POSITIVELY AWARE
HIV TREATMENT, PREVENTION AND HEALTH FROM **TPAN**
MAY+JUNE 2021

THE FORGOTTEN GENERATION

CAMERON SIEMERS, 39, diagnosed with HIV at age seven resulting from a blood factor he received to treat his hemophilia, is among a generation of younger, long-term survivors

AIDS AT 40

A MATTER OF JUSTICE

VACCINE NATIONALISM IS KILLING US

CONFERENCE UPDATE VIRTUAL CROI 2021

NOT HAVING AS MUCH SEX? YOU'RE NOT ALONE

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LIVE LIFE 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.

MAY+JUNE 2021

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EVERY ISSUE

THIS ISSUE

CONFERENCE UPDATE
VIRTUAL CROI 2021

ON THIS SPREAD AND ON THE COVER
CAMERON SIEMERS, PHOTOGRAPHED BY DAVID FRANCO

A new ‘Day’ springs forth

THE EQUINOX only happens twice a year, when day and night are of equal length. It marks the changing of the season; in some ancient cultures, the equinox also signifies a change in thinking. For this reason, A Day with HIV, POSITIVELY AWARE’s anti-stigma campaign, has taken place on the autumnal equinox in September since 2010. This year, a new springtime version was added, coinciding with the vernal equinox. On March 20, people captured a moment of the first day of spring in pictures, and shared on social media how they are affected by HIV using the hashtag #adaywithhiv. Here’s a sampling:

10:00 AM: SAN JUAN, PUERTO RICO >

“Esta semana me visitó una de mis parejas sexuales y uno de mis mejores amigos para hacerse las pruebas. El VIH se puede prevenir. ¿Te envío una prueba a ti también? Déjame saber.”

“This week one of my sexual partners and one of my best friends visited me to get tested. HIV can be prevented. Should I send you a test, too? Let me know.”
—**Andres**

2:30 PM: BALTIMORE, MARYLAND >>

“Living with HIV has inspired me to become a warrior, so that I can help educate people and help get rid of the toxic myths associated with HIV.” —**Nairobia**

5:29 PM: WINSTON-SALEM, NORTH CAROLINA >

“Today I feel peaceful, accomplished, and overall happy. Effects of inflammation from HIV and the many autoimmune issues that come with it are starting to make some days difficult, but I will prevail!”
—**Nicole Elizabeth Dye**

10:48 PM: LONGMONT, COLORADO >>

“It just so happens that I received my first COVID-19 vaccine shot today! HIV was not considered a serious second pre-existing condition until the fifth round in Colorado, but it is now. Take care and get your vaccine! Thank you Out Boulder County for your vaccine initiative!
— **Andrew Espinosa**

A Day with HIV **returns Wednesday, September 22, 2021.**

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EDITOR'S NOTE

JEFF BERRY
@PAeditor

The flip side of aging

This year marks 40 years since the first cases of pneumonia were reported in five gay men in Los Angeles, all of whom later died. That same year we also heard about Kaposi sarcoma, then known as the "gay cancer," being reported in gay men.

This is the story we've all come to know as the beginning of the AIDS epidemic (see page 14). But years earlier in 1968, Robert Rayford, a 15-year-old African American male, presented with a strange series of infections that baffled doctors in St. Louis. Three months after his 16th birthday in 1969, he died of pneumonia. An autopsy revealed that Rayford had Kaposi sarcoma lesions within and throughout his body, and thankfully tissue samples were preserved by the treating physician, knowing that one day they might prove useful.

According to a *Washington Post* article in 2019, "In time, the case of a poor young African American who apparently never left the Midwest would add a surprising twist to the understanding of a disease many connected with gay white men in cosmopolitan coastal cities. Researchers would come to see Rayford as the country's first known death from a strain of the human immunodeficiency virus, HIV, the virus that causes AIDS."

Ten years ago this month, we published POSITIVELY AWARE's AIDS at 30 issue. On the cover we featured Marc, who was born with HIV. In my editor's note, "The Year of Living Dangerously," I recounted my move to Chicago in 1981 just a few months after those first cases were reported, and how not long after, I developed a flu-like illness that I couldn't seem to shake. I went on to say that, "Like me, [Marc] also resided in Chicago. Like me, he and his mother...didn't learn until years later that they were both HIV-positive. And, like me, they are both still here. Our stories are so very different, and yet, they are the same."

In this issue, you will read about some of the younger long-term survivors we never hear about, the "forgotten generation." Their stories and voices remind us that there is indeed a flip side to HIV and aging that deserves our attention.

Another thing we don't always touch upon when it comes to aging with HIV is sex. Leave it to Mark S. King to approach the topic with humor and grace in this issue's Positively Aging column. And Being Bridgette debuts in this issue, an ongoing column by Bridgette Picou about living and thriving with HIV as a woman of color.

Like HIV, we're now in the midst of another pandemic that has forever altered our world. And yet many things remain the same, for better or worse. Institutional racism, White supremacy, the killing of innocent Black and Brown people at the hands of those sworn to serve and protect us—I often think, "it's overwhelming," but then stop myself. I mean, if it's overwhelming for me... And as a white cis man, do I even have a right to say I'm overwhelmed?

And then I read in *The New York Times Magazine* about an outbreak of pediatric HIV, "The City Losing Its Children to HIV," by Helen Ouyang. Eleven hundred children with HIV in a city of half a million people. It's a devastating and heart-wrenching report, an indictment of a poorly run and drastically underfunded healthcare system in Pakistan that was already on the brink of collapsing before COVID, and now threatens to wipe out any advances made in ending the HIV epidemic. Parents who put aside their own healthcare needs to have their children treated by quack doctors who are incentivized to give unnecessary injections and infusions, re-using needles, then often tossing them out the clinic window into the street where children are playing. And I become overwhelmed all over again.

But I push on, and I do the work, as we all do, hoping and praying that I'm making a difference. Trying to put into the world good energy, but not always succeeding. Knowing that each day, I have a choice to do things differently from the day before. We're all aging, and with age comes wisdom, right? So today I'm going to flip that aging coin, and see where it lands. Because whether it's heads or tails, it's up to us to make the next move.

In this issue, you will read about some of the younger long-term survivors we never hear about, **the 'forgotten generation.'**

Take care of yourself, and each other.

Jeff B

ENID VÁZQUEZ @ENIDVAZQUEZPA

Briefly

ERDIKOCAK-ISTOCK

An injectable HIV treatment that's administered every two months?

The FDA already approved Cabenuva in January as the first complete HIV drug therapy to be taken once a month, but soon, Cabenuva may also be taken just once every *two* months.

The company that makes Cabenuva, ViiV Healthcare, has asked the Food and Drug Administration (FDA) to allow its long-acting injectable treatment to be taken every eight weeks instead of every four.

"Today's submission of Cabenuva dosed every two months marks another meaningful step forward in our ongoing commitment to bring innovative HIV treatments to the community," said Kimberly Smith, MD, MPH, Head of Research & Development for ViiV, in a press release dated February 24. (See "At the nexus of body and soul," November + December 2020.) "This first-of-its-kind regimen reflects the evolving needs of people living with HIV, and, if this expanded use is approved, could allow adults living with HIV to maintain virologic suppression with six dosing days per year."

Cabenuva is administered as two intramuscular long-acting injections, in the butt muscle. One injection consists of ViiV's cabotegravir and the other of rilpivirine, from Janssen Pharmaceuticals. Injections begin after one month of taking oral forms of the medications (Vocabria and Edurant).

ViiV's supplemental New Drug Application (sNDA) was submitted based on the results of a study showing that the two injections given once every eight weeks was non-inferior to administering them every four weeks. Those results came from the Phase 3b international clinical trial ATLAS 2-M (Antiretroviral Therapy as Long-Acting Suppression every 2 Months).

Before taking Cabenuva, individuals switching to it must already be on a stable anti-HIV regimen and have undetectable viral load (less than 50 copies), and have no history of antiviral drug failure or resistance to cabotegravir or rilpivirine.

For more about Cabenuva, **GO TO** Cabenuva.com or positivelyaware.com/Cabenuva.

DHHS recommendation on Cabenuva

An expert panel of the Department of Health and Human Services (DHHS) issued a recommendation in February that switching to Cabenuva to optimize treatment is seen as a good strategy.

"Based on the clinical trial results from two large randomized controlled trials [RCT, representing the gold standard in clinical research], the Panel recommends that once-monthly cabotegravir and rilpivirine intramuscular (IM) injections can be used as an optimization strategy for people with HIV currently on oral antiretroviral therapy (ART) with documented viral suppression for at least 3 months (although optimal duration is not defined) (A1 [recommendation]), who—

- Have no baseline resistance to either medication,
- Have no prior virologic failures [detectable viral load on treatment],
- Do not have active hepatitis B virus (HBV) infection (unless also receiving an oral HBV active regimen),
- Are not pregnant and are not planning on becoming pregnant [due to lack of data in this population],
- Are not receiving medications with significant drug interactions with cabotegravir and rilpivirine."

"Before initiation of the IM injection, patients should receive oral cabotegravir and oral rilpivirine for 28 days as an oral lead-in period to assess tolerance to these drugs. Clinicians should refer to the product label for information regarding IM dose administrations as well as management strategies for planned or unplanned missed doses."

READ MORE on the recommendation regarding Cabenuva at hivinfo.nih.gov.

The panel noted that, "Switching to long-acting injectable therapy can be advantageous in patients for a variety of reasons, including but not limited to reducing pill fatigue, disclosure concerns or stigma associated with taking daily oral medications, and to improve quality of life."

Pediatric guidelines updated

A DHHS expert panel also updated its pediatric HIV guidelines. Several medications now have a different recommendation, based on new data. There's also information added about telehealth communication and telemedicine vs. in-person clinic visits.

Per the update:

- With the release of a new, dispersible tablet formulation of dolutegravir (DTG) [Tivicay], DTG plus two new nucleoside reverse transcriptase inhibitors (NRTIs) is now recommended as a *Preferred* antiretroviral (ARV) regimen for infants and young children (aged 4 weeks and older and weighing 3 or more kg [6.6 pounds or more]) rather than being limited to children aged 3 and older and weighing 25 kg or more.
- Bictegravir (BIC), which is available as a component of the fixed-dose combination (FDC) tablet bictegravir/emtricitabine/tenofovir alafenamide (Biktarvy), is now recommended as a *Preferred* ARV regimen for children aged 6 years and older and weighing 25 kg and more [55 pounds and more].
- The Panel now recommends raltegravir (RAL) [Isentress] plus 2 NRTIs as an *Alternative* integrase strand transfer inhibitor-based regimen for children aged 4 weeks and older, rather than Preferred, because of its twice-daily dosing requirement and lower barrier to resistance compared to DTG or BIC.
- Although the FDA has approved abacavir (ABC) [Ziagen] in infants aged 3 months and older, based on reassuring safety data, the Panel recommends ABC plus lamivudine or emtricitabine as a *Preferred* dual NRTI backbone for use in infants and children aged one or more months old.
- With the ability to use ABC in infants and young children, zidovudine (ZDV) is now recommended as an *Alternative* NRTI for use in infants and children aged at least one or more months old.

Long-acting regimen in development: islatravir, lenacapavir

Another complete long-acting HIV regimen is in the works, and is being studied as both oral and injectable therapies.

Gilead Sciences and Merck announced an agreement to develop two of their long-acting drugs, still in clinical trials in combination with each other.

According to a joint press release in March, "Islatravir and lenacapavir are both potentially first-in-class medicines in late-stage clinical trials, with significant clinical data generated to date. Both medicines have long half-lives and have demonstrated activity at low dosages in clinical studies, which support development as an investigational combination regimen with long-acting formulations, both oral and injectable."

The companies noted that, "While daily, single-tablet regimens are available for people living with HIV, options that would allow for less frequent, oral dosing or infrequent injections rather than daily dosing has the potential to address preference considerations, as well as issues associated with adherence and privacy."

Merck is also developing islatravir in combination with the company's doravirine (Pifeltro), and with doravirine and ViiV Healthcare's 3TC (Epivir). Merck is also studying islatravir as a medication for PrEP (pre-exposure prophylaxis—prevention), including a once-monthly oral formulation.

Gilead's lenacapavir has data supporting use as a subcutaneous injection administered once every six months, for both treatment of HIV and for prevention of the virus. Two PrEP studies are expected to begin this year.

The two medications come from drug classes not currently on the market. Merck's islatravir is a nucleoside reverse transcriptase translocation inhibitor (NRTTI). Gilead's lenacapavir is a capsid inhibitor. Clinical study of the combination is expected to start later this year.

Exciting news. Stay tuned.

PleasePrEPMe moves to HealthHIV

PleasePrEPMe.org, a comprehensive online educational resource originally created to bring together providers in California with people interested in PrEP (pre-exposure prophylaxis, or prevention) and PEP (post-exposure prophylaxis), has gone national and moved to HealthHIV.org. The user-friendly site provides information in both Spanish and English.

At the time PleasePrEPMe was formed in 2015, people interested in HIV prevention medications often had difficulty finding a receptive medical provider. This was true even with the emergency PEP schedule—treatment must be started within 72 hours of a known or suspected exposure to HIV.

"The opportunity to have been a part of creating a trusted, inclusive, welcoming source of HIV prevention information has been my honor," said PleasePrEPMe founder Shannon Weber, a Renaissance woman who's a social worker specializing in HIV services, an author, an advocate, and an artist. "I am confident HealthHIV will steward PleasePrEPMe to adapt and change in response to community needs."

HealthHIV provides an extensive number of HIV prevention and care training and education programs, for both individuals and health care workers.

Briefly

Out of the Closet thrift store opens in Orlando

Los Angeles-based AIDS Healthcare Foundation (AHF) has opened another of its Out of the Closet thrift stores, in Orlando, Florida. As with its other thrift shops around the country, the store will house a pharmacy and offer free rapid tests for HIV and a number of STIs.

"The grand opening [in February offered] the chance for Orlando shoppers to be among the first to discover the unique finds and hidden treasures for which 'Out of the Closet' is famous," said Jonathan Kreuyer, general manager of the stores, in an AHF press release. "With 23 other locations in California, Florida, Ohio, Georgia, and New York, AHF's Out of the Closet Thrift Store chain is the nation's largest retail fundraising venture for HIV/AIDS services, and 96 cents of every dollar earned is directed towards local HIV/AIDS awareness efforts and AIDS care to those in need."

Unlike the past, AHF now believes in PrEP.

Housing Works offers thrifting online

Housing Works opened an online version of its own thrift stores back on National Thrift Store Day, August 17. This version specializes in high-end designer and vintage goods. The selection is small, but exquisite. Sometimes funky fun. And not necessarily a piggy-bank-breaker.

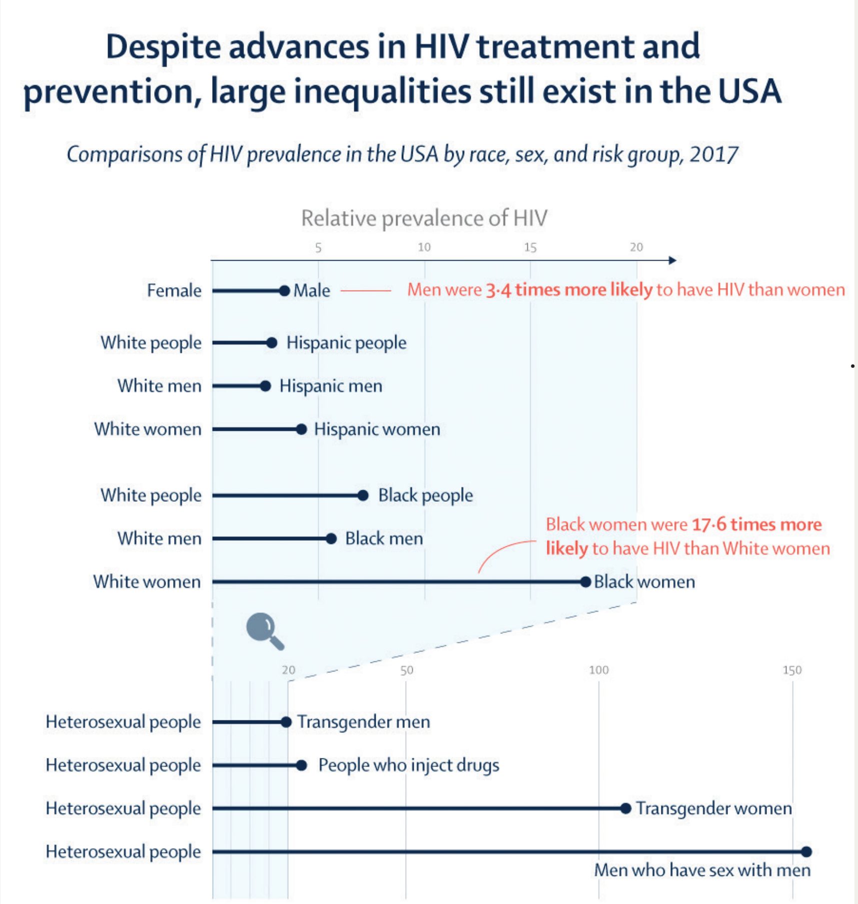
The New York-based non-profit, in existence for more than 30 years, provides housing and support services for homeless and unstably housed people living with HIV. It operates 10 thrift stores dotting Manhattan and Brooklyn. GO TO eshop.housingworks.org.

Lancet's call to action on Ending the HIV Epidemic

The Lancet Series "HIV in the USA" from the February 19 issue concludes with a "Call to Action" outlining the measures needed for Ending the HIV Epidemic initiative to succeed. Among the many items addressed in the call to action, U=U (Undetectable Equals Untransmissable, an education campaign about how undetectable HIV virus may pose no threat of transmission) has a critical role to play. Ensuring that people living with HIV have the treatment and services they need to achieve and maintain an undetectable viral load not only saves lives, but also prevents new transmissions.

The Call to Action states:

- A national culturally competent effort is needed to raise awareness of U=U as a promising approach to reduce HIV stigma, which has a powerful potentiating role in both acquisition risks and treatment challenges.
- Health-care professionals need to inform patients living with and affected by HIV about U=U to improve, first and foremost, personal health, as well as public health; sharing this information might greatly improve the social and emotional wellbeing of people living with HIV, reduce HIV stigma, reduce anxiety associated with HIV testing, and help motivate treatment uptake, treatment adherence, and engagement in care.



Despite advances in HIV treatment and prevention, large inequalities still exist in the USA

Comparisons of HIV prevalence in the USA by race, sex, and risk group, 2017

- Advocates should be equipped to use the so-called public health argument from U=U in advocacy to increase access and remove barriers to quality health care; ensuring people with HIV have the treatment and services they need to achieve and maintain an undetectable viral load not only saves lives, but also is an effective way to prevent new transmissions.

Providers should advocate for use of the concept of Undetectable equals Untransmittable (U=U) in messaging and support all patients to remain virally suppressed.

To view the entire series, GO TO thelancet.com/series/HIVinUSA.

—MICHAEL BRODER

THE LANCET

DHHS updates HIV and COVID-19 recommendations

The Department of Health and Human Services (DHHS) on February 26 updated its COVID-19 recommendations for people living with HIV (PLWH). Of note: PLWH should get vaccinated; it’s still not known if HIV leads to a greater risk for COVID-19 infection. Much of the new information is provided below. There is also a discussion of COVID-19 treatments, which should be used the same way in people living with HIV as in the general population. READ THE UPDATES AT clinicalinfo.hiv.gov/sites/default/files/guidelines/documents/HIV_COVID_19_GL__2021.pdf.

HIV and COVID-19

According to the update, “Whether people with HIV are at greater risk of acquiring SARS-CoV-2 infection is currently unknown. Data on the clinical course of COVID-19 in people with HIV are emerging. In the initial case series from Europe and the United States, no significant differences in clinical outcomes were found between people with HIV who developed COVID-19 and individuals without HIV. For example, data from the Veterans Aging Cohort Study compared outcomes in 253 mostly male participants with HIV and COVID-19 who were matched with 504 participants with only COVID-19. In this comparison, no difference emerged in COVID-19 related hospitalization, intensive care unit (ICU) admission, intubation, or death between patients with or without HIV. In contrast, worse outcomes, including increased COVID-19 mortality rates, in people with HIV have been reported in other cohort studies from the United States, the United Kingdom, and South Africa. In a multicenter cohort study of 286 patients with HIV and COVID-19 in the United States, lower CD4 count (less than 200 cells/mm), despite virologic suppression [undetectable viral load], was associated with a higher risk for the composite endpoint of ICU admission, mechanical ventilation, or death. In another study of 175 patients with HIV and COVID-19, a low CD4 count or CD4 nadir [lowest number ever found] was associated with poor outcomes. In a cohort study in New York, people with HIV had higher rates of hospitalization and mortality with COVID-19 compared to people without HIV.

“In the general population, individuals who are at highest risk of severe COVID-19 include those older than 60; those who are pregnant; and those with comorbidities, such as obesity, diabetes mellitus, cardiovascular disease, pulmonary disease, smoking history, sickle cell disease—as well as solid organ transplant recipients,” the report continued. “Many people with HIV have one or more comorbidities that may put them at increased risk for a more severe course of COVID-19. Both COVID-19 and HIV disproportionately affect communities of color. Based on the available literature, close monitoring is warranted for all people with HIV and SARS-CoV-2 infection, especially those with advanced HIV or with comorbidities.”

Vaccination in HIV

“People with HIV should receive SARS-CoV-2 vaccines, regardless of CD4 or viral load, because the potential benefits outweigh potential risks,” the guidelines advise.

- “Based on recent literature to date, people with HIV appear to be at increased risk for severe outcomes with COVID-19 compared with people without HIV and should be included in the category of high-risk medical conditions when developing vaccine priority.
- “People with HIV were included in clinical trials of the two mRNA vaccines; at this time, the safety and efficacy in this specific subgroup have not been fully reported. People with HIV who are well controlled on antiretroviral therapy (ART) typically respond well to licensed vaccines. Guidance for these vaccines, including for people with HIV, is available through the Advisory Committee on Immunization Practices (ACIP) and from the Infectious Diseases Society of America (IDSA). Confidentiality about their underlying condition should be preserved when administering vaccines to people with HIV.
- “Current recommendations of the ACIP, the American College of Obstetricians and Gynecologists (ACOG), and the Society of Maternal Fetal Medicine (SMFM) state that pregnant and lactating people who otherwise meet criteria for vaccination should not be restricted from vaccine access (ACOG, 2020). The CDC also provides information about vaccine considerations for people who are pregnant and breastfeeding.”

Links are provided in the document.

Other new considerations

“New onset or worsening dyspnea [difficulty breathing] warrants in-person evaluation.”

“Patients and/or caregivers should be aware of warning signs and symptoms that warrant in-person evaluation, such as new dyspnea, chest pain/tightness, confusion, or other mental status changes.”


ISTOCK

“Be aware that people with HIV with additional comorbidities may be eligible for one of the anti-SARS-CoV-2 monoclonal antibodies available through Emergency Use Authorization from the FDA.”

Added to the paragraph on greater risks of domestic violence during quarantine are the italicized words here, “Reports indicate that some measures designed to control the spread of COVID-19 may increase *the risk of intimate partner violence and/or child abuse*, as well as limit the ability of people to distance themselves from abusers or to access external support. Providers should assess patient safety at each clinical encounter, either in-person or via telemedicine, being cognizant of the patient’s ability to speak privately.”

Clinicians are referred to the NIH COVID-19 Treatment Guidelines (covid19treatmentguidelines.nih.gov/whats-new), which have a section on “Special Considerations in People with HIV.”

A lengthy section on pregnancy and another on children living with HIV have been added.

Neurocognitive impairment in people living with HIV

What you can do to stay sharp

BY JOSH MATACOTTA, PsyD, CAHIMS

ISTOCK

With the introduction of highly active antiretroviral therapy (or HAART), there has been a dramatic reduction in HIV-related central nervous system (CNS) opportunistic infections and severe cognitive disorders in people living with HIV (PLWH). People who have access to medications and quality care can enjoy a full and productive life. Although there has been an increase in the accessibility of treatment, it is disheartening to see that there are still a significant number of cases of neurocognitive impairment in the HAART era. Concerns about neurocognitive impairment persist for PLWH.

Neurocognitive impairment (NCI) is a general term to describe dysfunction that involves executive, motor, attention, memory, and less commonly language impairments to varying severity and frequency. The range of HIV-related NCI is called HIV-associated neurocognitive disorders (HAND). HAND syndrome is classified as asymptomatic neurocognitive impairment (ANI), mild neurocognitive impairment (MCI), or HIV-associated dementia (HAD).

ANI is challenging to diagnose despite using formal neuropsychological testing to evaluate performance in several cognitive domains. Unfortunately, the broad definition of ANI means up to 20% of the cognitively typical population of PLWH is classified as sustaining ANI. There is some evidence to suggest that people with ANI may progress to symptomatic HAND, thus making early accurate diagnosis important.

MCI, or mild neurocognitive disorder, involves noticeable cognitive impairment in two cognitive domains but does not always disrupt daily activities or functioning. While symptoms of MCI are easier to recognize compared to ANI, it is difficult to ascertain whether they result from HIV or other causes. Some people living with HIV may also manage mental health conditions such as depression, ADHD, or other learning disabilities. Determining the root cause of cognitive impairment requires an extensive evaluation by a mental health professional.

Thanks to HAART, we see less of the more severe forms of HAND caused by central nervous system damage from uncontrolled HIV replication in cerebrospinal fluid and brain tissue. People with HIV-associated dementia, or HAD, experience moderate to severe impairments in cognitive functions and considerable difficulties in everyday functioning. Antiretroviral medications that penetrate the blood-brain barrier can improve cognitive impairment, especially as people achieve complete viral suppression. Why then do we still have concerns about neurocognitive impairment for PLWH in the age of HAART?

Unfortunately, despite successful viral suppression, virus that escapes into the cerebrospinal fluid might explain some cases where HAND persists. While most antiretroviral medications penetrate the blood-brain barrier, poor drug concentration in the central nervous system may result in milder forms of cognitive impairment. Other explanations include persistent immune activation or chronic inflammation. Shortly after starting treatment, people typically experience a sharp decrease of systemic inflammation but not to normal levels. Other medical conditions such as cerebrovascular disease and hepatitis C co-infection may contribute to neurocognitive impairment.

Aging with HIV is another factor that challenges our complete understanding of HAND. There is an ongoing debate about premature aging or accelerated aging for some age-related medical conditions like cardiovascular disease in PLWH. It is not entirely clear if this suspected pattern of aging is present in neurocognition. Several studies suggest that HIV might accelerate brain aging through chronic neuroinflammation. However, study findings are inconsistent and complicated by comorbidities and the significant differences in life trajectories of PLWH. The pathogenesis of HAND continues to be studied, as are the roles of age, antiretroviral neurotoxicity, and comorbidities.

Biomarkers and improved assessment tools will help further our understanding of HIV and neurocognition so that we can identify neurocognitive impairment in the asymptomatic stage before further deterioration. Several neuroimaging techniques have been used to evaluate brain structure and function but are not widely used in clinical practice.

What you can do to keep sharp:

Stay informed

You're doing this now! Learning about HAND and staying informed on all things HIV will serve you well in the long run. Increasing your understanding of common co-occurring conditions can inform your conversations with healthcare providers. If you have concerns about cognitive function, talk to your primary care doctor, who can refer you to a specialist. Stay engaged in treatment and let your doctor know that you wish to be a collaborative partner in your care. Always ask questions and report any new symptoms or concerns you might have about neurocognitive impairment.

Focus on mental health and well-being

Take care of your emotional well-being and mental health. Depression, learning disabilities that persist in adulthood, age-related cognitive decline, and other mental health concerns may contribute to decreased cognitive functioning. For example, people with untreated depression often report difficulty with memory and attention or experiencing "brain fog" as a result of fatigue and depression. It is important to continue treatment with a licensed mental health professional should any of these issues be relevant to you.

After you read this, I'd like you to set some time aside to do a self-check inventory. This is an opportunity to reflect on your internal process and environment and ask yourself a few key questions. How are you feeling right now? Much of what a person feels is caused by what they say to themselves. People talk to themselves all day long with little awareness of it. Self-talk is automatic and carried out repeatedly. When we are not sure why something is the way it is, we often start looking outside of ourselves for the source of unhappiness. That's okay to do! But be sure to check your self-talk and internal process. Continue your self-check by reflecting on how you spend most of your days. What takes a lot of time and effort? Are you engaging in activities or hobbies that you enjoy and find fulfilling? How much sleep are you getting on average? Can you quickly name a few reliable and trustworthy friends or family members to reach out to if you were in a bind? Remember to conduct a self-check throughout the year.

It's normal for people to become a little more forgetful or to take a bit longer to remember a word or name now and then as they age. However, having consistent or increasing concerns about your cognitive performance warrants further exploration.

Nutrition and exercise

There is plenty of evidence to suggest that diet and exercise have a positive impact on brain health. Maintaining a healthy diet combined with aerobic and resistance exercise is an effective way to counter age-related cognitive decline, and will help with HAND. Avoid tobacco, alcohol, and other substances that are known to negatively impact brain health. Eat a nutrient-rich diet that consists of fruits and vegetables while minimizing the amount of processed food you eat.

Make time for exercise. I've often heard (and have said to myself), "Well, I'm not a morning person and I'm too tired at the end of the day. I don't know when I can exercise!" We manage to find time to do things for work or other people but are not so great at making time for ourselves. Don't put off things that are important to your health and well-being. Schedule time in advance if you must for exercise and make it a habit. Your brain will thank you for it.

Engage in new and novel activities

Finally, studies have shown that novel activities and experiences shape our brain's structure and organization. Activities that stimulate the mind like reading and puzzles will help keep you sharp. The Synapse Project conducted a study with 221 participants ranging in age from 60 to 90 to assess the effect of sustained engagement on cognitive function. A key takeaway from the study was activities that require active learning and sustained use of working memory, long-term memory, and other executive processes caused a significant increase in episodic memory. Episodic memory refers to a type of memory involved in recalling specific situations or events. Even the experience of learning something new can reinforce a growth mindset and boost confidence in the ability to learn something new.

Conclusion

Remember that your brain is just as important as the other organs of your body, and it changes as you grow older. It's normal for people to become a little more forgetful or to take a bit longer to remember a word or name now and then as they age. However, having consistent or increasing concerns about your cognitive performance warrants further exploration. If you commonly lose your train of thought, have difficulty with tracking a conversation, or struggle to find your way around a familiar environment, talk to your doctor. Mild neurocognitive impairment may not always be preventable. But research shows there are many things you can do to prevent it or slow its progression.

Josh Matacotta, PsyD, CAHIMS, is an assistant professor in the College of Health Sciences at Western University of Health Sciences. He also serves as board president and researcher at the Integrated Behavioral Health Research Institute.

FORMED IN RESPONSE TO THE EPIDEMIC, THE AIDS COALITION TO UNLEASH POWER (ACT UP) WAS FORMED IN NEW YORK IN 1987, AND SOON LOOSELY AFFILIATED GROUPS WERE LAUNCHED IN CITIES AROUND THE WORLD, INCLUDING CHICAGO, WHERE THIS DIE-IN PROTEST WAS HELD.

THE DAWN OF AIDS IN

Forty years later, AIDS is past, present, and future

BY **MICHAEL BRODER**

This year marks the 40th anniversary of the start of AIDS in 1981. To me, a 60-year-old gay man who was a closeted college student when the epidemic began, 1981 seems like yesterday. But it's not really yesterday. The world has changed a great deal in 40 years. And yet AIDS is still with us.

Worldwide, there are about 38 million people living with HIV, the virus that causes AIDS. Since the beginning of the epidemic, about 76 million people worldwide have acquired HIV, and some 33 million have died from AIDS-related illnesses.

Today there are highly effective treatments that allow many people with HIV to have decades of good health. But that rosy prognosis is far from uniform—better in North America, for example, than in sub-Saharan Africa, and better in some demographic groups than others, depending on factors like race, ethnicity, gender, income, and access to healthcare, to name just a few.

Today we have medications that can prevent HIV infection, but we still don't have a vaccine (compare that to COVID-19, for which two vaccines were developed within one year after the virus

LISA HOWE-EBRIGHT, COURTESY OF *WINDY CITY TIMES*

was identified, with a third now available and more in the pipeline).

Today, AIDS is past, present, and future—and that is how we will explore it in the remainder of this essay.

1981

The advent of AIDS unfolded like a movie montage of newspaper headlines. In the spring of 1981, there were rumors in New York City's gay community about an exotic new disease affecting gay men. In May, a young medical doctor with a penchant for journalism, Lawrence Mass, wrote an article for the *New York Native*, a pioneering gay tabloid, seeking to get at the truth of the rumors. Mass interviewed Steven Phillips, an epidemiologist from the federal Centers for Disease Control and Prevention (CDC) who had been assigned to the New York City health department. Phillips confirmed that a number of gay men had been treated recently in New York City hospitals for *Pneumocystis carinii* pneumonia (PCP), a fungal pneumonia usually seen only in people with severely compromised immune systems. Wittingly or not, Phillips minimized the significance of these cases, telling Mass that the rumors of a disease affecting gay men were largely unfounded.

At the time, Mass's article in the *Native* went largely unnoticed outside the local gay community. On June 5, however, the *Morbidity and Mortality Weekly Report* (*MMWR*), a publication of the CDC, published a brief item on recent cases of PCP in young gay men. I'll quote in full the three sentences that go down in history as the *Hindenburg* of AIDS:

"In the period October 1980–May 1981, 5 young men, all active homosexuals, were treated for biopsy-confirmed *Pneumocystis carinii* pneumonia [PCP] at 3 different hospitals in Los Angeles, California. Two of the patients died. All 5 patients had laboratory-confirmed previous or current cytomegalovirus (CMV) infection and candidal mucosal infection."

That's it. Forty-eight words. The first attack had been launched. The invasion had begun. The *MMWR* article was reported by The Associated Press, the *Los Angeles Times*, and the *San Francisco Chronicle*, spurring reports to the CDC from around the U.S. of similar cases of PCP, Kaposi sarcoma (KS), and other unusual presentations of severe infections among young gay men. Within weeks, members of the gay community were calling PCP "gay men's pneumonia."

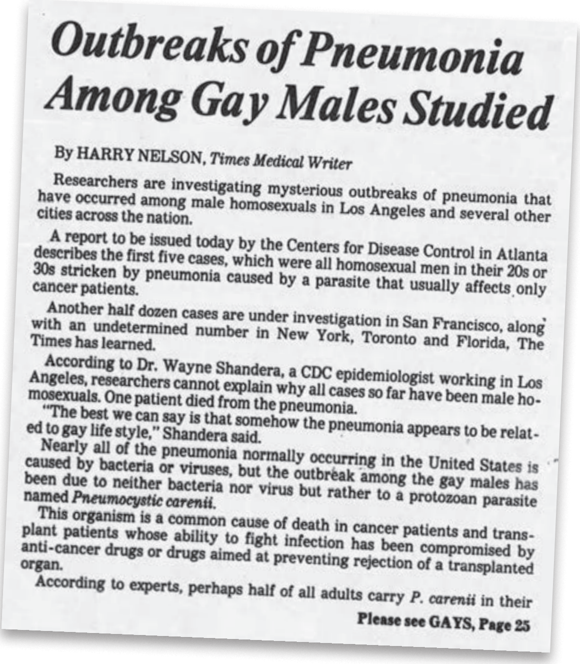
Just a month later, *MMWR* reported 26 cases of KS in the previous 30 months among young gay men in New York and California (mostly San Francisco). A very rare skin cancer, KS is usually found in elderly men of Eastern European, Middle Eastern, and Mediterranean descent. Its appearance in these numbers among men so young, all of whom were gay, was highly unusual, and the doctors who identified these patients were quite alarmed. The cancer was also unusually aggressive—eight of the men died within 24 months of their KS diagnosis; by contrast, the mean survival time among typical older males with the disease was eight to 13 years.

Among the young gay men diagnosed with KS, several had serious infections, including PCP, toxoplasmosis, severe herpes simplex, severe candidiasis, and cryptococcal meningitis, as well as past or present CMV. The term "gay cancer" now joined the recently coined "gay men's pneumonia" in the public lexicon. Cases of KS, PCP, or both, in conjunction with other serious infections, continued to mount in New York, San Francisco, and Los Angeles, overwhelmingly among young gay men.

The KS story was picked up by *The New York Times* as well—the first mention of the mysterious new scourge in the nation's touted newspaper of record. Key elements in the story of AIDS were already clear by then. One doctor quoted in the *Times* said that most cases had involved gay men with "multiple and frequent sexual encounters with different partners, as many as 10 sexual encounters each night up to four times a week." In addition, a number of gay men with KS, PCP, and other serious infections had deficient T cells and B cells—components of the immune system that play a role in fighting infections as well as cancer.

The *Times* also noted that many of the young gay men with this striking and unusual cluster of diseases had reported using "drugs such as amyl nitrite and LSD to heighten sexual pleasure." Amyl nitrite is poppers, and the belief that AIDS was related to poppers would take firm root in both the medical community

FATEFUL HEADLINE IN THE *LOS ANGELES TIMES*, JUNE 5, 1981



Outbreaks of Pneumonia Among Gay Males Studied

By HARRY NELSON, *Times Medical Writer*

Researchers are investigating mysterious outbreaks of pneumonia that have occurred among male homosexuals in Los Angeles and several other cities across the nation.

A report to be issued today by the Centers for Disease Control in Atlanta describes the first five cases, which were all homosexual men in their 20s or 30s stricken by pneumonia caused by a parasite that usually affects only cancer patients.

Another half dozen cases are under investigation in San Francisco, along with an undetermined number in New York, Toronto and Florida, The Times has learned.

According to Dr. Wayne Shandera, a CDC epidemiologist working in Los Angeles, researchers cannot explain why all cases so far have been male homosexuals. One patient died from the pneumonia.

"The best we can say is that somehow the pneumonia appears to be related to gay life style," Shandera said.

Nearly all of the pneumonia normally occurring in the United States is caused by bacteria or viruses, but the outbreak among the gay males has been due to neither bacteria nor virus but rather to a protozoan parasite named *Pneumocystic carenii*.

This organism is a common cause of death in cancer patients and transplant patients whose ability to fight infection has been compromised by anti-cancer drugs or drugs aimed at preventing rejection of a transplanted organ.

According to experts, perhaps half of all adults carry *P. carenii* in their

Please see GAYS, Page 25

and the popular imagination in the following years.

Experts did not know how or even if this cluster of KS, PCP, and other serious diseases in gay men was related. But members of the medical community who treated these patients and affected members of gay communities in the nation's urban gay meccas of New York, San Francisco, and Los Angeles could only surmise that something very, very bad was happening.

One August night, gay novelist Larry Kramer, then known especially for his groundbreaking 1978 novel *Faggots*, gathered scores of gay men to his New York City apartment to discuss the emerging health crisis. The guest speaker was Alvin Friedman-Kien, one of the dermatologists who contributed the initial case reports of KS in gay men. Kramer solicited contributions to support Friedman-Kien's research, because there was no other funding readily available to confront the burgeoning crisis.

A series of meetings like this would ultimately lead to the creation of both Gay Men's Health Crisis (GMHC) in 1982 and AIDS Coalition to Unleash Power (ACT UP) in 1987, both of which were spearheaded by Kramer, who remained an ardent (and often controversial) AIDS activist the rest of his life until his death at the age of 84 last year.

As winter approached, New York pediatric immunologist Arye Rubinstein treated five Black infants with signs of severe immune deficiency, including PCP. Several were children of women who used drugs and engaged in sex work. Dr. Rubenstein's assertion that these children were suffering from the same condition that was being observed in young gay men was initially dismissed by his medical colleagues, but this would ultimately prove to be the moment when AIDS emerged in the Black community, driven among men, women, and children by sexual contacts, injecting drug use, and mother-to-child transmission.

Also that winter, Bobbi Campbell, a 29-year-old nurse and a member of the gay community in San Francisco, became the first to go public with his KS diagnosis, calling himself the "KS Poster Boy" and writing a regular "Gay Cancer Journal" column in the *San Francisco Sentinel* to chronicle his experience. To alert the community and encourage people to seek treatment, Campbell posted photos of his KS lesions in the window of a local drugstore. Two years later, Campbell would appear on the cover of *Newsweek* with his partner Bobby Hilliard, illustrating the cover story "Gay America: Sex, Politics, and the Impact of AIDS." This was the first time two gay men were shown embracing on the cover of a mainstream national magazine. Campbell co-founded People With AIDS San Francisco in 1982, and a year later collaborated with men from across the U.S. to write The Denver Principles, the founding document of the burgeoning self-empowerment movement among people with AIDS. Campbell died in 1984 at the age of 32.

As the first year of AIDS drew to a close, there were over 300 reported cases of people with severe immune deficiency in the U.S., of whom 130 died by December 31. Cases had also been reported in Spain and the United Kingdom. Medical experts remained in the dark about what was causing the immune deficiency that laid people vulnerable to otherwise rare infections like PCP, cancers like KS, other serious infectious diseases, and ultimately death. The general public was still largely unaware of the emerging crisis. There had been no congressional hearings, no funding provided for research. The early center of gravity for the medical response was the University of California, San Francisco (UCSF) Medical Center, where Marcus Conant and Paul Volberding co-founded the nation's first dedicated KS clinic, and they along with their UCSF colleagues Connie Wofsy and Donald Abrams took the lead in treatment and research.

At the rate I am telling the story, this would be an excerpt from an 80,000-word book. We don't have room for that here. And there are plenty of ways you can get the whole story—or many different parts of the whole story, as no one book or film or theatrical work can capture the complexity of the AIDS epidemic, its origins, its unfolding, its legacy forty years later. Let's try it in 39 more sentences or less:

THE FOUNDING IN 1982 of both GMHC in New York and the San Francisco AIDS Foundation (under its earlier name, The Kaposi's Sarcoma Research and Education Foundation).

THE BRIEF EMERGENCE of the term gay-related immune deficiency (GRID) to describe the outbreak, until the CDC came up with acquired immune deficiency syndrome (AIDS), which stuck.

THE OPENING OF Ward 86 at San Francisco General Hospital as the world's first dedicated outpatient AIDS clinic.

THE POPULAR USE of the term "4H club" as shorthand to refer to the groups perceived to be at risk for the disease—homosexuals, hemophiliacs, heroin users, and Haitians (while the CDC did not coin the term, its use appears to

LISA HOWE-EBRIGHT, COURTESY OF *WINDY CITY TIMES*

derive from an *MMWR* article published in March 1983).

THE DIY PUBLICATION OF the pioneering safer sex pamphlets *Play Fair!,* written by members of the San Francisco Order of the Sisters of Perpetual Indulgence, and *How to Have Sex in an Epidemic,* written by boyfriends Richard Berkowitz and Michael Callen (a member of the gay male a cappella group The Flirtations).

THE PUBLICATION OF The Denver Principles, the founding manifesto of the National Association of People with AIDS, proclaimed by a group of gay men who stormed the plenary stage of the Second National AIDS Forum in Denver.

THE MORE-OR-LESS simultaneous discovery of the virus that causes AIDS, by the laboratory of French virologist Luc Montagnier (1983) and that of U.S. virologist Robert Gallo (1984)—originally called human T-lymphotropic virus III (HTLV-III), and later renamed human immunodeficiency virus (HIV).

THE CLOSING OF gay bathhouses in San Francisco (1984) and New York (1985).

THE DEATH OF Rock Hudson due to AIDS-related illness at the age of 59, who left $250,000 in his will to help set up the American Foundation for AIDS Research (amfAR), co-chaired by Elizabeth Taylor and medical researcher-cum-socialite Mathilde Krim.

THE OPENING off Broadway of Larry Kramer's play *The Normal Heart* at

CHICAGO PROTEST, LATE 1980s

New York's Public Theater, and the opening of *As Is*, by William M. Hoffman, the first play about AIDS to open on Broadway (1985).

THE BANNING from school of Indiana teenager Ryan White, who acquired HIV through contaminated blood products used to treat his hemophilia, and who becomes an outspoken advocate for AIDS research and public education (1985).

THE FIRST PUBLIC MENTION of AIDS by President Ronald Reagan, who called it a top priority and defended his administration's (lack of) response to the epidemic (1985).

THE BIRTH OF the AIDS Memorial Quilt, with the creation of the first panel by San Francisco AIDS activist Cleve Jones to honor his friend Marvin Feldman (1987).

THE DEATH OF flamboyant pianist and showman Liberace due to AIDS-related illness at the age of 67. Unlike Rock Hudson, Liberace hid his illness, and his gayness, to the end of his life (his publicist maintained that he died of complications from a watermelon diet, until a court-ordered autopsy determined the true cause of death).

We are about out of space, and we are only up to the winter of 1987. AIDS at 40 is indeed a long and complicated tale, by turns grim, heroic, and at times even exhilarating (see either the original Broadway production, the 2003 HBO miniseries, or the 2017 West End revival of Tony Kushner's *Angels in America*).

We cannot close the cover of our MacBook, however, without mentioning three things. First, the formation of ACT UP in 1987, the activist group that used direct-action strategies and tactics to radically change the response of government, the medical establishment, and the pharmaceutical industry to AIDS. Second, the remarkable history of treatment for HIV infection (antiretroviral therapy), starting with AZT in 1987, passing through milestones like the advent of protease inhibitors and triple-combination therapy in 1996, and flourishing today with multiple classes of drugs and ever more safe, effective, and convenient drugs and regimens. And third, the ascendency of treatment as prevention in several forms—treatment of women during pregnancy and delivery, and of infants after birth, to prevent vertical (mother-to-child) transmission; post-exposure prophylaxis (PEP) after a sexual or occupational exposure; pre-exposure prophylaxis (PrEP), meaning the use of HIV drugs by people without HIV to prevent them from getting it; or virologic suppression in people living with HIV (today often referred to as "undetectable equals untransmittable," or U=U, which is the concept that people with HIV whose virus is suppressed by effective treatment cannot transmit the virus to sexual partners).

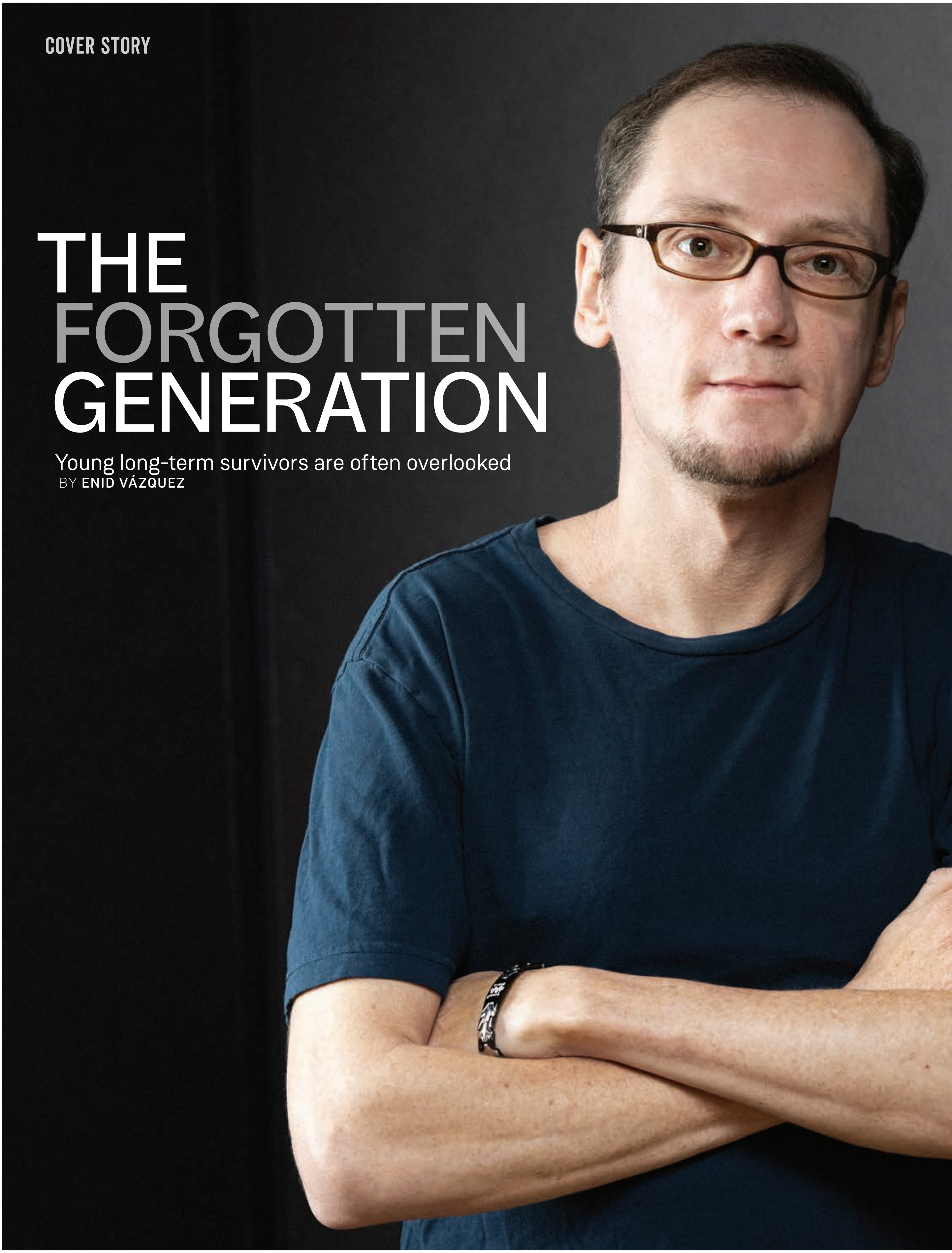
One final thing that must be stated as we mark 40 years of AIDS: the continually evolving demographics of the epidemic. AIDS was first recognized as an outbreak among mostly gay white men ages 25 to 49 in a handful of urban centers in the U.S. Clinicians and epidemiologists soon realized that the epidemic also encompassed non-gay men, women, people of color, and children born to mothers with HIV. Moreover, they realized that HIV could be transmitted not only through sex, but through contaminated blood products, sharing needles to inject drugs, and from mothers to their infants during pregnancy, delivery, or breastfeeding.

Today, the greatest beneficiaries of effective treatment and prevention for HIV have been gay white men in affluent countries—the very same men who first bore the overwhelming brunt of the emerging epidemic 40 years ago. That is a blessing; but we must always bear in mind that the AIDS epidemic still rages in specific regions and among specific populations the world over. On a global scale, the epicenter of AIDS has long since shifted to sub-Saharan Africa, followed by Asia and the Pacific (the Caribbean as well as Eastern Europe and Central Asia are also profoundly affected). Today, more than half of all adults around the world living with HIV are women, and HIV is the leading cause of death among women of reproductive age. Globally, young people (ages 15 to 24) account for about a third of new HIV infections annually. And about 1.8 million children are living with HIV worldwide. In the U.S., Black and Latinx people are disproportionately affected by HIV. Among all groups in the U.S., the rate of new HIV diagnoses is highest among those ages 25 to 34. The largest proportion of HIV cases in the U.S. continues to be attributed to sexual contact between men.

As we mark 40 years of AIDS, we still await a vaccine to prevent HIV, and a cure for people who are living with it. The remarkable development of vaccines to prevent COVID-19 has benefited immeasurably from 40 years of HIV research. Ongoing efforts to develop antiviral treatments for SARS-CoV-2, the virus that causes COVID-19, also rely heavily on the pharmacologic science of HIV—namely, the strategy of targeting viral proteins and using combinations of antiviral drugs, targeting different viral proteins, to more effectively and durably suppress or eliminate viral replication. Even the person leading the scientific and medical charge against COVID-19 in the U.S., Dr. Anthony Fauci, was tempered in the crucible of the AIDS epidemic. Similar observations could be made about the development of treatments—and in some cases cures—for hepatitis B and hepatitis C, as well as other viral infections and cancers. We as individuals affected by HIV and AIDS, and we as a society and a culture marked indelibly by this disease, have much to grieve, as well as much to be grateful for, at this moment in the history of AIDS.

Michael Broder is a gay, white, poz, Jewish, male, late-Boomer Brooklyn native (b. 1961). Columbia undergrad, MFA in creative writing from NYU, and PhD in classics from the CUNY Graduate Center. He tested HIV-positive in 1990, and started doing AIDS-related journalism while collecting unemployment insurance in 1991. He lives in Bed-Stuy with his husband and several feral backyard cats.

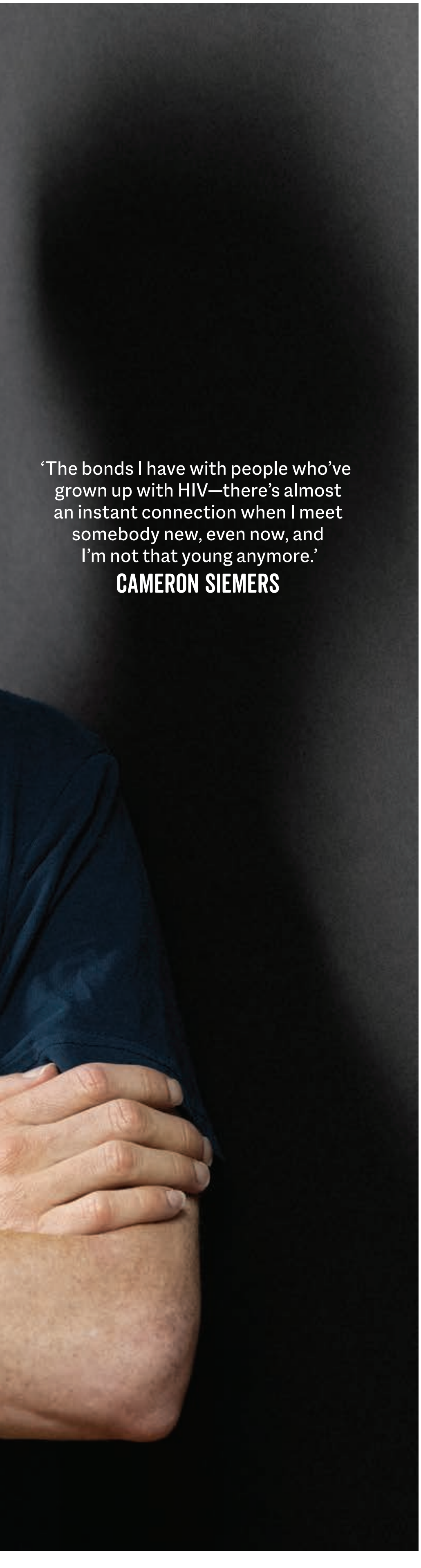
COVER STORY



THE FORGOTTEN GENERATION

Young long-term survivors are often overlooked

BY **ENID VÁZQUEZ**



> ‘The bonds I have with people who’ve grown up with HIV—there’s almost an instant connection when I meet somebody new, even now, and I’m not that young anymore.’
>
> **CAMERON SIEMERS**

DAVID FRANCO

With growing attention now focused on older people living with HIV, it’s easy to forget the young people, now mostly into their 30s, who acquired the virus in childhood. They too are long-term survivors aging with HIV. They’re just not what many people think of when they hear the words “long-term survivor” or “aging with HIV.”

“When I hear a lot of information about aging or long-term survivors, a lot of times those two are mistakenly intertwined,” says **GRISSEL GRANADOS**, who acquired HIV around the time of her birth 36 years ago.

“Yes, there are folks who were adults, or young adults, when they acquired HIV,” Granados continues, “but then there are also those of us who were born with HIV or acquired it in childhood and who are still under 50. We’ve been living with HIV longer than a lot of people who are also long-term survivors. We have been on medication for decades, and so we can experience a lot of similar issues that our older counterparts are facing as well.”

It’s not a question of pitting one group against another. Since the prediction was made that the majority of people living with HIV would be over 50 by the year 2015 (CDC didn’t make it official until 2018), a lot of attention has gone to this group.

But clearly, long-term survivors are not only people over 50.

Stigma. Pill fatigue. Complications from the virus. Time may not heal these wounds. Twenty years is twenty years, whether you started at age 25 or at five years old.

As Granados noted when titling the 2016 documentary she produced to remind the world that many children had also survived: *We’re Still Here*. (See the July+August 2016 issue of POSITIVELY AWARE.)

“I AM A LONG-TERM SURVIVOR of HIV and I am also 30 years of age,” says **TRANISHA ARZAH**, a writer and activist. “That may be odd to hear for some, but it’s actually nothing new. We were just the children, the grandchildren, and the kids who needed blood transfusions [or in Granados’ case, her mom].

“Long-term survivors are defined as having an HIV/AIDS diagnosis before 1996. They share those earliest and darkest years of the epidemic when there were no effective treatments. We were there too,” says Arzah. “We went through those dark ages along with the world, but we just didn’t have a platform or a voice yet.”

CAMERON SIEMERS, 39, was diagnosed with HIV at age seven from a blood factor he received to treat his hemophilia at age three. “It’s not like young survivors are forgotten about. It’s more like we’re never really thought of at all,” Siemers says.

“It’s not better or worse, it’s just different,” he says. “A lot of us who grew up with it have different issues and different problems and relating, in general, is harder. I’m not gay, and I’ve met plenty of gay people and they’re brave and amazing, but as far as relating in certain support groups, there are so many different problems they have that I never really had to face. A lot of us talk about that, how the support groups are mostly geared towards—and rightfully so—the gay and transgender population.”

Siemers finds a special solace from other people his age who also grew up with the virus, no matter their differences.

“The bonds I have with people who’ve grown up with HIV—there’s almost an instant connection when I meet somebody new, even now, and I’m not that young anymore. But the ones I have with the people I grew up with are amazing,” says Siemers. “Having had that connection as a kid really helped me a lot, and I think helped them as well. I guess it’s just like, *Oh, you get it.* That feeling of not being alone was, and still is, very supporting. We all as a kid didn’t really come out. It was a secret we had for a long time.”

Young people, however, come of age and scatter across the country for school, work, and other opportunities. The children who met in summer camps for those living with HIV and became lifelong friends are no longer able to go to dinner or socialize together. Fortunately, all three say that online is where they’ve found long-term survivors of their generation connecting, even before the isolation of the COVID-19 stay-at-home orders.

Arzah is emphatic: “We hope to have our space one day where we can reconnect or connect for the first time as long-term survivors born with HIV or acquired HIV at childhood age, just as our fellow long-term survivors have had in the past.”

As people reach out for connection one way or another, in HIV, the idea that “aging” represents a certain age seems to remain. Thankfully, that is changing.

“The Reunion Project has long supported and been inclusive of people born with HIV as long-term survivors,” says Matt Sharp, co-founder of the national

'I am a long-term survivor of HIV and I am also 30 years of age.
That may be odd to hear for some, but it's actually nothing new.'
TRANISHA ARZAH

network of long-term survivors of HIV. While there is currently no young long-term survivor on the network's expanded steering committee, it remains a priority to include them in leading their efforts going forward.

Granados agrees that advocacy efforts and events aimed at long-term survivors are increasingly recognizing younger people. At the same time, she sees younger people speaking up more for themselves.

"Over the past few years there's been an increase in inclusion," says Granados. "I think also that just like my peers have gotten older, they have gotten more vocal. I see us represented a little bit more, at least socially, when people are talking about long-term survivors.

"But it's still not like the go-to. It's not what people immediately think about. But I do feel like the community of long-term survivors is starting to be more aware and more inclusive of us. Which makes me happy," she says.

"Oftentimes we're left out of the aging with HIV community, but yes, we're aging too," Arzah notes. "We share similar health complications and experiences of feeling isolated, but it may just look different. Of course, we're different generations, but it's so important that different generations listen to each other, because we have so much to learn from each other and to connect over. At the same time, it is important for us and the public to witness our different lenses as long-term survivors of HIV."

EMILY CARSON, 36, became interested in HIV advocacy at the age of 12 when a friend at school was mistreated for having the virus. She began volunteering with Y+, an international organization working on behalf of young people living with HIV.

"When the focus 10 years ago moved to aging with HIV, when we hit that 30-year mark in the epidemic, it was really clear that young long-term survivors weren't being a part of that conversation," she says.

"Advocate for yourself. And advocate for your friends," Carson advises. "A lot of the social groups, and the art therapy groups, and the having-dinner-together and getting together and sharing needs to continue. *This weird thing is happening to me; is it happening to you too? Because I don't know what this is.* Because we're not getting back to normal in the near future. But we can do those things online."

"Where I see the lack of representation right now is in research, but also in just supporting one another and being able to create spaces where we can connect socially and get emotional support," Granados says. "I feel like that continues to be a need, although we really have taken it into our own hands. Folks have really started to connect on their own through social media."

BOTH GRANADOS AND CARSON expressed concern about research in young long-term survivors.

"It's interesting to look at people I know who were born with HIV or seroconverted when they were very young and see the same effects and the same medical issues as a lot of the people who are older, in their 50s and early 60s, or who have had HIV for 20 or 30 years," says Carson. "They're having a lot of the same symptoms and syndromes. Medical issues and issues with drug adherence. Drug access, because a lot of the medications don't work anymore. They really got tested on, because they didn't have pediatric formulas. A lot of people I know are on their last-chance drugs at this point. What does that mean for the next 35, 40 years of their lives? There's early onset dementia. I've seen it in my friends. And they've seen it within themselves."

"Right now, when I'm hearing a lot of the information about how HIV impacts folks who are aging, it's just so vague, because I'm aging too," says Granados. "I've been living with HIV just as long. So that's what I'm curious about. In terms of issues that come up, does it have to do with age or because we've been living with HIV so long and have been on medication this whole time and all of that. But there doesn't seem to be too many answers about what I should be expecting at my age even now."

Granados, who holds a master's degree in social work, continues working during the pandemic at the Children's Hospital in Los Angeles. As HIV Prevention Manager for the hospital, she hasn't worked at home during COVID-19 because her clinic remained open. Arzah works full-time with the Louisiana SPCA and contributes writing from her home in New Orleans. Carson, who grew up in the states, mostly New York, and struggles with a genetic condition, works at Uplift Kitchen in Toronto, helping to counter food insecurity.

Siemers hasn't been as lucky. He had to leave his job in health care. He had a kidney transplant five years ago. Although he felt immediately better after

‘I see us represented a little bit more, at least socially, when people are talking about long-term survivors.’

GRISSEL GRANADOS

COURTESY OF TRANISHA ARZAH AND GRISSEL GRANADOS

receiving his mother’s kidney, he spent three years on dialysis, a grueling process for someone as small and thin as he is. It also took a long time to find himself at the University of California Los Angeles (UCLA), with many resources and where experts could take care of his hemophilia, HIV, and heart disease, and perform his transplant. “All that’s taken a toll,” he says. “It’s the effects of being sick so long, and trying to find a normalcy in life that’s difficult to do. I think a lot of people I know who are growing up with HIV are just trying to be normal.”

All four say they’ve lost friends, first in childhood, and then childhood friends and newer friends later in life. Like Granados, who also grew up in Southern California, Siemers made lifelong friends at Camp Laurel for kids with HIV, and at Dream Street Camp, for children with physical disabilities.

“One of the kids who I knew since he was 13, we were actually in the same hospital at the same time, and had the exact same thing wrong with us,” Siermers says. “We shared a room and he … he passed away. And back then, when I was around 20 or 21, to see somebody I know and saw grow up, it was jarring for me. As of now, I’m doing really well, and all my friends from back in our youth, with the treatments—it’s doing a lot of good. But it’s still a concern, even now, because we’ve been infected so long that we have so many different problems from the disease, we don’t know if something’s going to come up and, you know, make us sick again.”

Siemers continues to speak out about HIV publicly when he can. “I’ve had very rare experiences where I’ve had to deal with people acting ugly towards me. And people have no idea about HIV and AIDS. They think it’s still a death sentence. They think you can get it through touching. It’s really weird to hear at this time. And I live in California, which is like, the most liberal state in the country, and there is so much misinformation, or lack of information, about HIV and AIDS. And having that stigma, when you do feel it, is one of the worst feelings ever, that people won’t even come near you or touch you.”

Siemers has a super power in a nonprofit he started in 2008, raising money for “life grants” for young people with life-threatening illnesses to help them achieve a dream job. Some are still contributing to the work they began more than 10 years ago.

“We give them money for a project they can do in the community that helps them and somebody else. We give them something that they can do beyond their life expectancy. I didn’t know what to do because I really wasn’t planning on a future. I just pretty much lived day by day. And when things like the future come up, a lot of people in my position are confused.

“One girl went to Africa, through a nursing program in her church, and lived in a village, and helped out a clinic nearby. She is amazing. Our applicants come up with incredible ideas. That’s my favorite part, meeting them and hearing what they have to say and what they want to do,” he says. “What do we do for a life we weren’t supposed to have? So we try to provide a little support for that.”

Arzah continues to blog. *We’re Still Here* from Granados has definitely left its mark, and Siemers is looking to produce a podcast with friends, including fun things in the mix.

Many long-term survivors had a life before HIV. They didn’t.

They’re still here.

GO TO cameronsiemers.org for more about his foundation.

First HIV and now COVID-19
A look at the past and the future

The president of the largest historically Black academic health center lays out the pandemic's effects on different populations

COMPILED BY **ENID VÁZQUEZ**

In this year,* *the 40th anniversary of the CDC's report of unusual immune deficiency found among young gay men, eventually leading to the discovery of HIV, CROI examined the COVID-19 pandemic in relation to the AIDS epidemic. James E.K. Hildreth, PhD, MD, President of Meharry Medical College, in Nashville, the nation's largest private, independent, historically Black academic health center, was invited to speak to the history of HIV and SARS (severe acute respiratory syndrome) and their unequal impact on specific groups of people. Dr. Hildreth began his plenary talk, "Disparities in Health: From HIV to COVID-19 and Beyond," with that CDC report, and how the fact that only gay men were affected created an atmosphere of discrimination. It was a discrimination that quickly encompassed other oppressed groups.

"It's important to know that many elected officials, from the president to senators to elected representatives in Congress, really treated this problem with outright disdain because of the strong association with being gay at the time," Dr. Hildreth said. But, "by the late '80s and early '90s, an interesting thing occurred when the majority of cases diagnosed in Stage 3 AIDS were among African Americans and Hispanics.

"You can actually see that for the decade from 1985 to 1995, there was a steady decline in whites who were diagnosed with AIDS. The situation for African Americans was just the opposite. There was a steady increase in the percent of African Americans who were representing the AIDS cases, and those two lines crossed. [Cases among African Americans continued to increase as the cases among whites continued to drop.]

"And even though antiretrovirals were available, there continued to be more and more diagnosed cases of AIDS in African Americans because they often came in late to care. And by the time they arrived for health care, their immune system had been destroyed, and there was not much that could be done for them. Even as late as two years ago, 2018, we still see that for the most part, African Americans especially, and Hispanic men who have sex with men, account for more than half of all the new HIV infections here in the United States.

"So, for almost the whole time we've known about HIV/AIDS, it's been a problem of African Americans and people of color around the world and here in the United States. Again, more than half of all the new cases occur among gay and bisexual men.

"In December 2019, officials in China reported dozens of cases of pneumonia of unknown cause. In early January they identified a novel coronavirus. On January 19, 2020, the first case was reported outside of China, in Thailand. On January 30, the World Health Organization, W.H.O., reported it to be a public health emergency of international concern. Quite honestly, it should have been declared a pandemic at that time. And then March, as we approach the first anniversary, W.H.O. declared it an outright pandemic.

"In China, an observation was made pretty early on that in a racially homogenous nation of over a billion people, seven out of 10 of those persons who died from COVID-19 shared something in common. They all had a co-existing comorbid condition: hypertension, diabetes, ischemic heart disease, chronic lung diseases. They'd had a stroke, or suffered from congestive heart failure.

"So, it's not a surprise that here in the United States, the burden of disease and death from COVID-19 has been borne by Black and Brown people, because all of those underlying conditions that made persons in China subject to severe disease and death are disproportionately present in minority communities. Half of African Americans or thereabout have some cardiovascular disease. A third, almost half, of them have hypertension. The overall rate of hypertension in the United States is 33%, but among African Americans it's much higher than that. For Blacks and Hispanics also there's a huge proportion of these individuals who are obese, and obesity has turned out to be a major determining factor for severe disease and death from COVID-19. And of course, diabetes as well.

"So, it is not a surprise that African Americans and Hispanics, who have all of these major conditions at a much higher rate than whites, have borne a disproportionate burden of severe COVID-19 disease and death.

"In data from late summer last year from just four states—Michigan (mostly Detroit), Illinois (mostly Chicago), North Carolina, and Louisiana (mostly New Orleans)—the differential rate of deaths between Blacks and whites per 100,000 individuals was almost ten-fold in Michigan and five-fold in Louisiana. [The rate for Blacks in Illinois was 7.2 and 1.3 for whites; in North Carolina, it was 0.6 for Blacks and 0.4 for whites.]

"These numbers and these statistics are quite alarming. And this has been consistent throughout this crisis. I should say even today there are counties in the country where the differential rate of death from COVID-19 is at least six-fold in some instances.

"So, it's not an exaggeration to say that COVID-19 has been devastating for people of color.

"If you look at the two pandemics spaced 40 years apart, both HIV and SARS reveal a deep chasm in the health status between African Americans and Hispanics and Caucasians. Both of these were also highlighted by failed national leadership because of politics and prejudice that delayed the response to these pandemics, but also made for an ineffective national response early on. And the longstanding disparities in chronic diseases are major contributors to the disproportionate impact of both of these viruses on disadvantaged communities. In order to understand the inequities revealed by HIV/AIDS and COVID-19, they are best understood in the context of what is called 'social determinants of health.'

"The W.H.O. definition of social determinants of health [SDOH] is 'the conditions in which people are born, grow, live, work, and age. SDOH are shaped by the distribution of money, power, and resources throughout local communities, nations, and the world.'

"There are five major categories. First, education, or the quality of education, and access to it. Then health care quality and access to it, and the built environment and nature of the neighborhoods we live in. There's also social and community context, and of course our economic status.

"The education status is important in this context because access to health information is also limited when there's limited access to quality education and educational institutions. I mentioned before one of the main concerns for HIV and the fact that so many African Americans were being diagnosed with late-stage disease is that oftentimes these individuals came into care very late, after the virus had decimated their immune systems.

'...health equity does not mean we need equality in health care.
What we need to do is make sure that each person has their needs met and each community has their particular needs met.'

"Another aspect of COVID-19 is that many of these individuals have poorly managed chronic conditions, like hypertension and asthma, because they don't have access to quality health care or many of them don't have a primary care physician. So access to health care and the quality of health care is a major social determinant of health that has been revealed by both of these pandemics.

"As just one example of the neighborhood and the built environment, which could also apply to the social context, many individuals who have been really stricken by COVID-19 live in multigenerational households where the virus can spread very quickly, especially when there are grandparents and older individuals living in those households. That's been a major contributor to the COVID-19 challenge.

"Also, as just one example of deaths related to both HIV and COVID-19, is mass incarceration, which is a big problem in this country for huge numbers, especially Black males, who have been incarcerated from an early age. That congregate setting has proven to be devastating for the spread of COVID-19. Many of the deaths that have happened here in the United States from COVID-19 have been because so many people have been incarcerated and the prisons were not tested quickly early on for the virus. And also for HIV, mass incarceration also created some social networks that made it quite easy for the virus to spread in Black communities. So, this social context and community context are really important social determinants of health as related to the two pandemics.

"One of the other factors that relate to both of these pandemics is access to health care and the quality of health care. And also the numbers of African Americans and Hispanics who are part of the healthcare system, especially as physicians. Between 1908 and 2008, the percentage of Black physicians in the United States never got to be more than 2.5%. It was only in 2008 that that number began to climb. And it still sits just under 5%. So, just under 5% of physicians in the United States are Black even though African Americans represent 13% of the population.

"There are a number of factors related to this. One of them has to do with pipelines. Not enough individuals, especially Black males, make it through college prepared to go to medical school. And that relates to what happens in high school. A lot of individuals do not make it through high school, so they don't have the opportunity to go to college in the first place. That observation is also true for Hispanics. That number is just under 6% of the physicians in this country even though they represent about 20% of the overall population.

"The disparity in access to health care is exacerbated by the fact that so few physicians are physicians of color. There are many data to demonstrate that the outcomes for minority communities and having access to primary care providers would be greatly enhanced if there were more physicians of color to take care of their communities. This is a really challenging problem that we need to find a way to deal with.

"I want to make the point that transitioning to health equity does not mean we need equality in health care. What we need to do is make sure that each person has their needs met and each community has their particular needs met. Our goal should be for each person to achieve their personal best health and wellness. Not every solution would be the appropriate one for all people.

"A great example of this is that the approach the United States took to dealing with COVID-19 was basically a population approach that assumed that the risk of COVID-19 was the same for all of the people in our country. That was clearly not the case.

"There are vulnerable populations that we knew about from the beginning—older individuals, people living in nursing homes and assisted living facilities, and also people of color in poor communities.

"We should have taken a more focused approach that recognized that the challenge in dealing with COVID-19 was not the same across the board for the whole population. So, the population approach was contributing to the inequities in outcomes of COVID-19. Achieving health equity does not mean equality in what we do for our communities. It means customizing our approaches to meet the needs of those communities and individuals who live there.

"So, two pandemics—HIV/AIDS and COVID-19—40 years apart, reveal a wide gap in health status in minorities compared to whites in the United States. Truthfully, this gap is longstanding, and is best understood in the context of the social determinants of health. Our goal should be for each person to achieve their best personal health and wellness. That means recognizing and meeting individual needs and community needs, and knowing that the same approach would not work for all. Closing the health gap here in this country, revealed by these two pandemics, is going to require coordinated efforts across a range of organizations, not just health care itself. Because again, health care only accounts for about 10 to 15% of the overall health of an individual. The rest of it is determined by social conditions and behaviors."

"So we're going to need a coordinated effort for over an extended period of time from national agencies and organizations, businesses, and agencies to solve this problem.

"I would also say that I hope that both of these pandemics make it clear that what we need to do in this country to make sure that this does not happen again is to take a more focused approach the next time we deal with a public health crisis like this, because it would result in many more lives being saved and less resources being needed to deal with it."

Dr. James Hildreth serves as Associate Director of the Tennessee Center for AIDS Research (CFAR) and was appointed to President Biden's COVID-19 Health Equity Task Force.

Vaccine nationalism is killing us

How inequities in research and access to SARS-CoV-2 vaccines will perpetuate the pandemic

BY **JEFF BERRY**

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This year's Martin Delaney presentation, usually one of the highlights of the conference and part of the young investigators pre-meeting, was for the first time highlighted in the CROI opening plenary. As Jim Pickett of AIDS Foundation Chicago stated in his introduction, "We could not be more thrilled at this opportunity to feature the voices of community and activism during this opening plenary of virtual CROI 2021, something unusual for CROI that's something I hope we carry forward." Gregg Gonsalves, a 2018 MacArthur Fellow, co-founder of Treatment Action Group and an assistant professor at Yale School of Public Health, and Fatima Hassan, a South African human rights lawyer and social justice activist, and founder of the Health Justice Initiative, had a sobering and timely discussion about how vaccine nationalism is impeding access to COVID-19 vaccines in developing countries around the globe, and what needs to be done to ensure equitable access.

Vaccine nationalism is "hedging your bets, where you're trying to get supply from… many different sources, with the result that many countries, over 130 countries in the global South, have very limited access to vaccines," noted Hassan. Gonsalves pointed out that we will be chasing variants of the SARS-CoV-2 virus for the foreseeable future. "If you vaccinate one quarter of the population, and you leave the other unvaccinated, it just needs variants to spread."

They also discussed the similarities and differences between the HIV/AIDS pandemic and COVID-19. Gonsalves, who graduated from high school in 1981, recalled that it took then-President Ronald Reagan seven years to say the word "AIDS" during his time in office. "As Larry Kramer said back then, AIDS was about disposable people, people who didn't matter. They were gay men, they're people who use drugs, they're people who are engaged in sex work, they're people of color across the United States. These were disposable people who really didn't merit a full-scale research-prevention-treatment enterprise by the largest country on earth. And millions of people around the world suffered from those early decisions, which delayed the fight against AIDS many, many years ago. Now, for many of us, if you fast forward to the current moment, we see another set of disposable people in the United States, the impact of COVID-19 among communities

'...philanthropy will not buy you equality'
...All of these institutions that are meant to actually be scaling up supplies, need to act with a bit more force and a bit more pressure, not just a moral pressure.

of color in the United States, it's just horrifying when you compare it with their European American counterparts."

There is reason for hope, however. "The scientists and clinicians...who supported us, during the HIV/AIDS years, did two important things," says Hassan. "They contributed to scientific knowledge, which they [are] doing right now. But secondly, they call it out. They call the nationalism out, they call governments out, they call pharmaceutical companies out, and they insisted that there be equitable access where public health is prioritized. And many of those scientists and clinicians are actually at the forefront of COVID-19 research in South Africa and in other parts of the world as well. And so we look to them again, for the leadership, for them to be the compass, to shine...a spotlight on the issues of inequity in relation to vaccine access for COVID-19."

One potential solution is what's referred to as the TRIPS waiver. According to Médecins Sans Frontières (MSF), "enabled by IP [intellectual property] monopolies, corporations continue to pursue secretive and limited commercial deals that exclude many low-and middle-income countries, even in the midst of the pandemic. The waiver proposal could help by removing legal uncertainties and risks for potential producers and governments to quickly start preparing to scale up production and supply of treatments, vaccines, and other essential medical tools."

Other solutions were touched upon, including the transfer of technology, and collaboration between governments, pharmaceutical companies, and global entities such as WHO, COVAX (COVID-19 Vaccines Global Access), and Gavi, The Vaccine Alliance.

"We cannot wait for volunteerism, and for benevolence and for charity," says Hassan. "Somebody a few weeks ago said it quite clearly—'philanthropy will not buy you equality'...All of these institutions that are meant to actually be scaling up supplies, need to act with a bit more force and a bit more pressure, not just a moral pressure. But they also need to now insist on certain minimum norms and standards, because if this is the way we're dealing with this pandemic, which we thought would be different after the HIV/AIDS pandemic, then what happens with the next pandemic? It means we'll never get to a system where we actually have equitable health and where we actually decolonize public health."

"We know what happens to infectious diseases left unchecked," says Gonsalves. "That was the lesson of the AIDS epidemic, but we all learned too late to avoid a global catastrophe. We're pleading, pleading with the attendees at CROI, to be activists with us again. Maybe you can't march, but you can get on the phones, you can email, you can get on social media and ask for a people's vaccine, so that we have access everywhere for everyone."

VIEW the entire presentation on YouTube: youtube.com/watch?v=2zYxBQHQbq8.

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Some take-home messages from CROI

BY **ENID VÁZQUEZ**

COURTESY OF VIRTUAL CROI

Is COVID-19 hospitalization more common among people living with HIV (PLHIV)? No. However, most studies have found a greater risk of severe COVID-19 complications among PLWH, but this was dependent upon age and comorbidities (co-existing conditions and illnesses such as diabetes)—the usual suspects for the new pandemic. Still, different groups of researchers saw contradictory findings when looking at COVID-19 in PLWH. It's a matter of the different comparisons used, which become apples to oranges across studies. For example, some report a higher rate of death due to COVID-19 in PLWH while others don't. "The Effect of HIV on COVID, Effect of COVID on HIV" symposium featured four speakers from around the world.

***Vive la France*—again.** On-demand PrEP with Truvada was just as good as taking the HIV prevention pill every day, first for one year in a previous report and now with updated results out to three years, according to the ANRS Prevenir study out of France. ANRS noted that on-demand PrEP with Truvada has been recommended as an alternative to daily PrEP for MSM (men who have sex with men) by guidelines from the International AIDS Society-USA, the European AIDS Clinical Society (EACS), and the World Health Organization, "but has not been endorsed yet by CDC due to limited real-world experience."

Non-Hispanic Black, Hispanic, and non-Hispanic Asian patients with HIV were more likely to contract COVID-19 compared to non-Hispanic White patients," according to the U.S. National COVID Cohort Collaborative.

Standard HIV testing may not be good enough to find an infection in someone using long-acting cabotegravir (CAB LA) for PrEP (which is still in clinical research). And four participants who acquired HIV still had on-time monthly injections and sufficient drug concentration in their blood to prevent the virus, out of 12 infections found after approximately two and a half years on CAB LA in the HPTN 083 study. Some of the 12 individuals had resistance to the HIV integrase inhibitor drug class, of which cabotegravir is one. With more than 4,000 people in the study (half on the comparator PrEP medication Truvada), the prevention rate shown was tremendously effective.

Cabenuva (CAB LA) was just as good when taken every 8 weeks as it was when taken every 4 weeks, according to the ATLAS-2M study. This was at nearly four years of clinical study with the new injectable HIV drug on the market, with more than 1,000 participants. Tolerability was good, and it was similar between the two groups. See *Briefly*. (ATLAS stands for "Antiretroviral Therapy as Long-Acting Suppression," and 2M refers to two months.)

In PLWH with lots of HIV medications under their belt (heavily treatment-experienced), control over their virus was found with a long-acting drug still in development, lenacapavir (LEN). With just two injections in half a year (administered once every six months), 19 out of 26 individuals in the study (73%) were able to achieve undetectable viral load (less than 50 copies). These individuals had extensive drug resistance. People can't take LEN alone, but need to use other HIV drugs as part of their treatment regimen. Findings are from Phase 2/3 results in the CAPELLA study. See *Briefly*.

THRIVE: Decreasing HIV in men of color
The THRIVE demonstration project funded seven health departments to establish community collaboratives providing HIV prevention and care services for MSM of color (including the promotion of testing and PrEP). Comparing these jurisdictions with others not funded, THRIVE found significant decreases in new HIV diagnoses for the Black and White MSM in funded jurisdictions, but not for Latinos. Only White MSM had decreases in unfunded areas. THRIVE is funded by the U.S. Centers for Disease Control and Prevention (CDC). (See Abstract 106.)

Gender-affirming surgery and HIV
The title from New York City's Department of Health and Mental Hygiene and Callen-Lorde Community Health Center says it all: "Gender-affirming surgeries accessed through Medicaid are associated with high and sustained viral suppression among transgender people with HIV in New York City, 2013-2017." The report from lead researcher Cristina Rodriguez-Hart, PhD, MPH, from the health department, and the study team noted that transgender people living with HIV "have indicated that gender-affirming and non-discriminatory healthcare was their top health concern" and that "mental health outcomes have improved over time after accessing gender-affirming surgery." (See Abstract 107.)

Pregnancy update plus HIV therapy for children

A round-up of CROI reports

BY **ENID VÁZQUEZ**

GO TO croiconference.org to read the abstracts and watch video presentations.

Dolutegravir in pregnancy

Once again, dolutegravir was shown to be safe and effective for pregnant women and their infants.

Previously, the DolPHIN-1 study found that for pregnant women, dolutegravir decreased viral load faster than efavirenz did in the first 26 weeks of treatment.

Now, the DolPHIN-2 study (Abstract 175) reported on what happens when pregnant women start antiviral treatment late in pregnancy, in their third trimester.

Half of the women on dolutegravir achieved undetectable viral load in around four weeks, while it took about 12 weeks for half the women on efavirenz to reach undetectable. This is a huge difference, especially for pregnancy, where time is of the essence for the infant, not just the patient carrying that baby.

Undetectable viral load (less than 50 copies) remained strong for both groups out to 72 weeks postpartum (116 of 125 women on dolutegravir vs. 114 of 125 women on efavirenz).

The research team noted that the study results support World Health Organization (WHO) recommendations for using dolutegravir at all stages of pregnancy as well as conception. The HIV perinatal treatment guidelines of the U.S. Department of Health and Human Services (DHHS) also support dolutegravir for conception and pregnancy.

There were three infant transmissions in utero for the dolutegravir group compared to one in the efavirenz group, which occurred postpartum to the baby of a breastfeeding mom. Both dolutegravir and efavirenz were effective in preventing postpartum transmission in breastfeeding (this was one of the goals of the study, for mothers who chose to breastfeed). The one infection observed despite adequate drug levels in the mother shows that transmission in this circumstance is still possible.

Women had fewer adverse events with dolutegravir than with efavirenz.

More dolutegravir in pregnancy

The IMPAACT study also reported good results with dolutegravir vs. efavirenz for new mothers and infants. Previously it reported similar good results with DTG vs. efavirenz in pregnancy. Now it reported 50-week post-partum data showing that safety remained similar for all the women and infants. For the moms, undetectable viral load results remained similarly high. (Abstract 177)

COVID-19 in positive pregnant women

For women with a high-risk pregnancy—complicated by conditions such as diabetes, obesity, HIV, or high blood pressure—COVID-19 was not more dangerous for the women who were living with HIV.

"No significant differences for COVID-19 infection impact and outcome were noted for [pregnant women living with HIV] versus those without HIV," reported a group of South African clinicians and researchers (See Abstract 171.).

But the positive women, the team noted, were on HIV treatment and had undetectable viral load.

COVID-19, however, hit the women hard.

According to the report, "The impact of COVID-19 infection in pregnancy was severe (40% complicated by pneumonia; 8% crude mortality rate); neonatal outcomes were favorable."

The study team from Stallenbosch University were in a good position to note differences in COVID-19 in pregnant women. Most of them are clinicians working in a high-risk pregnancy clinic outside of Capetown, at Tygerberg Hospital in Tygerberg, South Africa.

The women were tested for SARS-CoV-2 infection only when they had symptoms.

One hundred pregnant women had COVID-19, and 28 of them were also living with HIV. This was in line with the number of women in the clinic living with HIV overall, 24%.

The women living with HIV, however, had it well controlled. Most of them, 27, were on anti-HIV therapy. Nineteen had undetectable viral load (73%). Half of them had a CD4 count above 441 (with a range from 14–838).

The study team collected COVID-19 data from May 1 to July 31, 2020. They went on to collect pregnancy and birth outcomes out to October 31, 2020.

Most of the COVID-19 infections were diagnosed in the 3rd trimester (81%). Half

7X

greater risk of infant HIV if anti-HIV drugs are delayed until the third trimester rather than started during the first or second trimester of pregnancy.

WORLD HEALTH ORGANIZATION, REPORTED BY DOLPHIN-2

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of the women delivered within two weeks of the diagnosis.

Forty women developed pneumonia; 13 developed adult respiratory distress syndrome (ARDS); and six required invasive ventilation. Eight women died, seven from ARDS and one from advanced HIV with bacteremia.

Pregnancy outcomes included 91 live births (including 5 sets of twins), 5 stillbirths, 4 miscarriages, 2 mothers who died while still pregnant, and 1 medical termination of pregnancy. Birth outcomes for two women were unknown. The newborns did well, but one died shortly after birth.

CROI co-chair Sharon Hillier, of the University of Pittsburgh Medical Center and the Magee-Women's Research Institute, said, "The bottom line is COVID-19 is very bad for pregnant women, but is not influenced by ART [antiretroviral therapy]."

Liesl De Waard, MD, an obstetrician gynecologist who presented the study, said the clinician team feels they should at least give women the option of being vaccinated against COVID-19.

With regard to vaccination, Dr. Hillier said, "We heard about the need to generate data in pregnant women who were excluded from COVID trials. COVID vaccination in pregnant women is highly merited. Many of us who work in the women's health space really feel women ought to be able to decide for themselves. Certainly many women providers who are pregnant have elected to receive vaccination and many non-providers have elected vaccination."

Dolutegravir superior to other meds for children

Dolutegravir (DTG) was more effective at decreasing viral load in children than standard-of-care medications, which included efavirenz and protease inhibitors.

Anna Turkova, MD, said the study results "support an urgent call for dolutegravir scale-up in children."

Dr. Turkova, of the Medical Research Council Clinical Trials Unit at University College London, presented the study findings on behalf of the ODYSSEY/PENTA-29 Trial.

The study was the first randomized, placebo-controlled trial in children for HIV therapy. Children were taking HIV medication for the first time (treatment-naïve) or switching to their second-line therapy.

Dr. Turkova said that the results "clearly demonstrated dolutegravir was better." She noted that in the U.K., dolutegravir is already a preferred drug for children.

Children had a greater drop in their viral load at 48 weeks (one year) that continued out to 144 weeks (three years). They also had a better lipid profile with dolutegravir, which may be better for cardiovascular health, Dr. Turkova said. They also did not have the weight gain increases seen with dolutegravir in adults.

"DTG-based ART [antiretroviral therapy] was superior to SOC [standard-of-care] based on treatment failure [400 viral load or higher] by 96 weeks in children/adolescents starting first- or second-line," the study team reported (Abstract 174). "There were no safety concerns on DTG. These results support WHO guidelines which recommend DTG-based regimens as preferred ART for children [weighing 14 or more kg (31 pounds)] starting first- or second-line ART, allowing harmonization with adult treatment programs."

Results in children weighing less than 31 pounds are expected later this year.

Most of the 707 children in the study were in Africa, but some were in Thailand or Europe. Dr. Turkova said the results were consistent across the countries. Most of the children in the standard-of-care arm received efavirenz for first-line therapy while those on their second-line treatment had a protease inhibitor-based regimen (the majority given Kaletra and 25% given Norvir-boosted Reyataz).

CROI and COVID, and International Women's Day

LAST YEAR, the Conference on Retroviruses and Opportunistic Infections (CROI) struggled to stay on track in the face of a growing world-wide pandemic before shutting down the event scheduled to take place in Boston and going virtual instead.

This year, CROI organizers were old—and weary—hats at dealing with the new pandemic on top of the old one, in which conference attendees are already specialists.


HILLIER

HILLIER COURTESY OF UNIVERSITY OF PITTSBURGH

"We were very aware when we were planning the program that people would have Zoom fatigue," said CROI co-chair **Sharon Hillier, PhD,** of the University of Pittsburgh. "And so what we wanted every day was to have a limited number of live sessions that would allow lots of audience participation."

Indeed, virtual CROI 2021 was basically a half-day event during its run March 7–10, along with symposia recorded by speakers to be listened to at a later time. Once again, COVID-19 led to a precedent at CROI.

"We are in a unique time both with COVID and HIV," said Dr. Hillier. "We have a huge footprint of COVID science in this program. About half of our invited talks have some COVID content. And 25% of submitted abstracts have COVID as part of the topic."

The organizers created "Science Spotlights" to take the place of the interactive poster sessions in conference halls, where hundreds of attendees mill around looking at the research reported on posters and talking with presenters. "We can generate those chats that resemble somewhat what happens in those hallways," said Dr. Hillier.

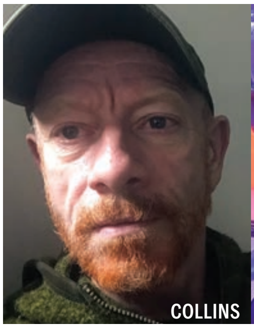
Dr. Hillier made her remarks on Monday, March 8, perfect for someone working in women's issues, as she does.

"Today is International Women's Day," she noted. "It reminds me how women have been disproportionately impacted by HIV. And we're hearing that women have been disproportionately impacted by COVID in terms of the job losses and economic loss. So today is also a good day to remember the women in our lives and the need to address disparities as they relate to women everywhere."

Amen, sister. —ENID VÁZQUEZ

Highlights from CROI's Community HIV

BY **KARINE DUBÉ** AND **MICHAEL LOUELLA**


COLLINS


CARTER


PETERSON


ANTHONY-GONDA


DROPULIĆ

The annual Community HIV Cure Research Workshop, sponsored by Treatment Action Group (TAG), many of the Martin Delaney Collaboratory CABs (community advisory boards), and other advocacy groups, went virtual again this year, breaking up into three sessions—two sessions before the 2021 Conference on Retroviruses and Opportunistic Infections, on March 4–5; and one session after on March 16. The workshop sessions (available on YouTube) aim to foster dialogue between biomedical HIV cure researchers and community members in an effort to deepen understanding of the science behind the search for an HIV cure. Following are a few highlights.

Simon Collins [i-base.info/about-us/i-base-staff/simon-collins] provided an overview of HIV treatment interruption studies in the time of COVID-19. Several research teams have halted HIV research activities in the last year. For trials that continued during the pandemic, additional safeguards have been put in place to ensure safety of trial participants. For example, some research teams have included COVID-19 directly as part of the informed consent, modified exclusion criteria to reduce COVID-19-related risks, and integrated SARS-CoV-2 testing and vaccination as part of the trial schedule of events. The HIV cure research community has responded rapidly to new changes due to COVID-19 while prioritizing participant safety. COVID-19 has given scientists an opportunity to evaluate whether risks of HIV cure trials are justified and how we can continue to mitigate risks. Several HIV cure trials are expected to re-open in 2021–2022. youtu.be/NSWzGn6DtqU

William B. Carter, the chair of the BEAT-HIV Collaboratory Community Advisory Board [beat-hiv.org/community-outreach] provided the perspective of an HIV cure research trial participant. Carter spoke about the importance of giving a voice to people who live with the virus and decide to contribute to the search towards an HIV cure. Recounting his personal journey, he discussed how he turned obstacles into possibilities in his life, and this carries now to his HIV cure research activism. Participating in an HIV cure trial has given him clarity and more energy to dedicate to community activism. He described his pleasant feeling of not having to take a pill every day and how participating in research has helped him tear down HIV stigma and demystify clinical research. youtu.be/D7wiUlv5H2I

Christopher Peterson, from the Fred Hutchinson Cancer Research Center and the defeatHIV collaboratory (defeathiv.org), provided an overview of gene therapy in HIV cure research. Gene therapy is the treatment of a disease by introducing or changing a gene within a cell that does not pass down to future generations. For HIV, new genes may be used to defend uninfected cells from virus entry or help clear out infected cells. Dr. Peterson discussed how several gene therapy approaches are borrowed from cancer, such as chimeric antigen receptor (CAR) T cells, that were approved in 2017 by the U.S. Food and Drug Administration for the treatment of acute

Cure Research Workshop

lymphoblastic leukemia. Several CAR T cell products are expected to be tested towards an HIV cure in the coming years.
youtu.be/-J7aibsjuz0

Kim Anthony-Gonda, MD, PhD, ASCP, and **Boro Dropulić, PhD, MBA,** from Lentigen Technology, Inc. [lentigen.com/home], discussed progress in moving duoCAR T cells to human testing. duoCAR T cells involve two chimeric antigen receptors—one to clear HIV-infected cells and the other to protect cells from HIV infection. duoCAR T cells have been highly effective against global HIV subtypes and have shown to be superior to monoCAR T cells. Preclinical studies also support the safety and efficacy of duoCAR T cells in animal models. A first-in-human phase I/II study is being planned to evaluate the safety and efficacy of duoCAR T cells in 18 ART-suppressed people living with HIV at the University of California, San Francisco (UCSF) [bit.ly/UCSFduoCARtcellstudy]. Relatedly, an organization called Caring Cross [caringcross.org] is working to make gene therapy more globally accessible to resource-limited parts of the world. youtu.be/UfYDThaVBqU

Mike McCune, MD, PhD [profiles.ucsf.edu/mike.mccune], from the Bill and Melinda Gates Foundation, discussed *bringing safe, effective, and accessible curative interventions to limited parts of the world.* A new collaboration exists between the U.S. National Institutes of Health (NIH) and the Gates Foundation to advance cell and gene therapy towards both sickle cell disease and HIV [nih.gov/news-events/news-releases/nih-launches-new-collaboration-develop-gene-based-cures-sickle-cell-disease-hiv-global-scale]. The goal is to find durable, safe, and accessible gene-based cures for HIV and sickle cell disease that can be scaled and implemented globally. A new HIV Cure Africa Acceleration Partnership (HCAAP) [thelancet.com/journals/lanhiv/article/PIIS2352-3018(20)30232-0/fulltext] has also been created to propel innovations in this area. youtu.be/K4vDvblpj10

Gary Steinkohl, **Matt Sharp,** and **Adam Castillejo** spoke movingly about the legacy of **Timothy Ray Brown**, the first person cured of HIV who recently passed away from leukemia. Timothy is perhaps the most famous example of a research participant coming out from the anonymity designed to protect participants. Known as "The Berlin Patient," he shared his experiences with the world and advocated for cure research. Each of these men has also come out as a cure research participant like Timothy; what they shared about their motivations, which range from survival to hope for future generations, was thoughtful and poignant. youtu.be/vB6FKJShvFI

FOR MORE INFORMATION:
Treatment Action Group's Pre- and Post-CROI Community HIV Cure Research Workshop (2021): treatmentactiongroup.org/webinar/pre-and-post-croi-community-hiv-cure-research-workshop

Karine Dubé is an assistant professor at the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. She is a socio-behavioral scientist focused on integrating a patient/participant perspective to HIV cure-related research.

Michael Louella serves as the defeatHIV Community Engagement Program Manager and is based at the University of Washington and the Fred Hutchinson Cancer Research Center in Seattle.

PETERSON: ROBERT HOOD-FRED HUTCH

A MATTER OF JUSTICE

POSITIVELY AWARE webinar shines a light on health inequities among PLHIV during COVID-19

BY **RICK GUASCO**

CLOCKWISE FROM TOP LEFT: **GINA MARIE BROWN**, **CHRISTOPHER HUCKS-ORTIZ**, **JEFF BERRY**, **RICHARD JEFFERYS**, AND **STEPHAUN E. WALLACE**

For people living with HIV, the COVID-19 pandemic has been especially stressful—from the uncertainty of whether HIV makes them more vulnerable to this new virus or prone to worse outcomes, to exposing them to stark social and health inequities. And with the development of COVID-19 vaccines have come more questions, arising from misinformation in social media and historical medical mistrust, especially in communities of color. To address these fears and questions, POSITIVELY AWARE organized a virtual webinar in March that brought together researchers and community advocates.

A Matter of Justice: COVID-19 Vaccines and Health Inequities in People Living with HIV featured **Richard Jefferys**, the director of Treatment Action Group's (TAG) Basic Science, Vaccines and Cure Project; **Stephaun E. Wallace, PhD, MS**, director of external relations at the HIV Vaccine Trials Network and the COVID-19 Prevention Network, and clinical assistant professor of global health at the University of Washington; **Christopher Hucks-Ortiz, MPH**, director of HIV and clinical services at Black AIDS Institute; and **Gina Marie Brown**, a community advocate who sits on the boards of the Black AIDS Institute and Sister Song, and is a member of The Well Project's Community Advisory Board.

"From the studies that have been done to date, it does look like [having] HIV...is associated with a somewhat increased risk of more severe COVID-19 outcomes," said Jefferys. "It's not a huge increase, and just something to be conscious of, not panic about."

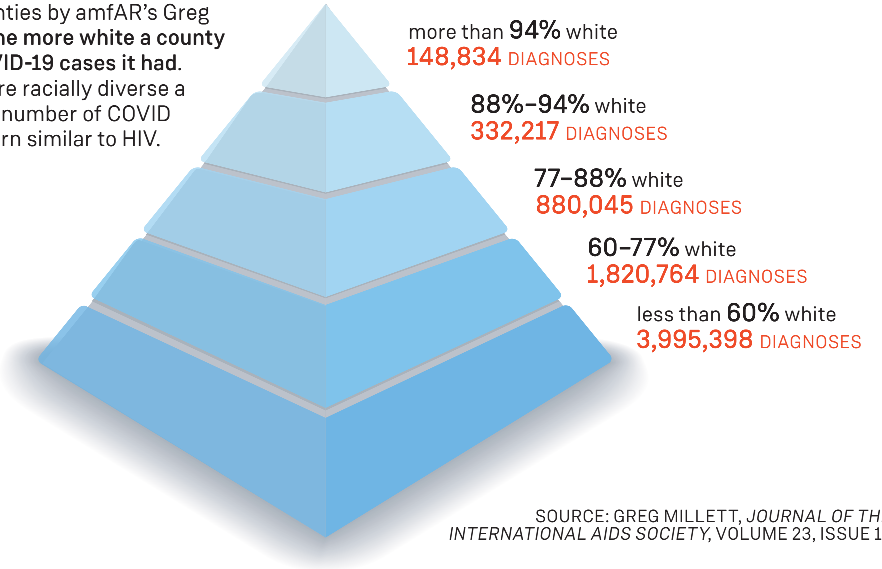
It is uncertain to what extent HIV by itself plays a role, he added, but a lower CD4 count might be significant. "It seems that having a lower CD4 count is a key factor where there's an increased risk of worse outcomes or mortality for people, particularly if they have less than 350 CD4 T cells."

Citing a presentation by Dr. Rajesh Gandhi, of Massachusetts General Hospital in Boston, he noted risk factors for severe COVID-19 outcomes:

- low CD4 count
- older age
- comorbidities and co-existing

Pyramid of disparity

A study of U.S. counties by amfAR's Greg Millett found that **the more white a county was, the fewer COVID-19 cases it had**. Conversely, the more racially diverse a county, the greater number of COVID diagnoses—a pattern similar to HIV.



SOURCE: GREG MILLETT, *JOURNAL OF THE INTERNATIONAL AIDS SOCIETY*, VOLUME 23, ISSUE 11

'We can't leave it up to the same folks who designed this system to design the new system. We'll find ourselves back in the same place.'

conditions such as cancer, cardiovascular disease, sickle cell disease, and type 2 diabetes

- compromised immune system due to solid organ transplant
- obesity (body mass index, or BMI, greater than 30)
- pregnancy
- smoking

Risk factors backed by mixed or limited evidence include:

- comorbidities and co-existing conditions such as moderate to severe asthma, hypertension, liver disease, neurological conditions such as dementia, and type 1 diabetes
- being overweight (BMI between 25–30)

Older adults make up the largest group of COVID-19 cases—and with the worst outcomes. Roughly 40% of the general population was over age 45, according to 2020 U.S. Census Bureau estimates, and more than half of people living with HIV in the U.S. are over age 50. People aging with HIV are more likely to have multiple comorbidities or co-existing conditions and illnesses, which often increase as they get older.

THE DISCUSSION TRANSITIONED to social determinants—and how racial, social, and economic forces, both institutional and systemic disparities, drive the pandemic for people of color who are living with HIV.

Stephaun Wallace pointed to a study by Greg Millett, vice president and director of public policy at amfAR, which compared the racial diversity of counties in the U.S. against the numbers of COVID cases.

"The number of diagnoses is so much higher in the counties where they're less than 60% white," Wallace said. "In a separate paper, he's shown exactly the same pattern for HIV diagnoses. And he created this kind of image to show what the parallels are… there [are] all these pathways through structural racism that contribute to this overlap between SARS-CoV-2 and COVID-19 and HIV."

People of color are over-represented in what have come to be called essential services industries—from retail inventory employees to hospital workers—with little ability to limit their increased public contact and greater potential exposure to COVID-19, said Dr. Wallace. Moreover, they are more likely to be in low-wage jobs that don't provide health insurance, paid sick leave, or the opportunity to work from home.

Citing results from a 2017–2018 survey by the U.S. Bureau of Labor Statistics, Dr. Wallace pointed out that 30% of white employees said they could work from home, while 20% of Black workers, and only 16% of Hispanics said they could.

People of color also tend to live in higher-density housing and in intergenerational home environments, increasing the risk of and vulnerability to COVID exposure.

These social disparities can turn into structural determinants when government funding—and public policy—are determined by data that fail to take into account, or offer only incomplete information about, race and ethnicity.

"There was a report produced by the Urban Indian Health Institute that graded the states on how well they're collecting race and ethnicity data that I think is absolutely important to read," Wallace said.

"What we're really talking about here are systems and how all of these systems sort of work or play together," he said. "Many of these systems are not just contemporary, they have historical standings and originations, and they continue to exist and permeate our communities now, and these things continue to work in opposition to healthcare."

Asked how to address missing demographic data in health and governmental systems, Wallace saw a role for activists.

"Allocation is left up to states to determine how they prioritize populations," he said. "These are opportunities to think about leading with an equity lens—that we don't just think about race and ethnicity, we also overlay that with older adults. And we also overlay that with other groups that are experiencing underlying health conditions that would place them at an increased risk. It would be really important for health departments that are thinking about this to think about this really critically. I would invite them to ensure that HIV advocates are part of the conversation, you know, when they're thinking about what their plans are, how they want to modify or update their plans to respond to the concerns regarding allocation."

HOWEVER, ANY DISCUSSION of public health systems must address medical mistrust, particularly within the Black community. Most often cited is the infamous "Tuskegee experiment," conducted by the U.S. Public Health System and the Centers for Disease Control and Prevention from 1932 to 1972, which studied 600 poor Black Alabama sharecroppers, 399 of whom had syphilis which doctors intentionally left untreated to observe its effects. The unintended, but inevitable, consequence of Tuskegee and many other instances of harm inflicted upon people of color was an ingrained distrust of the medical profession. There are other examples of institutional harm, such as the forced sterilization of poor women of color without their knowledge, but added to this legacy are the individual encounters of racism and dismissal that Black and Brown people have experienced at the hands of their own care providers.

Moved by Gina Brown's experience (see side bar), Christopher Hucks-Ortiz offered another dramatic example. Susan Moore was a Black physician who developed COVID-19, documented her doctor's dismissal of her pain and symptoms, and later died.

"She documented her experiences of not being listened to, because she put on a [hospital] gown and got into the role of being a patient—that's something we need to talk about in public health, is how people get dismissed when you are in the role of a patient, even if you're a competent medical professional," he said. "Even if I'm not a physician, I'm an expert in this [pointing to himself with both hands]. And I need you to listen to me when I say, *there's something that doesn't feel right*, or, *I have some concerns.*"

Dr. Wallace offered his own perspective, and a call to action.

"What was really egregious is not just that she died, and that she was a physician," he said. "She's another example of a Black woman who wasn't believed. It was the hospital's response to her death—*that's* what was so egregious. They basically painted her as a problem patient, and this is exactly the kind of thing that happens to Black people when we go into healthcare spaces. When I think about how we need to change the healthcare system, we need to dig deep. As we're digging deep and doing the work to transform systems, we also simultaneously need to envision what this new system is going to be. We can't leave it up to the same folks who designed this system to design the new system. We'll find ourselves back in the same place."

Hucks-Ortiz added, "Some of the work that Dr. Wallace is doing through the Vaccine Trials Network, and with some of the work I've been doing through the HIV Prevention Trials Network, we're trying to address some of these issues and dismantle some of this. But it's going to take more of us to elevate the voices and experiences, particularly of women and of people of color."

……

Greg Millett's report, *New pathogen, same disparities: why COVID-19 and HIV remain prevalent in U.S. communities of color and implications for ending the HIV epidemic*, was published October 2020 in the *Journal of the International AIDS Society*. **READ IT** at onlinelibrary.wiley.com/doi/full/10.1002/jia2.25639.

The Urban Indian Health Institute's report, *Data Genocide of American Indians and Alaska Natives in COVID-19 Data*, is at bit.ly/datagenocidereport.

Moderated by POSITIVELY AWARE editor-in-chief Jeff Berry, *A Matter of Justice: COVID-19 Vaccines and Health Inequities in People Living with HIV* was held March 4 via Zoom. This webinar was made possible with support from Janssen Pharmaceuticals. **WATCH THE PROGRAM** at positivelyaware.com/justice.


GINA BROWN

'My daughter would have been 36 this year'

"Tuskegee was however many years ago, but it still happens today," activist Gina Brown said. "I can go to a doctor, and I can tell my doctor what's hurting. My doctor will insist on telling me what they think is hurting me, or they'll switch my words around and say what they think they hear. Medical professionals have to learn to listen to us. It's not that my grandmother had a bad experience, it's that *I* had a bad experience."

That bad experience has included how her doctor has talked to her—or what the doctor didn't tell her.

"I never heard about U=U [undetectable equals untransmittable, how HIV cannot be sexually transmitted if someone is on successful antiretroviral treatment and has undetectable viral load] until Bruce Richman [founder and executive director of the Prevention Access Campaign, that raises awareness of U=U]," she said. "I have two degrees, I've been living with HIV a long time, and my doctor never thought it was important to talk to me about that. That's what needs to change."

Brown shared with the virtual audience how racism and disregard of Black women in need of health care profoundly altered her life.

"I had a daughter who would've been 36 this year," she said. "I was in labor prematurely, and I went to the doctor and told him what I was feeling. And they sent me home. They didn't listen to anything I said. Women are dying today, Black women are dying because when they are in labor, doctors are not listening. They're not hearing us. What should happen is that in medical school, they should be given these tools to really hear."

POZ ADVOCATE

SCOTT SCHOETTES
@PozAdvocate

Spring to summer to sex (with or without disclosure)

The 2021 state legislative sessions are winding down in state capitals across the country, which turns my mind to HIV criminalization and efforts to reform or eliminate these unnecessary laws in states throughout the U.S. This year has seen some successful efforts—in Virginia, where the law making mere non-disclosure a misdemeanor was eliminated—and some continuing frustrations, such as Florida, where some promising movement in 2020 was nowhere to be found this year. It was especially impressive to see victories this year, given the additional obstacles to lobbying and advancing legislation during the COVID pandemic.

While we should celebrate these victories, it is important for people living with HIV to keep in mind that HIV-based prosecutions can be brought in any state under general criminal laws, regardless of whether the state has an HIV-specific law on the books. Texas is a good example of a state where HIV-based criminal prosecutions still occur even though the state repealed its HIV-specific criminal law decades ago.

I recently represented a doctor in Texas called as a witness to testify against her own patient who was being tried under a sexual assault law for not disclosing his status. Once the prosecutors realized that the doctor was not going to cooperate, they offered the defendant a much better plea deal, essentially time already served while awaiting trial. But the fact that these types of charges—like sexual assault or reckless endangerment—are being used in the context of non-disclosure of HIV status serves as a cautionary tale for everyone living with HIV in every state.

People living with HIV can do things to protect themselves from becoming the subject of a prosecution like this. In some ways, I dislike even making these suggestions, because we should not need to do these things simply to be sexually active, but if taking one of these steps can prevent jail time, it seems worthwhile to consider them.

First, when it is safe, disclose your status prior to sexual activity. I know, I know—easier said than done, right? The idea that disclosure is expected or should be easy “if you really care about the person” is based on the antiquated, hetero-normative idea that sex only happens when two people are in a deeply connected, emotionally intimate relationship. Because sex in fact happens in all kinds of circumstances that don’t involve that level of intimacy or trust (or sometimes even the person’s name), disclosure can be a vulnerable, difficult, or even dangerous choice. I’m not saying that it is for everyone—or for anyone every time—but disclosure of one’s status does reduce the chances of prosecution.

Second, when you do disclose, try to document it. Again, this may be easier said than done. But if it’s in your Grindr profile or you disclose via a text message (and save the message), it is going to be a lot harder for the other person to claim that they were unaware of your status. You don’t need the person to sign a consent and release form, but getting them to acknowledge in writing that they are aware of your status is probably the closest thing we have to a foolproof method of avoiding an HIV-based criminal prosecution.

> **...keep in mind that HIV-based prosecutions can be brought in any state under general criminal laws, regardless of whether the state has an HIV-specific law on the books.**

Third, if you have access to care, try to be adherent to your HIV medications. If you are having sex without disclosing your status, having an undetectable viral load is probably the best thing you can do to avoid prosecution. Courts are slowly coming around to understanding that undetectable equals untransmittable (U=U), and criminal defense lawyers are starting to have more success in talking prosecutors out of pursuing cases in which there was no real risk of transmission. This suggestion is certainly not fail-safe by any stretch of the imagination, but it is quite a bit better than nothing. And, frankly, you’re getting a two-for out of it, because being adherent to your meds is also the very best thing for your long-term health. Worry-free sex plus physical health is a pretty good combination.

Finally, don’t talk to the police. If you do find yourself the subject of an investigation—or even if that hook-up that you didn’t tell because you were a little too drunk to care suddenly becomes curious about your status a few days after your encounter—don’t divulge anything that could result in a deprivation of your liberty. (I mean, if you’ve realized that hook-up is really the person of your dreams with whom you are going to spend the rest of your life, you may need to come clean about your status before you get to the altar—but that’s a different story.) Talk to a lawyer before you talk to the police or disclose your status to them. Too many times I have had to counsel someone who has already shared too much with the police. Though they will try to convince you otherwise, if they are investigating the situation, the police are *not* your friends and won’t “try to help you out.” Invoke your constitutional rights to remain silent and to have a lawyer present.

I’m not trying to frighten you too much or make you overly anxious, dear reader, but I am trying to scare you just the right amount. In a world where any person living with HIV is just one jilted lover or one night of awesome (or bad) sex away from potential jail time, you really can’t be too cautious. I hope the sex *is* amazing—and that you can keep yourself safe from prosecution at the same time!

SCOTT SCHOETTES is an attorney and advocate who lives openly with HIV. He engages in impact litigation, public policy work, and education to protect, enhance, and advance the rights of everyone living with HIV.

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Illinois HIV Care Connect will be continually posting on social media to communicate the benefits of Illinois HIV Care Connect to people living with HIV in Illinois.

Illinois HIV Care Connect is a statewide network providing medical case management, health care and support services to persons living with HIV. Eight regional offices coordinate the services provided through the program, which is funded by the Illinois Department of Public Health and federal grants and supported by the Illinois Public Health Association.

Visitors to the website can find valuable information about Illinois HIV Care Connect, as well as information about the Illinois ADAP Medication Assistance Program (ADAP-MAP) and Premium Assistance Program (PAP).

Illinois HIV Care Connect

hivcareconnect.com

Funding for this publication was made possible by the Illinois Department of Public Health.

MATT ROTH

Not having as much sex? You’re not alone

BY **MARK S. KING**

My sex life in the 1980s before AIDS came along was glorious. My endurance level was Olympian, my sexual response time was faster than a wink from a cute man, and body fluids went flying like they were shot from cannons.

Today, I am 60 years old. It’s easy to wonder what happened to that drive, but the answer is simple: 35 years. It can be hard to admit, considering our sexually-fixated culture, but I don’t have the drive, the interest, or the filled dance card that I used to have, and frankly, my dear, I don’t give a damn.

That’s a secret we don’t discuss nearly enough. We’re aging and we’re changing. It isn’t a crime to want sex less often. And, while it’s easy to blame my sexual insecurities on all those gay hookup apps and shirtless selfies, the fact is gay men didn’t invent a society in which sexual allure equates to social status. Just ask the parents of any teenaged girl.

As people living with HIV, our relationship with sex is complicated. When HIV arrived, it turned sex into something dangerous, sickly, and even criminal. We became walking vectors of disease to be shunned and dismissed. The very idea that we might pursue a satisfying sex life was viewed as ludicrous.

That kind of withering judgment sticks with a person. That’s trauma. It’s one thing to become an empowered patient, or to stand up for your rights as a person living with HIV. It’s quite another to come to terms with your body—and your bodily fluids—as something with the potential to kill people. Just imagine the ecstasy of orgasm with a sexual partner while, in that same precise moment, being scared to death you’ll spill something in the wrong place and hurt them.

Just when we got the “all clear” signal, our own interest in sex was already beginning to wane.

If you lived through the first decades of HIV/AIDS, you know what I mean.

The relatively recent science of “undetectable equals untransmittable” (U=U) has become a kind of sexual revolution for people living with HIV/AIDS—*we don’t transmit HIV to sexual partners if we’re virally suppressed!*—leading to a sexual reawakening among us, not to mention an avalanche of workshops and studies on the concept of sexual pleasure among people living with HIV. That focus was unthinkable only a few years ago.

Alas, timing is everything. We got this fabulous news about posing no risk to our sex partners around the time that most aging survivors were entering late-middle-age. Just when we got the “all clear” signal, our own interest in sex was already beginning to wane.

It’s bemusing to hear stories and read articles about all those happy, horny people living with HIV out there who are U=U-ing their brains out like it’s spring break in Fort Lauderdale. I’m happy for them, really. I bet most of them are younger than me.

My sex life with my husband has gone from three nights a week a decade ago to a lone date night on Saturday—unless there’s a new episode of something we’re binge watching. Then we might put the big event on hold a bit longer. (I know. I have a husband and he’s a sure thing, and he’s terribly underutilized. We’re okay with that.)

I might sometimes miss my sex life as it once was—it was adventurous and fun and terribly exhausting—but life still holds plenty of surprises. Aging is mysterious and freeing and terrifying. Hang on.

For similar feelings of emotional security and contentment—and for those of us who are without a regular sex partner—I have learned to lean on my friends for emotional support. I used to be too trapped in my masculine armor to tell the people close to me that I love them. Not anymore. I hug my friends, especially when it’s been a while (lord almighty, we all have some catching up to do).

Older folks living with HIV are entering a phase of life in which we discover profound pleasures that are not centered on sex, while the brains of our younger friends are too hormonally addled to notice them.

Good for us. Good for them. If they are incredibly lucky, they will live long enough to discover these secrets for themselves.

Mark S. King is a long-time HIV survivor and writer best known for his award-winning blog, MyFabulousDisease.com.

PHOTO: CHAD SAIN • BACKGROUND MURAL: ERNESTO RAMIREZ

BEING BRIDGETTE

BRIDGETTE PICOU

Too young to be this old

About eight years ago I became a grandparent. To be both dramatic and honest, I was a little traumatized. How did this happen? Overlooking the obvious "my kid had sex" thing, I was too young at 40 to have a whole human be my "grand" anything. I made the unilateral decision he was going to call me *GiGi* since it sounds somehow sexier and younger than *Grandma* or *Granny* or good grief, *Big Momma*.

Around that same time, I had been diagnosed as HIV positive. Honestly, my age didn't play much into that except as a footnote of gratitude that I had lived a little life and had some life experience to fall back on to help sort out what was and what would be. Folks get so caught up in what they think life with HIV is, they forget there is actually a life being lived under the acronym. It evolves for us just like it does for everyone. If I had a dime for every time someone said I didn't look like I had HIV or looked too young to have a grandchild, I'd be writing this from my vacation in Negril rather than my bed.

Fast forward to a little over a year ago, and Gigi's Baby came to live with me. Only now [insert more drama here], I'm too old for this grandmother thing! Parenting at nearly 50? He is a light in my life, keeps me on my toes, and on a good day both makes me laugh and need to rub Tiger Balm on my knees trying to keep up! I am simultaneously too young to be this old, and too old for this mess! I'm still trying to figure out when my joints got old enough for me to feel when it's going to rain, let alone keep up with Fortnite and YouTube personalities.

That's the thing about aging. It changes your reality. In small ways you're constantly coming to terms with both your own ageism and that of society. It's like when you were 16 and 21, with its promise of adulthood seeming to take forever. Being 25 and worrying about what you'd accomplish by 30, and throughout all of this your grandparents were practically decrepit if they were in their 60s. Your crazy Auntie June was 46, wild, smoked a little pot, and hung out with young folks, but still—she was old. My, my, what a difference living a decade or two makes for your perspective!

I'm the grandparent now. I'm the youngish-old aunt explaining to her nephew about vinyl albums and watching his fascination while the needle hits the record and his eyes light up while the music plays. I roller skate, and dance and hang out with younger folks. I'm still somehow surprised that I have an adult child. My son was absolutely mortified when my grandson found my massager (you know, the personal one). I told my grandson it was just that—a massager, to keep it simple—then proceeded to convulse with laughter over the next two days as he ran around using it as everything from a light saber and a rocket to a voice changer to tickling the bottom of his own feet with it. I thought my son was going to melt through the floor! I'm positive his dismay was more about the fact that I *had a personal massager* than my grandson playing with it. I can only imagine what my twenty-something self would have done if I had found one in my mother's drawer. Forty is the new 20, right?

Our own personal perspectives change as we age, but not everyone keeps pace with our changes. Society sometimes is slower to change within a time frame. The 40s are known for being a woman's sexual peak, but only cougars and loose women talk about that, right? It's more socially acceptable if I sit my HIV-positive self down somewhere and be still. Puh! Not. I'm single and trying to navigate dating, the desire to mingle, and maybe find love along the way.

General society thinks I'm supposed to be and look "sick" or like I "have something" with HIV, not be a good-looking woman with great skin (even if I do say so myself). Hell, as a woman of *a certain age*, having acquired HIV at a certain age, general society would like to know *how did I get HIV in the first place?* 'Cause you know, I don't fit the mold *[dramatic eye roll]*. I'm supposed to be taking a handful of medications instead of one pill once a day. All these old ideas people have about those of us living and aging with HIV have to deal with and try to dispel. I like to call how I live my life at this point *living by example*. I don't have to shout my status at every person I meet or try to convince them I'm fine, or better—that I'm *thriving*—I can just go about my business and live my life. Which means navigating a life process that includes aging with HIV, countering anxiety and depression with hope, and counterbalancing a small human to raise in a digital age when all I want is for him to go outside and play like I did when I was that young.

Folks get so caught up in what they think life with HIV is, they forget there is actually a life being lived under the acronym.

Even if I can feel the rain coming in my joints and while my knee hurts when I skate, I'm still going to enjoy the rain and skate 'til I'm 80. I'm still going to put the needle on the record and listen to it snap and crackle with my digital playlist on standby on my phone.

Oh, and get a massage every now and then.

Bridgette Picou is a licensed vocational nurse in Palm Springs, California. She is also an active HIV blogger and contributor to the CDC's "Treatment Works" public service campaign. Finding a voice in advocacy and activism is a natural progression, since she feels that every time she fights for someone else, she affirms her own life.

Looking deeper to dispel stigma and fear

Anne Aslett talks about the effects of HIV stigma, and the work the foundation is doing to fight it

INTERVIEW BY **JEFF BERRY**

Leading up to the first virtual 29th Annual Elton John AIDS Foundation Academy Awards Viewing Party with Neil Patrick Harris, Dua Lipa, Sir Elton John and David Furnish for the famed Oscar party, we asked EJAF CEO Anne Aslett about why this event and the work of the foundation to fight HIV stigma and discrimination is still relevant, all these years later.

How did the event come about?

The former Executive Director of Rock the Vote, Patrick Lippert, became ill with AIDS in 1993 and brought the idea to our Foundation to host an Oscar party at Beverly Hills' Maple Drive restaurant. Since then, the event has continued to grow and we're now preparing for our 29th annual Academy Awards Viewing Party. Since its inception, the funds raised at the Oscar party support the important, lifesaving work we do every day. EJAF is now working across four continents and is committed to overcoming the stigma, discrimination and neglect that keeps us from ending this pandemic.

As we mark 40 years since the first reported cases of AIDS, why do you think there is still so much stigma around HIV?

Stigma is born from fear, and lack of information. The heartbreaking thing is that people with HIV and AIDS are made to feel ashamed of their status and as a result, do not seek or are too afraid to access the necessary help and treatment. We can have all the effective testing, drug regimens and support services you could possibly want, but if people feel too scared to come and access these things, then we're not going to make progress. So stigma really is the huge barrier that stops us from optimizing all of the scientific and medical advances we've made in treating this disease.

What are some of the effects of stigma that you've seen in your work and that of the Foundation?

One of the worst effects of stigma is the social isolation of people living with or at high risk of HIV, often by excluding whole groups like the LGBT community, blaming them for disease, and even criminalizing them. This has also happened during COVID. The reality is that people who are excluded, shamed or punished hide in the shadows—which is damaging for them and for society. The fear of what we don't understand or can't control also leads to dangerously wrong or simplistic stories about a disease: how it's spread, who is responsible, how to stop it. This has also happened during the COVID-19 pandemic. It's harder to look beyond the myths or blaming tropes to work with those most at risk and find out why they are so vulnerable and how to address that. It's only by looking deeper, by recognizing our common humanity, that we really solve these problems. That's why it's so critical for us to work with young people, to dispel incorrect scare stories like

‘The fear of what we don’t understand or can’t control also leads to dangerously wrong or simplistic stories about a disease: how it’s spread, who is responsible, how to stop it.’
—Aslett

COURTESY OF ANNE ASLETT · JOHN AND FURNISH PHOTOGRAPHED BY MICHAEL KOVAC

HIV is spread by kissing and to understand that discovering and owning your sexuality and sexual health can be scary and confusing. If as adults we can role model empathy, compassion and a real desire to understand and fight epidemics like HIV, if we can make sure that the information we share is true and helpful, we give them the right tools for what the future will bring.

Do you have a personal connection to the work that you’d care to share?

In the 1990s I knew many people, mostly gay men, who were living with HIV and were absolutely terrified. The ‘gay disease’ had no cure. It was a death sentence and, in the eyes of many, a punishment for immorality. So on top of living with a disease that they knew would likely kill them, at the most vulnerable time in their lives gay men faced judgement and ostracism. How did that solve anything? That’s why I wanted to do all I could to understand and to help.

What is the Foundation doing to help battle HIV stigma?

Firstly, we want to keep as many people healthy and safe as possible, so we fund flexible and sensitive HIV testing and treatment programs all over the world, especially for those most vulnerable to HIV/AIDS. Their voices, their survival, is the engine that will make sure we address these challenges in ways that are most likely to succeed. As part of this work, we sensitize health workers, policymakers, community leaders and others who have the ability to change attitudes towards people living with HIV/AIDS. We advocate to change laws that judge or criminalize HIV, as is the case in some U.S. states, or groups at severe risk of the disease, like LGBT. Homosexuality is still a crime in 68 countries around the world. We develop programs with partners that allow people to receive confidential, accurate information and practical choices to protect themselves and those they love, like the online platforms we are developing for young people, with funding from our Academy Awards Viewing Party. Young people represent 25 percent of the world’s population but are disproportionately affected by HIV, making up 36 percent of new cases. That’s 1600 young people infected with HIV each day. This age group is smart and savvy and require health care services and support in different ways than adults do. The Foundation is working to ensure that services are accessible on the platforms that are best suited to young people.

ABOVE: ELTON JOHN WITH HUSBAND DAVID FURNISH

In the Southern U.S., where a gay African American man has a 60% lifetime chance of contracting HIV, we are bringing together non-profits with religious and cultural voices to change the conversation about homosexuality and HIV.

What can others do to help fight stigma and raise awareness about HIV?

Education is key, yet an evolving challenge. We must continue educating the public to help disprove myths and decrease fear and stigma. And treat people living with HIV like anyone else—with kindness and love.

Anything else you’d like to add?

Although the fight is far from over, I feel optimistic. Even though there is a lot of hate and ugly in our world today, we truly believe that humans are enormously resilient, kind and compassionate. If we continue working together, and operating from a place of love in all we do, the impact will be so much greater.

For more information **GO TO** eltonjohnaidsfoundation.org.

FRONT COVER BACKSTORY

Symbol of longevity

DAVID FRANCO

Sometimes it’s the little things that pack so much significance. Take sunflowers, which appear alongside Cameron Siemers on the cover of this issue. Among the many meanings in various cultures, sunflowers signify *longevity*. So it was only natural to incorporate them into the photo shoot.

At 39 years old, Cameron Siemers is a long-term survivor of HIV. He acquired the virus at the age of seven through a blood factor during treatment for his hemophilia. As a youth, he started speaking at colleges and events as an ambassador for the Elizabeth Glaser Pediatric AIDS Foundation. But it wasn’t until just before high school graduation that he became public about his status in his personal life.

“I kind of wanted to stop living with this secret,” he says. “I didn’t really feel like I needed this big secret anymore, especially because I wanted to continue to speak more openly at bigger events and have a larger platform. So, I actually spoke at my high school just before graduation.”

He has continued to address stigma and the ignorance and misinformation surrounding living with HIV.

“I can focus not only on being a positive man, but being something positive in the world,” he says. “The fact that we’re alive and still going, I think, is just positive in and of itself. The hard stuff we go through kind of gives us a perspective that most people don’t get to have, that we’re down through our core, pretty much the same and want the same things in life.”

FOR LOS ANGELES-BASED photographer David Franco the photo shoot presented creative and practical challenges in this COVID era.

“The main thing for me was to make sure he was comfortable,” Franco said.

“COVID-19 has changed how photographers approach shoots, and it can be a bit difficult to connect with clients while wearing a mask, but I’ve managed to make it work by keeping the vibe positive. Even though I’m fully vaccinated, I still wore a mask for the duration of the shoot. I want my subjects to let their guard down, and I think creating a safe inclusive space helps put them at ease.”

CHECK OUT Franco’s photography on Instagram: @davidfrancophoto

—**RICK GUASCO**

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 is a business of Merck KGaA, Darmstadt, Germany