"We know that the disparities are going to be there. They've always been there. They're going to continue to

be there. They're not just disparities for COVID-19. We see the same disparities for HIV. We see the same disparities for other respiratory conditions, like the swine flu that we had back a decade ago, which is similar to COVID-19, where we saw members of Latino communities more likely to be hospitalized.

"So we really don't need to keep documenting the disparities or writing papers around it.

"We do need to move forward on the policy implications. What are some of the other things that we can do to actually reduce these disparities and to help these communities that are at higher risk for COVID-19?" **PA**

WATCH THE PRESENTATION, including an update on Puerto Rico, at the Latino Commission on AIDS' YouTube channel. **FOLLOW PANDEMIC CASES** in real time with amfAR's COVID-19 dashboard: ehe.amfar.org/disparities.

"My experience was not the first with HIV discrimination.


I am speaking out because I would like it to be my last."

—Lambda Legal client Nikko Briteramos, after being refused a haircut because of his HIV status

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Do not receive TROGARZO[®] if you have had an allergic reaction to TROGARZO[®] or any of the ingredients in TROGARZO[®].

TROGARZO[®] can cause serious side effects, including:

- Allergic reactions. TROGARZO[®] can cause allergic reactions, including serious reactions, during and after infusion. Tell

your healthcare provider or nurse, or get medical help right away if you get any of the following symptoms of an allergic reaction: trouble breathing, swelling in your throat, wheezing, chest pain, chest tightness, cough, hot flush, nausea or vomiting.

- Changes in your immune system (Immune Reconstitution Inflammatory Syndrome) can happen when you start taking HIV-1 medicines. Your immune system might get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your health care provider right away if you start having new symptoms after receiving TROGARZO[®].

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Also tell your healthcare provider about all the medicines you take, including all prescription and over-the-counter medicines, vitamins, and herbal supplements.

For more information or medical advice about side effects, ask your healthcare provider. You may report side effects to the FDA at 1-800-FDA-1088 or the THERA patient support[®] program at 1-833-238-4372.



MIND, BODY, AND MEDICINE

Taking care of your mental health while living with HIV

BY JACOB PETERS, PHARM.D

Now more than ever, many of us are grappling with maintaining our mental health. Whether it is daily life, what you see in the news, or anything else going on, it is important to understand our mental health and the impact all these things can have on it. Living with HIV can pose challenges and raise some questions about how to be the best advocate for yourself and your well-being.

As a psychiatric pharmacist, I have specialty training to better understand the ins and outs of medication to help people with their mental health. I also have the privilege to work a couple days each week with people living with HIV, which has helped me better understand some of the unique challenges they face. Below are some questions patients often ask about their mental health and their medicine that you may be wondering as well.

What impact does not taking care of my mental health have on my HIV management?

Short answer, a lot. A diagnosis of HIV can be life-changing, which may lead to symptoms of different mental health diagnoses, like depression or anxiety. It's important to reach out for help if you are feeling more sad or worried than usual. Help can come in many forms, from talking with a trusted friend or a healthcare provider to going to a therapist or taking medicine. If you find yourself currently in crisis, like feeling as though you may want to attempt suicide, it's best to go to the nearest emergency room, reach out to your doctor, or use national hotlines like the Suicide Prevention

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Letting your providers know when a medicine is working or if you feel like it is causing side effects are essential to getting you to the right treatment as soon as possible.
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Hotline at 800-273-TALK (8255). Uncontrolled mental health problems can lead to people not taking their HIV medicines consistently, which may cause detectable virus levels, make you more likely to catch other illnesses (from the common cold to opportunistic infections), and overall decrease the control you have over HIV.

Taking medicine has become a habit for managing my HIV, and I know how important it is to stay undetectable. Now my provider wants to start me on a medicine for my mental health. Is that okay?

Medicine is also an important tool in the treatment toolbox for someone living with mental illness. Given the importance of HIV medicine to getting to undetectable, it's important to make sure there are not any problems like drug interactions with your new medicine. HIV medicines and medicine for mental health can be broken down or used by the



body in similar ways, which can lead to one or both medicines not working as well, causing more side effects, or sometimes both. It is best to make a habit of telling all your providers and pharmacists about all the medicine you take, including ones you buy over-the-counter, and asking them to be sure they are accounting for any potential issues.

Having medicines that interact sounds a little scary and I am not sure how I feel about that. How serious can these interactions be?

It is good to always ask these kinds of questions because some interactions are serious and should be avoided. Basically, they can fall anywhere on a scale of how severe they are and what kinds of effects they may cause. Some medications may cause your HIV medicine to not work

as well, either through increasing how fast your body processes it or by blocking it from getting where it needs to be in order to work. These are best avoided.

However, some interactions may not be as severe. For example, a few antidepressants can have their metabolism slowed down by HIV medicines. When that happens it may lead to more side effects. But, in those cases we start with lower doses and increase those doses much more slowly to make sure the medicine does not cause any problems. Or if it does cause a problem, we can address it sooner. Regardless, as a patient, letting your providers know when a medicine is working or if you feel like it is causing side effects are essential to getting you to the right treatment as soon as possible.

What should I expect if I start taking medicine for my mental health?

Most medicines for mental health

take some time to work. That is often not what someone wants to hear because they feel bad now. I would give anything to have a medicine that could work instantly, but until then, it is best to stay informed.

As an example, antidepressants may take six to twelve weeks to relieve all your symptoms. During that time, you may experience some improvement, but it is likely to take a while to feel at your best.

There also may be a need to try different medicines. Since each person is unique, it is difficult, if not impossible, to predict how each of us may respond. So long as you are not having intolerable side effects, what is important during this time is to keep taking your medicine. You may have heard it before, but a medicine you never take, never has a chance to work. And since these medicines take so long to work, some folks may stop because they think they are not effective. Do not do this. When you stop taking them or miss doses, the clock starts over and it may take even longer to reach effectiveness. Things that may help during this period would be trying therapy or engaging in healthy coping habits (art, exercise, etc.) to bridge the gap, which can always be helpful with or without medicine.

Speaking of coping, some days I just need something to drink when the day is finished. Can I still do this if I start medicine for my mental health?

Generally, alcohol or other drugs are not recommended to take with prescription medicines, especially medicines for mental health. A side effect of some medicines for mental health can be that they may lead to not being able to sleep as well. Alcohol, for example, contrary to popular belief, actually worsens peoples' sleep cycles. So, combining them may worsen a side effect of a medicine or worsen a symptom of your diagnosis.

Medicine aside, alcohol and other drugs can worsen mental health problems. From causing mood changes to worsened depression symptoms, it is best to avoid using alcohol and drugs for your overall mental well-being.

Additionally, some combinations of medicines with alcohol or other substances can lead to overdoses and can be lethal. If


you do decide to drink or use a substance, be honest with your provider or pharmacist about it. The more we know, the better we are able to care for you. It may be scary to think about admitting to doing something you think others will think is "wrong," but by being honest and open, we can better find treatment that best fits you.

I have started a medicine for my mental health, now what?

Great. Having that initial conversation and reaching out for help can be really difficult, so you should be proud of yourself.

A lot of people wonder if they will be on a medicine for their mental health for a long time, or even for the rest of their life. It really depends. One, it can depend on your specific diagnosis. Some mental health diagnoses do require long-term treatment with medicine, sometimes years up to the rest of their life. Others can be more short term. For example, if you are currently going through a stressful time in your life and you and your provider discuss and agree to try medicine, you may only need to take it for a short period of time, maybe just a few months. An open discussion with your provider will help you both settle on the best course for you.

Conclusion

Taking medicine is something that should not be taken lightly, but it is a central piece of helping you feel better in many cases. First and foremost, safety is very important. This article may leave you with still unanswered questions, or questions that are more specific to you. Your doctors, pharmacists, nurses, and other healthcare providers can give you important information about your specific medicine and what to keep an eye out for. But do not forget, you are your own best advocate. Having open communication with your providers can help us work with you to find the best medicine and treatment for you. 

JACOB PETERS, PHARM D, BCPP, BCPS, is a Clinical Pharmacy Specialist in Psychiatry for Indiana University Health – Methodist Hospital in Indianapolis.

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Since these medicines take so long to work, some folks may stop because they think they are not effective. Do not do this. When you stop taking them or miss doses, the clock starts over and it may take even longer to reach effectiveness.

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A great love endures

Remembering the humility and joy of Timothy Ray Brown

BY MARK S. KING

Timothy Ray Brown passed away in his home on September 29, 2020, with his loving partner, Tim Hoeffgen, at his side. "I was so moved by their devotion to one another," said activist Mark S. King, who wrote this story, "and I was honored they let me tell the story of their final days together. Timothy made history and it's a great loss, but no one will miss him more than his partner Tim."

Tim Hoeffgen did a quick google search of his Scruff date as he headed over to meet him. Tim was living in Nevada in early 2013, and the guy he had been chatting with on the dating app looked a lot like the man who was on the cover of the LGBTQ newspaper in Las Vegas that week.

When the door opened, Tim realized his hunch was correct. Greeting him was Timothy Ray Brown, the first man in history cured of HIV and the intense focus of scientific and public fascination around the world.

"I was charmed immediately by his personality," Tim tells me in a call from their Palm Springs apartment. "He is just the sweetest man." The two men, Tim and Timothy, have been together ever since.

Timothy Ray Brown is terribly shy. He also exudes warmth and humility, and is clearly grateful for his viral reversal of fortune. He is quite literally an HIV historical milestone, embraced by the community since he identified himself as "the Berlin Patient" in 2010.

The harrowing details of Timothy's medical journey, as a cancer patient and a man living with HIV, are complicated. Suffice it to say that, while Timothy was living in Berlin in 2008, an ingenious oncologist treated Timothy's leukemia with a stem cell transplant using a rare blood type that is genetically resistant to HIV infection. When all was said and done, HIV was no longer found in Timothy's blood and the scientific breakthrough, first reported at the 2008 International AIDS Conference, was celebrated around the world.

The treatment, it should be noted, nearly killed Timothy and has been successfully replicated exactly once— but has nevertheless provided vital insight into potential avenues of HIV cure research.

But that was years ago, and

Timothy's traumatized body has never been the same. Sadly, his health has been in freefall for the last six months, with a recurrence of leukemia that has invaded his spine and brain. His partner, Tim, the Scruff date from Nevada, has never left his side.

That is no overstatement. When Timothy was admitted to a cancer hospital in April, Tim camped in Timothy's hospital room for seven weeks. Because of COVID-19 restrictions, neither of them could leave the medical campus. "It was a blessing to be there with him," Tim tells me, "but it was rough. It's so much better to be home."

There is a hospital bed in the one-bedroom apartment Tim and Timothy share. Timothy is bedridden, and is receiving home hospice care. Tim divides his time between caring for Timothy and fielding calls from concerned friends as well as from various researchers to whom Timothy has generously provided endless blood and tissue samples over the years.

"Timothy is not dying from HIV, just to be clear," Tim says. "HIV has not been found in his blood stream since he was cured. That's gone. This is from the leukemia. God, I hate cancer."

Tim is speaking on the phone with me only a few feet from where Timothy is resting in his hospital bed. Tim sounds exhausted, and resigned to what lies directly ahead.

"The hardest part has been seeing Timothy go downhill," Tim says, bursting into mournful tears, the kind that strike without warning, even before the death



we are awaiting has occurred. "He's a person you can't help loving. He's so sweet. The cancer treatments have been rough. Sometimes I wonder if it's worse than the disease."

Indeed. Many of my friends lost to AIDS would agree with him. "Believe it or not," Tim adds, "this is the first time in my life that I will lose someone..." His composure breaks again.

Tim and I both know that his partner, confined to his bed and surrounded by medical devices, bears an unsettling resemblance to a man dying of AIDS. It's as if the Fates vengefully swept in to claim the AIDS patient who had escaped them.

Timothy has dutifully fulfilled countless media requests and invitations over the years, becoming an active public figure in the HIV/AIDS arena in spite of his social reluctance. He embodies a shared



TIMOTHY RAY BROWN (LEFT) AND TIM HOFFFGEN IN CAPETOWN, SOUTH AFRICA IN 2017

hope for a practical HIV/AIDS cure. At conferences and community events, people living with HIV gravitate to Timothy, reaching out for hugs and thanking him for the physical gauntlet he has been through. He is a projection of our longing for scientific discoveries and a marker for just how far we have come.

Tim, meanwhile, has been Timothy's loving guardian, intervening as necessary to be sure Timothy wasn't overwhelmed by requests. He has played the role of media agent and even bad cop in order to safely buffer Timothy.

I ask Tim if his partner knows he is dying. "Yes, he knows," Tim answers. "Well, sometimes he doesn't. It depends. But I have asked him what he wants me to tell people when we make his situation public. He said, 'Tell people to keep fighting. Fight for a cure for HIV that works for everyone. I never wanted to be

the only one.'"

Tim Hoeffgen will join a unique group sometime soon: the surviving partners of those with an elevated place in history. He will probably be known as the widower of Timothy Ray Brown for the rest of his life. "I would be honored to be known that way," Tim tells me. "I love him so much. I will gladly carry his message and his legacy."

Our time on the phone is growing short, and I know Tim has things to do for Timothy. I begin to wrap up our call when suddenly I hear Timothy's voice on the line.

"Hello there, Mark," Timothy says. "I hope you are doing okay." I tell him I am fine. I am tempted to thank him for all he has done, as a kind of goodbye, but it feels too intrusive. Instead, I tell him to fight for as long as he wants. In other words, *no longer* than he wants. "I'm

going to keep fighting," Timothy replies, "until I just can not fight anymore."

Tim takes back the phone, and I know it is time to go. I can tell he is stepping away from Timothy as he quietly confides something else.

"One of the researchers wanted Timothy's body, you know, to be left to science," Tim tells me. "I said, 'thank you, but no. I think he's done enough.'"

Tim Hoeffgen and Timothy Ray Brown asked me to tell this story as their way of thanking the community and sharing the news of this final chapter of Timothy's journey. They asked that we give them the space they needed during their remaining time together. Tim Hoeffgen will release further updates at the appropriate time.

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Reclaiming identity

A musician and educator reflects on his journey

BY RICK GUASCO · PHOTOGRAPHY BY DERRICK WOODS-MORROW

“You have to earn my story. I don’t owe you my story,” says Phillip Lambert, 34. Trust requires openness and work on both sides, he says. As a person living with HIV, he has been working hard to be open, and to show what life can be like on the other side of an HIV diagnosis.

Where are you from?

I’m actually from Chicago and will rep my city for life. Born and raised on the deep dirty South Side of Chicago, 93rd Street, affectionately called the Nine Tre.

Describe your experience as an HIV advocate.

I have been working in HIV prevention since 2004. I started as a sexual health peer educator in undergrad. When I was younger, I loved to play devil’s advocate, and that natural interest led me to educating in that space. After undergrad, I moved into HIV research at one of the leading LGBTQ+ health organizations. From there, I became an Outreach Worker, an HIV prevention program manager, and then a digital education ambassador for the CDC. People always thought I was positive because of how literate I was about transmission and history. I didn’t mind, but it bothered me that only people living with HIV are supposed to be knowledgeable about it, like it is positive people’s job to do the labor for the entire world, and for me that’s a hard *no*.

What got you interested in HIV advocacy and prevention?

I didn’t have anyone to talk to me about it. No one that I knew had the information either. I would read books and search in chat rooms looking for information about sex. Sex education should not be trial and error. I bought several whitewashed sexual health books at Borders when I was 15 and shared them with my friends. I think that was truly my first step towards my work in sex ed because I went out and got that knowledge and then brought it back to my community. I was just 15.

At the end of 2007 through the first part of 2008, I lived in Cape Town, South Africa where I worked exclusively with children with one or both parents who had died of HIV. These were kids who were now living in orphanages, many

of whom were unaware of their own HIV status. Although my undergraduate degree was in advertising, this experience led me to pursue my first job in HIV prevention research.

What drives your interest in working with youth?

I’ve always loved kids. From a very young age, I knew I was queer and was in tune with that queerness. I knew that the typical idea of what a nuclear family is was not in my future and would not look the same for me. I was always drawn to working with kids and supporting them in being their whole selves without judgment. I was the go-to babysitter and nanny as a teen, but when I lost my mom at 16 to lung cancer and didn’t have my dad to rely on because my entire life, leading up to that moment, he had struggled with a heroin addiction, it changed my relationship to my peers. It forced me to gain an even deeper awareness and understanding of youth. I was fortunate to have an extended family take care of me, but my chosen family was where home truly was. It’s where I flourished and it is what continues to sustain me. Biological family is what got me here; chosen family is what kept me here.

How did you learn you were living with HIV? How did you feel?

Life kept throwing me curveballs. After working for some of the leading HIV research institutions for over 10 years, I contracted HIV. In the summer of 2015, I was hospitalized for a blood disorder that causes me to have blood clots. They suggested that I get an HIV test which at first I declined because I had just recently received an STI test two weeks prior and all of my test results had come back negative. After staying in the hospital for 10 days, my doctors decided to run an HIV test again to confirm that I was negative. I agreed and was sure I had nothing to worry about. Moments before I was discharged, a doctor came into the room and told me that I had

tested positive. I was in a state of shock because I had just had a negative test result. I thought, “How could I have allowed this to happen to me?” The internalized stigma was too real. When the stigma directly affects you, it hits differently. Instantly, I blamed myself even though it wasn’t my fault. I went to see an Infectious Disease Specialist two days later and started my regimen immediately but also felt extremely ashamed and embarrassed. I went through a deep depression, failed out of the last year of my PhD, and I gained weight until I weighed nearly 700 pounds. In retrospect, it was the music and chosen family that saved my life. I want the people who read this, the people who are positive, to know that you have nothing to be ashamed of, that you are just as worthy as anyone else of living a full and rich life.

What was your “coming out” process like—to yourself and disclosing to others that you have HIV?

At first, I was just so shook and embarrassed to learn of my diagnosis that I didn’t talk about it at all with anyone except for a handful of people I trusted. Then, after a year, I decided to write a status on Facebook about my diagnosis. That was my way of coming out to friends and close family in a way that didn’t feel so pressured to me. The post was simple: *In honor of World AIDS Day, I challenge everyone to get tested & know your status; because knowing is not only beautiful but also self-care and self-preservation. As a person who has been living with HIV for the last year, know that adherence can at times be difficult but so worth it. SILENCE = DEATH and ain’t nobody got time for that.* I posted that in 2016.

I was still so depressed and immobilized by my depression. I thought often about my PhD program and was trying to find a way to reconnect with myself, to have some sense of normalcy. I was learning to grieve the death of who I was before my diagnosis. I connected with a friend and we decided to use music and writing as a form of therapy and as a way to practice disclosing, but it was so much bigger than that. From that, I wrote music that was defined both by advocacy and a form of reclamation of my own identity as a person and as a sexual being. The music was healing, provocative, sex-positive, and a banger. I used music to come

out to myself. I also used music to announce myself as a person living with HIV. For the last few years, I've been working as an educator and previously had been a full-time nanny. None of these people will be aware of my status until they read this story. I hate feeling that I'm compelled to share every part of my personal story with anyone when they haven't done any work to earn that trust. You have to earn my story. I don't owe you my story. I realize that my story doesn't have to be perfect to be shared. I don't know who needs to hear this, but I'm hoping that by being open and sharing my experiences of living with HIV I can help someone else who doesn't know that there is happiness on the other side of a diagnosis. That there is joy that comes in the morning, but that that joy will not be easy. The journey comes with hard work and deep healing and only you can decide when and what that looks like for you. Some days, I don't feel like taking my medicine. I mean I do, but I want to be and feel without having to worry about taking my medicine every day. I think it's important to be honest about that. I think it's important not to oversimplify or try to put a positive spin on our experiences as people living with HIV.

Talk about your art. Do you incorporate living with HIV?

Nina Simone once said, "An artist's duty, as far as I'm concerned, is to reflect the times," and that is exactly what I have chosen to do.

In 2015, I started using music to come out to myself. Getting a positive diagnosis pushed me into a depression that I couldn't seem to get out of. At times, I felt suicidal. I was immobilized and drowning emotionally. I was homeless. Some days, I couldn't move for days and weeks on end. It's very important to me to emphasize here how much of a struggle it is to access mental health services when you are Black, living with a chronic disability, and housing insecure. Not all therapists can understand those intersections and when you are poor, Black, and queer, it makes access to these services even more of a challenge. One of my friends who would visit me often (an up-and-coming music producer) encouraged me to look to music to express how I was feeling, to convey my state of being. That day, *Protection* was born. *Protection* is a work that chronicles the night that I was infected with HIV. It's about the ways that I moved through my own cycles of grief and the path I took to reclaim my desirability. I worked on it



for a whole three years and during that time sought out inspiration from Black artists that could help me to see the project through. I had Boys II Men's *Mama* on repeat for all of 2015 until Rihanna blessed me with *Anti* in 2016. *Anti* was my HIV coping anthem for a year until Sza dropped *CTRL* in 2017. It gave a voice and validity to my feelings. At one time, I didn't have my status publicly displayed on the apps. I would engage in chats and after disclosing my status, people would ghost me. There's a line from SZA's 2017 album where she says, *Why you bother me, when you know you don't want me*. Those words made me feel powerful. Those words reminded me that those people's rejection was not about me, but about them and the societal stigma surrounding HIV. In 2018, I released *Protection* into the world. For me, releasing that work signified relinquishing control from all the fear, shame, and stigma of my diagnosis and giving myself permission to be free and worthy.

My new EP, *Shine*, will be released in mid-November. I am in the early process of working on a book about my experience.

What has been your experience as a Black person living with HIV?

My experience living with HIV as a Black, fat person has been trying, to say the least. I have been working in HIV prevention. James Baldwin once said, *To be a Negro in this country and to be relatively conscious is to be in a rage almost all the time—and in one's work*. Then let's add fat, or seropositivity, or disabled to the equation. It can literally send you over

the edge. This wasn't something that I was able to understand until after I became positive and then all my intersecting identities really started to play out. So I have had to prioritize and center my joy and care while staying in the work for liberation because Black positive lives matter. Black fat lives matter. Black trans and non-binary lives matter. All Black lives matter and in the words of Fannie Lou Hamer, none of us can be free until all of us are free. *Period*.

Anything else you'd like to say?

To people living with HIV—you're worthy, you're whole, you're desirable. Some people aren't going to want to engage with you because of your status and that means they weren't worthy of your time. Ah! [in Megan Thee Stallion voice] Getting to and staying undetectable is a lot of work, but taking it one day and one step at a time gets the job done. Always remember, you're worthy regardless of if you fit into the U=U continuum or not.

To health care providers—healthcare is not a one-stop shop. Healthcare providers need to learn to take an individualized approach with every client. Not just nurses and nurse practitioners, but doctors, too. Doctors also need to invest in education that can help them to learn how to take anti-racist and anti-oppressive approaches to patient-centered care. Give the information anyway, 100% of the time.

To researchers and epidemiologists—Google Robert Rayford. He's a Black teen from St. Louis who died from HIV in 1968 whose death and diagnosis was "discovered" in 1987. The first AIDS patients were covered by *The New York Times* in 1981. What would have been different if Robert's case would have been the first declared? Also, hire racial equity and anti-oppression consultants and educators to teach you about how people at the intersections of Blackness, transness, youth, and homelessness are most impacted by HIV. Don't just rely on your intentions. Learn and study.

To artists and creatives—art helps people connect with the messaging of prevention and advocacy because health literacy is often presented in ways that exclude and dilute the voices and lived experiences of Black and Brown people—especially queer, trans, and nonbinary people. This is where art comes in to make prevention and anti-stigma messaging stay with people. Make your art anyway. Do it for the messaging, not the validation or the white gaze. Your work is important. **PA**

Everyday moments in extraordinary lives

BY RICK GUASCO

The equinox only happens twice a year. Although the dates change from year to year because of the earth's orbit, it is the time when day and night are of equal length, and signifies a changing of the seasons. In some ancient cultures, the equinox also symbolized a change of thinking. So, on Tuesday, September 22, 2020, the day of the autumnal equinox, what better day for POSITIVELY AWARE's annual anti-stigma campaign?

A Day with HIV portrays 24 hours in the lives of people affected by HIV—people take a photograph of their day and post it to their social media. More than 200 pictures from across the U.S. and representing 11 countries were posted, accompanied by the hashtag #adaywithhiv. But the real impact came from the personal experiences behind those images.

"HIV made me focus on all aspects of my health. It taught me the importance of being present, to focus on my goals and to keep moving," said Calvin as he took a break from his 6 a.m. workout in Olathe, Kansas.

"Focused on overcoming an unhealthy past—proud to be positive, excited to share my story, optimistic about my future," posted Matt Taylor from Philadelphia.

"In the past couple weeks and even months, I've been in and out of a dark space, yet still holding on to my light," said Richard Hutchinson, Jr., another Philadelphian. "I've been inspired by my struggles. I work every day to make better things happen in my life for those around me. At the end of the day, I'm an amazing human being, growing, learning, loving, creating."

But for many, a day with HIV is like any other day.

"This morning is like every other morning," said Rachel Feder, from Michigan. "My day starts at 7:30 a.m. I'm a social worker, and I continue to work remotely, so I was checking my email and my work phone before I wake my daughter up for virtual 6th grade at 8 a.m. Life doesn't stop."

"Getting my son ready for bed," said Aaron Laxton from Saint Peters, Missouri. "Thanks to knowledge and medications, I am healthy and able to keep up with an energetic toddler."

Because HIV stigma can affect anyone, regardless of

their status, a few allies also shared their support. "Today, I'm supporting a great friend of mine, Marissa Gonzalez, in raising awareness of HIV," posted Brittany Latresha Johnson from Fort Myers, Florida.

A number of people take part in A Day with HIV year after year. Through the succession of images, you can witness their life's journey unfolding.

A year ago, A Day with HIV coincided with the birthday of long-time participant T.J. Elston, who married his partner James the same day. The picture they took on the first anniversary is one of the three versions of this issue's foldout cover.

One of the most poignant images shared last year was a picture taken by Debbie Sergi-Laws with her father, who was in hospice care. Her photo this year captured a moment of remembrance and grief.

"Last year my photo was sharing my dad's hospice bed," she posted. "Spending the last month of his life with him I will always cherish. This year the challenges have been great. Dad, you shine in my heart just from further away. I love and miss you. Staying strong."

For some, A Day with HIV is an opportunity to live by example. "Tell me and I forget; teach me and I remember, involve me and I learn," said Zeke from San Antonio, Texas. "One person's revolutionary act against HIV stigma is a monumental act of kindness that is heard around the world!"

From Miami, Sannita F. Vaughn posted, "Love your life with grace."

SEARCH FOR THE HASHTAG #ADAYWITHHIV ON FACEBOOK, INSTAGRAM, AND TWITTER. IN ADDITION TO THE PICTURES THAT APPEAR ON THE NEXT SEVEN PAGES OF THIS ISSUE, AN ONLINE GALLERY IS ON DISPLAY AT ADAYWITHHIV.COM.



< 11:10 AM:
MIAMI, FLORIDA
Sannita F. Vaughn:
Love your life with grace.



< 5:20 PM:
ATLANTA, GEORGIA
Richard Hutchinson, Jr.: I'm a Black Queer millennial living with HIV! It's not always easy being on this journey, but God bestowed this journey on me to build me and make me the best version of myself as possible. Plus, I'm fine AF!!



< 5:54 PM:
SAINT PETERS, MISSOURI
Aaron Laxton:
Getting my son ready for bed. Thanks to knowledge and medications, I am healthy and able to keep up with an energetic toddler.



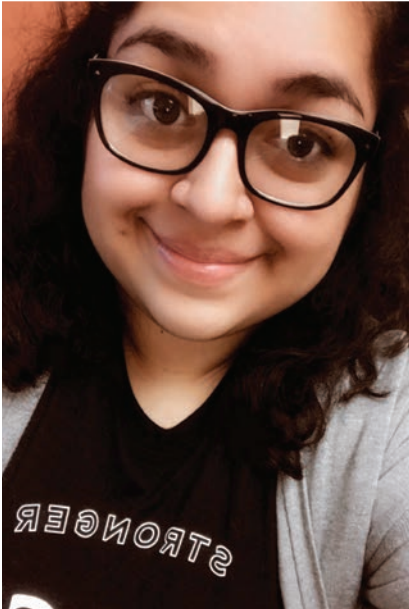
< 8:39 PM:
SAN ANTONIO, TEXAS
Zeke: One person's revolutionary act against HIV stigma is a monumental act of kindness that is heard around the world! Tell me and I forget; teach me and I remember, involve me and I learn.

6:30 AM: LUCKNOW, INDIA >
Neil Biswas: Sunrise with parrots in my garden. I've been HIV-positive from 2005, am 62 years old, a single gay man pursuing a career in athletics.



7:30 AM: FORT MEYERS, FLORIDA >>
Brittany Latresha Johnson: Today I'm supporting a great friend of mine, Marissa Gonzalez, in raising awareness of HIV. I have chosen to join this campaign to uplift, encourage, support, and motivate everyone who is impacted by it to continue to stay strong even when days get tough!

8:00 AM: MANSFIELD, TEXAS >
Ashley Maldonado: My day starts off with a daily reminder, "I will be okay, I am loved, and it's a bad day, not life." Twenty-five years living with HIV, and nothing is worse than the mind being your worst enemy.



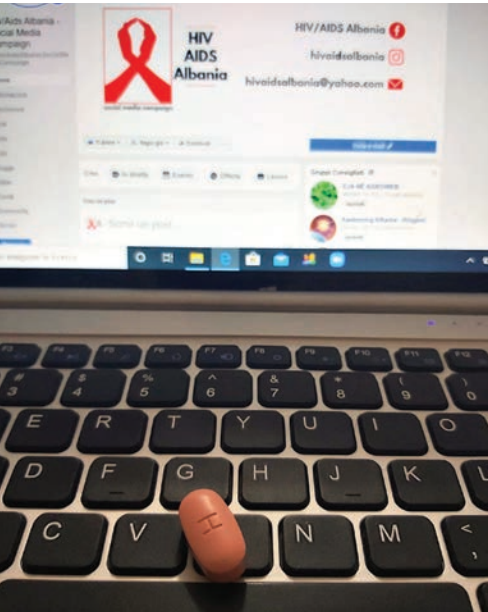
8:15 AM: OMAHA, NEBRASKA >>
Erin Shafer Fulton: I was 17 in 1994 when I tested positive in Omaha during my tests to join the military. Now I'm 44.

8:53 AM: FORT MYERS, FLORIDA >>>
Brian Keith Franklin, Jr.: Supporting my people in the HIV/AIDS awareness movement. Anytime we put a virus before a person we take two steps back as humanity.



9:05 AM: SAN FRANCISCO, CALIFORNIA >
Hank Trout: The workday begins! As long as my brain and my fingers can work together, I'll keep writing, trying to give voice to the trials and triumphs of surviving HIV/AIDS for 30+ years.

9:26 AM: LOS ANGELES, CALIFORNIA >>
Damone: A day with HIV sometimes is demythifying HIV to help break the stigma and educating my communities on the HIV/AIDS facts.



<< 9:35 AM:
TIRANA, ALBANIA
Erti: Part of my routine day. I try to provide information in the Albanian language about HIV/AIDS. I try to help by managing my HIV/AIDS Albania social media campaign, providing information and support for people living with HIV in Albania. This is my daily devotion.

<< 10:05 AM:
PORTLAND, OREGON
Benjamin Gerritz: Twelve years strong staying safe, positive, and hopeful, while engaging in a CDC conference call advocating for service quality improvements to increase cultural affirmations and trauma-informed practices.



<<< 10:17 AM:
CHICAGO, ILLINOIS
Timothy Jackson: A Day with HIV means finally accepting that I am more than my diagnosis, my life still has value, and my smile is worth sharing with the world.

<< 11:00 AM:
BOULDER, COLORADO
Barb Cardell: What I would really love to see is all my dedicated sibs posting pictures of themselves phone banking, text banking, getting out the mother loving vote!

<< 11:10 AM:
DALLAS, TEXAS
Alegandro Deets: I made it my purpose in life to help those just like me.



<< 11:31 AM:
DALLAS, TEXAS
Neen: Keeping safe during COVID-19, but never give up living your life!

<< 11:39 AM:
LAS VEGAS, NEVADA
Deral Takushi: Participating in my first Zoom video call with my coworkers since we started to work at home in March. I was excited to pick out my dress shirt (that no longer fits—thanks pandemic), my virtual background, my mug of choice, and happy to put on a smile for everyone.

11:48 AM: SHERMAN OAKS, CALIFORNIA >

Andrea de Lange: When I learned I was HIV positive at age 23, I never imagined I'd be alive at 57, let alone happily married, with a beautiful daughter.



12:00 PM: SAN JUAN, PUERTO RICO >>

Alexi Diaz: Trying to enjoy life as best as I can while talking about HIV and eliminating stigma through activism. That sometimes involves having a good time with friends while playing video games.



12:14 PM: ATLANTIC CITY, NEW JERSEY >>>

Jack R. Miller: At home auditioning for commercial and TV and film as a long-term survivor of AIDS over 26 years!

12:33 PM: SAN FRANCISCO, CALIFORNIA >

Bonnie Violet fka Duane Quintana: 8,030 days and counting. #blessed



1:25 PM: SAN JUAN, PUERTO RICO >>

Gaddiel Ruiz: Diariamente consumo mi medicamento para mantenerme vivo y saludable, pequeña acción que a la larga me ha permitido disfrutar de mis animales, de mi entorno y de las conversaciones dirigidas a combatir estigmas.

I take my medicine daily to stay alive and healthy, a small action that has allowed me to enjoy my animals, my environment, and conversations aimed at fighting stigma.

1:38 PM: CHICAGO, ILLINOIS >

D'Eva Longoria: Looking fabulous while working hard to empower my community!



2:10 PM: SAN JUAN, PUERTO RICO >>

Irving S. Rodriguez Acosta: Ever since I started the @Convihvir social media campaign, it has been great to be able to give voice to a cause that history has silenced. I don't live with HIV, but HIV affects me because those close to me (and not so close, too) who do live with HIV suffer from stigma constantly in Puerto Rico.





<< 2:15 PM:
SAN FRANCISCO, CALIFORNIA
Jesús Guillen:
Difficult times, so just giving flowers to all.



< 2:24 PM:
HOBSON CITY, ALABAMA
Marvellus S. Prater:
Patiently waiting on my turn to take the TB test for work at the local AIDS service organization. Living life in spite of stigma. Yes, I know that I am in need of a haircut... bad.



<<< 2:30 PM:
NAGPUR, INDIA
Jyoti Dhawale:
Gearing up for video-conferencing in an hour. My hair is my best asset—hence the Dyson AirWrap comes to the rescue. As a person living with HIV, looking your best can be quite a challenge.



<< 3:00 PM:
ATLANTA, GEORGIA
Nathan Townsend:
Living and aging well with HIV.



< 3:00 PM: **VALLEY STREAM, NEW YORK**
Nancy Duncan:
I stayed home today, browsing social media and was very saddened to learn about Timothy Ray Brown (The Berlin Patient).



<<< 3:00 PM: **BATTLE CREEK, MICHIGAN**
Ken:
I thought today would be my last radiation treatment, but I have one more day to go! In 2001, I was diagnosed with HIV. I didn't let that keep me down and I'm not going to let anal cancer defeat me either!



<< 3:08 PM:
KEW GARDENS, NEW YORK
Gamiel Martinez:
This is one of my hobbies that I do six days a week. Keep your body healthy and your mind healthier.



< 3:30 PM:
SONOMA, CALIFORNIA
Liberty Braw:
At a birthday party for my grandson. I have three grandchildren. I know not of a greater gift than living to witness one's grandchildren grow.

4:00 PM: LONDON, UNITED KINGDOM >
Before 96: Enjoying time with a few of the long-term survivors around the UK at our Before 96 group. Sharing experiences and providing support.



4:01 PM: LONDON, UNITED KINGDOM >
Emma Cole: Exercise hour at the Royal Hospital grounds in Chelsea—part of my self-care as a long-term survivor. Listening to Springsteen as I do my 5K.



4:10 PM: PHOENIX, ARIZONA >>
Tony Monarrez: Fighting stigma every day.

5:03 PM: FORT LAUDERDALE, FLORIDA >>>
Carlos Ernesto Masis: Every day has been a day with HIV for almost half my life. I am at peace. I'm joyful. I'm creative. I'm constant. I'm focused. I'm balanced.



5:05 PM: MINNEAPOLIS, MINNESOTA >
Cree Gordon: Just chilling with my infectious disease doc, Dr. Jason Baker, at Hennepin Health. Taking care of my health is one of my greatest acts of self-love, especially during the hard times of 2020.

5:24 PM: PETERSBOROUGH, ONTARIO; CANADA >>
Brittany Cameron: Thought I would grab a quick photo before our next peer interview.



< 5:32 PM:
MEDELLIN, COLOMBIA
María Natalia Sáenz Agudelo: Trabajando desde casa. Presentando nuestro libro, "Partiendo de sero—Cadena de historias positivas," a estudiantes de la Universidad de Antioquia. Porque el VIH también tiene rostro de mujer.

Working from home Presenting our book, "Starting from zero—A chain of positive stories," to students at the University of Antioquia. Because HIV also has a woman's face.

<< 6:00 PM:
WINSTON-SALEM, NORTH CAROLINA
Wanda Brendle-Moss: It's my privilege to be collaborating with Gregg Cassin of Shanti.org. Today I met the Cancer Divas—what positive energy! It truly is my honor and privilege to be "the Glue," as Gregg calls me. COVID-19 has caused us to rethink how we connect in the advocacy world. Zoom keeps us close!

<< 6:57 PM:
FORT MYERS, FLORIDA
Ylondra Marrero and Ariel Vazquez, JEM Fab Fashions: We are supporting a great friend of ours, Marissa Gonzalez, in raising awareness of HIV. We want to remind everyone about the importance of getting tested.

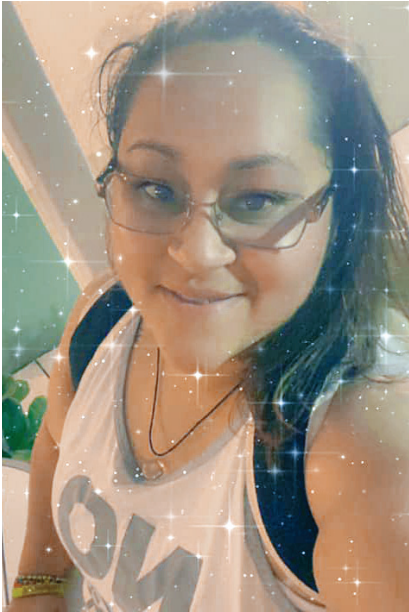
< 7:03 PM:
NEW HAVEN, CONNECTICUT
Jonique: Today I live with a smile.

<< 7:30 PM:
WASHINGTON, D.C.
Larry Bryant: Malcolm X Park, NW D.C. #thisis34yearswithhiv

< 7:37 PM:
SÃO PAULO, BRAZIL
Saul Júnior Machado: Na minha casa. In my house.



7:38 PM: FORT MEYERS, FLORIDA >
Marissa Gonzalez: As an HIV+ heterosexual woman, the dating scene is *rough!* I've literally had dudes tell me "bye," because of my status. It still stings a little bit, *but* I know what I offer and I promise they wouldn't be able to handle it.



7:40 PM: LAUDERHILL, FLORIDA >>
Ieshia Scott: After a busy day of case management, a hot shower, and a cousin's Zoom meeting for my mental health, I'm just tired and ready for bed.



7:53 PM: BROOKLYN, NEW YORK >>>

Thamicha Isaac: It's that time of the day—Biktarvy time! This is a reminder of what's keeping me undetectable.

7:57 PM: LONG BEACH, CALIFORNIA >
Brooke Davidoff: Taking a break from Zoom college. One day I will become an HIV-positive women's activist/peer advocate.



9:00 PM: ATLANTA, GEORGIA >>
John Patton: I've been THRIVING with HIV since 2006. I had no other choice but to; all of the other options sucked!

9:36 PM: QUINCY, ILLINOIS >
Tamara Dietrich: Found out I was HIV positive when I was seven months pregnant with my first born. Seventeen years later, Donovan is HIV-negative, a working high schooler doing what kids do—making us parents crazy. I'm blessed with this guy. He is my sunshine.



11:02 PM: LONDON, UNITED KINGDOM >>
Shamal Waraich: HIV is a part of me, but it doesn't define me. I take ART (antiretroviral therapy) every day, allowing me to live well with the virus. Just two pills keep my immune system strong, alive, and healthy, making me undetectable and the virus untransmittable.





POZ ADVOCATE
 SCOTT SCHOETTES
 @PozAdvocate

COVID and people living with HIV in jails and prisons

This is my second column for POSITIVELY AWARE and my second column about COVID-19. I *promise* I am going to write about other topics in future columns, but because the COVID pandemic is so pervasive and consequential, I want to share information about how it affects people living with HIV in jails and prisons while still timely.

To assist in this—and in keeping with my plan to share the work of other advocates in this column—I interviewed Richard Saenz, a Lambda Legal Senior Staff Attorney focused on criminal justice issues and my co-author for the chapter on prison and jails in *AIDS & the Law*.

SCOTT: We have heard about outbreaks and higher levels of COVID in jails and prisons; can you explain why people in jails and prisons are particularly vulnerable during this pandemic?

SARS-CoV-2, the virus that causes COVID-19, is a highly contagious virus transmitted primarily through respiratory droplets by people in close proximity to each other; currently, the best ways to prevent it are by meeting only outdoors, remaining at least 6 feet from others, wearing a face covering, and frequently washing one's hands with soap and water. All of these ways of preventing transmission are harder to make happen in jails, prisons, or detention facilities, so once the virus finds its way into one of these places, it spreads quite easily. A recent study showed that the rate of infection in state and federal prisons is 5.5 times higher than in the public at large.

COVID has been also been particularly problematic in senior living facilities for some of these same reasons but also because older people are more likely to suffer the most severe consequences of this virus; are there traits of jail and prison populations that place them at higher risk?

Yes, people in jails and prisons are more likely to have one of the pre-existing conditions that makes people more susceptible to COVID-19. The less-than-ideal medical care for chronic conditions like HIV while incarcerated increases the chances of contracting COVID-19 and suffering the worst consequences of it. After adjusting for age, people in prison are 3 times more likely to die of COVID-19 if they get it.

What are jail and prison officials doing to help reduce the risk of COVID transmission in jails and prisons?

Practices vary widely, particularly across state prisons and local jails. In addition to the prevention techniques mentioned above, the Centers for Disease Control and Prevention (CDC) recommends limiting the transfer of prisoners from other facilities, minimizing movement across housing facilities, and suspending programs (like work release) that involve moving people in and out of the correctional facility. One very effective way of protecting people is to release them, and tens of thousands of people across the United States have been released from jails. Congress has expanded the authority of the Federal Bureau of Prisons to release individuals to home confinement, resulting in home confinement or early release for over 1,000 federal prisoners with “extraordinary and compelling reasons.”

Have legal actions in court been successful in improving conditions or securing the release of more individuals?

Legal advocates have had some success in securing preliminary orders to improve conditions only to see those orders reversed by appellate courts. This has been a source of frustration. Showing that prison officials acted with the “deliberate indifference” required to state a legal claim in such situations is difficult, because it provides for a wide range of acceptable behavior on the part of prison officials. One bright spot has been the order secured by immigration advocates requiring the nationwide release of vulnerable individuals from ICE detention. Many detainees have been released pursuant to this order, though it is also now on appeal.

Do you have suggestions for people in jail or prison who are living with HIV?

People living with HIV who are taking their medications and, as a result, do not have a compromised immune system are likely not at increased risk, so it is more important than ever that everyone take their medications every day. The other thing I would advise is to take advantage of every precaution made available: maintain your distance from others whenever possible; if face coverings are provided, wear them whenever you can; and whenever you have the opportunity, wash your hands. And, if you do get it despite taking all these precautions, try not to panic—the vast majority of people survive COVID-19.

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SCOTT SCHOETTES lives openly with HIV and is the HIV Project Director at Lambda Legal, where he engages in impact litigation, public policy work, and education to protect, enhance, and advance the rights of everyone living with HIV.

People living with HIV who are taking their medications and, as a result, do not have a compromised immune system are likely not at increased risk, so it is more important than ever that everyone take their medications every day.

Past, present, future

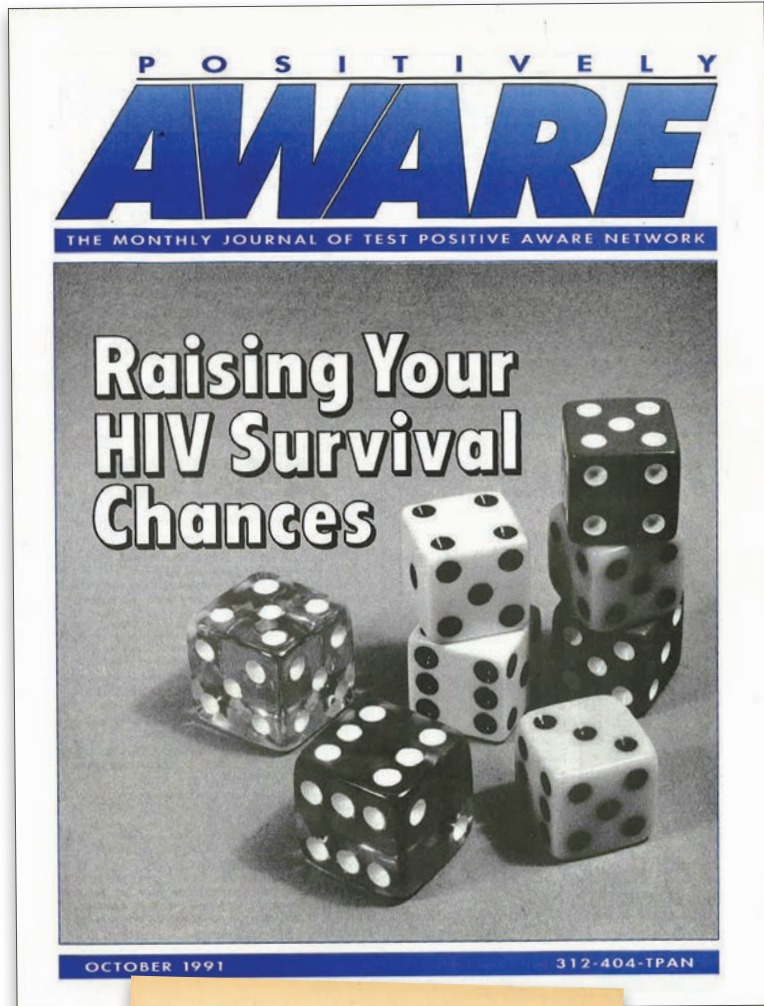
Survival allows the story to be told
BY ENID VÁZQUEZ

In this, our 30th year of empowering people living with HIV with support and information, we look back and see recurring themes. Medical advances. Political battles. Frontline challenges. The stories come and go, and years or decades later, some become outdated.

But it's the personal journeys that raise the spirit and often pierce the heart, and so remain immortal. And so we say good-bye to this anniversary in a fitting issue, alongside our anti-stigma photo campaign, A Day with HIV. In dozens of vignettes, readers living with and without HIV speak to overcoming stigma and thriving, and working to educate and help end the epidemic.

"Raising Your HIV Survival Chances" (October 1991) is one cover that speaks perfectly to our anniversary—each one. Inside, the editor's note tells us, "If you look carefully at our front cover, you'll notice that the dice on the left are 'fixed.' One has 5 dots on each side' the other has only 6 or 2 dots. Any way you roll these dice, you get 7 or 11. Clearly, your chances are increased.

"Do HIV-positive people have ways to increase their chances of survival? Today, more than ever, the answer is 'yes.' ... We trust you and your friends will benefit from these reports."



La 12a. Conferencia Mundial del SIDA
AUTUMN 1998
For several years, a quarterly Spanish-language edition was published, such as this issue covering the 12th International AIDS Conference.

"You Should Be Reading..."
JULY 1991
As shown by many community-based publications now gone, POSITIVELY AWARE, like many people living with HIV, is itself a long-term survivor.



If you're living with HIV, are taking your meds, and experiencing decreased energy and unintentional weight loss, ask yourself the following questions:

Have you experienced **weight loss**?

- Have you recently lost weight without trying?
- Do any changes in your weight negatively affect your health and how you feel?
- Do your clothes fit more loosely than normal due to unintentional weight loss?
- Have friends, family, or coworkers noticed any changes in the way that you look based on changes in your weight?

Do you have **a loss of physical endurance or energy associated with unintentional weight loss**?

- Are any activities more difficult to perform?
- Are you exercising less?
- Do you need to rest more often?
- Do you frequently feel tired after certain activities?



If you answered “yes” to any of these questions, bring this sheet to your healthcare provider to discuss whether you have HIV-associated wasting. Treatment options are available. Together you can discuss the next steps. To learn more about HIV-associated wasting, visit: [lsltwasting.com](https://www.lsltwasting.com)

The San Francisco Principles

Advocates issue new declaration for a new era

LONG-TERM HIV/AIDS SURVIVORS IN SAN FRANCISCO have written a statement of principles demanding greater inclusion in policy making, according to a report in the *Bay Area Reporter*. The San Francisco Principles were announced on HIV Aging and Awareness Day, September 18, at an in-person news conference in San Francisco's Civic Center.

Hank Trout, the senior editor of *A&U: America's AIDS Magazine*, said he and several other long-term survivors looked to the past of AIDS activism for answers about how to address the lack of representation.

"We were inspired by the Denver Principles in 1983, when people with AIDS demanded they be included and represented in policy, research, treatment and care and we decided on a statement of principles for long-term survivors," Trout told the BAR. "We need to be included."

Who we are

We are artists and musicians, healthcare providers and essential workers, community organizers and entertainers, writers and caregivers. Among our ranks are long-term HIV/AIDS survivors. Although myriad definitions of "long-term HIV/AIDS survivors" exist, for our purposes, we are The AIDS Generation, diagnosed with HIV during the 1981-1996 fifteen-year period before the advent of HAART. We bore the brunt of the AIDS pandemic from the very first, and today people over the age of 50 comprise the largest



FROM LEFT: VINCE CRISOSTOMO, SAN FRANCISCO SUPERVISOR RAFAEL MANDELMAN, JOANIE JUSTER, PAUL AGUILAR, MICHAEL ROUPPET (KNEELING), HARRY BREAU, BILLIE COOPER, DR. SANDRA WIN, HANK TROUT. PHOTO BY SAUL BROMBERGER.

segment of people living with HIV. We are the ones who suffered the first diagnoses and the unmitigated fear of catching or spreading the disease; we are the ones who buried our friends after watching them slowly disintegrate, some of us losing our entire social circle; we are the ones ignored by our public health officials, laughed at by politicians, condemned by religious leaders, and shunned within our own communities; we are the ones who put our bodies on the line as unpaid guinea pigs for pharmaceutical companies; we are the ones who submitted to the first toxic trials and research programs; we are the ones still living with

PTSD from the early, horrendous days of this pandemic.

Now we are in our fifties, sixties, seventies and beyond, living lives we never expected to have, lives that have been riddled with isolation and loneliness, the expense of medications and healthcare visits, declining physical health, untreated substance use and mental health problems. We live with a sense of having been forgotten, shoved to the side by AIDS researchers and service providers, unknown to geriatricians. We survivors are routinely ignored at HIV/AIDS conferences, while funding for research and services is consumed by prevention

techniques and programs. While we recognize the importance of prevention, and heartily support the goal of ending the AIDS pandemic, we insist that prevention not drain resources from caring for those of us who have lived with HIV for thirty, thirty-five, forty years. Our surviving still faces an economic system that continues to evict, separate, and destabilize us. The burden of compounding healthcare costs, a fragmented healthcare system, and increasing costs of living continue to export many of us away from adequate healthcare delivery systems.

As the first generation of people to age with HIV, we



face the debilitating physical and mental effects of aging at an accelerated rate.

We embrace in our definition of “long-term survivors” our HIV-negative sisters and brothers who faced the same fears, suffered the same losses, and endured the same grief as we HIV-positive survivors. And to this day, they continue to suffer the same PTSD, especially those caregivers and activists who rushed to the front lines of the fight against AIDS.

We acknowledge that we proffer this Statement in the midst of the COVID-19 pandemic. We never imagined that we would experience the second viral pandemic of our lives. For many of us, this debilitating pandemic has triggered more PTSD,

intensified our isolation, and interrupted our access to healthcare—enhancing the urgency of our mission.

Nearly everything the world knows about HIV/AIDS has been learned on the backs of us long-term survivors. And we will no longer be ignored.

Challenges

From the research on the effects of HIV on aging, we know the following:

Today, people over the age of 50 comprise more than 55% of the people living with HIV in the U.S.; in some cities, like San Francisco, that percentage is about 65%, and experts predict that people over fifty will comprise 70% or more of the U.S. HIV community by 2030.

Long-term survivors

experience accelerated aging due to the ravages of HIV on the immune system. Comorbidities can appear in long-term survivors some twelve years earlier than in their negative counterparts. At age 50-54, cognitive and physical abilities diminish much more quickly in long-term survivors. We are more prone to cardiac arrest, frailty (osteoporosis), balance issues, diabetes, CMV infection, and innumerable other conditions.

These health concerns are exacerbated by the intersectional problems of poverty, depression, the costs of and access to healthcare, unstable housing, mental health concerns including substance use, racism, sexism, homophobia, and transphobia.

While some ASOs [AIDS service organizations] have begun to offer programs and services to long-term survivors, there remains a severe dearth of those services and programs, which reach only a small fraction of the long-term survivors in the country and provide little geriatric healthcare.

Long-term survivors are routinely relegated to the sidelines at national and international AIDS conferences, both in planning and in presentation.

Our demands

In solidarity with the 1983 Nothing About Us Without Us dictum of the Denver Principles, we proffer the following San Francisco Principles for Long-Term HIV/AIDS Survivors:

There are severe shortages of HIV/AIDS specialists and geriatrists in the US. Given the escalating costs of medical education, the lack of

government subsidization for medical education, the lack of respect for and prestige often associated with these specialties by the American healthcare system, and the time and physical demands required by the practice of these specialties, the majority of medical students have gravitated away from these specialties. Therefore, all medical professionals serving long-term survivors and/or older adults living with HIV must be trained in the proper care and to ensure state-of-the-art geriatric healthcare specific to their needs. Providers, especially non-HIV-expert ones, must be made cognizant of the physical, mental, and psychosocial indignities faced by aging long-term survivors.

Mental health services for older people living with HIV must be provided on demand, at a reasonable cost or free, and without judgment and stigma.

Mental health professionals serving older people living with HIV *must* be trained to address issues of the psychosocial damage suffered by long-term survivors, primarily but not limited to isolation and loneliness, depression, and alcohol and substance use, including psychological services and harm reduction services.

Long-term HIV/AIDS survivors MUST be included in the planning and implementation of any programs and services offered to them. Again, **Nothing About Us Without Us**.

Long-term HIV/AIDS survivors MUST be given a prominent seat at the table in planning all national and international AIDS conferences to ensure that we are not the “forgotten majority.”

Resources must be allocated to programs and services grounded in the information and data gathered in HIV and aging studies.

We must align the fight for long-term HIV/AIDS survivors with other social and health-care justice movements, such as Black Lives Matter, the LGBTQ rights movement, the women’s movement, the Native Americans’ movement, and all other movements and organizations working to end racism, sexism, ageism, homophobia, and transphobia around the world.

With these principles in mind, we are ready to lead the fight for health and social justice for long-term HIV/AIDS survivors everywhere. From San Francisco to the world, we invite you to join us in this fight.

DATED: SEPTEMBER 2020, SAN FRANCISCO, CALIFORNIA

Paul A. Aguilar
writer; filmmaker; member, San Francisco AIDS Foundation HIV Advocacy Network; community activist and advocate

Harry Breaux
writer, community activist and advocate

Vince Crisostomo
program manager, Elizabeth Taylor 50-Plus Network, San Francisco AIDS Foundation

Michael Rouppet
homelessness, affordable housing, tenants rights and harm reduction activist

Hank Trout
senior editor, A&U; America’s AIDS Magazine; writer; community activist and advocate

Sandra Win, MD, MS, AAHIVS
HIV/AIDS specialist and consultant, medical epidemiologist, HIV and fair housing activist and advocate, board member, Marty’s Place Affordable Housing Corporation

AFFILIATIONS FOR IDENTIFICATION PURPOSES ONLY



IN-YOUR-FACE REALNESS

If you've faced HIV-related stigma how did you confront it?

That's the question we asked our followers on Facebook, Instagram, and Twitter. They served up some honest feelings and experiences

"Since becoming positive in 1985, I have always been honest about my status. Every time someone tried shaming me, I would educate them as much as possible. Education stops stigma."

—MARCELO F. LEVY

"By holding my head up high as well as educating not only myself but everyone about HIV."

—@NAI4EVER

"Soon after receiving my diagnosis I would lower my head in shame, lock myself in a room and cry. Today, four years later, I know my HIV does not define me and the

opinions of uninformed individuals do not change who I am inside. Depending on the situation, I advise them to Google some facts or I provide them with information. We are all in need of a little education, especially in dealing with myths about HIV."

—MARISSA GONZALEZ

"As a nurse working with people living with HIV, I am desperate to find ways to help patients overcome as much of the stigma as possible. It's killing people and it's the saddest thing ever, in my opinion.

"A large portion of my work continues to be working

with folks who are struggling with adherence to the meds and with staying engaged in their care. With this group of patients, the stigma and internalized shame is often palpable. Having to take medicine daily becomes a constant reminder of the trauma of their diagnosis. Instead of being able to see the medication as offering them better health and life, they struggle with seeing the value of their life. I have watched many people die agonizing deaths because of this, and I struggle with trying to help them accept and understand that they did not do anything wrong—that

truthfully it was bad luck and they are as deserving of love and life as anyone else. Despite life's tragedies and hardships, by taking their medication they can at least have more energy and feel better; they deserve that at the very least."

—JONAH PIERCE

"I didn't allow stigma in. Around 1983, a friend took her own life following an AIDS diagnosis. After my own diagnosis in 2014, I stepped out of the shower, and saw I was skin and bones, fragile and frail. Deathly looking, my ass cheeks literally hanging off me. I looked at myself in the mirror dead in my eyes and I said, "I have AIDS!" I immediately thought of my friend, and promised myself shame would not bring me down or take my life. From that day forward I have spoken publicly and informatively about my HIV status, allowing me to live a stigma-free life. I share that courage as well as giving others a public platform to live stigma free."

—ZEE STRONG

"I confronted them without coddling their feelings. When people would say ignorant things or ask inappropriate questions, I would simply inform them that it is inappropriate and that my disclosure is not an invitation to hurt me or be intrusive."

—JONATHAN MATTHEW MADISON

"After years of hiding and wondering if people knew my status, I took back my power and my voice and disclose publicly now. Stigma still exists, and it can come from people you would least expect. I had recently been told by a family member that I am waving my 'flag of indiscretions like a war hero.' *Oh, buddy... you got that right.* Yes, I am!"

—ERIN SHAFER FULTON

"As an individual who has felt HIV-related stigma, education plays an essential role in reducing stigma and

discrimination. I offer support and speak out to correct stigmatizing myths and stereotypes about HIV. Education starts with the self. Realize that different people face HIV-related impacts differently. Becoming an advocate is walking with confidence.”

—ANTHONY ADERO

“I’m a long-term survivor of AIDS, since 1994. I remember when my friends would be here one week and dead the next. Stigma was very hard to deal with back in the day when HIV/AIDS was a death sentence. It was a scary time, when you really didn’t want anyone to know your status due to discrimination and the stigma of being labeled as ‘the GRID [Gay-Related Immune Deficiency] guy.’ Many people were losing their homes, apartments, and jobs. It was a scary time. When better treatment and care became more available, stigma was handled completely different by educating the masses with current information on condom usage, sex, and taking care of oneself with this growing epidemic at hand! For me, it made me gain a tough exterior on the outside and compassionate heart on the inside. Over the years I learned how to educate my family members and loved ones about the importance of safer sex and treatment.”

—JACK R MILLER

“I was wearing an HIV Long-Term Survivor T-shirt as we were coming back from AIDS Watch. We stopped for gas in a town that was half the size of Mayberry, RFD. I wasn’t even thinking about the shirt when I went inside the gas station to get some coffee. This rough-looking guy, the stereotype of a backwoods Bubba, starts walking towards me. It was then that I realized that my choice of shirt might not have been a good idea. Bubba stopped in front of me, asked me how long I had been HIV-positive. I told him 34 years. He proceeded to tell me about his

Pa, who had died of AIDS. Without stopping to see who might have been looking, he gave me a big bear hug. I am not a hugger, but that hug made my day/week/month and year. He turned back to me and said, ‘Whatever you’re doing, keep it up!’”

—MARK L GRANTHAM

“I hid my status as self-stigma within took over. My story includes addiction to street drugs; for years I didn’t always adhere to my HIV medications, and I developed resistance to a few classes of drugs. Living in the South, I saw stigma within my own communities. After waking up from a medically-induced coma following acute double pneumonia, my only options were to go into a nursing home or to stay with family. I chose my family. After rehab, I didn’t understand why I was still alive and why I did not die. I had wanted to die. As time went by, I started attending a few support groups and realized I had to share my story and take back control. That’s when I opened up about my status and drug usage. I no longer had to lie about the real me or hide my past. I started to live again, this time with no shame. The last six years, I’ve been trained in prevention, HIV testing and outreach, and in STI and hepatitis C education. I am now on the South Carolina HIV Planning Council as a voting member and am chair of the DHEC HPC Positive Advocacy Committee. Through this advocacy work, I bring information back to my community. By being open, I hope others will see they don’t have to follow the same path I did. It’s getting better in the South, but we still have a go way to go.”

—KELLY JOHNSON

“Since becoming positive in 1985, I have always been honest about my status. Every time someone tried shaming me, I would educate them as much as possible. Education stops stigma.”

—SIMON JOHN COYLE



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Tom Skilling



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*Also known as excess visceral abdominal fat



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