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POSITIVELY AWARE
HIV TREATMENT, PREVENTION AND HEALTH FROM **TPAN**
JAN+FEB 2021

THE AT HOME ISSUE

ROBERT GAROFALO, MD, MPH, AND **FRED**

WHEN DOGS HEAL

THE TRANSFORMING POWER OF UNCONDITIONAL LOVE

V=V: VIREMIA EQUALS VULNERABILITY

WHO'S ZOOMIN' WHO?

EXERCISE AND NUTRITION

THE TESTERS ARE BEING TESTED

POSITIVELY AWARE

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

BE GREEN.
SHARE OR RECYCLE
THIS MAGAZINE.

WHO'S A GOOD BOY?
FRED AND ROB GAROFALO PHOTOGRAPHED AT HOME BY JOHN GRESS. READ *A DOG'S POWER TO HEAL,* **PAGE 20**

JAN+FEB 2021

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THE CATEGORY IS...

NEW YEAR REALNESS

What's your biggest hope for 2021?

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

"**I am hoping** for normalcy after this troubled year. No more, no less. Just normalcy."

—MARCELO F. LEVY

"**My hope** for 2021 is that there will be a bit of joy, happiness, and health. I hope that we experience a little bit of togetherness and unity."

—MARK L. GRANTHAM

"**I hope** COVID-19 vaccines are available sooner rather than later, with little to no side effects to anyone with a compromised immune system; i.e. the HIV positive population."

—JOSUÉ E. HERNÁNDEZ

"**More awareness** of the risk and spread of HIV through drug use. Drug use is rapidly increasing as is overdose deaths due to the pandemic. Having HIV increases a person's chance of overdosing and dying by 71%. Yet despite this, people who die from an overdose are not tested for HIV, even though it could be an underlying or partial cause of death."

—RENA HUMBERT

"**My hope** is for life to get back to some semblance of normal. Being able to see my doctor in person; going to hospital because I may be having a heart attack; and not catching COVID while being hospitalized. Seeing friends in person and being able to share a HUG."

—XIO MORA-LOPEZ

"**My biggest hope,** as a 38-year survivor, is that this horrible pandemic will have taught everyone that stigma is the wrong reaction to any disease. For too many years, I walked around feeling like an unclean leper."

—KEITH B. DOLE

"**My biggest hope** for the New Year is that people will take COVID-19 seriously. We 'live with' HIV at this point, but a disease that attacks the upper respiratory system is particularly dangerous for folks with a disease in which pneumonia often is what takes lives. Today, that is my number one priority! Once that is addressed, [my second hope is for] awareness of what it is like to live with HIV on meds, so that younger folks who seem to think 'it's no big deal' because it's just a pill a day don't get an idea that there are no side effects, physical and mental, that we have to deal with."

—BRANDON WIGGLESWORTH

"**I'm really** looking forward to life returning to a semblance of normalcy. I honestly can't wait. The past year was rough. And we've got a ways to go yet before it starts getting better."

—JEFFERY PARKS

"**In regards** to life with HIV/AIDS, I hope that there will be continued strides made in treatments that will allow those of us living with the virus to have a better quality of life, especially for long-term survivors like myself, a 30+ year survivor. For the general population, I hope that the COVID pandemic will finally slow its pace of sickness and death, as the vaccine(s) do their job, and that we as humans will do our part, by continuing to wear masks, social distancing, and other measures, so that life might return to a more normal one. Sometimes we just have to live, using the opportunities given to us each day, and moving through and beyond the perceived obstacles we encounter along the way.

"Hope, as they say, is planting daffodils in the autumn, so that one might reap the benefits come spring."

—HAROLD SCOTT

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JOHN GRESS

EDITOR'S NOTE

JEFF BERRY
@PAeditor

Finding home in a pandemic

When I think of home
I think of a place where there's love overflowing
I wish I was home
I wish I was back there with the things I've been knowing

—From the song, *Home*, by Charlie Smalls
in the musical, *The Wiz*

"Home isn't a place, it's a feeling."
—novelist Cecilia Ahern

This issue of POSITIVELY AWARE is our at-home issue, and explores some of the changes in our lives during the past year in the midst of a pandemic. Home can represent a place of safety and solitude for some, especially in the before times. I used to be able to deal with all of the crazy stresses of work and life, knowing that at the end of the day, I could head home to share the evening with my husband Stephen, our dog Kylie, and our cats, to unwind and leave it all behind—"Calgon, take me away," as the old TV commercial for bath suds went.

I recognize, now more than ever, that I come from a place of privilege when I say this. If they aren't already unstably housed or homeless, millions of people are facing evictions. Food lines formed by cars of families have stretched for miles in 2020, and the outlook doesn't look good for 2021—food programs have lost or stand in danger of losing funding and turning more people away this year. Many small businesses that we depend upon that form the lifeblood of our economy may not survive the COVID-19 pandemic and the shutdowns. Unless new policies are enacted to address the structural inequities and systemic racism that disproportionately affect people of color and marginalized communities, who bear the brunt of these inhumane conditions, many will lose their homes, businesses, and livelihoods.

Thankfully there is hope on the way, in the form of preventative vaccines and therapeutic treatments for COVID-19. The speed in which the Pfizer, Moderna, and other vaccines are being developed is truly remarkable, and is due to a number of reasons. Some of them include the fact that we've been studying coronaviruses for 50 years, so we have some idea of how they work. Plus there was worldwide collaboration between scientists who shared their data with one another, and new methods were employed using mRNA technology, which has never been done before. There were a lot of people who volunteered for these studies, and we had many more study sites than usual. Operation Warp Speed allowed for companies to begin stockpiling doses of the vaccines even before the FDA approved them for use.

But medical mistrust is still real, especially among people of color, and will need to be addressed using effective public health messaging, changing the way we deliver healthcare, and through building back trust. According to a recent report in the *Washington Post*, while Black people in the United States are 1.4 times as likely as non-Hispanic Whites to contract the disease, and 2.8 times as likely to die of it, some may be less likely to take the vaccine. "The root of the problem lies not in Black communities themselves, but in a medical system that has historically dehumanized them and continues to do so. The result is that the history of medical racism in the United States presents a significant barrier to anything approaching equitable care in the present and future."

Unless new policies are enacted to address the structural inequities and systemic racism that disproportionately affect people of color and marginalized communities, who bear the brunt of these inhumane conditions, many will lose their homes, businesses, and livelihoods.

Even facing such seemingly insurmountable challenges, we have a new incoming administration that will need to, and is more likely to, address some of these inequities and injustices head on. In the meantime, there are things we can do at home, or wherever we are, while we adjust to the new norm. In this issue Michelle Simek looks at how HIV testing sites are adapting to the pandemic. As this issue went to press, TPAN, the publisher of POSITIVELY AWARE, was set to roll out a new home-testing initiative that includes delivering direct to clients' homes HIV testing kits, condoms, lube, and other materials and information, as an alternative to coming in to the agency to get tested. Margaret Danilovich explains the role of diet and exercise in the era of COVID-19. And poet Natalie Patterson provides ways we can exercise self-care through journaling and other relaxation methods.

Just like we can't go home again, we won't ever be going back to what was normal—nor do we want to. Look at where normal has gotten us. We need to create a new normal, a more just and equitable society, one that has a place for everyone and a level playing field for all. Only then will we all finally find a place that we can proudly call home.

Take care of yourself, and each other.

Jeff Berry

ENID VÁZQUEZ @ENIDVAZQUEZPA

BRIEFLY

Long-acting injectable PrEP effective for cisgender women

The HIV Prevention Trials Network (HPTN) announced that one injection every eight weeks showed strong efficacy for preventing HIV in cisgender women.

The HPTN 084 study compared a long-acting injection of cabotegravir (CAB LA), a drug still in development, to a daily oral tablet, Truvada, for HIV pre-exposure prophylaxis (PrEP). Both regimens were highly effective at preventing HIV in this study of cisgender women, the study found.

On the strength of the results, the independent HPTN 084 Data and Safety Monitoring Board (DSMB) recommended that the study be unblinded going forward after reviewing the results on November 5. The trial was originally designed to continue through 2022 as a blinded study (where participants do now know what medication they are receiving). Participants given Truvada will be able to choose the injections as the drug becomes available.

HPTN 084 is sponsored by the U.S. National Institute of Allergy and Infectious Disease (NIAID), part of the National Institutes of Health (NIH). According to NIH, **this is the first time a large-scale clinical trial has shown a long-acting injectable form of HIV prevention to be highly effective for cisgender women**. The trial enrolled 3,223 cisgender women ages 18 to 45, in seven African countries.

"The results from HPTN 084 are incredibly important for women in Africa where lowering HIV incidence remains a priority," said Dr. Sinead Delany-Moretlwe in an HPTN press release.

The demonstrated efficacy will help bring CAB LA PrEP to women all over the world, not just Africa.

Dr. Delany-Moretlwe, who is the protocol chair for HPTN 084 and director of research at Wits Reproductive Health and HIV Institute at the University of the Witwatersrand in Johannesburg, said, "We know that adherence to a daily pill continues to be challenging, and an effective injectable product such as long-acting CAB is a very important additional HIV prevention option for them. We are grateful to the women who volunteered for this study and the research staff, as this study would not have been possible without their commitment to HIV prevention."

The drug earlier last year had also demonstrated efficacy for cisgender men and transgender women who have sex with men, in the HPTN 083 trial. That study was also unblinded early as a result and that research also continues.

The Phase 3 HPTN 084 trial was launched in late 2017. In the data presented in November, of the 38 women in the study who had acquired HIV during follow up, four had been given CAB LA (for an incidence rate of 0.21%) and 34 had been given Truvada (1.79%). The research team declared superiority for PrEP with CAB LA based on statistical criteria. NIH reported that, "The higher-than-expected level of adherence to [Truvada] throughout the study and overall low incidence rate in both arms of the study clearly demonstrate both drugs were highly effective at preventing HIV acquisition."

CAB LA is also being studied for HIV treatment, in combination with a long-acting injectable formulation of rilpivirine (Edurant, RPV).

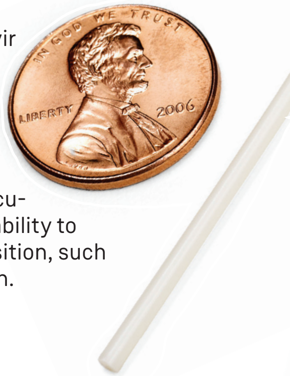
Islatravir for PrEP

In another PrEP study, once-monthly oral islatravir was scheduled to enter Phase 3 clinical study in women and adolescent girls with high risk for HIV acquisition. The **IMPOWER 22 trial is scheduled to begin this year in sub-Saharan Africa**, where more than half of the world's new HIV acquisitions take place.

Islatravir is being developed by Merck & Co. for HIV treatment as well as for PrEP. It is a nucleoside reverse transcriptase translocation inhibitor (NRTTI), a new drug class. Merck announced a collaboration with the Bill & Melinda Gates Foundation for funding of the Phase 3 pivotal trial, which is used to bring a drug to regulatory approval.

"We will not turn the tide on HIV globally until we turn the tide on the virus in Africa, and this clinical trial seeks to help advance this effort through its focus on women, especially younger women, who remain disproportionately at risk on this continent," said trial investigator Professor Elizabeth Anne Bukusi, PhD, principal clinical research scientist and co-director of the Research Care Training Program at the Center for Microbiology Research of The Kenyan Medical Institute, in a press release from Merck.

Islatravir PrEP is also being studied in other groups with particular vulnerability to HIV acquisition, such as gay men.



PREP: ISTOCKPHOTO · ISLATRAVIR: MERCK · *AQUI COMO SOY*: SERGIO DE PAULA/UNSPLASH
VÁZQUEZ: JOHN GRESS

Aqui Como Soy: New report focuses on gay and bisexual Latinos

ViiV Healthcare, a pharmaceutical company which focuses on drug development in HIV treatment and prevention, has released a new report about gay and bisexual Latinos living with, or vulnerable to, HIV.

“For Latinx men, including cis and transgender men, who have sex with men (MSM), **navigating sexual and cultural identity amid social pressures poses significant challenges to accessing healthcare**,” the report says.

“Latinx communities in the U.S. face many of the same challenges as other communities of color, including poverty, poor access to education, poor housing, and unreliable or unsafe public transportation, all of which impact health outcomes for Latinx MSM. On top of this, anti-immigrant laws spread fear and insecurity that keep these men and their communities from utilizing life-saving services including healthcare. When they do attempt to access care, many experience fear, discrimination, and rejection from service and clinics,” the company reported in a statement.

“Here As I Am” (*“Aqui Como Soy”*) features findings based on firsthand accounts gathered through community-based research, facilitated by the Latino Commission on AIDS. The report examines five key issues that arose:

- Family and community are central to men’s lives and identities, shaping their health and wellness for better or worse
- Interruptions in care happen for many reasons beyond men’s control
- Anti-immigrant sentiment and anti-immigrant laws have a powerful effect on men’s health
- Men want diverse and responsive care that reflects their needs, identity, and language, and
- Resilience is activated through networks and services by and for Latinx men, especially youth

The report’s findings will be incorporated into ViiV’s Positive Action for Latinx Men program, “a community-giving initiative.”

LISTEN to some of the men from the report tell their stories and read the report itself, available in Spanish and English; viivhealthcare.com/en-us/positive-action-for-latinx-men.

- An estimated **186,900 Hispanic/Latino gay and bisexual men** were living with HIV in the United States
- An estimated **80% of all new diagnoses** among Hispanics/Latinos were among gay or bisexual men

SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION HIV SURVEILLANCE REPORT 2018

- In 2016, about **1 in 3 Hispanic/Latino gay and bisexual men** living with HIV did not have undetectable viral load

SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION HIV SURVEILLANCE DATA (JUNE 2019)

Liquid Tivicay for infants

Two pharmaceutical manufacturers specializing in the making of generics are bringing a **strawberry-flavored HIV medication for pediatric use in resource-poor countries**. The announcement was made by the Clinton Health Access Initiative and Unitaid on World AIDS Day, December 1.

The generic formulation of the powerhouse medication dolutegravir (DTG, brand name Tivicay) will be dispersible as a liquid. According to the two global health initiatives, generic strawberry dolutegravir for kids will cost $36 a year, a sharp discount from the $480 generic adult dose. There are 1.7 million children around the world living with HIV, said the announcement, with only half receiving antiviral therapy.

“Children in low- and middle-income countries often wait years to access the same medications as adults, hindering their quality of life, or even resulting in preventable deaths,” Unitaid executive director Philippe Duneton said. “This groundbreaking agreement will bring quality assured dispersible DTG to children living with HIV, helping them to remain on treatment and saving thousands of lives.”

Tivicay tablets are available in the U.S. for children weighing at least 77 pounds, but not for years after adult therapy came on the market. Development of pediatric therapy lags behind adult treatment. Dolutegravir is also contained in the single-tablet regimens Dovato, Juluca, and Triumeq. It is recommended for first-line

New director is a sign of recovery for CDC

WALENSKY

Rochelle Walensky, MD, MPH, began her career in the mid-1990s fighting the HIV/AIDS epidemic. Chosen by president-elect Joe Biden as director of the U.S. Centers for Disease Control and Prevention (CDC), she'll play a key role in the fight against COVID-19 and managing the largest vaccine campaign in the country's history.

Before her selection, she was the Chief of Infectious Diseases at Massachusetts General Hospital (MGH) and a professor of medicine at Harvard Medical School. An expert HIV/AIDS clinician passionate about health care equity and access to treatment, she helped lead MGH's fight against COVID-19 since almost the start of the pandemic.

Her arrival comes after a challenging time that saw the CDC sidelined by the Trump administration, which often forced the agency to put political considerations ahead of medical science, tarnishing its reputation and sinking morale among its doctors and researchers.

"In selecting @RWalensky, **Biden has chosen one of the most respected infectious disease docs in the world**," tweeted Jen Kates, a senior vice president at the Kaiser Family Foundation. "She has a long history working on HIV and has, in the past year, become a tour de force in addressing COVID. She'll take the helm of CDC at perhaps its most critical moment."

Walensky replaces Robert R. Redfield, MD, who was named CDC director in April 2018; the appointment does not require Senate confirmation.

—**RICK GUASCO**

HIV therapy in the United States and for use by pregnant women (under most circumstances).

Pediatric weight for Selzentry

The minimum weight needed by pediatric patients before they can be given Selzentry (maraviroc) HIV antiviral has been lowered from 22 pounds (10 kg) to **4.4 pounds (2 kg). Pediatric dosing is based on weight.** Selzentry is not recommended for pre-term neonates. See the drug package insert for new data and changes added by the U.S. Food and Drug Administration (FDA).

HRSA guides for aging with HIV

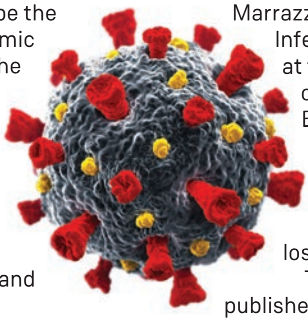
Two new reference guides to help medical providers treat patients aging with HIV were released in November.

Incorporating New Elements of Care **highlights screenings for common health and social needs of people aging with HIV. Putting Together the Best Health Care Team discusses how all members of a health care team can contribute to care.**

"What was once considered a deadly disease, HIV is now a manageable, chronic condition that allows a nearly normal lifespan, thanks in large part to the Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) and expanded access to HIV treatment services and medical advancements," wrote Laura Cheever, MD, ScM, of HRSA's HIV/AIDS Bureau. "In 2018, 46.1% of RWHAP clients were aged 50 years and older. Of RWHAP clients aged 50 years and older receiving HIV medical care, 91.5% were virally suppressed." **GO TO** hiv.gov/blog/hrsa-s-hivaids-bureau-releases-two-new-aging-hiv-reference-guides.

IAS leads its second COVID-19 conference

The International AIDS Society (IAS) takes on COVID-19 once again in a conference focused on prevention. "**Many HIV professionals are leading the COVID-19 response** in their respective countries and conducting related prevention research," IAS president and conference co-chair Adeeba Kamarulzaman said in a statement. "After the first IAS-hosted COVID-19 Conference in July 2020, I am excited to announce the second iteration that will help shape the global pandemic response." The conference, to be held virtually February 2, focuses on prevention-related science, policy, and practice.



For more information, or to register **GO TO** covid19.iasociety.org.

Deaths due to HIV drop by half

The overall number of deaths in the U.S. directly related to HIV among people living with the virus was cut nearly in half between 2010 and 2018, according to an analysis by the U.S. Centers for Disease Control and Prevention (CDC). But decreases weren't as significant for women, people of color, and people who live in the Deep South, underscoring health disparities.

The **rate of deaths directly related to HIV dropped 48.4 percent**—decreasing from 9.1 per 1,000 people living with HIV to 4.7 deaths per 1,000 people living with HIV (PLWH). The rate of non-HIV-related deaths also decreased, by 8.6%—from 9.3 in 2010 to 8.5 in 2017. CDC researchers examined data from the National HIV Surveillance System.

In 2017, more than 16,000 people living with HIV died—about 5,500 of those deaths were attributed to the virus.

"Continued efforts in diagnosing HIV early, promptly initiating treatment, and maintaining access to high-quality care and treatment are necessary for continuing progress in reducing deaths and eliminating differences across populations," CDC reported in its summary.

"This is not just about the drugs. It's the entire structure that supports people," said Dr. Jeanne Marrazzo, Director of Infectious Diseases at the University of Alabama in Birmingham, in a *New York Times* article about the rate drop. "Sometimes that's lost in the dialogue."

The results were published in the CDC's November 11 *Morbidity and Mortality Weekly Report*: bit.ly/MMWR-2020-11-20.

WALENSKY: JEFFREY ANDREE, MGH PHOTOGRAPHY

Report recommends a 'framework' of support for aging with HIV

A new report highlights the needs of people age 50 and over who are aging with HIV, and offers recommendations to care providers. Produced by Grantmakers in Aging (GIA), *Moving Ahead Together: A Framework for Integrating HIV/AIDS and Aging Services* focuses on isolation and stigma, the need for holistic and integrated services, and updating government policies.

"People living with HIV age into a sort of no-man's land that can be a lonely and potentially dangerous place," said John Feather, PhD, GIA's CEO. "**Aging services and HIV services both deliver excellent care but have no history of working together, and people aging with HIV can get lost.** The need for greater coordination, expertise sharing, and inclusion has been strongly affirmed by leaders in both sectors, and, importantly, by people who are themselves aging with HIV/AIDS."

Recommendations were informed by leaders in the fields of HIV and aging, and through a virtual summit. Among them:

- Help geriatricians and primary care providers improve their knowledge of HIV in older people, including testing, prevention and sexual health counseling.
- Incorporate principles of trauma-informed care and increase cultural competence of providers and staff in all care settings, including senior centers and long-term care facilities.
- Help HIV specialists gain expertise in geriatric issues including multiple co-existing conditions, cognitive impairment, and HIV's effect on aging.
- Co-locate and coordinate HIV and aging services, including case management and social services.

The report also includes first-person reflections, video interviews, and illustrations by older people living with HIV; it was supported by a grant from Gilead Sciences. GIA is a national membership organization of philanthropies. For more information and a downloadable PDF of the report, **GO TO** giaging.org/initiatives/hiv-and-aging.

—**RICK GUASCO**

'I'M NOT DYING FROM IT, I'M LIVING WITH IT' (2017), BY BETSY PONCÉ IS AMONG THE IMAGES BY PEOPLE LIVING WITH HIV TO ILLUSTRATE THE REPORT.

DASKALAKIS VIA TWITTER

Daskalakis takes on CDC's HIV prevention

New York City's deputy commissioner for disease control has been named the new head of HIV prevention for the U.S. Centers for Disease Control and Prevention (CDC).

Dr. Demetre **Daskalakis became the director of the Division of HIV/AIDS Prevention of the CDC's National Center for HIV/AIDS, Viral Hepatitis, STDs, and TB Prevention** (NCHHSTP) in late December. Known for his work in creating and leading many HIV and STI programs in New York City, Dr. Daskalakis is credited for reducing HIV rates in the city to historic lows.

"We are excited for him to bring this leadership and experience to DHAP to advance meaningful research, guide surveillance and programs, support and implement effective policy, and ultimately prevent HIV infections and increase health equity across the United States," said NCHHSTP director Jonathan H. Mermin, MD, MPH, in a statement.

As deputy commissioner for the Division of Disease Control at the NYC Department of Health and Mental Hygiene, Dr. Daskalakis directed the city's infectious disease control programs, including HIV, tuberculosis, sexually transmitted infections, vaccine-preventable diseases, and general communicable diseases. He was the department's incident commander during the city's measles outbreak in 2018–2019, and for the current COVID-19 pandemic.

Dr. Daskalakis, who grew up in Arlington, Virginia, attended NYU's School of Medicine, completing his residency at Beth Israel Deaconess Medical Center

DASKALAKIS

in Boston. He completed clinical infectious disease fellowships at the Brigham and Women's Massachusetts General Hospital combined program, receiving his master's from the Harvard T.H. Chan School of Public Health. He has written or co-authored more than 50 scholarly articles, earning awards from the Treatment Action Group, the Latino Commission on AIDS, and GMHC.

He began his medical career as an attending physician in New York's Bellevue Hospital, where he spearheaded several public health programs focused on community HIV testing and prevention. He has been a staunch advocate, addressing stigma, key social determinants of health, and making prevention options such as PrEP accessible and affordable to all.

"We have the tools at our hands to prevent infection and to keep people living with HIV healthy," he said. "Our barrier to achieving this vision is no longer science; it is systemic racism, sexism, homophobia, and transphobia."

—**RICK GUASCO**

THE TESTERS ARE BEING TESTED

How HIV testing sites are adapting to the COVID pandemic

BY **MICHELLE SIMEK**

> **“I love my job—I’m an emotional Pisces.** I’m a fixer and I’m working all of the time. If I’m available, I will be there for my clients. I’m not even close to burn-out.”
>
> —**TONY CHRISTON-WALKER**, AIDS ALABAMA

CHRISTON-WALKER WITH HIS BOYFRIEND’S DOG, CHIEF

PHOTO COURTESY OF TONY CHRISTON-WALKER

In March, 2020, the hustle and bustle of life in the United States came to an abrupt halt due to the explosion of the COVID-19 pandemic. Workers were sent home with laptops and notepads and pens and files crammed into their work bags. Toilet paper was scarce and disinfecting wipes were scarcer. Dry goods like rice and pasta were gone. And COVID tests were hard to come by, regardless of what then-President Trump kept insisting.

However, very quickly, the frontline workers of the AIDS pandemic—HIV testing counselors—knew that they had to get back to their jobs. This new pandemic didn’t negate the old one. People were still getting HIV or didn’t know that they already had it. Testing programs had to take stock and figure out how to serve their communities without putting their staff at risk. Remarkable stories of commitment and resilience can be told from every corner of the country. And an actual at-home COVID test kit received emergency authorization from the U.S. Food and Drug Administration (FDA) in November 2020.

AIDS Alabama

BIRMINGHAM, ALABAMA

Tony Christon-Walker, Director of Prevention and Community Partnerships at AIDS Alabama, is a fighter. Diagnosed with HIV in the mid-1990s “when all of my friends were dying,” he is also a colorectal cancer survivor and has been cancer-free for the last five years. He not only fights for his own health, he also fights for the health of people of color in Birmingham. “We are in the buckle of the Bible Belt. It’s hard to talk about HIV down here.”

Tony’s program “never shut down but we scaled back” and added face masks and temperature testing at the doors. AIDS Alabama’s testing program serves mainly Black and Latino men who have sex with men (MSM). Their client breakdown is approximately 90% Black, 5% Latinx, and 5% white. While clients are able to enter AIDS Alabama facilities, staff also provide in-home HIV testing and drive a nondescript car to clients’ homes. In those cases, his team goes in pairs, “both for the safety of the staff and of the client.” Pre-COVID, “we were testing 30–40 people a week; now we are testing 30 a month.” Although on one November day, they had 11 walk-ins for HIV testing, something that Tony calls “remarkable.” And “people test because they are scared. They put into their mind that if they only sleep with one person, instead of the whole city, they will be safer.” But five people tested positive for HIV in the past five weeks at one of AIDS Alabama’s sites. Their reactions to their HIV diagnosis during COVID are much the same as pre-COVID. “They get that lump in their stomach. Some cry themselves into a puddle. Some blame other people. Some live, and even thrive, with it.”

Tony and a colleague went to the home of a young Black man who has sex with men who wanted an HIV test. He lived with his mother and grandmother, though, so Tony and his colleague had to “sneak in when the coast was clear.” Luckily, the client’s room was right by the front door. “His grandmother was in the back, watching *The Price is Right* and neither his granny or his mom had any clue that we had even been there. Fortunately, he remains HIV-negative, because if he needed treatment, I don’t know how we would get him out of that apartment.”

During the first week of November 2020, AIDS Alabama started testing for COVID. Staff conducts testing at their sites and in people’s homes, “if we need to in order to eliminate those barriers.” Quite ironically, Tony was interviewed for this article on Tuesday, November 10, and tested positive for COVID on Friday. The night before testing positive, he had watched *Avengers: End Game* with his family—his husband, son, and grandchildren—and some family members went dancing later. Tony was shocked “and mad! I’ve been being very careful!” At work, he had been using PPE and staying six feet apart from coworkers and clients since March. Thinking it was a false positive result, a colleague went to his home to retest him. Frustratingly, “that bright red indicator showed up again.” No one else in Tony’s family tested positive for COVID and he quarantined himself from his husband and son. “I feel kind of guilty,” he says. “How did this happen to me? Everyone else is dying and I feel just fine. It doesn't seem fair." He feels the same sense of guilt when he goes to his follow-up appointments at the oncologist's office and sees the very sick people in the waiting room. Tony specifically wanted to include his COVID diagnosis in this article, "because if it can happen to me, it can happen to anyone." And while he has no symptoms, "just because I'm okay, it doesn't mean that you're okay or will be okay." Tony quarantined himself, worked from home, did not develop the classic COVID symptoms, and returned to his office on December 1st. "But the [political] left only talks about the deaths, the right only talks about how many people have it but don't have symptoms, there is no discussion in the middle. I almost feel like COVID is a sentient being that decides what it is going to do with somebody. I didn't have those symptoms but I felt it when I got it and felt it when it left me." As of the writing of this article, another AIDS Alabama employee tested positive for COVID and has lost their sense of taste and smell.

Howard Brown Health
CHICAGO, ILLINOIS

Antonio Elizondo is the Manager of Reproductive Health Outreach Services at Howard Brown Health. A network of clinics across Chicago, Howard Brown provides medical services to the LGBTQ community, including HIV, sexually transmitted infection (STI), and COVID testing. Approximately 40% of their clients are white and 60% are people of color. About 55% are male and 45% female (this includes people who are transgender). Since March, Howard Brown's testing programs have "temporarily gone backwards"—meaning that there are a limited number of clinics that are open, and those that are "have moved primarily to telehealth." Their smaller clinics "have lower capacity to see clients but those clients are still sexually active—even during COVID." Across the Howard Brown clinic system, HIV testing numbers fell by 1,000–2,000 each month from March through October. Although the number of in-person clients decreased, their seropositivity rates had spikes. In May and September, their HIV positivity rates for 2020 were higher than in 2019. In May 2019, the positivity rate was 0.36% compared to the following May's 0.81%. And in September 2019, the positivity rate was 0.26% vs. 0.99% in September 2020.

But Howard Brown is not letting COVID win the battle against HIV. In April 2020, the agency started offering free at-home HIV testing via their website, mailing out OraQuick In Home HIV test kits to 20 states across the U.S. (as well as to Puerto Rico and Ontario, Canada). This particular kit tests for HIV antibodies present in the mucous membrane of the mouth and involves an oral swab. Along with the standard list of HIV/AIDS resources included in the test kit, Howard Brown included information about their own HIV testing and counseling program and how to contact their counselors. They also sent out free safer sex packets (again, via online order) which include condoms (receptive, insertive, and/or latex-free), lube, dental dams, cloth face masks, and safer injection kits (works but no needles). From April through September, "we filled orders for 377 OraQuick In Home HIV test kits, 6,350 condoms, 2,900 lube packets, 226 cloth masks, and 112 safer injection kits"—an impressive set of numbers. At the time of this article, Howard Brown had not received any contact regarding positive at-home HIV test results. But that doesn't necessarily mean that no one has had a reactive result. A client could have contacted a local resource or one of the national resources included in the kit (or, they might not have reached out to anyone at all, which is concerning).

ELIZONDO OUTSIDE THE TENT WHERE TESTING IS CONDUCTED

PHOTO BY CARLOS FRAGOSO

COVID testing at home

LAST NOVEMBER 17, the FDA issued an emergency use authorization (EUA) for the very first rapid, at-home COVID test, called Lucira. Previously, anyone who was worried could purchase a COVID test-kit online (at various price points), test at home, and send the kit to a lab for processing (which meant quite a bit of waiting time for the results). The new test is a nasal swab and is only available via prescription from a medical doctor. The Lucira test can be self-administered at home by anyone who is at least 14 years old; the test can also be used in medical settings (such as hospitals, urgent care facilities, and emergency rooms). After collecting the swab, it is swirled in a vial that is placed inside the test unit. In approximately 30 minutes, the results are visible in the lit display. If a positive result appears, it is recommended that the patient immediately contact their medical provider and self-quarantine. FDA Commissioner Stephen M. Hahn, MD, stated that, "While COVID-19 diagnostic tests have been authorized for at-home collection, this is the first that can be fully self-administered and provide results at home." At the time of this article, various questions remained unanswered about how the test will be distributed, its cost, and whether health insurance will cover it.

—**MICHELLE SIMEK**

In September, Howard Brown changed their HIV and STI testing protocol yet again, working with a third-party vendor, MyLabBox. The company ships, receives, and processes HIV and STI tests and informs Howard Brown of any positive results. Prevention staff are then able to be proactive, reaching out to patients directly and linking them to care and treatment. Test kits remain free and can be ordered online (STI tests are now only shipped within the state of Illinois so that a licensed medical provider can prescribe treatment).

According to Michelle Evers, NP, Assistant Site Medical Director, "I think that COVID-19 has had a direct impact on people's access to care. Many patients are apprehensive of coming onsite to engage in services. Also, some people are not aware of, or have issues with, our telemedicine service line. A large majority of our newly diagnosed patients are young MSM of color. Many of them have had interruptions in their PrEP refills or appointments. They have lost insurance and do not have the resources to understand how to navigate our public health systems. This creates a need for us to try to reach people of color during this time."

That being said, "Howard Brown currently links 87% of patients to care within three months of their HIV diagnoses, as per the guidelines set by the National HIV/AIDS Strategy," says Antonio.

Howard Brown has been testing for COVID since the safer-at-home orders began in March. The agency "usually tests quickly and in person, out in the community under tents, which reduces travel and indoor contact." To reach the communities hit hardest by COVID, Howard Brown partners with local community-based organizations, such as Project Vida, which serves the Latinx community. "There is a high utilization of COVID testing at the Latinx site and a high COVID positivity rate," said Antonio. "And there are higher infection rates per household. Culturally, Latinx families are used to seeing each other and being together. It is hard for them to adjust and accept the new normal." In the coming freezing winter months in Chicago, tent testing will be unpopular at the very least, and probably not even possible. Howard Brown Health is already considering their next pandemic pivot: drive-through testing.

Sadly, Antonio's own family will have to accept the "new normal" for the Latinx community. His maternal grandmother passed away from COVID-related complications over the Thanksgiving holiday weekend. His grandfather doesn't have COVID, so they have to keep him, and other vulnerable family members, safe. At the time of this article, only 10 people were allowed to gather for a funeral or memorial in Illinois. Antonio is concerned that, even with restrictions, the "natural reaction is to hug or touch somebody," which could lead to COVID transmission. A Zoom memorial is being planned for this normally close-knit family.

Common Ground

VENICE, CALIFORNIA

Jacob Heller, the Prevention Supervisor at Common Ground, has worked at the agency for six years. In addition to HIV-related social services, Common Ground offers testing for HIV, hepatitis C (HCV), and STIs, along with a robust syringe services program (SSP). The Venice Family Clinic (VFC) is right next door, and treats HIV, HCV, and STIs, thus providing other medical care to the beach community.

In March 2020, Common Ground saw "a huge decrease in testing numbers—half the rate compared to what we normally do. We work with a risky population. They test out of a situation—something specific happened that scared them," says Heller.

Common Ground has had to adjust their testing protocols since March. Previously, they would test and counsel in a "small, intimate space." But "the rules in Los Angeles have changed so much. Now we test in a larger space with more room and oxygen." Sadly, the testing team "can't spend as much time with clients as they used to. This is a bummer because staff want to take the time to get to know them and so that the clients tell us the truth [about risk factors]." Currently, everyone who wants an HIV test must have their temperature checked and answer symptom questions at the door of the friendly ASO. Heller's program discussed passing out home HIV test kits but decided against it because a large percentage of their clients are homeless and therefore might have barriers to accessing the post-test resources included with the kits.

COVID has also forced changes to their syringe services program. Previously, this service would take place in an exam room, and staff "could take their time with each client and build a layer of trust with them." Now the SSP is out in the open and goes much faster, making those important provider-client relationships harder to build. Common Ground staff wear both masks and face shields, "and the people who inject drugs (PWID) population [are] put off by those barriers," a blow to a program that "has grown every year for the past four years." And overdoses in Los Angeles increased in 2020, which could be due to COVID-related stress or the presence of fentanyl in the drugs that people consume.

In contrast to other testing and SSPs across Los Angeles, Common Ground's clients tend to be White, straight, homeless men. They test more people during the summertime, which makes sense as the agency is located a mere six blocks from the famous Venice Boardwalk. Their seropositivity rate is generally 1–3 per month. When someone is diagnosed with HIV, "we just walk them next door to VHC" for HIV treatment and ancillary services and "teach them to be a champion of their own health."

Similar to what's being seen at AIDS Alabama and elsewhere, client responses to testing positive for HIV during COVID are much the same as before COVID, "there are a range of reactions from resigned to freaked out. Most people who test positive have a lack of education and need the counseling and education that comes with HIV testing. Generally, youth are not aware that there are meds to treat and control HIV." And their HIV status may not be a priority in clients' hierarchy of needs. Food and shelter may come first. The Medical Care Coordination Team (MCC) at VHC started delivering medications and food to clients who were nervous about leaving their home during COVID. One newly housed client did not have anything to put into her new residence. Common Ground staff came together and donated couches and other items that she needed in order "to make her home a home."

HELLER AT THE ENTRANCE TO COMMON GROUND

PHOTO BY PAMELA KERR

"We go the extra mile," says Heller. "We care about our clients. They have experienced so much trauma and anxiety and fear. We are not here by force, we are here by choice."

MICHELLE SIMEK has worked in HIV/AIDS for more than 20 years. She currently works at the UCLA Center for Clinical AIDS Research and Education (C.A.R.E.) and is a popular HIV/AIDS educational presenter, both locally and nationally. In her spare time, she is an actor, avid reader, enthusiastic concert-goer, and proud mom of Baxter, her rescue cat.

ISTOCKPHOTO

Surviving and thriving during another epidemic

The role of diet and exercise in the era of COVID-19

BY **MARGARET DANILOVICH PT, DPT, PhD**

As of the writing of this article, more than 250 days have passed since The World Health Organization declared the novel coronavirus (COVID-19) outbreak a global pandemic. Sadly, with over a quarter of a million Americans dead from the virus and rising numbers of cases, cities across the country have reinstated curfews, banned indoor activities, and limited group gatherings.

While these measures are undoubtedly important to slow the virus spread, these guidelines also have the side effect of limiting social interaction, reducing opportunities for physical activity and exercise, and causing greater isolation, significantly impacting physical and mental health.

Within 30 days of the March 11 pandemic declaration, worldwide physical activity dropped nearly 27%. Reduced physical activity can be detrimental particularly for older adults who even pre-COVID were not meeting recommended physical activity guidelines.

Rates of inactivity are even worse among those aging with HIV. A 2018 study found that people aging with HIV only achieved 3,442 steps per day (the goal being 10,000) and attained only 35 minutes of moderate-vigorous physical activity each week (the goal being 150 minutes). People aging with HIV spent 75% of their day in sedentary (sitting or lying down) activities. The COVID-19 pandemic has only worsened these rates of inactivity.

HIV is associated with muscle wasting, peripheral neuropathy and balance dysfunction, and higher rates of fatigue. Independently, normal aging also results in reduced muscle strength, decreased nerve function leading to more balance impairments, and reductions in cardiovascular health that limit endurance and create more fatigue. Together, people aging with HIV face a form of “double jeopardy”—experiencing the physiological changes due to HIV as well as normal age-related changes. The end result is that aging with HIV is associated with even greater losses of muscle strength, increased risk for falls, and lower endurance than peers of the same age who are aging without HIV. Unfortunately, being inactive and not participating in regular exercise only accelerates these normal age-related changes, leading to greater risks for falling, loss of independence, cognitive decline, and illnesses such as cardiovascular disease, diabetes, and cancer.

Exercise recommendations

The good news is that it is never too late to get more active and there are solutions to becoming healthier safely in the time of COVID.

While fitness centers may be closed and winter weather limits outdoor activities, there are ways to exercise and be more active in your home. YouTube is a great source of exercise programs, and a search of “fitness class for seniors” will bring up a variety of free programs of various lengths and fitness styles to try. Silver Sneakers offers a variety of on-demand exercise classes for free with certain Medicare insurance plans. You can see if you are an eligible member at silversneakers.com. CJE SeniorLife offers a variety of evidence-based falls prevention group classes on Zoom and over the telephone. A listing of their programs is available at cje.net/falls. Even household objects like laundry detergent, gallons of water, or heavy books can serve as weights for resistance exercise.

Research shows that those aging with HIV should participate in a combination of aerobic (endurance), resistance (strength-training), and balance exercises.

Aerobic exercise

Aerobic exercise elevates your heart rate and breathing rate to keep your heart, lungs, and circulatory system healthy. Examples of aerobic exercise include activities such as walking, riding a bike, jogging, dance, and swimming. Older adults aging with HIV should strive to achieve at least 150 minutes of aerobic exercise each week. For the best health benefits, aerobic exercise should be done at a minimum of a moderate-intensity level, a level where you could talk during the activity, but not sing. In contrast, a vigorous-intensity level would be where you could talk, but only for a few words before needing to take a breath. If you cannot reach 150 minutes per week right now, do what you can. Every minute counts and each additional minute of activity provides even more health benefits.

Resistance exercise

Resistance exercise (strength-training activities that build muscle) should be done two-three days per week at a moderate-high intensity for 10–12 repetitions and 1–2 sets for major muscle groups (biceps, chest, quadriceps, and glutes). To build strength, you need to lift a weight that provides a challenge. If you are unsure of where to start, aim for a weight that you can lift at least 10 times comfortably. If you can lift the weight more than 15 repetitions, it is likely too light and if you can't lift at least 8 times, it is likely too heavy. It is also important to note that when starting resistance exercise, you may feel a little sore in the 24–48 hours after exercise. This soreness is a normal response to activity, but sharp pain should not be.

Physical activity recommendations for older adults

Aerobic
GOAL: 150 minutes per week at least at a moderate intensity

Resistance
GOAL: 2-3 days per week; 10 repetitions and 1-2 sets per muscle; use a moderate-high intensity

Balance
GOAL: Daily practice of balance activities (activities that make you feel slightly unstable) for more than 15 minutes per day

SOURCE: NATIONAL PHYSICAL ACTIVITY PLAN

Balance exercises

Finally, balance exercises are activities that make a person feel a little unsteady and off-balance—activities such as standing with feet in different positions, standing on an unsteady surface, or adding in movements like turning your head and closing your eyes. Addressing balance is important to prevent falls, which can lead to significant injuries affecting mobility, and even death.

Balance exercises should be done daily. Research shows it will take about 50 hours of practice to see a significant improvement in balance so it will take time and effort to improve this area. Because many people aging with HIV face co-existing conditions such as peripheral neuropathy which affects balance, seeing a physical therapist can be a great place to get a tailored balance assessment and exercise program. Every state in the U.S. allows for evaluation and some form of treatment without a physician referral so you can access a physical therapist directly for this care. To find a physical therapist, go to apta.org/findaPT.

Nutrition

It is also important to maintain good nutrition, especially during the COVID-19 pandemic. Because of muscle loss that occurs with HIV, protein intake, in particular, is especially important to maintain strength, energy, and immune function. In general, older adults and those aging with HIV need 1.0–1.2 grams of protein per kilogram of body weight each day (1 kilogram is about 2.2 pounds). While meat is typically the first protein source that comes to mind, protein is also found in fish, chicken, dairy, beans, nuts, and tofu, making it possible for vegetarians and vegans to also have adequate protein intake.

Community

In the AIDS epidemic of the 1980s, gay men (in particular) faced serious shame and stigma which helped unify the community in the face of crisis. In our current COVID epidemic, social distancing and isolation necessary to prevent disease spread make it harder to unify, and the impact on mental health has been severe. People over the age of 65 have been particularly hard hit given that they are at a higher risk for contracting COVID and account for 80% of all COVID-related deaths.

According to a Kaiser Family Foundation report, nearly 25% of people over the age of 65 report anxiety or depression due to COVID. While there has not been research yet on the population aging with HIV, it is highly likely that they are facing substantial mental health challenges as well. One study on young people living with HIV in Asia and the Pacific found that 70% felt anxious or very anxious about COVID.

Mental health needs should be addressed with a healthcare provider so that you can access necessary resources and appropriate care from a counselor, psychologist, or psychiatrist. There is some evidence that participation in physical activities can improve mood. Research shows that regular physical activity reduces anxiety, lessens symptoms of depression, and builds confidence in one's physical function—simply put, physical activity tends to make you feel more confident and better about yourself!

Getting started

So, how can you get started?

First, review the guidelines for exercise and physical activity participation (see above) and see how your current activity levels match to the guidelines. If you are not currently meeting these guidelines, that's okay! Every minute of activity counts towards reaching these levels and you should aim to increase your activity by 5% each week.

Second, find physical activities that you enjoy! Especially with free content available on the internet, try a variety of different classes or exercise programs—Zumba, yoga, Pilates, dance, walking, and weightlifting, to name a few. If you don't enjoy a particular activity, try another class or a different instructor and find something that brings you enjoyment! Research shows that greater enjoyment with activity predicts future physical activity participation, so if you want to create an exercise habit, find activities you enjoy and keep them ongoing!

At the end of the day, the best exercise or physical activity program is one you actually do consistently. And for optimal health benefits when aging with HIV, strive to achieve the physical activity guidelines through creative and safe solutions during the COVID-19 pandemic.

DANILOVICH: BARB LEVANT PHOTOGRAPHY

MARGARET DANILOVICH is the senior director of the Leonard Schanfield Research Institute at CJE SeniorLife and an adjunct assistant professor at Northwestern University, where she directs the dual degree Master of Public Health and Doctor of Physical Therapy program. A physical therapist by background, she has practiced her entire career with older adults. Her current research has been funded by the NIH, Retirement Research Foundation, and Third Coast Center for AIDS Research and focuses on exercise interventions for older adults with frailty.

Exercising self-care

Relaxation and writing exercises toward healing

COMPILED BY **ENID VÁZQUEZ**

***As the world attempts** to bring the coronavirus pandemic under control, it's also struggling to deal with the emotional effects of sheltering in place. How do isolation and the minimizing of social interaction affect us? This is where the "softer" side of HIV care can help. While the HIV epidemic needs medical development to control the virus, there's also a need for personal and social care for everyone in the struggle, living with HIV or not. "Fearlessly Forward: Journaling to Fuel Mind, Body, and Spirit" was a panel discussion and workshop during the 2020 virtual U.S. Conference on HIV/AIDS (USCHA), held in October. Poet and educator **Natalie Patterson** led a panel—and an entire webinar audience—through a series of relaxation exercises to get at the heart of anxieties, all in the name of healing.* —**ENID VÁZQUEZ**

You can write

"There is so much power in writing, and being able to articulate your emotions and really advocating for yourself," said Natalie Patterson. "Self-care looks different for every single person. And because I'm a poet and because I'm a writer, I've designed a writing workshop. So, I hope all of you at home will join me and the Fearless Five [panelists] on a little writing adventure. This is really a tool. It's one that I use for healing, for processing, and for activating my best life ever."

Release judgment

"You are divine and perfect and absolutely amazing," she said. "So you can't do this wrong. I want you to just let go of any fear that might be rattling around in you. 'I haven't done that since third grade!' Just let that go. Go ahead and let it go. You're amazing. You have written things down before. You won't get judged if you spell things wrong. That's okay too. No one's judging you. There is no judgment and this is really an opportunity."

Kintsugi

"I want to start with this idea: It is this word *kintsugi*. *Kintsugi* means 'join with gold.' That's the literal translation," Patterson said. "It's a 15th century Japanese practice that invites us to consider the philosophy behind *kintsugi*, which treats breakage and repair as part of the history of an object rather than something to disguise. And I love that. The process of repairing, instead of throwing something away. It's literally a bowl that is filled with gold. It's broken and then repaired. Over a month or up to two years this could be a process of bringing it back together. Filing it away by hand, so that all the grooves match.

"It is reconstructed again. I love that because in many ways it mimics healing. It mimics the *process* of healing. I wanted to offer you this metaphor because the work that we're going to do really mimics this art and this practice of *kintsugi*."

Take a breath

"A little bit of warm up. We're going to breathe a little bit. We're going to breathe on purpose," she said. "I know it's a novel idea. And then we're going to write some stuff. Maybe we'll feel some new feelings by the end."

Make a list

"I want to introduce you to intention building. Many of us do this practice anyway. Thinking about what intention you hold while entering a space. As a writer I know that if I'm not really feeling it, my writing is crappy. But when I ground myself and when I think about who I am and whose I am and what I'm trying to accomplish, something beautiful happens. So I want to invite you into that space.

"Think for a moment. What do you need to show up in this moment fully? What do you need? Maybe that's to give yourself permission to be here. Maybe that's to ignore the dog that's barking behind you. (Laughing) Maybe that's to try something new, to be playful. I want you to write that at the top of the page."

The Feelings Wheel

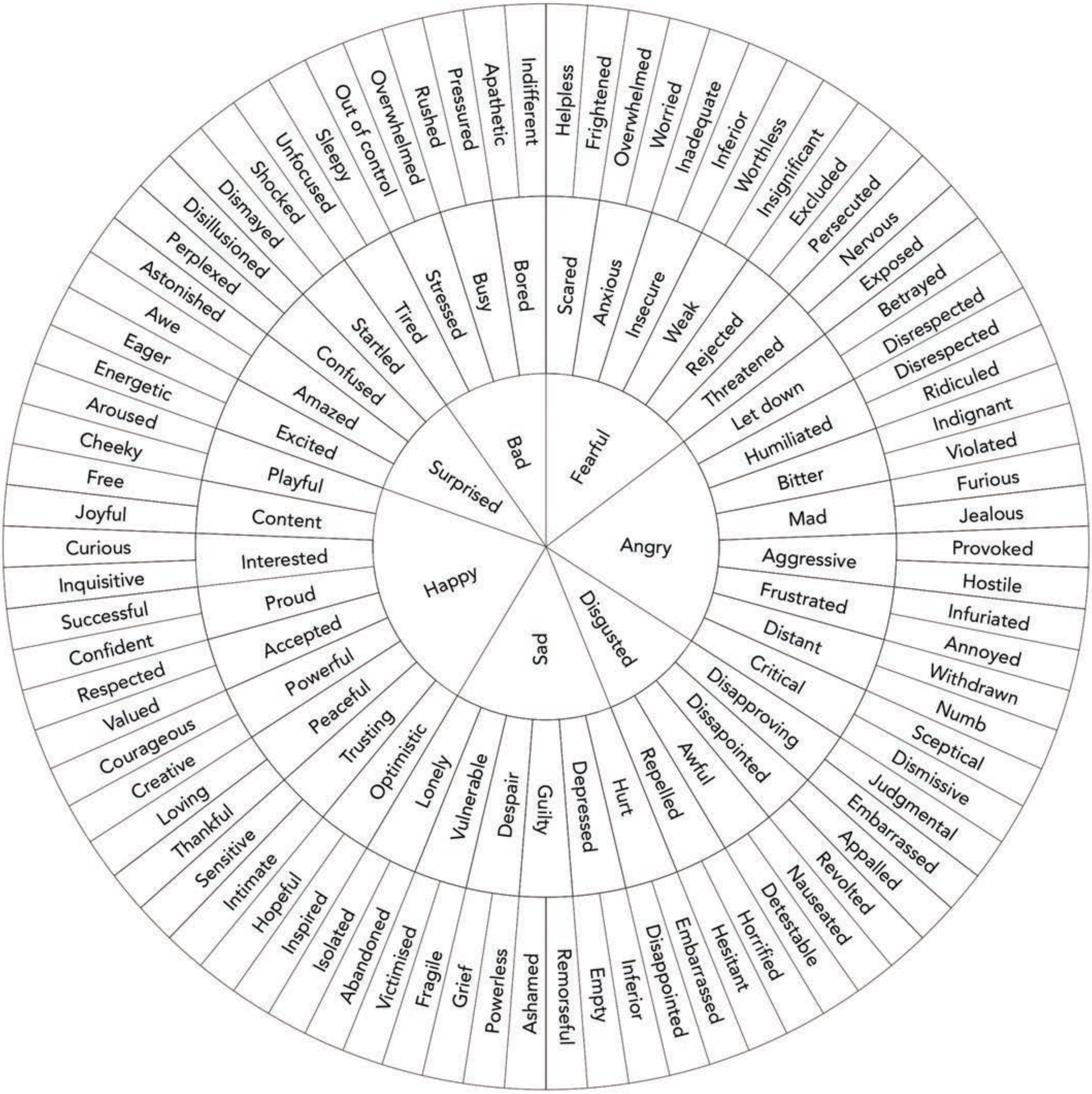
"I want to offer you this Feelings Wheel [see next page], created by Dr. Gloria Willcox, a psychotherapist. The first time I saw this, my entire mind was blown. The Feelings Wheel encourages you to know your feelings. In the center are the typical feelings that we generally have: happy, sad, angry, scared, powerful, and peaceful, the stuff we more typically experience. As we get further and further out on that circle, it's more nuanced. It's more articulate. It's the things we don't really talk about but might get at the root of the feelings we're expressing to the world, the look on our face. Think about this, and think about what are you really carrying right now? What are

KINTSUGI IS THE JAPANESE ART OF PUTTING BROKEN POTTERY PIECES BACK TOGETHER WITH GOLD, BASED UPON THE IDEA THAT EMBRACING FLAWS AND IMPERFECTIONS CAN CREATE AN EVEN STRONGER, MORE BEAUTIFUL PIECE OF ART.

MARCO MONTALTI/ISTOCKPHOTO

THE FEELINGS WHEEL

GIVE IT A SPIN! Explore your emotions. Coloring the wheel is an opportunity to get to know your feelings and contemplate each word.
SOURCE: blog.calm.com/blog/the-feelings-wheel



CRAYONS: ISTOCKPHOTO

the feelings you're feeling right in this moment? I invite you to take a breath, an intentional breath. We breathe all day, but rarely on purpose. So take a breath. Find your center. And give yourself permission to investigate how you're feeling right now. Just write a couple of words at the top of your page. How are you feeling right now? Name those feelings.

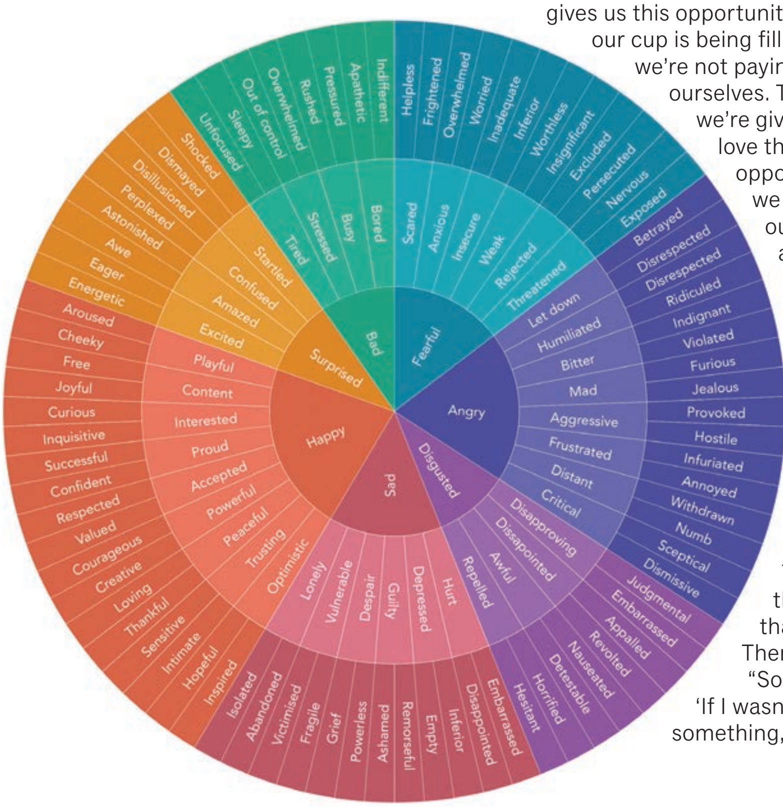
Take two

"I want you to jump in now to make some lists. You only have two minutes, so don't overthink it. You don't even have time to overthink it. I want you to make a list of the biggest things that are unfinished in your life. All the things, big or small, just name them. We don't have to process them right now, but we can name them. That email you know you were supposed to respond to six weeks ago.

"Now, as you finish up, take a breath and think about how this feels, to look at this page filled with all these things that are unfinished, with all the things you're worried about. Hold that paper up—and separate it from yourself. I want you to remind yourself that these words no longer exist inside your body. That's a gift, to have a vantage point, to be able to see it clearly and from somewhere else. You no longer have to house these things inside of your own body. You can check back with them. You can look back at them and think, 'Oh, these are my worries.' But you don't have to hold them in your spirit. There's liberation in that.

Take two more

"I want you to now envision deeply. If I had a magic wand and I was your fairy godmother and I came through like, 'Resolved! Resolved, resolved, resolved! You get freedom!' None of these words exist anymore. The magic. How would you feel if all the things on your list were finished and complete? What if all of these things were gone? Really, really in your spirit—what would you feel like? The moment all of these things were complete and finished? What would be the feelings rattling around in your spirit? What would the look on your face look like if you had this kind of liberation? It's all done. What would it feel like to stand in the sun of your liberation?



"So, I invite you to write for a moment or two just what that would feel like. Can you even imagine that for yourself? What would it feel like for all of these things to be resolved, for you to be standing in your freedom and liberation?

New day, new world

"As you're sitting with and imagining this liberation and this freedom and all of these things resolved and completed, I want to know if you have been planning for your joy. Have we really been spending as much time with our joy and our future planning and our future world building? Have we been sitting with that as much as we sit with our worry?

"Because I think we need to, in these grim and dark times. We've got to be planning for a better day.

"We might be planning for the joy tomorrow, like the joy of our paycheck, but are we really imagining liberation for ourselves and for other people? Because that's what we have to do to begin to heal ourselves, but also heal this world and these toxic thoughts.

"I love this exercise because it really gives us this opportunity to see where our cup is being filled. To see where we're not paying attention to ourselves. To see where we're giving too much. I love this because it's an opportunity. Anytime we get to sit with our feelings and anytime we get to sit with our truth is an opportunity for us to get to know ourselves better. And that's a gift. Even in the midst of tears. That's purification. That's releasing the toxicity. So, that's blessed. There's joy in that.

"So many of us feel, 'If I wasn't worried about something, who would I be?' Really, that's the invitation to think about. To solve these larger problems, we have to be larger people. We have to be people of integrity. We have to be noble. We have to be wise. Because if we're not, we're being circumstantial, situational. You see the evidence of that in the world. You look at everything and think, 'Oh, this is a one-off. And this is a one-off. And this is a one-off.' Instead of looking at the whole breadth of the experience.

"I think about being a Black woman. Being a Black queer woman. Being a Black queer artist. All these intersections—they're not separate from me. They're all the same lived experience. There's my whole entire life. I'm not like, 'Well, I'm going to be a Black woman today. And I'm going to be queer tomorrow.' No, no, no. That's not how it works. I walk out and I'm all of those things at the same time. It's an opportunity to think about how we can be whole in the world—and be happy, and be with joy. It's not, 'Well, when this happens' or 'if this happens.' No, no, no.

"We sit in both places at once. I think that's the complexity of being human. We're not superheroes. We're human. We're not weak. We're strong.

"That freedom is a process. Healing is a process. And wherever you find yourself today, just take another step forward. And another step forward. And another step forward. We get preoccupied with the outcome sometimes. We're like, 'Well, I'm not liberated today!' Well, that's not how things happen in real life. It's not Instagram, honey. Your healing ain't going to be an upload. We're going to have to do it every single day. Which is why I offer you this practice that you can continually come back to and return to yourself. Find your joy. Whether it's from age 19, or 7 or 4. Come back to that and re-commit to it.

"I encourage you to practice this over and over. Wherever you are in the process is beautiful and information for yourself of how to stay tuned up, and really that's the point. It's a self-care practice, meaning every time we do it, we're not going to be good at it. But sometimes we're going to strike gold, and it's going to be really, really beautiful." PA

POSITIVELY FEARLESS is sponsored by Janssen Therapeutics. **WATCH** videos of Positively Fearless panelists telling their stories at positivelyfearless.com. There are several versions of the Feelings Wheel available for download online. **AT** blog.calm.com/blog/the-feelings-wheel, there's a black-and-white version for coloring, which is not only relaxing, but helps people familiarize themselves better with the feelings on the wheel. For more from the presenter, **GO TO** NatalieIsPoetry.com.

A DOG’S POWER

A new photo book illustrates how a dog’s unconditional love can transform the lives of people living with HIV

BY **RICK GUASCO**

TO HEAL

GAROFALO WITH
HIS YORKIE, FRED

PHOTO: JOHN GRESS

This is a story about the healing power of unconditional love. More like 36 stories—that's how many are shared in a new book, *When Dogs Heal*, about the bond between people living with HIV and their dogs, and how it changed their lives. Through a dog's love, people found acceptance, and overcame stigma, shame, and other issues.

In 2010, Rob Garofalo, MD, MPH, was struggling in the aftermath of an assault and a series of traumatic events that led to his HIV diagnosis. As director of adolescent HIV services at the Ann & Robert H. Lurie Children's Hospital in Chicago (where he is now division head of adolescent medicine), he has always been passionate about the care of LGBTQ youth.

"Although I had spent my life caring for people affected by HIV, I found it hard to offer myself the same love and compassion that I had spent my life teaching others to have for themselves," he says. "I didn't think things like peace and joy were ever going to be possible in my life again.

"Many of us living with HIV have had those moments. In that moment, I had this not really rational, impetuous thought. I sat on my bed, debating taking my own life, and at the next moment I was like, maybe I should get a dog! I remember calling a friend who thought that was the craziest idea ever, probably because it was."

Finding Fred

GAROFALO DID a Google search for *puppies* and *Chicago*, and a picture of a Yorkshire terrier pup appeared. He contacted the breeder, who was in the area, and within a couple days, Garofalo brought home the pup, whom he named Fred.

"Honestly, it was a selfish decision," he admits. "I couldn't even care for myself, what made me think I could care for a dog? But the one thing about having a dog—he didn't have any patience for my self-pity. He didn't have any room for my self-isolation. He wasn't going to put up with my not being present.

"What my dog has been is my anchor—an anchor to goodness, an anchor to unconditional love, an anchor to this pure little soul that needed me. People living with HIV can understand this. I needed to be needed, and Fred as a puppy was that for me. He needed me to feed him and walk him and care for him. In doing that, he literally brought me back to life."

Garofalo rebuilt his life around his dog, creating a nonprofit organization called Fred Says, raising money for various HIV service organizations throughout the U.S., including TPAN, publisher of POSITIVELY AWARE. During a trip to Los Angeles, he was having coffee

Adam and Laila

"Laila showed me what unconditional love truly is. When humans were casting me out by saying hurtful things behind my back, Laila showed up for me—she was consistently loyal—and she still shows up for me. Every single day, she meets me with love."

with friends, writer/editor Zach Stafford and dog photographer Jesse Freidin, to discuss ideas for Fred Says. That's when he blurted out, *when dogs heal*. Uncertain at first what form the idea would take, it became a photo book, telling the stories of people in their own words, of the transformative experience of a dog's love following their HIV diagnosis.

"We talked about how powerful it was, how [Rob's] dog helped him move through to acceptance of his own diagnosis," recalls Freidin. "From there, we wondered if there were other people who are dealing with HIV who have stories like this. We got so excited at the prospect of telling a new story about HIV."

Dog tales

WHAT FOLLOWED was a nearly six-year-long project, finding people living with HIV who would share their stories, and interviewing and photographing them for the book. Stafford and Garofalo's niece, Christina, a Los Angeles-based TV writer and journalist, worked on the interviews and stories. Each of them brought something personal to the book.

"I like to work on projects that center around joy and celebration of queer people and what we've been through," says Stafford. "What was fascinating was that so many people told similar stories in different contexts—they felt no one would love them, that they did not feel deserving of love. The dogs changed that for them. They learned how to love themselves."

Christina, who is also the voice of Fred Says on social media, was brought in to finish the interviews when Stafford's schedule became too busy. "It's not unusual for me to talk to a stranger and learn a lot about them. I let them tell their story. I've had my own mental health struggles with anxiety and shame. Having grown up with dogs, I understand feeling alone but how a dog can make a difference."

Work on the book unfolded over the years as Garofalo and Stafford traveled to Chicago, Los Angeles, San Francisco, and Atlanta. They contacted local AIDS service organizations and used dating and social media apps to find dog owners living with HIV who might be interested in being interviewed.

"Recruitment wasn't easy, but it's definitely part of the story of the book," Garofalo says. "Each city was really different. In San Francisco we met a lot of somewhat older men who were long-term survivors of HIV, some who had been diagnosed in the '80s. Their stories were very different from some of the younger people we met, say, in Atlanta. Even the stigma was different. The people we met in San Francisco were much more apt to be open about their diagnosis, whereas in Atlanta, we had a lot of people who initially expressed interest, but when they found out that they had to be open or disclose their HIV status as part of such a public project as a book, a number of people backed out. It was a balancing act. The introduction of the book, which I wrote, tells this well. It was trying to find a unicorn—you had to be HIV positive, be open and talk about being HIV positive in a public space, have a dog, and have a compelling story to tell about your dog. When you read the book, the people in it are really brave and beautiful.

"I think about Paulo and his dog Stud, and all the trauma he went through as a Hurricane Katrina evacuee, how he acquired HIV after being evacuated from New Orleans to Chicago, is such a heartbreaking story. In each story, you hear about how devastating the diagnosis of this disease was, but in the end, the central theme is about life and living and love. There's a story about Brad and Thor in San Francisco. Brad was using drugs, and in a police raid, his roommate's dog, Thor, was stabbed. In that moment, in order to take care of the dog, Brad decided to get clean and never use drugs again. There's a story about R.J. and Stoli, in Atlanta. R.J. was marginally housed and really wanted to participate in the photo shoot. He needed a lot of support; I called an Uber to get him and his dog to the photo shoot. The story about what his dog helped him to overcome in terms of R.J.'s physical disabilities is powerful.

"When you read the book, you see that for each person, the journey was different. For each person, their dog—or dogs—served a different role. But at the core of those stories is coming back from some form of devastation. Their HIV diagnosis had brought them to their knees, whatever that meant in their lives. Each of them

PHOTOS FROM 'WHEN DOGS HEAL' BY JESSE FREIDIN

found the strength and the power to go on in part because of the unconditional love their dogs provided them."

The care of a dog

HOWEVER, having a dog is not for everyone. "Getting a dog is not a panacea that resolves the stigma surrounding HIV," Garofalo admits. "Getting a dog wasn't enough. I grappled, and continue to grapple over the years, with depression, anxiety, addiction, and recovery. I've had challenges over the years, and I've had to surround myself with good things and people.

"Everyone has to do a bit of self-exploration and self-examination. The truth is, I am a man who has a great deal of privilege, and so I've been able to have a pet sitter, and afford many aspects of having a dog that far too many people living with HIV might not be able to. The decision to have a dog in your life is not one that should be taken lightly. I accept that my decision was impetuous and selfish—I don't advise that strategy.

"They have to ask themselves if they feel that they have the time, the capacity, and willingness to take care of another living creature. What will the addition of an animal or a dog mean for them and their lives? It's truly a commitment. I'm not naïve enough to say it's like having a child. It's not the same. But they do require from us a lot of love and nurturing and caring. If for whatever reason, someone is incapable of making that type of commitment, either emotionally, financially, or with their time, then having a dog might not be the right answer.

"There've been news stories about an increase in dog or pet adoptions during the pandemic, I think particularly for people who are living alone. I'm someone who has clung to his sobriety as a lifeline over the years. I don't know if during the isolation of the pandemic, [how I would manage] without my dog being the one thing to consistently keep me company through stay-at-home orders and self-quarantines. I have such profound gratitude for my dog the past year that transcends even the gratitude I have for him around my HIV diagnosis. There's an element around COVID and this pandemic for many of us who have pets, especially dogs in this case, that I live in a newfound state of gratitude around the magical qualities they bring to our lives."

On many levels, says Garofalo, some of the people featured in the book had to be convinced that getting a dog might be helpful to them. For each of them, he says, there came a moment when they recognized how mutually beneficial the relationship was.

"What I've learned through this book, and in part what I've learned from my dog Fred, is that authenticity and honesty about who I am in my journey is in some ways my superpower. If I'm not honest in both my personal and professional spaces, then HIV retains some power over me that I refuse to give it. I'm fully honest about my HIV status, about my history of addiction and recovery, about all the things I need to be in order to live my best life." PA

SELECTED PERSONAL ACCOUNTS from When Dogs Heal can be found at whendogsheal.org/portraitsandstories. Scheduled for release on March 3, the book can be pre-ordered on Amazon.com.

TO HELP identify people living with HIV in Chicago who might benefit from the companionship of a dog, Garofalo, who serves on TPAN's board, worked with the organization to create a program called Paws 'n' Effect. Applicants are thoroughly screened before being paired with a rescue dog from a local animal shelter. For more information about the program, **GO TO** tpan.com/paws-n-effect.

Sharon and Dulk

"One day, my sister went to an animal shelter and adopted Dulk. From the moment she brought him home to me, he never missed a beat. Dulk became the thing I'd needed most since my diagnosis: a companion."

U=U, and V=V

A look at the vulnerabilities behind detectable virus

COMPILED BY **ENID VÁZQUEZ**

‘There are social and economic and environmental reasons why one may not be able to achieve or maintain their viral suppression.’
LEISHA McKINLEY-BEACH

MCKINLEY-BEACH: TONYA REEVES PHOTOGRAPHY

The world is still catching up to the facts of U=U: people on effective treatment with undetectable HIV viral load are untransmittable—they cannot pass the virus on to their sex partners. But what about individuals who are unable to achieve—or maintain—undetectable viral load? Black advocates stress the need to also understand V=V: viremia equals vulnerability. Here, viremia refers not just to virus, but specifically to detectable viral load. At the virtual U.S. Conference on HIV/AIDS (USCHA) 2020, held in October, longtime HIV prevention specialist and consultant **Leisha McKinley-Beach**, of Atlanta, discussed these issues with **Larry Scott-Walker**, co-founder and executive director of Atlanta-based HIV support organization THRIVE SS.

LEISHA MCKINLEY-BEACH: We know that the science behind U=U is undisputable. We’re talking about people with HIV who have achieved—and maintained—an undetectable viral load by taking their meds every day cannot sexually transmit the virus to others. So that’s a *huge* milestone within our HIV movement when we talk about the tools and the skills that we now have to see ending the HIV epidemic.

When we look at this term “undetectable,” what does that really mean? Is it that today I went in and I got my viral load done and it’s undetectable, and that’s it? So from here on out I’m undetectable? We know that is not the case. The U=U campaign is very succinct. We have to be able to explain to people who are living with HIV and their support network truly what *undetectable* means. But it is also ensuring that there are systems in place to help that person sustain their undetectable status.

It’s also understanding that with the best efforts, not everyone achieves that status. So are we indirectly adding to the stigma, specifically within Black communities, when we have individuals who may not be able to achieve or maintain viral suppression? It’s not just about the medical aspect. There are social and economic and environmental reasons why one may not be able to achieve or maintain their viral suppression.

And finally, when we talk about any of our initiatives, particularly those that have centered people living with HIV, let’s not always talk

V=V is a way of understanding the why, the who, and the how we best support people who are living with HIV who may be out of care or may not be on their ARVs and similar situations.

about it from a place of risk, but let's talk about it from a place of improved health. Let's talk about what that means for Black love. For *self* love. And be able to support those individuals that even with their best effort may not be able to achieve viral suppression, and that that is okay. And that there's no shame or judgment. Let's continue to focus on how we center them to help them get to the best quality care and health that's possible.

LARRY SCOTT-WALKER: Campaigns can actually do harm when we don't express them fully. The PARTNERS [serodiscordant couples] Study [is important] because the campaign is nothing without the science behind it.

With V=V [viremia equals vulnerability], notice that we didn't say "viremia equals vulnerable," because we're not our HIV status. I'm not vulnerable. We're resilient. We're powerful. We're magic. But the vulnerabilities that present for people living with HIV are with unchecked viral load. It leaves us open as people living with HIV to a host of opportunistic infections, illnesses, complications, social stigmas that should not exist, and also leaves us vulnerable to early death. We all want to live long, thriving lives.

We have to be grounded in the understanding that not every person who is living with HIV, who is detectable or has a detectable status, is in a vulnerable state. Some people may never reach undetectable status. And they could take their medication every day. As long as we are working with our doctors and our care team to stay healthy and to stay in the driver's seat of our health, then we're doing what needs to be done. V=V is speaking to those people who for whatever reasons—stigma, change in life status, or anything like that—that they're actually disenfranchised or unable to take care of their HIV status. [Some] are at a place where they elected to stop taking their HIV meds.

Look, detectability happens. Even when we're taking our meds. There should be no shame or shaming around a person living with HIV's viral load. We as people living with HIV, especially as Black people living with HIV or highly marginalized people living with HIV, have so many stigmas working against us. Our ability to maintain or reduce a level of virus in our system should not negate or keep us from being loved or valued by our community.

V=V is a way of understanding the why, the who, and the how we best support people who are living with HIV who may be out of care or may not be on their ARVs [antiretrovirals] and similar situations.

People who are left vulnerable because they may be living with unchecked HIV viral load are sometimes people

'We're resilient. We're powerful. We're magic.'
LARRY SCOTT-WALKER

SCOTT-WALKER: KEVIN KENNER

> **‘If there is truly a commitment to ending this epidemic,** then there is a commitment to helping folks achieve viral suppression under whatever campaign

who don’t have their hierarchy of needs met. If you don’t have a place to stay, if you don’t have food to take with your medication, if you don’t feel safe—you are not going to prioritize that pill.

Some young Black gay men and some other demographics of young people may feel invincible. *I’m healthy. I’m young. I don’t feel sick and I don’t want to take this pill.*

Social determinants of health

- Income level
- Educational opportunities
- Occupation, employment status, and workplace safety
- Gender inequity
- Racial segregation
- Food insecurity and inaccessibility of nutritious food choices
- Access to housing and utility services
- Early childhood experiences and development
- Social support and community inclusivity
- Crime rates and exposure to violent behavior
- Availability of transportation
- Neighborhood conditions and physical environment
- Access to safe drinking water, clean air, and toxin-free environments
- Recreational and leisure opportunities

Some Black women ... I’m actually in Baltimore, Maryland right now because my sister was a person living with HIV. She succumbed to HIV because she dealt with a lifetime of stigma. Because she was a woman, she was living with HIV, she feared the judgments for both herself and her sons.

For some of us living with HIV, taking that pill every night is a reminder that I’m a person living with HIV and that I have to take this pill for the rest of my life. And for some of us, just saying, *Oh, you can live a long, healthy life* doesn’t remove the stigma. Doesn’t remove the hurt and the pit in our stomach that we feel as people living with HIV.

Some people who use drugs are incapable of sustaining viral suppression. They take their meds every day; they go to the doctor. They may just not achieve less than 50 copies of HIV.

Some long-term survivors aging with HIV have been taking different medications over the years for various reasons and may not be able to achieve viral suppression, especially in this time of COVID. We have the largest network of Black gay men living with HIV in the country. A large portion of them are people aging with HIV, over the age of 50, who’ve been living with HIV for over a decade. They’re challenged in general with isolation, with feelings of depression, because they’re aging. Their social status may have changed in the community because it seems that some communities are obsessed with youth. And being in this place of COVID and told to physically distance is bringing some things up for many long-term survivors. I’ve heard many say that they’re challenged to take their medications.

Some of the reasons why people elected to leave care or may not adhere to their medical regimen that stuck out for me were ... bad provider experiences. I cannot tell you how much we hear this at THRIVE. We link [many] people back to care or to care for the first time and one of the main reasons that people note for leaving care was due to some bad experience with a provider. *My doctor doesn’t listen to me. The girl at the front desk yelled my name and I felt like everybody saw me. That caused me to lose the will to even want to engage medical care anymore.* Or maybe something changed. *I lost my job. I lost my house. I lost my insurance.* ... Or your job switches your insurance, so now where you go they don’t accept the insurance. That disruption may actually cause a person to leave care.

Social stigmas—the stigmas that are put on us *every* day, and not just HIV-related stigma. But racism, sexism, transphobia. These stigmas impact how we see ourselves, how we move through the world, how we address our HIV.

There’s stigma attached to care facilities. I will never forget when I first moved back to Atlanta. I was working at an ASO and I was on the bus. We passed one of the largest care facilities for people living with HIV, and the bus driver said, “Oh, that’s the AIDS clinic.” I was aghast. And hearing this on the bus I immediately thought, what if I were a young person who felt a high level of stigma and I was going to my first appointment? I might have stayed on that bus and went back home because I wouldn’t want to be seen as a person going into the AIDS clinic.

Lack of support—support saves lives. Actually, through an effort of THRIVE, the CDC updated their recommendations for HIV testing to include support for people living with HIV, directly linking them immediately to support, understanding that support can save lives. That lack of support is a social determinant of health.

Now, we say “social determinants of health” a lot in public health. I wanted to break down the social determinants of health here. [See box.] A lack of income, educational opportunities, safety in your area, you know, even seeing your area not being a beautiful area. I’m from East Baltimore and growing up I saw broken bottles and people who were on drugs and things like that, and that stuff actually seeps into your mind. It affects not only your health physically, but your mental health. These are all things that impact a person living with HIV’s desire to engage in medical care.

We are more than just our status. Our main goal is not viral suppression. Yes, we want to be healthy. Yes, we want to live happy, long lives. But ... we’re more than HIV. And when we as practitioners and people who work in community negate that, when we make viral suppression the main goal for a person, we actually become a barrier.

We operationalize V=V by first understanding that we are people. That we are not disease states. I am not HIV. I am virally undetectable, but I’m not undetectable. I’m very *detectable*. I’m here. You know I have worth and agency. Inquire about our whole lives to identify barriers—vulnerabilities—that may challenge our ability to take care of ourselves. But also inquire about our lives to identify those things that you use to empower us around mental health and utilize our goals. My goals were how my parents and my umbrella.’ —LEISHA McKINLEY-BEACH

brother helped to push me through my education and keep me focused because they would hold my goals up. We should do that same thing for people who have HIV.

Remember that there is no pill to rebuild will. And if our minds and hearts aren’t well, or our ability to take care of ourselves is challenged, then we’re not going to prioritize HIV.

You know, it’s maddening to think that a person can say *I’ve been really depressed* because of something that’s going on in their life and that’s the reason why they decided to not take their pills, and for a practitioner to say, “Take your pills because you can live a happy healthy life.” No, deal with the thing that’s going on with my life and when you address and honor that real thing that’s happening, you inspire me. You don’t have to drag me to this place of undetectability because I’ll feel that you care and I’ll be open to your messages.

Also understand that in order to sustain U=U we have to train ourselves to be aware and to be looking for rising vulnerabilities, especially those that don’t directly relate to HIV. You and your boyfriend just broke up? How’s that making you feel? Understanding that losing your partner is not an effect of HIV, but it’s a thing that could impact your living with HIV. So I’m going to do everything in my power to get you to wherever you need to get to so that you can deal with the loss that you’ve experienced, the grief around losing a person you love, and so that you can continue to prioritize your HIV care and treatment.

LEISHA McKINLEY-BEACH: Phill [Wilson, of the Black AIDS Institute] would say that we were greater than the middle passage, we were greater than Jim Crow. And I’m adding now, we are greater than police brutality. We’re greater than COVID, and we’re going to be greater than HIV. With leaders like you, who keep showing up and reminding us that it’s not just the HIV, it’s all the other issues that got us here, to have a conversation about HIV that has to be addressed. If there is truly a commitment to ending this epidemic, then there is a commitment to helping folks achieve viral suppression under whatever campaign umbrella. U=U, V=V, combining them together—if the commitment is real, then we have to address all of the vulnerabilities that got us here in the first place.

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The presentation has been edited for space. **READ** the complete transcript online, including a look at U=U campaigns.

How women of color living with HIV helped win the election

Building on the power of the HIV community, Vote Positive USA is ready for more

BY **JD DAVIDS**

POSITIVE CAMPAIGN: TANA PRADIA (RIGHT) STANDS NEXT TO **REP. SHELIA JACKSON-LEE,** WHO WAS ENDORSED BY VOTE POSITIVE USA AND WON RE-ELECTION.

On the night of November 3, 2020, the polls were just starting to close and a weary nation awaited the results of a deeply contentious election in the midst of an escalating pandemic. But the leaders of Vote Positive USA (VPU)—primarily Black and Brown cisgender and transgender women living with HIV—gathered online with a sense of well-earned victory, knowing that no matter what the outcome, their year-long efforts to build and focus the power of communities most affected by HIV had been a massive success.

"It's been a wonderful day," said LaTonya Roby in Atlanta, speaking on a Facebook Live video featuring VPU organizers from Colorado, Georgia, Pennsylvania, and Texas [bit.ly/Vote-Poz-Debrief]. "I'm super excited. We've actually been phone banking thousands and thousands of people for weeks, we've been just trying to get out the vote, and we're pretty excited about what we were able to accomplish. Today we spent 12 hours at the polls, from seven to seven.

"The thing that I'm *most* excited about is that we had so many new people who volunteered, who had never worked the polls before... So, they had a chance to get their feet wet. And these are our future leaders, so I was excited about their excitement, and just the prospects of what we can accomplish in Georgia, and the groundwork that's been done... We had a great time," said Roby.

The excitement felt by VPU organizers was further bolstered by the massive numbers of people whose lives they touched over a year of organizing. According to a statement released by VPU right after the video session, their team had canvassed nearly half a million voters through phone banking, texting, and other efforts. They helped people to register to vote and make plans for mail-in or early voting, ensured that folks could get to the polls, and even participated in poll site monitoring in some of the states most anticipated to determine the results of the presidential election.

‘We’ve been hitting the ground running
since the beginning of [2020], before coronavirus even came into our lives.’

FROM LEFT: **CRYSTAL TOWNSEND**, **CHRISTINA SANDERS**, AND **SHADAWN McCANTS**

ABOVE: **KENYA MOUSSA**, A VPU LEADER IN PHILADELPHIA LIVING WITH HIV, ASSEMBLES VOTER PACKETS FOR SOCIALLY DISTANCED LIT DROPS

PHOTOS COURTESY OF VOTE POSITIVE USA • JD DAVIDS: SULLIVAN CARMONA

“We’ve been hitting the ground running since the beginning of [2020], before coronavirus even came into our lives,” said Teresa Sullivan, a Philadelphia-based VPU organizer. “We were door knocking and registering people to vote, giving people the information they needed. People’s anxieties were high even before coronavirus, because they were still feeling the impact of what happened in 2016.”

Even when the COVID-19 pandemic struck, Sullivan detailed the persistence of the VPU team, explaining that “we switched gears real quickly, we did what we needed to do. Wasn’t messing around. We have a strategy that’s in place here on hand here in Pennsylvania because we are a battle state in this election.”

Like other VPU organizers across the country, the Philadelphians’ effort intensified on Election Day. “We even had people on the ground, poll watching in the primary and tonight as well. We were answering questions in real time, things that were happening at the polls in Pennsylvania, and making sure that we were addressing them and putting out alerts about what was going on at polls... People have that hotline [phone number] so that they’re in the line and if they said, ‘Well, you can’t vote, we don’t see your name,’ they can make their phone call right then and there.”

As we enter 2021, people living with HIV and their loved ones have perhaps guarded but real hope for the way forward. The incoming federal administration has vowed to tackle the massive COVID-19 pandemic and to renew efforts to sustain and extend access to health care that is vital to ending the HIV epidemic. And—unlike the Trump administration’s predominantly white and cisgender male Cabinet—the Biden/Harris team says they will staff their agencies with a diverse team that “looks like America,” including members of communities most affected by HIV that look like the ranks of VPU—LGBTQ people, people of color, and people with disabilities.

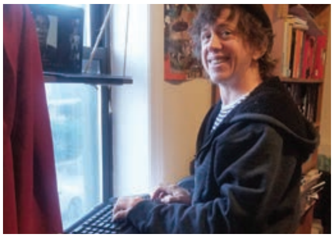
The terrain ahead will not be easy, but VPU is ready to continue to stay focused on building the power of the HIV community. Naina Khanna, Director of Vote Positive USA, delivered a rousing call to sustain their efforts:

“We do this work because we understand that as people living with HIV, our destiny, our fate, our human rights, and the dignity of our people... all of that is directly impacted by political leaders who are making decisions about our lives every day. And we understand that elections are not the be-all and end-all—we organize every day, all year round, 365 days a year... but we also understand that elections and electoral politics are one lever of power to build long-term community power for our people, our Black and Brown folks, low-income folks, LGBTQ folks, people who are at the intersection of many different forms of marginalization and oppression.

“Our people are powerful, and they have demonstrated their power and they showed their power, all throughout this election cycle and we are so proud of them,” she concluded. PA

AFTER THE ELECTION

In the lead-up to the January 5 run-off election in Georgia for the state’s two U.S. Senate seats, VPU partnered with Women Engaged, an Atlanta-based nonprofit organization led by Black women, to do voter engagement. Volunteers were recruited by VPU for Women Engaged’s phone and text banks to register new voters.



JD DAVIDS is a longtime HIV movement strategist and writer who is creating the Cranky Queer Guide to Chronic Illness and can be found @TheCrankyQueer. He is a member of the What Would an HIV Doula Do collective and is a board member of ME Action.

DISCLOSURE: The author has volunteered for Vote Positive USA and worked on two small contracts to provide written materials.

Who's Zoomin' who?

Etiquette for a new era of video chat

Let's face it: communicating with others during stay-at-home advisories and working from home are difficult. So here are some suggestions, compiled from Zoom's own website as well as other sources, which will help you stay productive, connected, and not-embarrassed as much as possible while we struggle through this new era of office work and communication.

Some of the most common-sense meeting decorum—avoiding eating and drinking, minding your body language, and being respectful to whoever is speaking—are no-brainers. Here are some additional tips to help ensure a focused and effective virtual meeting.

Make sure to introduce everyone at the beginning.
Just like a real meeting or social event, you wouldn't initiate a conversation between two acquaintances who haven't met without introducing them. The same practice applies to a virtual meeting. Be sure to introduce all parties you are hosting at the beginning to create a welcoming environment and stimulate engagement.

Use the video option when possible.
It lets people see you and confirm you're not some super-sophisticated AI voice. This is particularly important if you're the one hosting the meeting or a speaker, and slightly less so if you're an attendee.

Stage your video area.
Keep in mind that people aren't just seeing you, they're also seeing whatever the camera is pointed at behind you. Maybe arrange it so that your camera isn't facing towards a pile of unfolded laundry? For greater privacy, use a close-up video or move the camera. For example, sit with your back to a wall. Or, if your computer or device allows, use a virtual background for complete privacy.

More light is better.
Video quality is dramatically improved with more lighting. And don't you want everyone to see your beautiful face, now that you've gone to all of the trouble to put on actual clothes and stuff? An extra nearby lamp is usually helpful. Just make sure the light is in front of you, not behind you—being backlit makes you harder to see.

Try to look into the camera.
If you're presenting or speaking to a group, looking into the camera will give the appearance of eye contact with whomever you're talking to. It's also definitely better than being forced to stare at your own face and realizing how badly you need a haircut.

Do your own tech support before you start.
Make sure you do a test run at some point, and that you're aware of your audio and video settings before you start. Most video conference services allow you to see a test of what your camera is recording before you start broadcasting it to everyone else, so have it arranged the way you want it. Zoom, for instance, has a feature that lets you test your settings before your meetings begin: GO TO zoom.us/test.

Stay on mute if you're not talking.
Background noise can be really distracting. If you aren't sharing anything at the moment, go ahead and hit mute until you do. That way, no one has to listen to the car alarm that goes off in your neighborhood or your neighbor's perpetually barking dog.

Don't eat during the meeting.
It can be a little gross to watch other people eat sometimes. Or listen to them chewing, for that matter. Hold off if you can, or if not, maybe turn off the video and audio.

Don't do other private things while on a meeting.
Speaking of gross: have you heard any horror stories about people being caught picking their nose or using the bathroom while on a video conference, thinking they were muted or had their video off? Don't become a statistic. It can be easy to forget that people can hear or see you if you're in a group of 30 coworkers, so don't risk it!

Stay focused.
It's a scientific fact that everyone hates meetings. Don't make this one go longer than it needs to. Stay on task (which can be very difficult while working at home) and keep unnecessary conversations to a minimum. It can get very hard to be productive when several people are all talking at once.

If you're the host, stick around.
The general rule for meeting hosts: Wait until everyone else has left the meeting before hanging up, so attendees can leave at their own pace and get any final words in before disconnecting. Zoom will assign an alternate host if the original host exits first, but it's not a good look. A host leaving everyone else in the meeting is much like bailing on your own party.

ADAPTED FROM pennlive.com/coronavirus/2020/04/zoom-meeting-etiquette-15-tips-and-best-practices-for-online-video-conference-meetings.html and blog.zoom.us/video-meeting-etiquette-tips.

POZ ADVOCATE

SCOTT SCHOETTES
@PozAdvocate

It’s a new day for people living with HIV in America

2020 was a challenging year in so many ways, and it capped off the very challenging four years of the Trump administration. In June 2017, I led a group resignation from the Presidential Advisory Council on HIV/AIDS (PACHA) because it had become crystal clear in a few short months that Donald Trump was not going to take advice from us (or anyone) and that he did not really care about people living with HIV or ending the HIV/AIDS epidemic. Sure, the leaders at the Department of Health and Human Services got him to mention HIV in his State of the Union address in 2019 (a “Teleprompter Trump” moment), but he never involved himself in the plan he announced that night, except to falsely brag about all he was accomplishing.

That is not to say, however, that progress was not made on HIV during the Trump administration—it was just progress made despite Trump, not as a result of anything he did. As I said in the op-ed announcing the group resignation from PACHA, lots of career folks at HHS care deeply about HIV, and they continued to move things forward. We witnessed the introduction of the “Ending the HIV Epidemic: A Plan for America” and the beginning of its implementation. It is a plan deeply rooted in a biomedical approach to ending the epidemic: get everyone tested, get everyone who tests positive into treatment, and get PrEP to everyone at higher risk who tests negative. All important features of any plan to end the HIV epidemic, but the Trump plan failed to meaningfully address social determinants of health and barriers to implementation of the biomedical interventions.

While I am confident that implementation of all of those biomedical approaches will continue under the Biden/Harris administration, we can also look forward to actions that will demonstrate a commitment to addressing the social determinants of health and dismantling barriers to care, such as the following:

Acknowledge and Address Structural Racism and Sexism. In September, President Trump issued an executive order that would prevent federal contractors and grantees from training people to recognize their implicit biases, to acknowledge different types of privilege they may possess, or to address structural racism and sexism. Lambda Legal sued to stop implementation of this executive order in November, and President Biden will undoubtedly rescind whatever remains of it on his first day. We will not eliminate the HIV or COVID epidemics unless we address these racial and gender inequities.

Recognize and Promote the Civil Rights of Transgender and LGB People. The Biden/Harris administration will reverse course on what has been a nonstop assault on the rights of transgender people during the Trump/Pence years. Biden will undo the infamous Trump tweet (and ensuing policy change) that prevented the open military service of transgender people—the subject of another Lambda Legal lawsuit—and will stop denying that gender identity and sexual orientation are covered under federal nondiscrimination laws. On this latter change, Lambda Legal was at the forefront of the legal campaign to persuade courts to recognize that the federal employment nondiscrimination statute (Title VII) covers sexual orientation and gender identity, leading to a favorable U.S. Supreme Court ruling in *Bostock v. Clayton County* in 2020. The federal government cannot gain people’s trust and engage them in care while attacking them at every turn. (The Biden administration has also pledged to lift restrictions on the military service of people living with HIV—more on that in a future column.)

Treat Health Care as a Human Right. Assuming the Affordable Care Act survives the Trump/Republican-led challenge currently pending before the U.S. Supreme Court, expect to see a Biden/Harris administration repair the damage inflicted by Trump over the past four years and build on the solid foundation provided by Obamacare. In addition to maintaining greater access to PrEP, the survival of the ACA will sustain expanded Medicaid eligibility, access to health insurance for people with pre-existing conditions, and protections against discrimination in health care based on sex (which includes sexual orientation and gender identity) and disability status. The importance of the ACA in defeating HIV cannot be overstated.

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There are a slew of other things the Biden/Harris administration can—and likely will—do to improve engagement in care and the lives of people living with and at higher risk for HIV. The above steps are a good start—and I am (once again) hopeful about what can be accomplished by a leader who believes in science and embraces solutions to address social determinants of health. It’s a new day!

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.

Still advocating after all these years

BY **SAUNDRA JOHNSON**

As POSITIVELY AWARE celebrates 30 years, I reflect on the myriad ways this magazine has affected not only the lives of people living with HIV/AIDS but also my life as an HIV negative ally.

In 1990, I began volunteering at Open Hand Chicago, a meals delivery program for people living with HIV. After three weeks, coordinators asked me to make a long South Side route my regular route. I loved it! Pretty soon I had a delightful young man as my driver and together we spent Friday nights delivering food to mostly families of color. Many of the caregivers looked surprised to see someone who looked like them. When some of them started to ask questions about the availability of various services, I hit upon the idea of giving them POSITIVELY AWARE—in a plain white envelope so as not to out anyone's status. It was seldom mentioned but never was it refused. I repeatedly heard that Black and Brown people abandoned their own, but here were folk invisible to most, going about the daily business of taking care of a loved one, oftentimes alone. It was both beautiful and heartbreaking to behold.

As time progressed and I got a better handle on my job, first as a case manager at Chicago Women's AIDS Project and then as a health educator at New York's Gay Men's Health Crisis (now GMHC), *PA* became an indispensable resource for my clients. With first-rate reporters and writers, issues affecting the everyday lives of my clients were taken out of the closet and aired in public, so the fear, ignorance, and stigma could dissipate.

They got word about new and ongoing clinical trials that were still enrolling, such as ACTG 175, a landmark study that made special effort to enroll at least 15% women and had women-related sub-studies. They learned about informed consent so they wouldn't be blindly signing up. They also read the debate over whether or not low-dose oral alpha interferon deserved a proper drug trial since there were anecdotal reports that it worked in Black people, but not so much in others. Also, both providers and clients found the report-back from major HIV/AIDS conferences very helpful.

One enduring feature of the magazine is the HIV Drug Guide. It is a functional marvel covering HIV drugs, side effects, and drug interactions. Everyone I know, both client and provider, has come to rely on it. Another valued feature are the profiles of people living with HIV.

Because Test Positive Aware Network (now known as TPAN) as an organization was self-advocacy focused, so was the magazine. The magazine facilitated self-empowerment so that the women living with HIV/AIDS I worked with could better navigate safer sex, working in partnership with their medical providers, use safely, and generally take better care of themselves even under difficult circumstances.

The magazine facilitated self-empowerment so that the women living with HIV/AIDS I worked with could better navigate safer sex, working in partnership with their medical providers, use safely, and generally take better care of themselves even under difficult circumstances.

Although I've retired and no longer formally work in HIV/AIDS, I use *PA* as a way to keep in touch with what is happening in the field. In addition, the lessons learned are now being applied to my own life, especially as I age with chronic medical issues. The knowledge gleaned from studies of people aging with HIV/AIDS has lessons for the wider aging population—such as what chronic inflammation does to the body, drug side effects and brain health, bone health, and immune responses to new technologies.

I also use what I have learned to be my own healthcare advocate. For instance, I have idiopathic chronic congestive heart failure (CHF), and the self-advocacy I learned from being in HIV communities has saved my life more than once. It has led me to clinical trials and helped me get medications through patient assistance programs from pharmaceutical companies. Above all, I learned how to work in partnership with medical and social service providers. As I age, I worry about some of the same things people living with HIV/AIDS worry about. What will happen to me when I become unable to care for myself at home or cannot afford my home, since I have neither a spouse nor children? I worry about suffering. I worry about becoming mentally incompetent. I worry about being alone. Living wills, advance directives, and powers of attorney can only take one so far. I have come this far by watching the struggles and successes of my brothers and sisters living and dying with HIV/AIDS and by adjusting accordingly my actions toward myself and others. PA is essential to my continued knowledge and well-being.

SAUNDRA JOHNSON was an activist with ACT UP Chicago, HIV Case Manager with Chicago Women's AIDS Project (CWAP), and an HIV/AIDS-TB Health Educator with GMHC. In addition, she was a part of the core faculty at the Black AIDS Institute's African American HIV University as well as a volunteer with several agencies providing services to people living with HIV. Even as Saundra has been on disability since 2013, she still advocates for herself and others.

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Our mission has always been to get dependable, accurate, timely information about HIV treatment and health into the hands of everyone who needs it—today, more than ever. If you've been picking up POSITIVELY AWARE, but would rather get it safely—and discreetly—delivered to your home, **order a free subscription**.

Scan this QR code with your smartphone to get yours.
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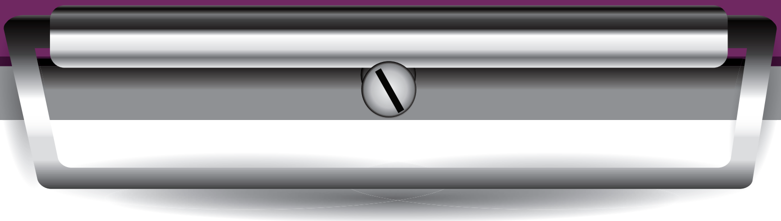

If you are living with HIV, ask yourself the following questions:

Have I lost weight?

- ☐ Have I lost weight without trying?
- ☐ Does the change in my weight impact how I feel about myself or my health?
- ☐ Is my clothing looser than before because I have lost weight without trying?
- ☐ Have those I know mentioned that my appearance has changed?

Do I have less energy?

- ☐ Are any of my usual activities more difficult to perform?
- ☐ Am I exercising less than in the past?
- ☐ Do I need to take a break more often?
- ☐ Do I tire more easily after certain activities?

If you answered "yes" to any of these questions, take this questionnaire to your next appointment with your healthcare provider to start a conversation about HIV-associated wasting and to inquire about treatment. Together you can discuss next steps. To learn more about HIV-associated wasting, visit: **IsItWasting.com**

EMD SERONO