POSITIVELY AWARE
JOURNALISM. INTEGRITY. HOPE.

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"We need to continue to share our stories of hope and survival, and write like we're running out of time."

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"My sister's not worried about dying, and that's good to hear."

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"There is no single 'face of HIV.' HIV affects all of us. Just look at the many faces of A Day with HIV."

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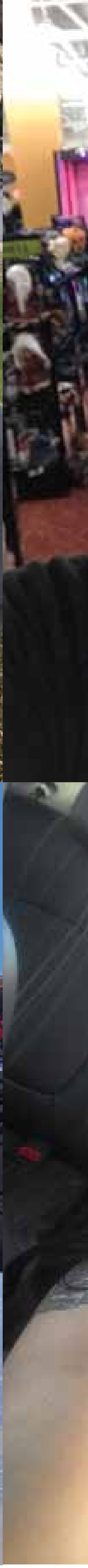
FOUR COVER PHOTOS, TWO FOLDOUT COVERS, A DAY WITH HIV

This issue of POSITIVELY AWARE features two versions of a foldout cover featuring four pictures selected from A Day with HIV, the magazine's anti-stigma campaign.

5:42 PM >
DENVER, COLORADO
Davinna Conner: At the park with my great niece. Showing everyone that joy doesn't stop. Live life to the fullest. Stop HIV stigma.



10:00 AM >>
DULUTH, MINNESOTA
Erick Santiago: Even though HIV hit me like a truck, it hasn't stopped me from enjoying life and to keep working hard! I have been seven months sober—no drinking or anything. It's always a challenge, but we are all stronger than we believe!

2:00 PM >
SAN DIEGO, CALIFORNIA
Mark Holmes: I've been HIV-positive over 32 years; undetectable 10 years. Stigma? I know it's out there, but have never let it stop me. I just turned 63, and learned to skydive last year, with 120 jumps under my belt. Skydivers get it; life's to be lived.

5:29 PM >>
BOSTON, MASSACHUSETTS
Christina Carta: Picking up my son from college. It's been 22 years since I tested HIV-positive. I never thought I would see today. I'm healthy, alive, and enjoying each day.

SEE MORE PHOTOS FROM A DAY WITH HIV IN A SPECIAL SECTION BEGINNING ON PAGE 33.

NOV+DEC 2016

VOLUME 26 NUMBER 7

IN EVERY ISSUE

FEATURES

SPECIAL REPORT: LONG-TERM SURVIVORS

SPECIAL SECTION

A DAY WITH HIV

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

AWARENESS

I am an HIV-positive gay man currently serving time in Oregon. As an Australian citizen who was holidaying in the United States when arrested for a DUI-related incident, this has had some effect on my health, mental and physical. Fortunately I have been able to find stability in my incarceration by facilitating the hepatitis, HIV, and AIDS awareness program here at Deer Ridge Correctional Institute. As a result of this, I find that people in the community of Deer Ridge are more open to speaking to me regarding their diagnosis than medical professionals (who I always refer them to as well). It was in one of these conversations that a fellow inmate showed me your magazine. What a revelation and wealth of information. Thank you for the service you provide and the thoughtful manner in which you deliver it.

—**NATHAN SALMON**

PA AT THE VA

At the Hines Veterans Administration Hospital [in Maywood, Illinois] this afternoon, Dermatology and then the pain clinic. Blessed this place is here for me. **Check out some of the reading material here on the fourth floor.** The ID clinic is here. I put PA out after yesterday's HIV self-help/education group—feeling positive.

—**ROY FERGUSON**

PHOTO: JOHN FERGUSON

LONG-TERM SURVIVAL

Thank you for running my letter on long-term survival with HIV (Insights from a former volunteer, September + October). I hope people will be encouraged to talk about their experiences, so that we can help one another.

I have had HIV for about half my lifetime. I wish I could convince everyone that has told me I "have it easy" because I don't "have to be employed" that I wish I could work! I can't tell you how many times I have nearly slammed someone for telling me that. Yes, I don't work because I am too weak to do so. My labs are okay, but the wasting is painful. I would love to have a useful life again. The time one can spend earning a living, going to college, or having a family (whatever orientation they have) is slipped into time on the telephone trying to have a drug approved for payment.

The only thing I don't like about my housing is being so private about being gay and my HIV. I'm reluctant to get to know anyone. I was able to get a Section 8 voucher after the friend I was taking care of died. I am now in a safe "old folks home" for people over 50 because it accepts Section 8. I was lucky because the wait list wasn't very long, and I got my apartment in three months. It's safe and secure, and it's actually a very nice apartment.

After describing my situation, one might think I am clinically depressed. I am reasonably happy. I am thankful that I can share my experiences to help others. I miss being a volunteer. I wish I could be more active.

—**BOB BROWN**
SAN JOSE, CALIFORNIA

'DON'T WANT TO DEAL WITH IT'

Thank you so much for sending me POSITIVELY AWARE. I would still like to receive it. On September 27, 2016 I saw my doctor and asked her to stop ordering my Isentress, lamivudine, and Viread. I'm not looking for sympathy. It is a choice that I've been thinking about for a long time. She asked me to sign a refusal form and I did. My last count was CD4 100, viral load 23,000. I'm tired and don't want to deal with it. All my friends gone—my lover, too. Take care, God bless all my family at TPAN and all around the world! Much love to you all.

—**NAME WITHHELD**
HUGHES UNIT; GATESVILLE, TEXAS

EDITOR'S NOTE: Thank you for your letter, and for sharing your situation. I can only imagine how frustrated you must feel. Many long-term survivors get tired and lack the will or strength to keep on fighting. But I hope you will reconsider stopping treatment. Have you requested a resistance test? Since you have a detectable viral load it may be that you have developed resistance to one or more of your medications. A resistance test would show that, and it's possible you could switch to a different regimen to bring your virus under control, which might help improve how you feel and possibly get your T-cells back up. Whatever you decide, I wish you the best. —JB

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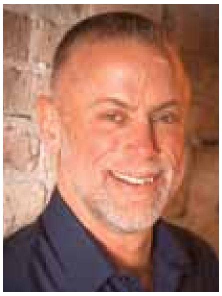


PHOTO: CHRIS KNIGHT

EDITOR’S NOTE
JEFF BERRY

RUNNING OUT OF TIME

‘Why do you write like you’re running out of time?’
—from the song *Non-Stop*, in the Broadway musical *Hamilton*.

Almost two years ago POSITIVELY AWARE published an issue focused on HIV long-term survivors. It was one of our more popular issues, generating scores of comments and letters. It seemed to have struck a chord with many of our readers who are long-term survivors of HIV themselves, and are now having to deal with issues they never dreamed of, such as affordable housing, dwindling finances, and the psychosocial issues that often come with experiencing such great loss and trauma.

In September at the United States Conference on AIDS (USCA) in Hollywood, Florida, the film *Last Men Standing* screened on a Saturday night, followed by a panel that included journalist Erin Allday, the health reporter who conceived of the project, along with Jesús Guillén and Mick Robinson, two of the men featured in the film. Allday, and the filmmakers Erin Brethauer and Tim Hussin, followed eight HIV long-term survivors for nearly a year (which she said is unheard of and had never been done before by the *San Francisco Chronicle*), detailing their lives as gay men living in San Francisco in the ’80s and ’90s and who survived the AIDS epidemic, but not unscathed. Immediately following the film’s screening at the conference a friend turned to me and said, “You don’t see this film, you *experience* it.”

I’ve experienced *Last Men Standing* four times now, most recently when TPAN, publisher of POSITIVELY AWARE, co-presented the film at Reeling 2016: The Chicago LGBTQ+ International Film Festival, and each time I see it I recognize another little piece of me somewhere in the film. *Last Men Standing* ran first as a special section in the *Chronicle* in March of this year, and then as a documentary, which premiered at the Castro Theatre in April. Allday informed us that the film will be available on one of the big streaming services probably sometime later this year or early 2017.

Two of the men in *Last Men Standing*, Ralph Thurlow and David Spiher, also participated in our A Day with HIV anti-stigma photo campaign this year, and are included in a special section in this issue (see page 33). Their story of dealing as a couple with the effects of Ralph’s HAND (HIV-associated neurocognitive disorders), is prominently featured in the film, and serves as a poignant reminder of the beauty and fallibility of survival.

Brethauer, one of the filmmakers, told me recently in an email that she thinks “the most powerful thing this film can do is both bring awareness to our communities but also bring a measure of healing to all the people who lived through this era. We’ve seen that in the cities where we’ve screened the film. People want to talk afterwards and share their experiences. The men who bravely opened themselves up to share the darkest parts of their experiences as long-term survivors, make it possible for all of us to understand, empathize, and hopefully continue these important conversations about how to help this community continue to heal and be heard.”

Stories have the power to move us, to illuminate, and to be transformative. *Last Men Standing* is a story of tremendous hope, and of dreams lost. It’s also a story of resilience, and acceptance. It’s a tale of a generation who suffered, and walked through the fire, but who continue to try to find meaning though their own unique experiences of survival.

I was really excited to see issues around HIV and aging and long-term survivors being addressed at this year’s USCA, including a Sunday morning seminar I co-presented with my colleagues from The Reunion Project, a program for long-term survivors we started a year and a half ago. Towards the end of the seminar Judith, a long-term survivor of HIV, stated that, “We are the voices and the faces that are going to make a difference for those behind us,” and ended with, “This is my first USCA, but not my last. Because I’ve found my tribe.”

That is why we need to continue to share our stories of hope and survival, and write like we’re running out of time. Writer, professor, television host, and political commentator Melissa Harris-Perry said it best during one of the conference plenaries: “Nobody promised you would be here for the win. But know that there were people who did the work before you, and there will be people who do the work after you. And during your part of the relay, pick up the baton. You don’t have to do it alone—engage, ask questions, go ahead and be bold, or fail; do something that you don’t expect to win. Write something that is better than who you are.”

Take care of yourself, and each other.

Stories have the power to move us, to illuminate, and to be transformative. *Last Men Standing* is a story of tremendous hope, and of dreams lost.

@PAeditor

BRIEFLY

ENID VÁZQUEZ @ENIDVAZQUEZPA

If you're HIV-positive, could you be arrested for sneezing? Apparently, yes

ONE MAN HAD a plastic bag zip-tied over his head because he had the "communicable disease of HIV."

This was one of the horror stories told at the HIV is Not a Crime II training academy for legal and social change, which you can watch in a short video.

Noah Raper, an HIV criminalization survivor from Tennessee, was arrested after someone made a false accusation against him. "It just took someone saying that I spit on them trying to give them AIDS," he said, then "handcuffs went on and I was the one assaulted."

Because the incident took place in a large store, video surveillance proved his side of the story. "So it proved that I never spit on anyone, but all it took was for me to admit that I had HIV [to be arrested]." He said were it not for the surveillance evidence, "I would be telling my story from behind bars." Raper seemed so shaken while telling his story that he appeared to be on the verge of tears.

In Oklahoma, a woman accused Apollo Gonzalez of giving her HIV by sneezing on her. "They [the police] got to put a bag over my head and zip-tie it," he said, his voice shaking at the memory. Like Raper, he appeared on the verge of tears.

Leslie Flaggs of Iowa said, "I went to jail and I don't think it was right, but I didn't tell him [her partner]. I'm not gonna lie. I didn't tell him I was positive. But as time went on I finally told him. So it was a big confrontation going back and forth." She received four years of probation and put on a sex offender registry. "I couldn't go to pools. I couldn't go by schools."

Monique Howell-Moree from South Carolina, another criminalization survivor, said it's very hard to disclose "when you don't even know *how* to disclose." She said people living with HIV should not be labeled "monsters" by those who don't know what it's like to walk in their shoes.

As previously reported in POSITIVELY AWARE, HIV is Not a Crime II focused on expanding the HIV anti-criminalization movement by joining forces with other movements for justice. Immigrants and people of color, as do people living with HIV, tend to receive harsher punishment and unfair execution of the law.

"I remember fighting the original [HIV criminalization] legislation years ago when they passed and I've always wanted to get rid of them," said Colorado State Senator Pat Stactman. He did so with the help of the "Mod Squad," organized in 2014 at the first HIV is Not a Crime. Other speakers included Mary Fisher and Democratic presidential candidate Hillary Clinton, via a taped address.

WATCH THE VIDEO BY HIV JUSTICE WORLDWIDE: **hivisnotacrime.com**.

TOOLKIT FOR AGING WITH HIV: The HIV/AIDS & Mental Health Training and Resource Center established an online toolkit for older people living with HIV/AIDS (PLWHA). According to the center, "PLWHA are living longer lives, and we are just beginning to understand the long-term effects of the disease and associated treatments. The HIV and Aging Toolkit contains information, tools, and research to help guide mental health practitioners as they support whole-person care." Go to hivmentalhealth.edc.org/toolkits/hiv-and-aging-toolkit.

Hep C treatment could risk reactivating hep B infection

In October, the FDA added a boxed warning to the drug labels of direct-acting antiviral (DAA) medications for the treatment of hepatitis C virus (HCV). The warning states that there is a risk of hepatitis B virus (HBV) becoming an active infection for patients with a current or previous infection with HBV and treated with one of the DAAs for HCV. The DAAs are Daklinza, Epclusa, Harvoni, Olysio, Sovaldi, Technivie, Viekira Pak, Viekira Pak XR, and Zepatier.

According to the AASLD/IDSA guidance panel (go to HCVguidelines.org):

- All patients beginning DAA treatment should be assessed for HBV
- All susceptible individuals should be vaccinated against HBV
- Patients who meet the criteria for treatment of active HBV infection should be started on HBV therapy at the same time—or before—HCV DAA therapy is started
- Patients with low or undetectable HBV DNA levels should be monitored at regular intervals

HIV transmission free

"At the United States Conference on AIDS (USCA) this week, NASTAD (National Alliance of State & Territorial AIDS Directors) announced its commitment to communicating one of the most groundbreaking developments in the last two decades of the epidemic: people living with HIV on effective antiretroviral therapy (ART) cannot transmit HIV," NASTAD reported in a press release dated September 15. "The announcement, as a sign-on to the Prevention Access Campaign's consensus statement, reinforces the belief that many have had and that science has now proven." Details at NASTAD.org.

Don't take Latuda with your HIV meds

The FDA in September announced a drug label update stating that Latuda (lurasidone), an antipsychotic used to treat schizophrenia and depressive episodes in bipolar 1 disorder, cannot be taken with the following HIV medications: Aptivus, Genvoya, Norvir (and Kaletra, which contains Norvir), Lexiva, Prezista, and Stribild; it also cannot be taken with Reyataz if used with Norvir. Nor can Latuda be used with the rarely used HIV medications Crixivan, Invirase, and Viracept. The drug labels for Evotaz and Prezcobix already stated that Latuda cannot be used with them. The FDA said Latuda cannot be used with these medications due to the potential for serious and/or life-threatening reactions.

Genvoya drug label updates

The FDA in September added longer-term safety and efficacy data to the Genvoya drug label, as well as stating that it can be used with the hepatitis C medications Epclusa and Harvoni. Also added was information about pregnancy.

New Sustiva drug interaction

The FDA in September added QTc prolongation, a heart complication, to the list of potential side effects of Sustiva (efavirenz, also found in Atripla). The agency said alternatives to efavirenz should be considered if patients are at higher risk of Torsade de Pointes or also taking a drug with a known risk of Torsade de Pointes; also if taking the anti-infective clarithromycin or the anti-malarial artemether/lumefrantrine.

Opioid treatment guide

In August, the American Society of Addiction Medicine (ASAM) released an opioid addiction treatment guide for patients, families, and friends. Go to asam.org/quality-practice/patient-guidelines-resources.

Depression and HIV

Depression in people living with HIV increases their risk of heart attack, according to a study from the U.S. Department of Veterans Affairs. The report from the Veterans Aging Cohort Study was published online in *JAMA Cardiology* over the summer. Go to economictimes.indiatimes.com/magazines/panache/depression-in-hiv-patients-may-increase-risk-of-heart-attack/articleshow/53857391.cms.

New PEP factsheet, plus hepatitis info

PrEP has been all the rage, but many people don't realize that PEP exists, or forget about it. HIV prevention with PrEP comes *before* exposure, while PEP—post-exposure prophylaxis—comes *after* exposure. In September, AIDSInfo.nih.gov updated its PEP factsheet to show the latest on what you need to know about taking PEP.

AIDSInfo has also added three new factsheets: HIV and hepatitis B; HIV and hepatitis C; and HIV and tuberculosis. Factsheets are available in Spanish.

HIV antidiarrheal Mytesi

Previously known as Fulyzaq (generic name *crofemeler*), the only FDA-approved drug for treating HIV-related diarrhea has been acquired by Napo Pharmaceuticals and is now marketed under the name Mytesi. The company has launched patient co-pay and patient

MYTESI: NAPO PHARMACEUTICALS

assistance programs to allow for broader access to Mytesi. For details, go to mytesi.com/mytesi-savings.html.

Finding a PrEP provider

The **interactive national PrEP Provider Directory through Emory University and MAC AIDS Fund** went live in September. To find a medical provider to prescribe the HIV prevention pill (Truvada as PrEP, or pre-exposure prophylaxis), go to preplocator.org. Although any prescriber can prescribe PrEP, there's been a reluctance on the part of many providers to do so.

"PrEP has the potential to substantially reduce the number of new HIV infections in the United States but only if people know how and where to get it," says Aaron Siegler, PhD, in a press release. He is a research assistant professor in the Department of Epidemiology at Emory University's Rollins School of Public Health. "Importantly, the tool features a search function that allows users to search for PrEP providers who would prescribe to individuals without insurance."

New factsheet: Epclusa

The Treatment Action Group (TAG) has added a new factsheet on the latest hepatitis C (HCV) medication, Epclusa. **The TAG hep C factsheets include other medications** (Sovaldi, Olysio, Viekira Pak, Harvoni, Daklinza, Zepatier, and ribavirin) as well as diagnostics and adherence. The set is available in Spanish and English. TAG reported that its Hepatitis/HIV Project "focuses on optimizing quality of, and broadening access to, HCV care and treatment for communities and individuals by continuing its domestic and international work with other activists, regulatory agencies, pharmaceutical companies, clinicians, and the patient community." Go to treatmentactiongroup.org/hcv/factsheets.

Advocacy campaign for HIV health insurance

"In the face of highly restrictive and discriminatory health insurance plans within the Affordable Care Act (ACA) Marketplaces, the Center for Health Law and Policy Innovation of Harvard Law School (CHLPI) is undertaking **a new advocacy campaign to enforce the health care rights guaranteed by the ACA** for people living with HIV and other chronic conditions," the organization reported in September. For more information, go to chlpi.org.

New campaign seeks #FairDrugPricesNow

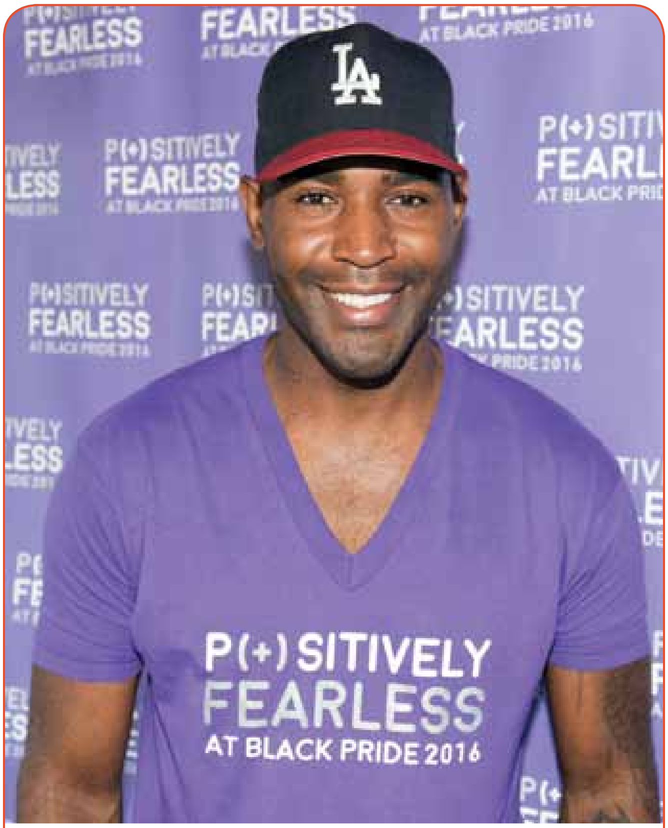
Three advocacy organizations—Treatment Action Group, Human Rights Campaign, and the Fair Pricing Coalition—have launched a new campaign to mobilize LGBTQ people and allies to address the continuing rise of prescription drug prices in the U.S. For details, go to fairdrugpricesnow.org.

Mondo's USCA installation

Fashion designer Mondo Guerra "yarn bombed" the U.S. Conference on AIDS (USCA) with an installation labeled "Positivitrees." In an artist statement, the winner of the *Project Runway All Stars* debut season, who's living with HIV, said, "This project is rooted in the importance of having an ongoing dialogue: with my work, with project collaborators, with my doctors." Guerra is part of Merck & Co.'s *I Design* HIV awareness campaign. Go to ProjectIDesign.com.

Taking the long view on care and prevention

A number of HIV organizations, including Gay Men's Health Crisis (GMHC), have teamed up to **advocate for people with and without HIV regarding their prevention and health needs free of stigma** and using best medical practices. "If we are going to meaningfully advance HIV education, prevention, treatment, and care, it will be due to multidisciplinary collaborations like *HIV: The Long View* that identify and strive to help work through the complex socioeconomic and healthcare factors that currently deny a long-term healthy future to many people living with and at risk for HIV," said GMHC Chief Executive Officer Kelsey Louie in a press release. Read their report at HIVTheLongView.com, which uses qualitative and quantitative research from The Future Foundation. Funding for the advocacy effort comes courtesy of partner Gilead Sciences.



Black gay men can be 'Positively Fearless'

KARAMO BROWN (above), who became the first openly gay African American in reality TV on MTV's *The Real World* in 2004, spoke at Atlanta's Black Pride Celebration in September as part of Janssen Pharmaceuticals' "Positively Fearless" campaign. According to a company press release, "'Positively Fearless' is a movement that **celebrates being Black, being gay, and being HIV-positive**." Also joining the campaign is advocate Deondre Moore, who became HIV-positive while a teenager. Together, the men encourage people to get tested and if HIV-positive, to take an active role in their health.

BRPWN MIE IMAGES-MARCUS INGRAM

NOT ONLY AM I DEALING WITH MY OWN ISSUES and struggles, but I'm learning how, in spite of it all, to be a selfless individual and give back to others.
—**ABRAHAM HOUSE-EL**

WE CAN BE HEROES

TPAN's gay men's health event promotes living your life

STORY AND PHOTOS BY **ENID VÁZQUEZ**

Abraham House-El was on top on the world back in the day—driving a new sports car, living in a fancy apartment, and making big money working for a Fortune 500 company.

Then he crashed and burned on drugs, including alcohol. He became addicted and ended up in and out of prison.

It was in a downstate Illinois prison where he came across POSITIVELY AWARE. Surrounded by people living with HIV, he said he picked up a new message about his out-of-control life: empowerment.

When he was released, he returned to Chicago and called TPAN, the publisher of POSITIVELY AWARE, to learn more about the epidemic and recovery. After graduating from TPAN's TEAM program (Treatment Education Advocacy [now Adherence] Management), he was asked if he could mentor someone. So, he joined the Buddy Program.

House-El came back to TPAN on Gay Men's HIV/AIDS Awareness Day, September 27, to speak to the agency's "Hero" event for gay men's health. >>

You can choose to be happy, or you can choose to be sad. Love yourself. Because if I don't love myself, nobody can love me.

TAMMY BELIFA JONATHAN

"Discover how you can be a hero to yourself," the event publicity trumpeted.

"Taking on a buddy allowed me to become a better person and allowed me to be a selfless person and help others," House-El told the audience of primarily men. "I learned how to pull myself up by my bootstraps and give back and help people. Not only am I dealing with my own issues and struggles, but I'm learning how, in spite of it all, to be a selfless individual and give back to others. Can you learn to be a model of selflessness and service? I had to learn that for me a hero is someone that simply does the right thing at the right time for the right reason."

House-El had gone from being a volunteer to joining the TPAN staff as its volunteer coordinator and earning a college degree. He left the organization for a time, but then, "TPAN called me and said, 'Hey, Abraham, we just got this multi-million dollar grant from SAMHSA [Substance Abuse Mental Health Services Administration]. It's a grant for African American MSM (men who have sex with men). Can you come back, start the program?' Even though coming back here meant taking a decrease in my salary, it was the right thing for the right reason."

After getting POWER (Positive Outcomes for Wellness, Education, and Recovery program) off the ground and running smoothly for several years, he left to work with veterans as a program coordinator through Featherfist, an organization that provides a variety of programs to help empower homeless people, in addition to housing. (POWER operated with partner Heartland Human Services, also located in Chicago.)

Many of the men—60%—have been incarcerated and 20 to 30% of them have been recently released. "And the doors for them are shut," said House-El, "just like the doors for me were continuously being shut. And I try to find ways to show them where there are doors that are open."

"We're just trying to convey that we're all superheroes inside," said Kevin Bernal, TPAN's Peer Health Navigator and coordinator of its Total Care Portal program. He headed up the agency's staff committee that organized the Hero event. "We have those [comic book heroes] and we have the everyday heroes inside."

He pointed to support group members and other men sitting in the audience who participate in TPAN programs, including HOTTER (Healthy Outcomes Through Treatment, Empowerment, and Recovery), a program for young African American men and transgender women vulnerable to HIV and mental health problems, or already living with the virus.

Coming together to share support in the face of stigma is heroic.

"I just want to be who I am," said social worker and LGBT activist Tammy Belifa Jonathan, 25, a HOTTER participant from Nigeria who's seeking asylum in the U.S. Some states in Nigeria allow execution as punishment for homosexuality. Even those who help LGBT individuals, including parents who don't "report" a child's homosexuality, can be imprisoned, he said.

"You have to fight to be who you are," said Jonathan. "Who am I really? Why should my life be based on what people say?"

"I am better [than what anti-gay proponents say I am]. I am gay. I am human first. My sexuality doesn't define who I am. It takes more—it takes a lot to be you," he told the audience.

Meeting LGBT advocates from the U.S. who were living with HIV, "proudly and confidently," helped crystalized the oppression he experienced in his country.

"You've been told that you ... are ... evil. They tell you that you're the devil. You will just internalize what's been told to you and you will feel that you are less than others," he said.

He called TPAN his second home and is also active in his church.

"Why should God bring me into this world if he knew that I was going to be gay and live with HIV? I'm made perfect," he said. "God doesn't make mistakes."

He said he came to understand homophobia as "being about their issues."

"I just want to be true to myself. If I don't talk about it who's going to talk about it?" he asked. His gay friends in Nigeria, he said, don't have that option.

At the same time, he believes that self-acceptance is important. "Everyone is not going to be your friend," he said. "You can choose to be happy, or you can choose to be sad. Love yourself. Because if I don't love myself, nobody can love me."

As the day ended, music played. David Bowie sang out, *"Oh, we can be heroes."*

Meningitis clusters are real —and potentially deadly

BY **ENID VÁZQUEZ**

OVER THE PAST several years, there have been meningitis outbreaks among gay men throughout the country. At TPAN's recent Hero event in September (see "We Can Be Heroes," page 9), Thao Vo, PharmD, presented slides and videos on meningitis.

Hero event lead organizer Kevin Bernal said he wanted to be sure that men knew about the continuing risk of this bacterial disease that causes brain inflammation. A popular gay bartender in Chicago died of it years ago during the city's first outbreak among MSM. (As this issue went to press, a second death due to meningitis was reported by the Chicago Department of Public Health.) "One day he was fine and two days later, he died," said Bernal, who still works as a professional deejay evenings and weekends. He was devastated, and wants to be sure that no one else dies from this highly preventable infection.

One individual attending the Hero event said that his cousin died of meningitis last year. "One day she was fine, washing dishes, and the next day she was dead. She left three little girls behind."

Hosea Thomas was lucky. One evening in March, while hanging out with a friend, he suddenly felt chills and couldn't stop shaking. "I knew something was wrong," he said.

He went to the emergency room, where a battery of tests was run. On the second day, he was told he needed to have a spinal tap. The test revealed that he had meningitis. He believes he picked it up at the shelter where he had stayed. Fortunately, he was treated before suffering severe consequences of the disease.

These consequences can include amputation, speech difficulties, and major neurological dysfunction (malfunctioning of the brain).

Dr. Vo showed three very short videos from the National, Meningitis Association in which people tell their story of surviving meningitis or losing a loved one to the infection.

Meningitis is very easily transmitted through casual contact, usually through saliva.

"Can I taste your drink?" That's all it takes.

"Can I have a puff of your cigarette?" That's all it takes.

Sharing a straw for cocaine? That's all it takes.

French kissing, anyone? Yes, that's all it takes.

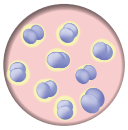
Meningitis is usually caused by bacteria or viruses, but can be a result of injury, cancer, or even certain drugs.

Some people may have the bacteria without any symptoms. They may still be contagious to others. This carrier state may last for days or months before disappearing on its own.

Most cases of meningitis, in fact, occur from exposure to these carriers who are asymptomatic—they have no symptoms.

Some carriers have been vaccinated, but to be clear, the vaccine does not cause any type of carrier effect.

Vaccination, however, can also protect you. Talk to your doctor or pharmacist about getting vaccinated. There are two types of meningitis vaccines; the vaccine is based on your age and health conditions. Those with HIV or compromised immune systems require a booster shot within two months of the first shot; HIV-positive individuals should be re-vaccinated after five years. Go to immunize.org/askexperts/experts_men.asp for more information.



MENINGITIS OUTBREAKS IN THE U.S. AMONG MEN WHO HAVE SEX WITH MEN INCLUDE:

NEW YORK CITY	CHICAGO	LOS ANGELES
August 2010	May 2015	March 2016

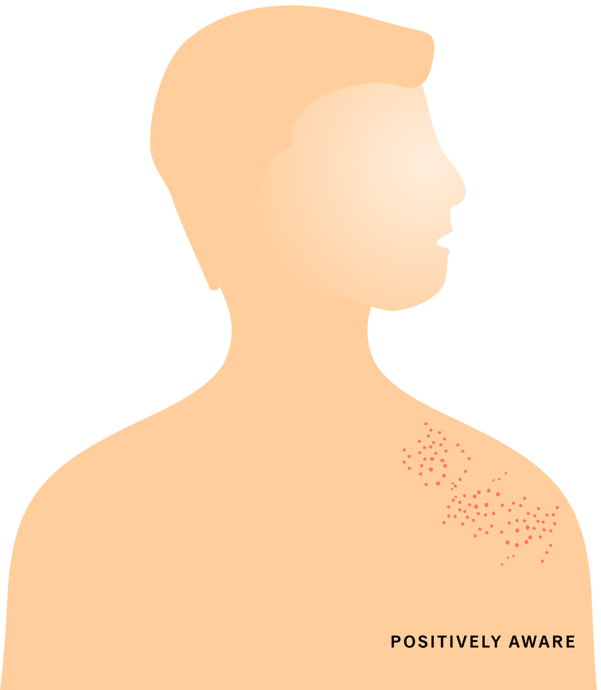
"We're urging all men who have sex with men to get vaccinated, it's that simple. It's preventable," said Dr. Allison Arwady, Chief Medical Officer for the Chicago Department of Public Health, speaking to the media earlier this year.

In this year's Southern California outbreak, there were 25 cases, of which two men died. As of December 2014, there were 22 confirmed cases in MSM in New York City, including seven deaths.

"If you know it's easily spreadable, if you know it's dangerous, if you know it's preventable—are you empowered to do something about it?" asked Dr. Vo.

Meningitis tends to feel like the flu, but symptoms (see below) can vary from person to person.

Bernal was astounded that a support group member in the audience had never heard of the meningitis threat from his HIV doctor. "That's why we're here," said Dr. Vo. "We all want to be heroes today, so spread the word."



MENINGOCOCCAL DISEASE: SIGNS AND SYMPTOMS

HEADACHE, DROWSINESS, CONFUSION, DELIRIUM, SEIZURES, OR LOSS OF CONSCIOUSNESS

PHOTOPHOBIA (INABILITY TO TOLERATE LIGHT)

GENERAL ACHES

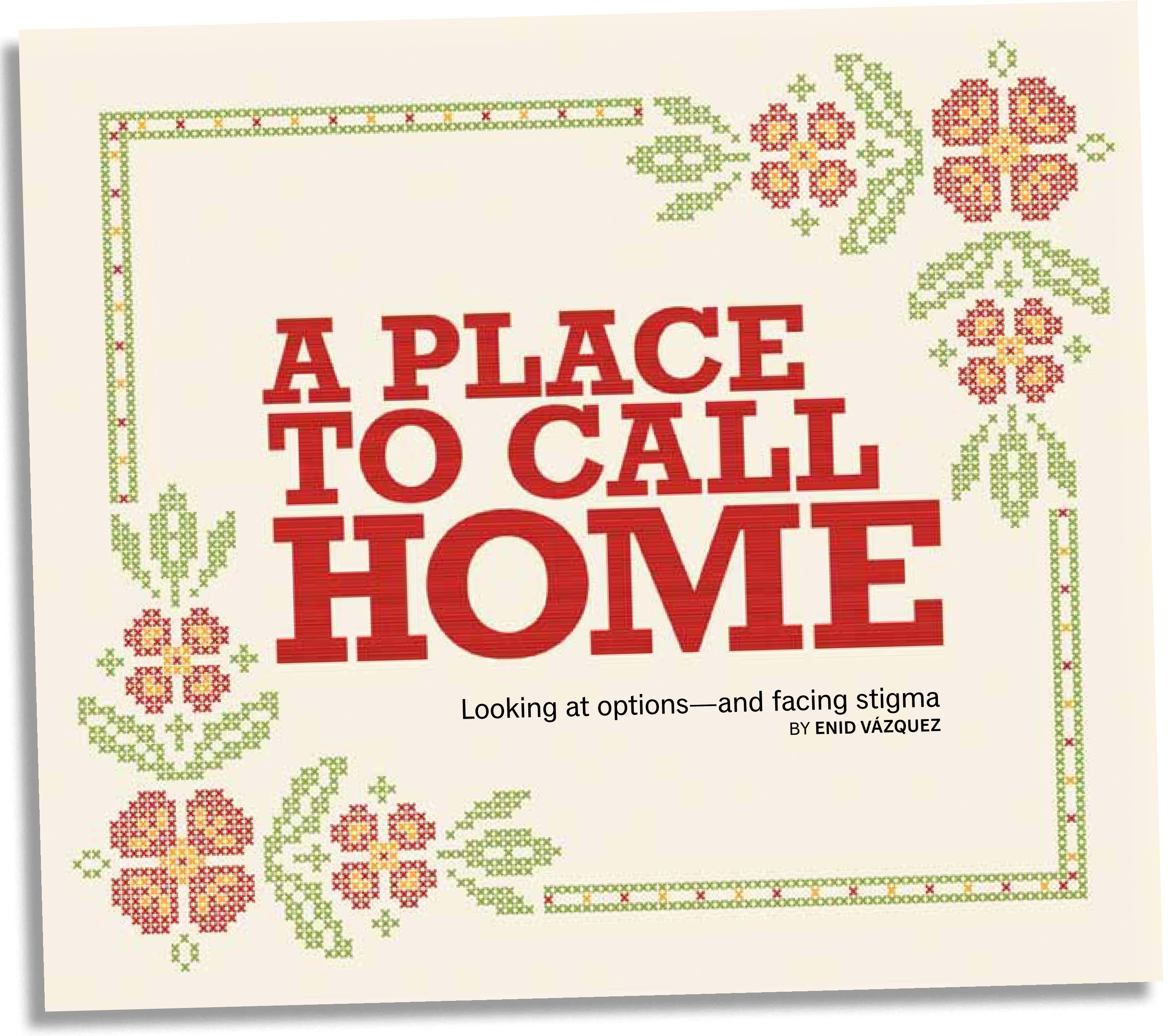
VOMITING

STIFF NECK

RASH

SYMPTOMS MAY DEVELOP within hours or may take a few days. The time from exposure to the bacteria to the time of developing symptoms (the incubation period) can be one to two weeks.

ILLUSTRATION: ISTOCKPHOTO



A PLACE TO CALL HOME

Looking at options—and facing stigma

BY **ENID VÁZQUEZ**

LONG-TERM SURVIVORS of HIV are not necessarily elderly … or disabled …or poor. They may or may not be LGBT (lesbian/gay/bisexual/transgender). Their housing needs may not include medical services.

At some point, however, just like anyone else, they may need specialized housing, including medical care.

Although probably most long-term survivors today are technically only middle-aged, many may already experience debilitating physical and financial effects of surviving HIV from a time of difficult—or no—treatments, not to mention psychological trauma. To that extent, as with other serious illnesses, there's overlap with elder care.

If and when the need for specialized housing arises, the potential for stigma becomes perhaps more important than ever. To be more vulnerable when you need greater support is a frightening thought.

To that end, advocates are working to ensure that managed housing can be free of stigma and discrimination when serving people who are living with HIV or are LGBT, or both.

Discrimination in specialized housing communities already exists. As just one example, there's a short video about a man forced out of an assisted living center because he has HIV. (It was produced for the Graying of AIDS project of AARP.)

With the potential for more long-term survivors of HIV needing services

ILLUSTRATION: ISTOCKPHOTO

established for elders, LGBT or not, there's a greater need for equal rights and treatment, and being able to reinforce them.

"Housing is always very, very high on the list for most concerns, especially in people with lower income," said Hilary Meyer, Director of Social Enterprise & Special Projects for SAGE (Services and Advocacy for GLBT Elders). "The number one issue for our constituency is affordable housing. Having a long-term disability just compounds the issue. It limits where they can live."

People want housing that they can afford, but some urban areas have "extraordinarily high housing costs," she said. Limited incomes may become especially challenging when coupled with mobility and other health issues. Some places, such as walk-ups, can be dangerous.

There's far more need for affordable housing than is available, she added, and further, because of stigma and discrimination, people may end up living in places where they don't want to live.

To ensure that housing meets the needs of LGBT elders, the organization started SAGECare, a training program for providers of elder services, including housing and medical care. Staffs are trained to comfortably engage with LGBT elders, ask sensitive questions, be open and non-judgmental, create LGBT-inclusive programming, and learn "best practices" (a government term for services found effective based on research). The program, started earlier this year, presents varying levels of credentials to agencies trained.

WHAT ABOUT HIV?

"We certainly have experiences with hearing stories about caregivers not understanding how to work with HIV, appalling things such as concerns with contact," said Meyer. "There's still very much a stigma and misinformation. Our training addresses myths and debunks them." SAGECare providers learn to be "respectful and welcoming and inclusive," she said. "Fear of being discriminated against is quite pervasive."

"I would feel really uncomfortable going into a retirement village that doesn't respect me or honor me. I wouldn't want that," said Tom Hunter, MA, LCSW, the Senior Care Specialist for Chicago House, an agency that provides housing and other services to people with HIV and other marginalized populations, and a gay man himself living with HIV. "I think in some cases people *are* going to be forced to go into a nursing home or other facility and it's very important for the staff to be trained in cultural competence. You would think that in this day and age people would be well-educated and accustomed to having LGBT people around, but they're not."

As for HIV, he notes that there's still stigma even among gay men. "I've experienced it myself, and I've heard of it happening to others," said Hunter.

Marina Kurakin of the AIDS Legal Council of Chicago, who wrote a story on finances for this issue, said that the Americans with Disabilities Act (ADA) outlaws nursing home discrimination against people living with HIV. But it still happens, she said.

Hunter points out that people living with HIV may not disclose, just as people who are LGBT may closet themselves to avoid discrimination. "They pick and choose who they tell it to, even in the gay community, looking for support from people they can trust." He noted that people with other health issues like diabetes or heart disease may not necessarily disclose either.

He also pointed out that senior housing built for LGBT individuals cannot discriminate against heterosexuals, an irony learned when these types of buildings began opening around the country, such as Town Hall Apartments in Chicago.

As for housing for individuals living with HIV, people want a subsidized apartment where they pay approximately 30% of their income, he said, but those are in very short supply. There may be temporary housing opportunities—lasting as long as years—that help people get back on their feet until they are able to obtain permanent housing, he said.

Chicago House and other housing agencies and services for people with HIV in the city are LGBT-friendly, while other places may not be, he said. That adds another layer of difficulty for LGBT people who are living with HIV.

"There at least has to be some cultural competency training for staff, and they really have to believe in it and follow it because those people are going into assisted living facilities, nursing homes, or retirement communities and some of them often feel afraid of being abused. I've heard story after story about this, how people feel either their sexuality goes back into the closet or they can't be themselves because they're afraid of being mistreated or ostracized," said Hunter.

A report published two years ago by SAGE and the Equal Rights Center documented this problem, looking at housing discrimination against elderly gay couples.

Aaron Tax, Director of Federal Government Relations for SAGE, said the challenges for elderly LGBT people and people living with HIV are similar, including stigma and discrimination. For LGBT individuals, however, there appears to be a higher level of social isolation.

"This is a population that's largely disconnected from their families of origin and often have to rely on friends, neighbors, and others who are of the same age, and as a result, that presents its own challenges," said Tax. "They're older or frail or having other health challenges, so who are the obvious go-to people there to help them?

"The LGBT statistics show that LGBT older adults are twice as likely to be single and four times less likely to have children than their heterosexual and cisgender counterparts," he continued. "And day-to-day, that creates a challenge because they don't necessarily have people around for socialization, such as family members, and for the day-to-day tasks, whether it's health care or taking medication, getting to the doctor, chores around the house, and all those sorts of things."

In addition, he said, LGBT elders face a much higher poverty rate than the general population, as well as having a lack of access to culturally competent services and support.

"Then there's this whole other layer of this challenge, the stigma associated with HIV," said Tax. "So what does this mean? This is a population that's in greater need of services and support provided by the central government and the state governments

THROUGHOUT MANY COMMUNITIES, people with HIV risk losing their housing due to factors such as increased medical costs and limited incomes or reduced ability to keep working due to related illnesses.

HOUSING AT aids.gov

and other agencies, yet because of stigma and the discrimination they face are much less likely to take advantage of services and support that are there to help them."

Moreover, there are challenges and stigma associated with HIV even within LGBT services, he said, in addition to stigma associated with aging.

SAGE is working on government policies to provide national protection for elderly LGBT individuals, such as the Equality Act and a comprehensive LGBT civil rights bill that would cover discrimination in housing and all public accommodations.

It's not all talk and policy, however. The organization is set to open two LGBT senior living buildings this year, in the Bronx and Brooklyn.

"But we also realize we can't build our way out of this," Tax said. "The wider housing stock has to be either affordable and/or targeted low-income, and be welcoming. And if there are any services or programs attached to that housing, it needs to be provided in a culturally competent way. That's in part what we're doing through our federally funded National Resource Center on LGBT Aging [lgbtagingcenter.org; the resource section includes the aforementioned video], to ensure that the services out there provided either by the LGBT community or by the aging network are culturally competent and serve the needs of LGBT older adults and those living with HIV. We're going to continue working to try to ensure that the federal government policies on HIV and those on aging take into consideration on the one side aging and on the other side HIV, so that aging policies are HIV-inclusive and HIV policies are aging-inclusive."

Tax noted that, "If you're in New York City, perhaps you can get into an LGBT-targeted building, but there are plenty of people who *won't* be able to get into a building like that. If you're in rural Mississippi, perhaps you'll never have an LGBT-targeted older adult building. You'll want to know that if you go to a long-term care community where you live that you feel welcomed and you can be who you want to be and who you are in that setting."

Tom Hunter echoed those comments. "People in this population will probably want to be in major cities with easy access to culturally competent, good medical care. It may be nice to get a house in the country out in Montana, but you can be very far removed from an infectious disease doctor and without a staff who understands you and accepts you."

He thinks people may buy a unit or a building together to form their own housing and self-help community. Said another gay man, "Maybe this is why gay men have loved *The Golden Girls*. A shared living situation with friends sounds comforting in the face of getting older." PA

TYPES OF HOUSING FOR PEOPLE WITH SPECIAL NEEDS

HILARY MEYER OF SAGE OUTLINED THE TYPES OF HOUSING AND HOME-BASED SERVICES FOR PEOPLE WITH SPECIAL NEEDS.

Home and community-based services (for example, Meals on Wheels and others that assist with "activities of daily living")

Services in the home (for example, home health aides for various medical needs)

Controlled residential settings, with varying levels of care providers

- Independent living community—residents are older but highly functional, needing little if any help
- Assisted living—more medical services
- Skilled nursing facility and nursing homes—where people are sick and may need hour-to-hour attention; includes memory care for those with dementia

THERE ARE ALSO a wide variety of programs available for low-income people living with HIV, such as vouchers to pay for movers and a rent deposit, or temporary rental assistance. Call the AIDS Info hotline at (800) HIV-0440—(800) 448-0440—for organizations near you that can provide more information.

Read the excellent article "Housing Options for People Living with HIV in the U.S." from The Well Project, at thewellproject.org/hiv-information/housing-options-people-living-hiv-us. Also, go to the U.S. government webpage for housing for people with HIV, aids.gov/hiv-aids-basics/staying-healthy-with-hiv-aids/taking-care-of-yourself/housing.

PHOTO: ISTOCKPHOTO/RICHARD SHARROCKS

PHOTO: ISTOCKPHOTO/ BAONA

DISCOVERING RESILIENCE

Reducing the impact of psychosocial stressors on long-term survivors

BY **DAVID FAWCETT, PHD, LCSW**

I WATCHED the young, thin man leaning heavily on his cane as he struggled up Seventh Avenue. The winter wind blew through the New York streets in powerful gusts that nearly toppled him. Looking painfully weak, every step he took was as deliberate as it was uncertain. I came forward to assist him when he stumbled and I saw that he was nearly totally blind. As he grabbed my hand I recognized the terror in his eyes. We both understood he was dying of AIDS.

It was 1985 and, at that time, I was unaware that the virus had already begun its slow-motion destruction of my own immune system. Pneumocystis pneumonia (PCP), Kaposi sarcoma, dementia, and blindness from cytomegalovirus (CMV) were terrorizing the gay community. Painful death was everywhere, one after another, countless friends and strangers falling away. Those of us left behind, the survivors, the caretakers, were battered by fear and stigma, anger and hopelessness, and most of all, a deep, numbing grief.

There was light in the darkness. The crisis led to tremendous acts of selflessness. Ignored by government and lacking systems of care, strangers stepped up to assist those suffering from AIDS. The larger community, including our lesbian sisters, created soothing spaces for those in their final days. While some of us were fortunate to have supportive families, others were not and they too were embraced. We cared for those rejected by fear and stigma. We buried those whose churches refused to do so. Persistent efforts of advocacy and courage, such as those of ACT UP, provided access to medications. The Denver Principles declared a series of rights for people living with the virus, including not being treated as victims and equal participation in the fight against HIV/AIDS. Many of us were transformed as we began a lifelong fight for survival against stigma and oppression.

Yet, despite these contributions, and even as mortality began to improve, the impact of this tragedy on those who lived through it was irreversible. These men and women, the long-term survivors, continue to be plagued by a host of concerns, including depression, anxiety, post-traumatic stress disorder, addictions and, for some, a deeply internalized sense of shame and even worthlessness.

Long-term survivors are diverse. Some, like me, date from the pre-protease inhibitor era when our T-cells dropped to four or five. After 1996, with the introduction of protease inhibitors, people living with HIV/AIDS (PLWHA) had a different experience, characterized less by certain death than increased risk for isolation and depression. Others, such as women, communities of color, and the trans community, have all had a unique experience of HIV shaped by stigma and other psychosocial issues.

Remarkable medical advances have altered the course of the epidemic and changed its focus to one of healthy living, a narrative that unfortunately overlooks the experiences of many long-term surviviors living with HIV/AIDS. This lack of acknowledgment in stories about HIV/AIDS only further contributes to social isolation and unmet psychosocial needs.

HIV suddenly became very personal for me when I was diagnosed in 1988. A terrible case of shingles, followed by an HIV test and labs, confirmed that my immune system had significantly deteriorated. I began taking the only treatment, AZT (ritonavir), every six hours as prescribed. Because there were no other options and no history by which doctors could dose this medication, by taking it I entered into a human drug trial in real time. Unfortunately, AZT created such dangerous anemia that I was hospitalized for transfusions.

Over the ensuing years I lent my body to numerous other drug trials in a desperate attempt to stay alive, some of which also proved so toxic that I was twice hospitalized with pancreatitis and I still suffer crippling neuropathy. Fearful

Psychosocial complications

BELIEFS ABOUT SELF

An HIV diagnosis is a blow to our identity and beliefs about who we are. “I am damaged goods.” “I am unlovable.” “I am unworthy.” Fueled by shame and stigma, these beliefs resonate with those resulting from other stigmatized identities such as being gay, from an ethnic or racial group, or an addict. There are ample messages from the world reminding someone living with HIV that they are dirty, worthless, even dangerous. These words become deeply internalized and create a jumble of worries about a foreshortened future, rejection, isolation, even criminalization. Such negative self-talk must be identified and corrected. This requires both persistence and support from peers along with healthy role models to eradicate these shame-based beliefs about oneself.

TRAUMA

Most, if not all, people living with HIV/AIDS have experienced trauma and/or abuse in some form: emotional, physical, sexual, intellectual, and even spiritual. Trauma not only results from an HIV diagnosis, but a history of trauma can put someone at risk for becoming HIV-positive by creating feelings of low self-worth that lead to high-risk sexual behavior or deadening painful emotions through substance use. No matter the source, trauma leads to a variety of symptoms that are disruptive to a healthy emotional life. These include hypervigilance, isolation, emotional numbing, trust and intimacy issues, and even survivor guilt. There are various therapeutic interventions that can help individuals heal from traumatic experiences, and trauma-informed care has now become an important standard for recognizing its far-reaching impact.

MENTAL HEALTH ISSUES

People living with HIV/AIDS (PLWHA) have a significantly increased risk for mental health concerns. In any given year, nearly 50% of PLWHA meet the criteria for a depressive mood disorder, up to 40% can be diagnosed with anxiety, and many others are diagnosed with post-traumatic stress disorder (PTSD) or suicidal ideation. Psychotherapy, sometimes combined with medication, can be very effective for these conditions. Anyone experiencing such symptoms should seek out providers familiar with both HIV medications and the emotional concerns of long-term survivors. HIV-related dementia was once a very serious problem in the early days of the epidemic. Fortunately, rates of dementia have greatly decreased with newer medications but today nearly half of long-term survivors are estimated to experience HIV-associated neurocognitive disorders (HAND). Symptoms can include confusion, forgetfulness, and behavioral changes which are indistinguishable from symptoms related to the aging process. For now, the best intervention for HAND is to keep one’s viral load at undetectable.

SUBSTANCE USE

PLWHA are at greatly increased risk for some form of addiction. Injection drug use (IDU) accounts for about 8% of new cases of HIV, and with the opioid epidemic there are concerns this number will increase. Many PLWHA find that certain substances and behaviors numb uncomfortable emotions and alleviate inhibitions and shame. While use of any substance can become problematic, methamphetamine is a particularly destructive drug reaching epidemic levels. Many long-term survivors who feel isolated, “invisible,” or less sexual succumb to the artificial boost to self-esteem provided by meth, resulting in high-risk sexual behavior. This euphoria is short-lived, however, and creates both physical and emotional havoc. In addition to all its other destructive potential, addiction often leads to non-adherence to HIV medications. Treatment, along with self-help recovery groups such as Alcoholics Anonymous, Narcotics Anonymous, and facilitated groups such as SMART Recovery are effective for addiction.

Creating resilience

BECAUSE OF psychosocial challenges it is essential to create resilience in order to maintain emotional health. Such resilience is not a personality trait, but rather a process unfolding over time. It is comprised of numerous decisions and beliefs about oneself, all of which reflect empowerment, social connection, and compassion for oneself and others. Here are some skills to build emotional resilience.

LIVE WITH INTENTION

A key foundation of emotional resilience is making the decision to live intentionally. Careers, families, and the future imagined by every long-term survivor were disrupted at an early age. Most of us had a sense of a foreshortened future and learned to live day-to-day, not believing we would survive. Consequently, many lost a sense of purpose. Today we know that discovering meaning for one's life is tremendously healing. Working in some aspect of the HIV/AIDS epidemic provides the perfect opportunity for many, transforming their experience into action that contributes to both themselves and their community.

DISCOVER COMPASSION

Shame and stigma undermine the lives of everyone living with HIV/AIDS. Finding compassion for oneself, including changing negative core beliefs, is tremendously healing. Mindfulness, the process of noticing one's thoughts in a non-judgmental way, is useful for becoming aware of undermining beliefs and patterns and provides an opportunity for change. Finding trusted persons who can reflect back how they see us provides a wonderful opportunity to correct a distorted self-image and replace shame with affirmation and pride.

PRACTICE SELF-CARE

Learning to care for oneself physically, emotionally, mentally, and spiritually is essential to counteract psychosocial stressors. Eating well, getting adequate sleep, and daily exercise can sometimes be a challenge for PLWHA, yet being mindful of these daily aspects of living carries tremendous benefit, especially as long-term survivors begin to experience metabolic syndrome (which includes diabetes), cardiovascular problems, and liver and kidney complications. Such self-care also includes addressing any addictions, which only compound health problems.

STAY CONNECTED

Isolation, stigma, and physical concerns all contribute to social withdrawal, and each can lead to poor health outcomes. Perhaps the single most important component of emotional resilience for long-term survivors is social connection.

Getting together with friends, support groups, and social outings are all ways to create healthy social connections. Buddy programs, common in the early days of the epidemic, are very effective at preventing someone from sinking too far into isolation. Opportunities to interact with others who have had similar life experiences, such as The Reunion Project or Let's Kick ASS (AIDS Survivor Syndrome), transform the impact of living with an uncertain future, multiple losses of partners and friends, and the prospect of rapid aging into one of empowerment and connectedness.

that my employer would discover my status, I received pentamidine treatments (to prevent PCP) anonymously at a public clinic and helped bring unavailable drugs into the country.

In 1994, when I was hospitalized for non-Hodgkin's lymphoma, my family was assembled to be present for my death, but I somehow survived. Financial hardship followed when my health insurance failed to cover all the costs of the hospitalization, forcing me to declare bankruptcy. For years I focused on simply surviving until the next medication was released. Twenty years into the epidemic, many, including my then-partner of 22 years, began developing resistance and ran out of medication options. Like many others, he died.

My history is not unique. I share this journey with thousands of other men and women who, starting in the early days of the epidemic, had a very different experience than someone diagnosed with HIV today. For us, even an undetectable viral load cannot reassure our worry about the cumulative toll of the drugs and the virus on our minds and bodies, especially as we age. The psychosocial concerns listed have a significant impact on health and well-being (see "Psychosocial Complications").

HIV has become a manageable illness, and today we can even speak of a cure. While I am truly grateful that we are conquering this epidemic, it saddens me that the devastation to my generation increasingly seems to be lost to so many, including a portion of the younger HIV workforce. And although this history is being documented on film and through our sharing, it falls to us alone to rewrite the narrative of our lives with HIV. We are still here. We survived, but we are doing much more. We are using resilience to transform our lives, thereby healing us and influencing those that follow.

DAVID FAWCETT PHD, LCSW, was diagnosed with HIV in 1988, and has worked with HIV and co-occurring mental health and addiction concerns among men and women for over 25 years. Along with his clinical practice and workshops, he writes for TheBody.com and is an advisor for the SAMHSA-funded HIV/AIDS and Mental Health Training & Resource Center. His book, *Lust, Men, and Meth: A Gay Man's Guide to Sex and Recovery* (Healing Path Press 2015) explores the intersection of drug use and high-risk sexual behavior.

SISTER, SISTER

Long-term survival is an age-old story of love and loss. For PA Associate Editor **Enid Vázquez**, this is the chance to get it right

PHOTOGRAPHY BY **PETER SEROCKI**

For a time, I was estranged from my sister Sylvia. While I had gone away to college, she had gotten married. But her husband was a drug user, and she acquired HIV. Later, she had no phone where I could reach her. Besides, I was busy building my career. We had never been particularly close anyway, even though we're only 15 months apart and can still pass for twins.

Today, however, we find ourselves at the same point in life, looking for peace and comfort as we face our golden years.

I'm grateful she's survived 36 years with HIV, for so many reasons. Among them is the chance to renew our relationship. I want to make up for the bad things that happened to her, none of which she deserved. I want to give her lots of love. Her survival makes all of that possible.

I had never really considered the possibility of her death, because I've always seen her as such a strong person. In recent years, however, I began wondering, *Who knows how much longer I will have her in my life?* I don't want to waste those years, whether it's three or thirty. She's smart, she's funny, she's loving, and I've always appreciated those qualities in her.

There's a strange lesson you often learn in the epidemic. You watch people with AIDS survive as other friends and family members die or become disabled. It happened to our family. Our youngest sister died two weeks before her 40th birthday, from a congenital heart disorder no one realized she had. More than a decade later, the sister with AIDS continues to thrive.

This year our father died. I feel that we're at a stage where life is more important than ever, as we see more death in our family.

"When I was first diagnosed, the doctor told me I had three to six months to live," Sylvia told me. "I was very bitter and very angry, because I was told to pack it up, get my affairs in order. [She was 25, but the doctor estimated that Sylvia had picked up the infection earlier, in 1980.] And I think a lot of people gave up because of that. 'Why am I going to stop using drugs? Why am I going to stop doing this or that? I'm going to die anyway.' This is what the doctor did to me. It's funny, how simple words from a doctor, a nurse, or caregivers, can dictate a person's life. So for two, three years I was waiting to die. It was difficult."

She had three small children to raise. The thought of leaving them orphaned devastated my sister.

"When I finally told myself, 'Damn, I've been around three years and I haven't gone nowhere,' I think that's when I realized, I ain't going nowhere," Sylvia said. Then she

I HAD NEVER REALLY CONSIDERED THE POSSIBILITY of her death, because I've always seen her as such a strong person.
—**ENID VÁZQUEZ (BELOW) WITH HER SISTER SYLVIA**

laughed. "That's when I realized I should live my life."

So she gave up on her death sentence a long time ago.

"The disease taught me how to live," she said of this new phase in her life. "It taught me that I'm not just alive, but that I'm living."

After she overcame the addiction she picked up through her husband, who had since died, Sylvia emerged from her old life triumphant. She worked full-time as an HIV peer counselor, including several years at TPAN, the non-profit HIV/AIDS service organization that publishes POSITIVELY AWARE. She had a beautiful home and raised three children on her own.

Today, when Sylvia comes to Chicago from her home in Wisconsin to see her HIV specialist at Northstar Medical Center, I take her to lunch, and then we go thrifting. I try to take the day off from work if I can to spend time with her.

This summer, I was able to visit Sylvia a couple of weekends. We go out to lunch, go thrifting; we walk her dog Hercules to a beautiful public garden nearby. We have sleepovers, talking well into the night or watching true crime stories on TV.

Sylvia lives across the street from a large park. I tell her to never move; the view is so beautiful.

But living on her own is costly now that she's on disability. After paying bills, she has very little left for day-to-day expenses. But Sylvia says it's worth her peace of mind, not having to deal with the rules and regulations of any housing that's been set aside for people in need. And that's *if* it's available. Under typical restrictions, Sylvia says, you can't have a dog that weighs more than 20 pounds. Sylvia's dog is a playful 70-pound pitbull mix. You can't "do drugs," but her occasional migraine headaches—and accompanying nausea—are controlled with marijuana.

"Why can't I get Ryan White [funding] to give me $200 a month to go towards my rent?" she asked. "I'm in heaven. I'm in peace. I have my dog. I pay my rent, and $200 dollars is what I can put towards my light bill. People say I'm in Kenosha, what can I expect? But it's like this everywhere. 'Oh, we got this funding to do this,' and then they add all these stipulations so that you don't qualify for it. How are they helping me?

"So sometimes it means going a little hungry," Sylvia tells me. "That's okay. In four days I'll get my money and I'll get food. You've got to learn to live that way. I'm grateful for the little bit of rice that I've got. I'm grateful for three eggs in my fridge. It's things like that, Enid. Realizing that at one point I was homeless, that at one point I didn't have food. To have three eggs is like I'm a rich person. But the most important thing is that I have a roof over my head. I have somewhere to lay my head."

She has family and friends who can occasionally help her out financially, even if it's only with a loan. Still, sometimes she's down to those three eggs.

Yet, Hercules gets his nails clipped at Petco, if Sylvia can get a ride. She recently paid for both his grooming and that of her youngest son's dog, when her son was strapped for cash. The next time, however, he was able to pay back the favor. Somehow, she gets by.

SYLVIA WITH HERCULES.

PHOTO: ENID VÁZQUEZ

"Awww, Enid, sometimes I really wish I could work," she tells me. "Financially, it's difficult." She spends 78% of her monthly income on rent. (The standard cost should be 25–33%.) She receives additional funds for food.

She would love to go back to counseling survivors of domestic violence.

The deficits of money, of health, and of a shortened work history echo the challenges many people face, even those without HIV. The extra challenges of living with the virus, however, include stigma. But when you don't give a damn about the stigma, as Sylvia doesn't, you're that much more free, that much further ahead. She believes in taking care of yourself, especially through releasing stress.

Sylvia says that while at one point it was important to her to have a partner, it wasn't about being taken care of. "I think it was more about wanting to feel *loved.* (Long pause.) If you're in a relationship to get loving, let me break it down ... that is not the way to go. You have to love yourself. I am happy to be alone. I'm not looking. I feel that with my goddesses, my god, my light of love and peace, which is what I go by, I'm content. But if it's meant for me to have someone, a person will come along. I'm so happy where I'm at right now."

"I don't like support groups because of the whining," she continues. "I would like arts and crafts with other people, or say, 'Let's go as a group on a cruise.' That would be fun."

Although she believes in a positive outlook as a spiritual practice, she can be negative. I wonder if this is part of the AIDS-related dementia that she was diagnosed with long ago. I know that it can lead to personality changes. It makes me want to be supportive of my sister all the more.

Whatever her difficulties, Sylvia is here and I have her company to enjoy. I no longer take it for granted.

Sylvia said she would be very lonely without Hercules. She sings to him a song from a commercial about a man and his dog—*You're my buddy, my pal, my friend, you'll be with me to the end, and wherever you go, I want you to know, you're my buddy, my pal, my friend.* PA

MONEY TRAIL

Some guidance for the journey

BY **MARINA KURAKIN, MSW, MFA**

PHOTO: ISTOCKPHOTO/ ALEX BELOMLINSKY

PEOPLE OFTEN COME to AIDS Legal Council of Chicago, a program of the Legal Council for Health Justice, with questions about Social Security, insurance, and estate planning. Strategizing for the future can look very different for different people. I want to highlight some of the most typical concerns introduced to us by people aging with HIV. Much of the information described below (and much more) can be found in our legal guides, available in Spanish and English, legalcouncil.org/resources/legal-guides. Please keep in mind that our agency is based in Chicago and the guides contain some state-specific information.

You can discuss your short- and long-term goals and create strategies for the future by consulting a financial planner.

Planners can be expensive, however. Some higher education institutions offer free financial clinics for low-income individuals. There are also lots of new online tools to start the process on your own (such as Mint, Moneystream, and Quickbooks). AIDS community organizations often have referral relationships with financial counselors.

The AIDS Legal Council assists clients in Illinois in applying for public benefits, appealing denials, and ensuring smooth insurance transitions. Most states have Ryan White-funded legal aid services, just like ours, that can be an important part of planning for your future comfort.

The easiest way to discover what's out there is to simply call and ask.

Can I get life insurance as a person living with HIV?

THERE IS ONLY ONE commercial life insurance company that sells policies specifically for people living with HIV, Aequalis.

Almost all insurance companies refuse to sell life insurance to people with HIV. They ask your HIV status on their application forms and if you lie and say you don't have HIV, they won't pay your beneficiary after your death. Another possibility is to buy one or more small "guaranteed issue" plans (one type is called "final expenses"). These policies are available to anyone, but pay nothing if you pass away within the first two years after buying the policy.

Even if you can get a life insurance policy, it is important for you to read the small print. Many policies refuse to pay death benefits if the cause of death is from a pre-existing condition. In other words, if you pass away from something you have when you get the policy, the insurance company won't pay your beneficiary anything after you die. Check the policy carefully for a pre-existing condition clause before you buy.

Estate planning

EVERYONE OVER the age of 18 should create power of attorney for healthcare, property, and will documents. These legal documents vary state to state, but are an essential part of taking control of situations where one usually has very little control.

As we age, these documents become even more important. Who will make medical decisions about your care if you become incapacitated?

Estate planning protects your choices, your independence, and your ability to define the type of care you prefer, without putting the pressure of making those decisions on your loved ones.

What is power of attorney?

A POWER OF ATTORNEY is a legal document that lets you name someone you trust to take care of your affairs, including health care, if you are ever unable to do so yourself. That person, called your agent, can check you into a hospital, consent to medications or surgery, take you to a nursing home, or make any of the health care decisions you normally would make. Your agent can also make your final arrangements, such as a funeral or cremation.

A power of attorney for property allows you to name an agent to help handle your financial affairs while you are unable to do so yourself. “Property” refers to anything you own—your money, your car, your household things, and so on. Your agent can sign your checks, buy and sell things for you, and pay your bills using your funds.

What is a will?

A WILL IS A legal document that lets you do at least three important things: 1. Put someone in charge of your estate (all your possessions) after you die. This person is called your executor. 2. Decide who inherits your money and possessions after your death. 3. Nominate a guardian for your children.

What happens if you die without a will? Without a will, only a spouse, civil union partner, or biological relatives have the right to inherit. If you have a spouse but no children, your spouse inherits everything. With children, the spouse inherits half and the children divide the remainder. If you have no spouse or children, your immediate relatives divide everything.

Applying for disability

AS WE GROW OLDER, our health becomes more of an issue. Although being diagnosed HIV-positive no longer makes you eligible for disability on its own, many individuals feel like they cannot continue working when experiencing a mixture of illnesses.

There are two different types of Social Security benefits available for individuals disabled by HIV, AIDS, or other conditions: Social Security Disability Insurance benefits (SSDI) and Supplemental Security Income benefits (SSI).

SSDI-eligible individuals have a work history and have paid into disability insurance for at least 10 years. SSI is for disabled individuals who haven’t worked much and have very little money. You can apply for either one by going to your local Social Security office or by calling (800) 772-1213. If you don’t know which program is right for you, Social Security will help you figure it out. See the table on this page for a comparison of the two programs.

COMPARING PROGRAMS

ELIGIBILITY REQUIREMENTS AND BENEFITS

Social Security Disability Insurance (SSDI)	Supplemental Security Income (SSI)
Need work history of 10 years	No work history required
Up to $2,200/month	$733/month maximum
Amount awarded based on work history	Fixed amount for everyone
No asset limit	$2,000 asset limit
Can get back pay up to one year	No back pay, paid from date of application
U.S. citizens and Green Card holders	U.S. citizens, no work history required; Green Card holders must have work history

How does Social Security define being “disabled"?

SOCIAL SECURITY HAS very specific rules about how disabled you have to be to be eligible for SSI or SSDI benefits. It’s not enough that you have an AIDS diagnosis or if your doctor believes that you are unable to work. Social Security uses a five-step process to evaluate your case.

First they look to see if you are working when you apply. If you are working and earning more than the Substantial Gainful Amount (SGA in 2016 is $1,130) in gross monthly income (before taxes are taken out), then Social Security will conclude that you can work, even if you’ve had to cut down your job and hours.

Then they look to see if you have a severe condition which they consider to be disabling. It’s important to note that conditions have to be at a certain level of severity to be automatically disabling.

If Social Security doesn’t find that any of your conditions meet a disability listing, they will look at all of your medical problems together to see how they affect your ability to function. This will include investigating how well you carry out your daily activities, how well you get along with others, and how well you stick to a job and get it done on time. Social Security can determine that your combined problems seriously interfere with your abilities to function. If not, they go to the next step.

Social Security will evaluate whether your medical conditions prevent you from doing work you have done before. If you can still do any job you’ve ever had, then you will not be found disabled. But if you can’t do any of your past work, Social Security will go to the next step.

At the final step, Social Security will look to see if you can do any other type of work, based on your age, education, skills, and past work experience. If you cannot maintain any job on the market, you will be found disabled.

The majority of disability claims, 90% of them, are denied, so press on through the appeal process. If Social Security denies your disability claim at the initial level, you can appeal this decision and have it reviewed. If this reconsideration is also denied, you can again appeal and request a hearing in front of a judge. Appearing before a judge is usually your best chance at obtaining disability.

It is important to note that documenting your medical condition is essential in winning disability. This involves getting regular medical care, reporting any issues or symptoms you are

DOCUMENTING YOUR MEDICAL CONDITION is essential to winning disability. This involves getting regular medical care, reporting any issues or symptoms you are experiencing to your medical team, and ensuring that medical records are being sent to Social Security.

experiencing to your medical team, and ensuring that medical records are being sent to Social Security. If your medical records are spotty, you will have a harder fight.

Applying is also a time-consuming process. It can take two years to get to the hearing level, where having legal representation can be an important asset. In many states, Ryan White offers funds for legal services for people living with HIV. This allows HIV-positive individuals to get more help in applying for and keeping disability.

When you reach retirement age and your SSDI converts to retirement, you no longer have an earnings cap. This means that you can work and earn as much as you like, and continue receiving your Social Security retirement income. This is only true if you were getting SSDI and not SSI.

If you were receiving long-term disability benefits through past employment along with SSDI, this benefit usually stops when you turn 65. It's very important to speak with your benefits coordinator about health insurance, long-term disability, and any other benefits you may be receiving at age 64. If you are getting Social Security disability benefits when you reach full retirement age, your disability benefits then automatically convert to retirement benefits, but the amount remains the same.

Who is eligible to receive Medicare?

PEOPLE 65 AND OLDER who have paid into the Medicare system through their taxes, and their spouses, including same-sex couples, are eligible for Medicare. Additionally, persons with disabilities are eligible once they receive SSDI for 24 months. Individuals receiving disability who are diagnosed with ALS or are on dialysis are eligible for Medicare immediately.

You can enroll in Medicare at three unique times. Everyone who is eligible has an Initial Enrollment Period. This starts three months before you turn 65 and runs to three months after. If you do not sign up when you are first eligible because you have insurance through work, then you can delay enrollment until you lose comparable coverage. You must then enroll in Part B within eight months of losing your work insurance or suffer a financial penalty.

If for some reason, you do not enroll when you are first eligible then you can do so during the General Enrollment Period. This is from January 1 through March 31. You can enroll by calling Social Security and asking to sign up for Part B. This coverage will then begin July 1 and your part B premium costs may be higher if you did not sign up when first eligible. Since enrollment is confusing, we always recommend that you speak with a counselor. You can get help by calling the Senior Health Insurance Program at (800) 548-9034.

Medicare is made up of different parts. Generally, you can think of this coverage being responsible for 80% of your medical costs.

❶ **Medicare Part A (hospital insurance)** covers inpatient hospital care, skilled nursing, home care, and hospice. Generally there is no premium for this coverage if you have sufficient work credits.

❷ **Medicare Part B (medical insurance)** covers doctor's care, outpatient services, and lab work. There is a monthly premium charged for coverage. Part B costs go up each year, but for now they are between $104—$121, depending on whether the premium is automatically taken out of your Social Security check.

❸ **Medicare Part D (prescription insurance)** Medicare uses private drug plans to pay part of your drug costs. A monthly premium is required and the insurance company sets the premium. This coverage is voluntary and you have to choose to enroll.

❹ **Medicare Part C/Medicare Advantage (hospital, medical, and prescriptions) HMO** replaces Part A, B, and D coverage through enrollment in private health insurance. (Not all doctors who accept Medicare accept Medicare Advantage plans.) The premium rates are established by the private insurance companies.

❺ **Medigap Plans** are purchased through approved insurance companies to cover the gaps in Medicare A and B coverage (covers the remaining 20%). Medigap plans usually have high monthly premiums, but are good to have if you anticipate high medical costs. There are many state and federal programs that can help offset the costs of all of these Medicare components. Medicaid is a state program that helps eligible seniors pay for medical care if they are at 100% of the federal poverty level (FPL) or below.

There is also a federal program called Extra Help, which assists with Part D premiums and medication copays. To learn if you qualify for Extra Help and to apply, go to ssa.gov/medicare/prescriptionhelp.

Another program which helps with Part B premiums, deductibles, and copays is called Medicare Savings. This is a federal program that is run by the states. You can find the eligibility guidelines here: medicare.gov/your-medicare-costs/help-paying-costs/medicare-savings-program/medicare-savings-programs.html-collapse-2614.

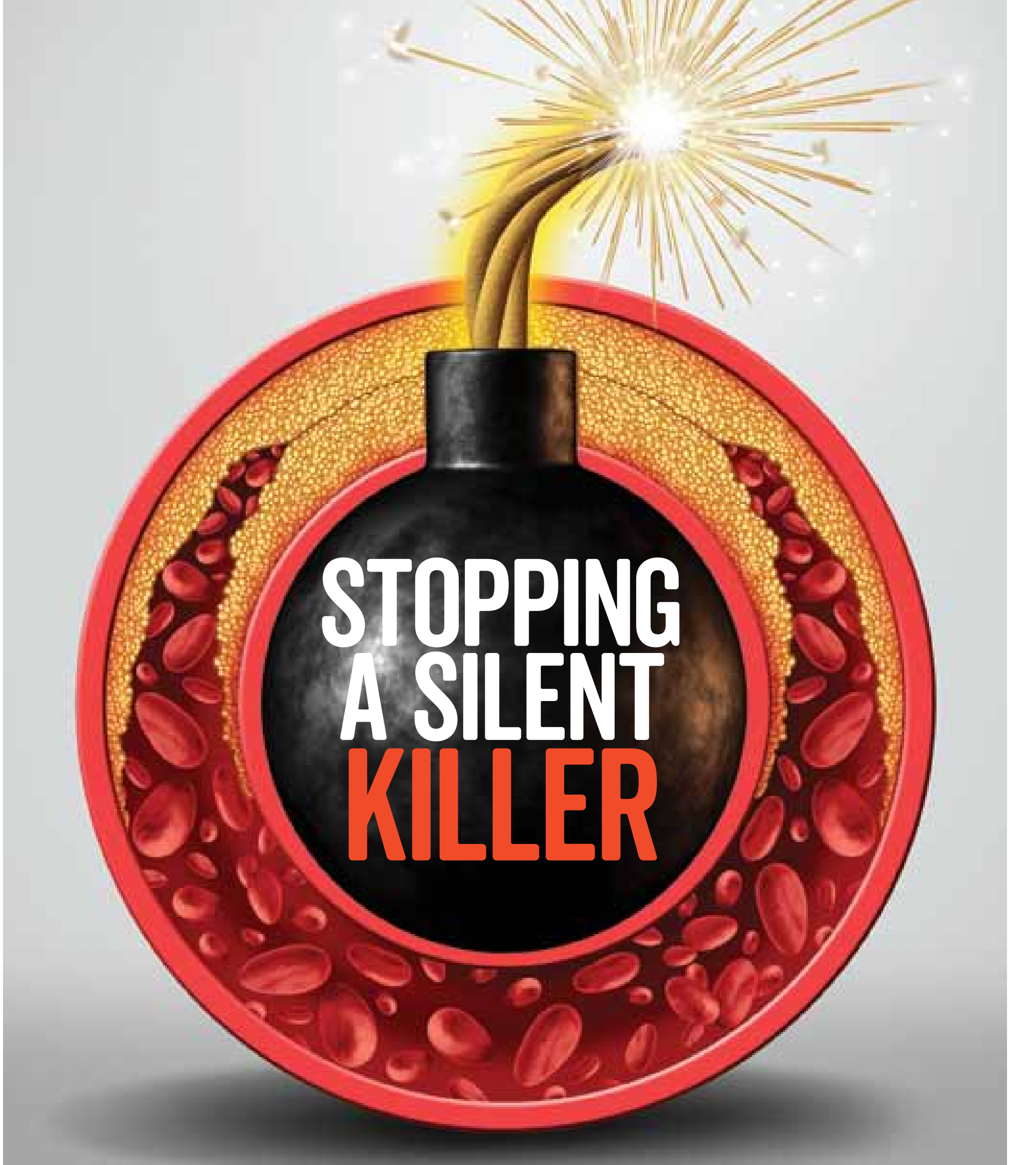
Case management

WHILE ADAP HELPS many people access medications and health coverage— paying premiums for Markeplace, Part D, Medigap, dental, and vision plans—there are also other resources available through Ryan White case management. A medical and housing case manager can help you find vital assistance programs and guide you through the maze of applications. They can connect you with help applying for SNAP benefits (for food), Medicaid, emergency housing assistance, and Ryan White-funded therapy and oral care.

Benefit check ups

THERE ARE MANY THINGS to consider when turning 65. Because of the amount of programs out there, and the variety of eligibility requirements and rules, navigating these systems can get very confusing. To get a quick snapshot of your Benefit Eligibility, you can start by taking this 20-minute survey: benefitscheckup.org/cf/index.cfm?partner_id=61&gohome=true&subset_id=57&CFID=1386751&CFTOKEN=62121318. Once you get your results, you will have a better idea of our social safety net.

MARINA KURAKIN, MSW, MFA, is a paralegal and healthcare advocate at the Legal Council for Health Justice, where she leads legal clinics focused on health insurance and public benefits. She has extensive experience in working with refugees, people living with HIV, and other vulnerable populations. Because health is linked to social determinants, she concentrates on increasing resource access for all.



STOPPING A SILENT KILLER

Know the facts about heart disease and HIV

BY **KATHLEEN FITCH, MSN, FNP**

"I HAD NO IDEA that since I have HIV, I may be twice as likely to have a heart event compared to the general population," said Frank Carroll, a 63-year-old man who has been living with HIV for over two decades.

Unfortunately, that is the case for the majority of people who are living with HIV. Up to this point, there has been very little research conducted regarding heart disease and HIV, but here is what we do know:

People with HIV often have what is known as "inflamed non-calcified plaque" buildup in the heart. This plaque is considered "high risk" plaque because it is a leading risk factor for heart disease. This is important to know because "inflamed non-calcified plaque" is extremely vulnerable to rupture and that can lead to a sudden heart event, such as a heart attack. Traditional risk factors, including high blood pressure and high cholesterol, are well-known contributors to heart disease for those with HIV and the general population. However, an additional and significant HIV-related risk factor for developing heart disease is constant activation of the immune system; this happens even with antiretroviral therapy and when the virus is undetectable.

Heart disease rates among people living with HIV are elevated compared to the general population. If you add to that the fact that heart disease is often a silent killer with atypical symptoms, it is easy to understand why more research needs to be conducted on this subject.

It is important that health care providers gain a better understanding of the intersection of HIV and heart disease to inform how they educate, treat, and monitor patients. It is equally important that heart disease prevention tools are developed and tested, specifically among people living with HIV, to determine the most effective ways to treat and prevent heart disease events in these patients.

"We know that people with HIV are living longer and aging. The HIV community has worked very hard for these successes; they have participated in research studies for the past 30 years to help develop antiretroviral therapy that works to suppress HIV. It is our goal now to find ways to keep people with HIV healthy as they age and help them achieve a full and healthy lifespan," said Dr. Steven K. Grinspoon, Director of Massachusetts General Hospital Program in Nutritional Metabolism and Professor of Medicine at Harvard Medical School.

Gaining a better understanding of how HIV may contribute to heart disease and determining effective prevention strategies will enable health care providers and patients to act before significant damage and co-morbidities develop. The time to take action is now, before this silent killer strikes.

Be proactive about heart health

"I NEVER REALLY thought I would live to be an old man, so it was not until a few years ago that I made the decision to take control of my overall health. I quit smoking and am now more conscious of my diet and exercise activities than in the past. Research has come a long way in helping people with HIV, but there are many things we can do as patients to help ourselves as well," said Mr. Carroll.

Members of the HIV community should make it a priority to talk with their health care provider about additional ways to remain heart healthy. There are always helpful resources available at local HIV clinics such as smoking cessation programs, exercise groups, nutrition services, and research studies.

PHOTO: ISTOCKPHOTO/WILDPIXEL

HEART DISEASE RATES among people living with HIV are elevated compared to the general population. If you add to that the fact that heart disease is often a silent killer with atypical symptoms, it is easy to understand why more research needs to be conducted.

A “whole-body” approach to living longer with HIV is critical. HIV patients and their health care providers alike should understand that there are many pieces to the puzzle when it comes to keeping those living with HIV heart healthy.

“I have treated many patients who were overweight, who smoked, and rarely exercised. In these instances, I always made it a point to explain the risk factors associated with heart disease and the concerns regarding inflamed non-calcified plaque unique to the HIV population. In future visits, many of these patients made lifestyle changes that, in the long run, led to increasingly positive health outcomes,” said Dr. Grinspoon.

GIVEN THEIR INCREASED RISK of cardiovascular disease, people living with HIV need to be proactive when it comes to heart health. It is important that they follow dietary and exercise guideline recommendations to keep their heart healthy. Among the recommendations:

- Eat a variety of fruits and vegetables
- Eat fats from plant-based foods instead of animals (i.e., eat nuts instead of cheese)
- Avoid excess sugar
- Do some sort of physical activity most days of the week
- Quit smoking

Although smoking cessation, eating a healthy diet, and exercising are excellent ways to stay healthy, clearly, there are more tools needed to prevent heart disease among people living with HIV.

Could statins be the ideal heart disease prevention tool?

“RECENT STUDIES SHOW that statins may reduce immune activation and shrink dangerous plaques in the blood vessels in the heart. Statins may therefore be a potentially useful treatment to prevent heart disease in the HIV population,” said Dr. Grinspoon.

Statin medications are a validated strategy with the potential to prevent heart disease, and target traditional and nontraditional risks in people living with HIV. In small studies examining the effects of statins among HIV-positive study participants, statins significantly decreased low-density lipoprotein (LDL) cholesterol, a known risk factor for heart disease. Statins also reduced blood markers of immune activation, inflammation, and inflamed non-calcified plaque in the coronary arteries of these study participants.

However, at this time, it remains unknown if statins will prevent heart disease events in people living with HIV. **Although statins have proven safe and are widely prescribed, it is not fully understood how they will be tolerated in the HIV population.** For example, some studies suggest older statins may cause an increase in blood sugar. However, newer statins, broken down by the body differently than those in the past, have not been shown to cause an increase in blood sugar. In fact, a 2013 study explored the effects of a newer statin called pitavastatin in over 200 HIV-positive study participants and results proved there was no effect of pitavastatin related to increased blood sugar levels. This study was reassuring to researchers because it indicated that newer statins are well tolerated among people living with HIV.

Given the crucial need to find a heart disease prevention tool for the HIV community, investigators from the AIDS Clinical Trials Group (ACTG) Network and Massachusetts General Hospital sought funding from the National Institutes of Health (NIH) to conduct the largest heart disease prevention research study to date among people living with HIV.

About the REPRIEVE Trial

“I CHOSE TO participate in the REPRIEVE Trial because I want to do everything I can to prevent developing heart disease. It is also a way for me to give back to the researchers, the HIV community, and those amazing HIV study participants who came before me. Basically, it is a win-win situation for me,” said Mr. Carroll.

The REPRIEVE (Randomized Trial to Prevent Vascular Events in HIV) Trial launched in April 2015 and will test whether pitavastain prevents heart disease events in people living with HIV. REPRIEVE study participants will be randomized to take one pill, once a day of pitavastatin or a placebo, for an average of 4-5 years. REPRIEVE will enroll 6,500 HIV-positive study participants who are considered to have low to moderate traditional known risk factors for developing heart disease, but are likely at an increased risk due to HIV. Trial sites are located throughout the United States, Canada, Thailand, South America, and Africa.

A unique aspect of REPRIEVE is that there are several sub-studies incorporated into the clinical trial design. In one of the sub-studies, study participants will have a picture of their heart vessels taken by a CT scanner; the picture will be taken before the study medication is started and two years after to see if there are changes in inflamed non-calcified plaque with pitavastatin. Other sub-studies will explore if, by decreasing inflammation, pitavastatin improves kidney function and measures of quality of life.

Women also have a special place in REPRIEVE. To encourage women’s participation in REPRIEVE, there is a campaign just for women called *Follow YOUR Heart. Follow YOUR Heart* has an interactive website with helpful resources on HIV, heart disease, and women’s health and was developed to focus on including and educating women living with HIV about the clinical research process.

Until we know the results of REPRIEVE, people with HIV should follow the important steps outlined to prevent heart disease, such as not smoking, exercising regularly, and eating nutritiously. People living with HIV need to talk to their health care provider about heart health and consider joining the REPRIEVE trial. Joining REPRIEVE is a way for patients to learn more about their own bodies, while helping to determine a successful prevention strategy for the greater HIV community.

LEARN MORE ABOUT REPRIEVE; GO TO reprievetrial.org.

KATHLEEN FITCH, MSN, FNP, is the Project Manager for the Clinical Coordinating Center of the REPRIEVE Trial located at Massachusetts General Hospital. Kathleen has conducted several research studies that have increased the understanding of metabolic complications of HIV including lipodystrophy syndrome, diabetes, and cardiovascular disease. She has also explored different treatment strategies for these abnormalities, including lifestyle modification. In addition, she is a volunteer community educator at several HIV/AIDS service organizations throughout New England.

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POSITIVELY AWARE

8:00 AM: KHAYELITSHA, SOUTH AFRICA
Generation Ubuntu: Each day our kids start class with their Adherence Chant: *On Monday Tuesday Wednesday too, I take my medicine when it's due. Thursday Friday come along, I take my medicine to make me strong. On Saturday, Sunday it's fun to play, I take my medicine every day.*

12:15 PM: CYPRESS, TEXAS
Tammy: I am 46 years old, and have been HIV-positive for 22 years. This is me getting my every three week, seven-hour infusion of immunogammagobulin to help boost my immune system. It's been a hard road, but someday I will feel no more pain or illness. I kinda can't wait for that day, but looking at my mom, my sisters, and all my nieces and nephews, it keeps me fighting.

1:41 PM: BROOKLYN, NEW YORK
Cecil Baldwin: Recording the podcast *Welcome to Night Vale* from the home studio today. Being HIV-positive and undetectable for 10 years has changed the way I view life, love, sex, and the American health care system. The one thing it hasn't done is keep me from following my dream of becoming an actor!

EVERYDAY PICTURES, EXTRAORDINARY LIVES

It seemed like any other day, but Thursday, September 22 was **A Day with HIV**, and dozens of pictures were being posted on social media, accompanied by the hashtag #adaywithhiv.

POSITIVELY AWARE's anti-stigma campaign portrays a single 24-hour period in the lives of people affected by HIV. Participants are encouraged to capture a moment of their day, and include a caption telling what inspired them to snap that picture. Now in its seventh year, the message of A Day with HIV is that, regardless of HIV status, stigma affects everyone.

"I face you in adversity," said Robert Dunn, as if addressing the virus. "I stand firm, I am not afraid. I am me, I am not afraid!"

Family was a motivating factor among many of those who shared their story. "HIV doesn't stop me. It motivates me to live for my daughter," said Felisha Moore, posting a picture with her child.

"It's been a hard road, but someday I will feel no more pain or illness," admitted Tammy, who endures seven-hour immunogammagobulin transfusions every three weeks to bolster her immune system. "I kinda can't wait for that day, but then when I look at my mom, my sisters, and all my nieces and nephews, it keeps me fighting."

Wearing a t-shirt emblazoned with the word "GUNCLE" in all caps, Cody L. Hall posed in a New York City subway station. "I have two little guys who will call me 'Guncle Cody' when they can finally speak. I will not let HIV stigma define me and I will not let those little guys grow up into a world that perpetuates stigma."

Underscoring the campaign's message that stigma can affect anyone, Peter Farmi related the stigma he faces from friends because he is on PrEP to protect himself from HIV.

For some, HIV is not the only challenge they confront. "I beat anal cancer, fought the demons of alcohol and drugs," Daniel Garza said. Erick Santiago shared his experience, "I have been seven months sober—no drinking or anything. It's always a challenge, but we are all stronger than we believe!"

Various HIV/AIDS organizations also participated. Among them were the San Francisco AIDS Foundation, APLA (formerly AIDS Project Los Angeles), Frannie Peabody Center, and the Los Angeles Women's PrEP Network. Researchers at the Microbicide Trials Network at the University of Pittsburgh and the AIDS Clinical Trials Group in Cambridge, Massachusetts took part as well.

From England, activist David Rowlands demonstrated his active lifestyle as he climbed a tree. Andrew Espinosa took a touristy snapshot from Sofia, Bulgaria, where he was attending a European AIDS treatment conference.

One of the most moving posts, however, was a video posted by Generation Ubuntu, a South African AIDS organization that cares for HIV-positive children. The video shows children singing their daily "adherence chant," recited every morning as they take their HIV meds.

Among the number of HIV long-term survivors who took part in A Day with HIV was Hank Trout, a 27-year long-term survivor who writes for *A&U* magazine, the HIV/AIDS magazine that focuses on culture and the arts. "I have taken it upon myself to ensure that the history of the continuing AIDS crisis is told accurately and passionately," Trout wrote.

Ralph Thurlow and David Spiher shared a personal moment: "Ralph's home healthcare worker wasn't able to show up or call in time to arrange other plans, so Ralph is at my office as I do my development job." The couple was featured in *Last Men Standing*, the documentary film based upon the *San Francisco Chronicle's* in-depth examination of long-term survivors and the issues they face.

The following six pages offer a selection of the some 200 photos taken on September 22 for A Day with HIV.

—**RICK GUASCO**

VIEW a gallery of photos taken on A Day with HIV; go to adaywithhiv.com. Pictures will be posted throughout the year on Facebook, Instagram, and Twitter with the hashtag #adaywithhiv. A traveling exhibit of pictures taken in previous years is co-sponsored by the Centers for Disease Control and Prevention. For more information about PA's anti-stigma campaign, email photo@adaywithhiv.com.

3:07 AM >
FISCHERS, INDIANA
Evelynn: I will never agree to be defined by my HIV status. I know I am beautiful, intellectual, and hardworking as I am.

4:45 AM >>
MINNEAPOLIS, MINNESOTA >>
Robert Dunn: I face you in adversity. I stand firm, I am not afraid. I am me, I am not afraid!

7:30 AM >>
EAST ORANGE, NEW JERSEY
Rasmir Mantree: Testing HIV-positive on Jan. 28, 2016, I was blessed with talent to produce House music. My meds work best when I'm working on music. Presently, I'm undetectable; my T-cells are 1,350. Just because I'm HIV-positive doesn't mean you have to be so negative.

8:20 AM >
JONESBORO, GEORGIA
Jimel Virges: I am still here!!!

8:30 AM >>
CHARLOTTE, NORTH CAROLINA
Felisha Moore: HIV doesn't stop me. It motivates me to live for my daughter.

9:00 AM >>>
COLUMBUS, OHIO
Mike: No HIV stigma. My HIV is not a secret. HIV-positive 21 years. It absolutely has changed my life, but this is my life path and I'm grateful for who and where I am.

<< 11:00 AM
LECICESTERSHIRE, ENGLAND
David Rowlands: I was diagnosed with HIV in 2003, aged 21. Living with HIV, you need to be motivated to stay on track. I am the director of Design-Redefined.co.uk, delivering healthcare communications to enable people with HIV and/or hepatitis C to become better engaged with their treatment and care.

< 11:25 AM
LOS ANGELES, CALIFORNIA
Charles McPeak: This year, I have had the honor to be a triathlon swim coach for TEAM TO END AIDS (T2) of APLA Health (formerly AIDS Project Los Angeles). I am healthy, I am full of life and I am achieving goals that I never thought were possible before.

< 11:41 AM
ARECIBO, PUERTO RICO
Angel Hernandez: Attending the Global Community Advisory Board Conference Call. I am passionate about all things related to HIV—advocacy, empowerment, research, community education, and meaningful involvement.

<< 12:00 PM
SAN FRANCISCO, CALIFORNIA
Hank Trout: I am a 27-year long-term survivor, diagnosed in 1989. Have lived in San Francisco since 1980, the last 11 years with my fiancé Rick. I write features and a bi-monthly column, For the Long Run, for *A&U: America's AIDS Magazine*. I have taken it upon myself to ensure that the history of the continuing AIDS crisis is told accurately and passionately.

< 12:05 PM
SOFIA, BULGARIA
Andrew Espinosa: HIV will never stop me from traveling! This is me at Alexander Nevsky Cathedral. I'm excited to be here for the 2016 European AIDS Treatment Group General Assembly with my HIV/AIDS activist friends!

12:14 PM >
ST. GEORGE'S ISLAND, FLORIDA
Barb Cardell: I celebrated today (and so many days) being grateful for 23 years with my wonderful husband, Tom Bogdan.

12:36 PM >>
NEW YORK, NEW YORK
Cody L. Hall: After running errands, I get a sacred moment of pause while waiting for the train. I have two little guys who will call me "Guncle Cody" when they can finally speak. I will not let HIV stigma define me and I will not let those little guys grow up into a world that perpetuates stigma. Stigma is something we learn; we aren't born with it.

12:45 PM >
PORTAND, MAINE
Katie Rutherford: We are Frannie Peabody Center, supporting people in Maine living with HIV/AIDS today and every day. Fighting stigma, and putting our clients first.

12:46 PM >
CLEVELAND, OHIO
Robert Toth: Hangin' with my peeps.

1:00 PM >>
GURGAON, INDIA
Jennifer Chin, DESIRE Society: Our three youngest babies (Annie, Ishan, and Anjali) are dressed up for Janmashtami, an Indian festival. DESIRE Society is a non-profit organization that provides homes for children who are HIV-positive or have been orphaned by HIV/AIDS. We hope to raise awareness, and end the stigma.

<< 1:10 PM
SANDY, UTAH
Timothy W. Vogel: Who wouldn't have a positive day when you work on beautiful holiday displays like this! I am so lucky to have a job that I absolutely love. I have been HIV-positive for about 20 years, and I'm having the time of my life. I'm also into bodybuilding and making great gains in the gym. I love my family and friends for being so supportive.

< 1:15 PM
HOUSTON, TEXAS
Sam: Me and the Road Dog, doing what we do.

<< 1:59 PM
BROWNSTOWN, MICHIGAN
Tiommi Luckett: Lying alongside a pile of folded laundry that will be packed for my trip to Fort Walton Beach, Florida, to attend a Positively Trans meeting, Trans Institute, SPEAK UP!, and Positive Living.

< 2:24 PM
BELGRADE, SERBIA
Djurica Stankov: HIV-positive 24 years.

<< 2:35 PM
HAYWARD, CALIFORNIA
Ralph Thurlow and David Spiher: Ralph has had AIDS for 15 years, and an AIDS dementia diagnosis for three years. David has been HIV-positive since December 1985, and has had AIDS since January 1989. Ralph's home healthcare worker wasn't able to show up or call in time to arrange other plans, so Ralph is at my office as I do my development job.

< 2:45 PM
DENVER, COLORADO
Robert Riester: This small river rock caught my eye on my way to the Denver Botanic Gardens, which I fondly refer to as "My Backyard." I go there often to become grounded and to see the finer things in life. Whoever wrote "Smile" on this rock with a Sharpie made me do just that today. :-)

3:00 PM >
BROOKLYN, NEW YORK
Shatoya Brown: Loving the skin I am in. I was coming home from work and decided to sit outside and just reflect on how far I've come. I've been HIV-positive for 20 years, and I am doing great. I love me some me.

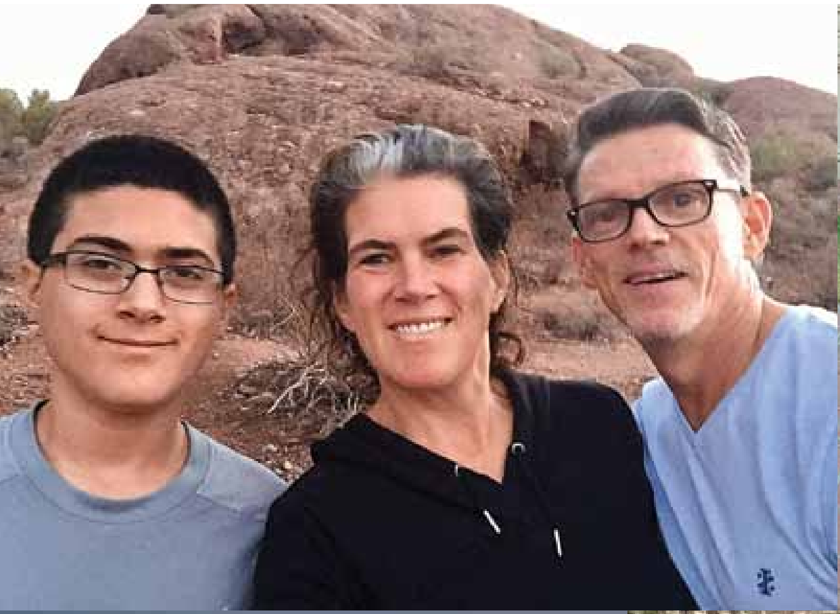
3:50 PM >>
KALAMAZOO, MICHIGAN
Doran Konja: Showing clients how to use insertable/female condoms! It's the little things that count.

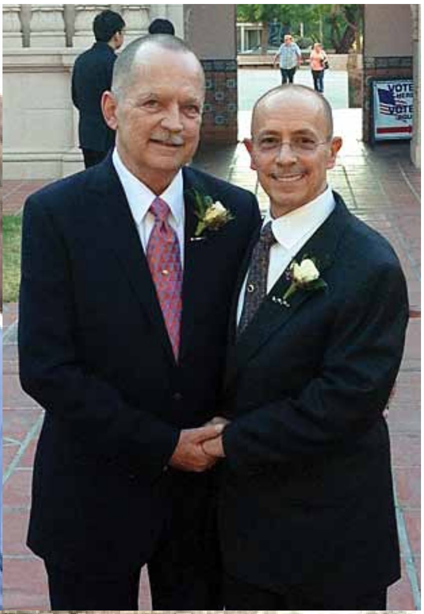
4:00 PM >
LOS ANGELES, CALIFORNIA
Faith Landsman: Los Angeles Women's PrEP Network—getting shit done!

4:10 PM >>
LAGUNA BEACH, CALIFORNIA
Daniel Garza: I'm a 15-year AIDS survivor; I beat anal cancer, fought the demons of alcohol and drugs, and I'm still here to smile at the world!

4:16 PM >
NEW YORK, NEW YORK
Peter Fahrni: As someone who is HIV-negative, I can only fathom the hurtful, dehumanizing stigma faced by many in the HIV community, but I do experience the reactions of some of my friends when they learn I'm on PrEP.

4:31 PM >>
BOSTON, MASSACHUSETTS
Christian Daniel Kiley: Recording voiceover for the fourth installment of a five-part series of video essays about the representation of HIV-positive folks in mainstream movies and television. Next, I'll snuggle with my cat (not pictured) and do some writing for the upcoming second season of my web series, *Unsure/Positive*, which is about my experience with HIV; plus drama. Pun. Intended.





<< 5:35 PM
SCOTTSDALE, ARIZONA
Heidi Simon: 60 years of POSITIVE LIVING ready to take on any mountain! Blessed to have family, friends, and much love in our lives!

< 6:00 PM
TUCSON, ARIZONA
Lawrence Wardzala: 24 years living with AIDS, 34 years with HIV, and living to see the day we could get married. Happy.

<< 6:33 PM
HUNTINGTON BEACH, CALIFORNIA
Alexander Smith: As the sun sets, I surrender in Lotus headstand. Grateful for the courageous ones who stood before me and fought for a cocktail of medications that sustain undetectable levels of HIV in my body. *Namaste!*

< 7:18 PM
JOHANNESBURG, SOUTH AFRICA
Pabiwabatho: I took this picture with my colleagues, who have now become my friends because I spend the most time with them! So blessed to be surrounded by people with winning attitudes.

<< 7:50 PM
PHILADELPHIA, PENNSYLVANIA
Daniel Trawick: King Koa had a busy day. He was a part of the Speakers of Life training, and then we had some playground fun. He's going to sleep great tonight.

< 7:56 PM
NORTHERN CALIFORNIA
Daniel Rita: I stand on a mountaintop to signify that HIV will soon just be another disease that is in the history books. Everyone should get tested; knowing your status is an affirmation and you do not have to be in isolation.

THE EFFECT OF AIDS ON

Art AIDS America exhibit to open in Chicago

INTERVIEW BY **JEFF BERRY** PHOTOS COURTESY OF **THE ALPHAWOOD FOUNDATION**

A groundbreaking exhibition, Art AIDS America explores HIV and AIDS in American art, opening in Chicago on December 1, World AIDS Day, for its final run. This is the culmination of a national tour that started at the Tacoma Art Museum in Washington State several years ago. It is the first major exhibition to look at how the AIDS crisis touched the art world, and forever changed art in America.

The Chicago exhibition features more than 100 contemporary works by artists such as Judy Chicago, Chloe Dzubilo, Karen Finley, Robert Gober, Félix González-Torres, Keith Haring, Jenny Holzer, Derek Jackson, Kia Labeija, Annie Leibovitz, Robert Mapplethorpe, Kiki Smith, Joey Terrill, David Wojnarowicz, and Martin Wong. Added to the traveling exhibition exclusively for its Chicago presentation will be works by a variety of other artists, among them major works by famed Chicago imagist Roger Brown.

The exhibit, co-curated by Jonathan David Katz, director, Visual Studies Doctoral Program at the University at Buffalo (The State University of New York) and Rock Hushka, chief curator and curator of contemporary and Northwest art at Tacoma Art Museum, is made possible in Chicago by the Alphawood Foundation.

POSITIVELY AWARE editor Jeff Berry sat down with co-curator Jonathan Katz to talk about the exhibit, why it's important, and what his connection to Chicago was during the early days of the epidemic.

JEFF BERRY: Tell us about yourself, and how you came to be involved with this project.

JONATHAN KATZ: I have been doing art history and specifically queer curating for well over a decade. I see my role as attempting to take one of the last bastions of heterosexism in contemporary culture, which is the art museum, and make it safe for queers; specifically for questions of not only sexual differences of all sorts but also core-related issues like AIDS. Thus this whole exhibition is entirely of a piece of my larger professional life. I did "Hide/Seek: Difference and Desire in American Portraiture," which was the first major queer exhibition at a national museum. It was at the Smithsonian in 2010, you may remember something of the brouhaha attendant upon that; it was attacked by Congress.

When you say *queer curating*, what does that mean?

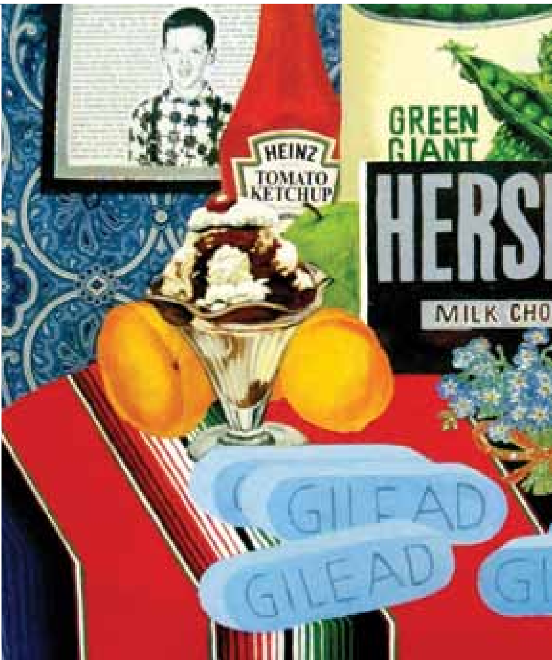
What that means is taking seriously questions of sexual difference in the history of art. What it means essentially is overturning an effective blacklisting of questions of sexuality and AIDS since Robert Mapplethorpe's "The Perfect Moment" exhibition was cancelled at the Corcoran Gallery in 1989. That blacklist remains largely in place; these issues are largely off the table for the American art world. Our museums are among the most conservative cultural institutions we have, if not *the* most conservative. One recent study indicated that people learned more about sexual differences in professional sports than they did in the American art museum.

Why now, and why Chicago?

The exhibition has been part of a traveling exhibit in multiple venues across the United States. It opened in Los Angeles two years ago and it has been subsequently in Tacoma, Washington, then Atlanta, and now at the Bronx Museum in New York. Frankly this all came about because I was complaining about the fact that none of the

LADZ, Eden #31 (2012); chromogenic color print, 32" × 52½" by John Arsenault and Adrian Gilliland.

AMERICAN ART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TOMATO KETCHUP
HERS
MILK CHO
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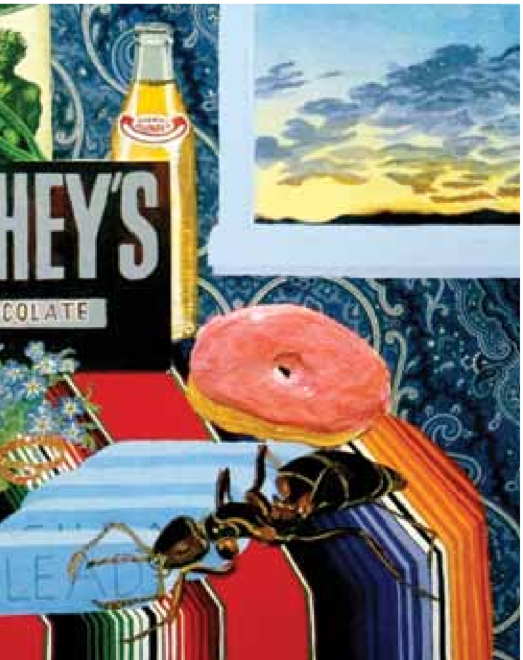

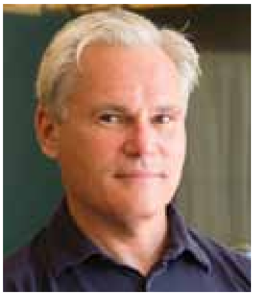

IT WILL BE THE *DEFINITIVE* ITERATION of the exhibition. It's going to be larger, and it's going to be more comprehensive than any other venue.
—JONATHAN KATZ

Chicago major institutions were interested in the exhibition, and that troubled me greatly as Chicago is a city that I used to live in. I'm a graduate of both University of Chicago and Northwestern. Through contacts made in the funding world and Alphawood we received this unprecedented offer to essentially create a pop-up museum but at the highest standards, for not only a version or iteration of the exhibition, but what will be the *definitive* iteration of the exhibition. It's going to be larger, and it's going to be more comprehensive than any other venue.

A *New York Times* review of the Bronx show noted a lack of diversity among the artists included in the exhibit, and I understand that an effort is being made to have this exhibition be more diverse?

I am not sitting quietly any longer about that. I think this is a controversy that has very little historical understanding. What ultimately happened is that the press made it seem like we were completely unaware of issues of race as we went through this project, and nothing could be further from the truth. We've done many, many years of research, and what we found was that there was a very small number of African American artists doing work around AIDS historically. Now if we move this to the contemporary moment it would be a completely different thing, but the show was weighted on the historical—it was about, in essence, the historical. What we did then, subsequently, was essentially crowd source. We went to everyone we could think of after the controversy erupted, and said, "We did our homework, we couldn't find anything, can you find something?" And indeed, there were three historical works that are in the show now from that period. There are theories on why there is such a paucity of work from African American artists, and one is that being African American in the art world was already a slam against you, and taking on HIV yet another.

StoryCorps is involved.

It's just one of many partnerships that have been engendered over the course of curation of this exhibition and its development, to further use the exhibition as a catalyst for renewed attention to HIV/AIDS.

What would you want people to know who are considering coming to the exhibition? It runs through April, right?

It runs through April, and in addition to the exhibition there will be conferences, symposia, film showings, theater—there is a range of things that will be happening to make this a much more comprehensive spotlight on HIV/AIDS.

Anything else you would like to say about the exhibit?

The only thing I would add about this is that the exhibition very much looks at what we, even people like me who lived through all the horror, have tended to forget, which is the degree of anti-AIDS politics in American national life at that moment, in the early days of the plague. We probably for our own survival have suppressed a lot of that negativity, but the exhibition really underscores how profoundly not only was the virus the enemy, but so too the government and even to a large extent society at large.

We do tend to forget about that, and I think some of the films we've seen come out in recent years such as *How to*

Clockwise, starting from upper left. **Eternal Lovers** (2010); oil on wood, 18" × 24" by Tino Rodriguez (born 1965). **Silence Equals Death, Washington, D.C.** (1987–90); gelatin silver print, 20" × 16" by Rosalind Solomon. **San Francisco City Hall, Candlelight March for AIDS #2** (1986); pigment print, edition 1 of 3 with two artist's proofs, 18" × 12½" by Catherine Opie. **Still Life with Forget-Me-Nots and One Week's Dose of Truvada** (2012); mixed media on canvas, 36" × 48" by Joey Terrill. **Blood and Semen III** (1990); chromogenic color print, edition 1 of 4, 40" × 60" by Andres Serrano.

***Survive a Plague* and *Last Men Standing* have allowed us the chance to step back and reflect on something that may have been too difficult to do until now.**

And frankly, you asked, *Why now?* I think part of it is the advent of effective drug treatment has changed the dominant cultural perception of AIDS sufficiently, that we can now have a more dispassionate and historical understanding of what happened.

And you said you lived in Chicago?

Yes, when I was in graduate school and very politically involved in the city I started the first guerilla clinic for HIV/AIDS way back in 1982, before there were any HIV medications. People were dying and there was really nothing that anyone was doing. So my partner and I made contact with a national group that was saying look, these drugs may or may not work, we have no way of knowing, but it was at least something. We set up a guerrilla clinic and sent those drugs out. Now we know they were sort of mild immune boosters, and they didn't do much, but those were desperate times, and we did that until we got closed down by the police. There were various guerilla clinics all over the U.S. quietly in operation.

Sort of like buyers' clubs then?

Well, they weren't buyer's clubs because we never charged anything, everything we did was for free. Chicago always had this sort of strange relationship with HIV/AIDS in the early days, because though people were in fact dying, the city somehow understood itself as having bypassed the brunt of the plague. Yet, I knew people who were dying, so it wasn't true!

Yes, it kind of hit us like a second wave. I remember reading about it, and I was working in the clubs as a DJ, and bartenders and waiters started getting sick. But it happened a few years after we were hearing about it in New York and San Francisco.

I think that's true, but I think it's also true that the unintended consequence of all this was that there were people who were sick in the first round, and those people had no social services and very little social support, and we saw ourselves as trying to support those people in those early days. I remember doctors taking care of a friend of mine in the hospital in complete haz mat suits, and he had terrible neuropathy, and his legs were killing him, and nobody would touch him or massage his legs. Which we had to end up doing, and we had to sign a form acknowledging that we were at risk, blah blah blah. That's the way it was in those days.

I hope that this exhibit will help people gain a better understanding of a time that has gone by. I know a lot of works were probably destroyed by families who didn't want them or who didn't understand. It's good that these pieces have been curated for the exhibit, so thank you.

Absolutely. PA

STARTING DECEMBER 1, Art AIDS America Chicago will be open Wednesdays and Thursdays, 11 am–8 pm; and Fridays, Saturdays, and Sundays, 11 am–6 pm. Admission to the Alphawood Gallery, 2401 N. Halsted St., in Chicago, is free; however, timed tickets are required to enter the exhibition. Visitors are strongly encouraged to reserve tickets online to ensure a specific entry time, although walk-ups will be available on a limited basis. Tickets at ArtAIDSAmericaChicago.org.

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