Surviving Together

Long-term survivors are advocating for people living with or at risk for HIV.

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“This is not a nostalgia thing, all right?” says Cleve Jones of his latest HIV advocacy project. “It’s important for people to remember what happened, because someday there will be another pandemic.” In fact, notes Jones—one of the world’s best-known long-term HIV survivors largely due to his conceiving of the now iconic AIDS Memorial Quilt—it’s already happened: COVID-19.

“Once again, we had angry parents storming school board meetings,” he says. “Once again, we had a U.S. president who failed to act, and when he did, he mocked the people suffering. Once again, we saw the horrible racial disparities play out. Once again, we saw people refusing to wear masks, just as some once refused to wear condoms. And once again, we saw quackery and misinformation.”

In addition to preserving the past so future generations can learn from it, Jones has another urgent reason for pursuing his latest project, which aims to preserve HIV history. Many long-term survivors have already died, if not of AIDS or AIDS-related illness, then of cancer, heart disease or COVID. Bluntly speaking, he adds that the rest of them will likely pass in the next decade or two. So he has started working with the San Francisco AIDS Foundation, which he cofounded in 1982, and the long-term survivor network The Reunion Project to bring an HIV anthology to life.

“It’s the same reasoning as the folks who created the Holocaust Museum,” Jones says. “We need to capture this history before the people who experienced it are all gone.” He speaks these words as he’s always spoken—ever since he was a fledgling gay political operative working for the late and legendary Harvey Milk in the 1970s—with razor-sharp clarity powered by an intense passion heard in his voice.

“If I’m allowed one more big project in my life,” Jones adds, “this is going to be it.” The project’s working title? He articulates it carefully: “We Live: Voices of the First Generations to Survive HIV/AIDS.”

The anthology project arrives at an inflection point for long-term survivors. For years, the group was often defined as people diagnosed with HIV before the advent of effective antiretroviral treatment in the mid-'90s, a population that likely numbers around 300,000 of the roughly 1.2 million Americans living with HIV. These days, many people have expanded the definition to include those who have been living with the virus for 10 or more years.

For the past decade or so, countless articles, seminars and social media posts have detailed the plight of the long-term survivor. The grief, loss, loneliness and guilt that come with having survived when so many others did not. The depression and addiction that sometimes accompany those feelings. The financial instability, even poverty, that ensues after having had to put one's life and working years on hold for so many years of illness. The uncertainty about living into their golden years. The way having HIV for years compounds the health complications of aging. The horrible feeling of having been forgotten—or, at best, seen as a relic—in a 21st-century world where HIV is usually easily managed and is more preventable through the use of pre-exposure prophylaxis.

And all of this has been only partially offset by the fact that while many long-term survivors may feel alone, statistically they're not. It's been widely noted that over half of folks with HIV in the United States are now older than 50—a proportion that is expected to rise to 70% by 2030.

But in recent years, at least in the HIV community itself, much of the relationship to long-term survivorship has evolved from merely laying out the elements of the plight to concrete, uplifting and often joyous action that brings long-term survivors together, both online and in-person. These efforts not only celebrate the community's collective resilience and help survivors enjoy some hard-earned fun but also serve to crowdsource ways to make life better for survivors on both the personal and policy levels.

For the past decade, The Reunion Project (TRP) has valiantly done much of this work. Founded in 2015 by long-term survivors Jeff Berry and Matt Sharp as a "town hall" intended to weave together survivors nationwide into a sustainable network, TRP has evolved into an enterprise that hosts in-person and virtual survivor forums and has a paid staff of four and about 2,500 members.

Jeff BerryCourtesy of John Gress

Berry says TRP started when it did because by then, survivors of the AIDS epidemic were feeling a need to talk about what had happened to them and whom and what they had lost—and also because by then it was clear that some members were dying not of AIDS-related illness per se but as a result of the collateral damage, such as depression and addiction.

“The death of Spencer Cox was in many ways a catalyst [for the start of TRP]”, says Berry, referring to the beloved New York City–based treatment activist who died in late 2012 after he stopped taking his HIV treatment amid crystal meth addiction. “Matt and I realized that loneliness and the inability to deal with [past trauma] were really affecting people’s quality of life,” says

Berry.

At the heart of TRP is the message “You are not alone”—a reality check that many TRP event participants have said provides an overwhelming emotional relief, even when they’ve participated only online. The group also broadly defines long-term survivor to include anyone who has lived with HIV for 10 years or more. That includes Jasmine Davis, diagnosed in 2012, and Kyra Kincaid, diagnosed in 2004, two transgender Black women who serve other trans women of color at Ochsner Health, a large medical network in New Orleans. In 2023, Davis and Kincaid served as regional hosts for a TRP event in that city. TRP always collaborates with local folks living with HIV who reside in the city where it’s hosting an event.

Davis says she considers herself a survivor of both HIV and of being “a Black woman of trans experience in the South, where my life expectancy was 34—and I’m 47.” Kincaid, 53, says that though she was diagnosed not just with HIV but also AIDS, including AIDS-related dementia in 2004, she’s pretty sure she’s been living with HIV since the ’90s. They both say putting together the event was especially meaningful because it was coming not only after years of living with HIV and other challenges they faced as trans Black women but also after the period of isolation—and, often, loss—of COVID.

“It was really something I wanted to take part in, because people can’t forget us,” says Kincaid. “We’re still here, people who are traumatized from living with HIV.” She says the “we’re all going through this together” energy of TRP reminds her of the HIV support groups that years ago helped her get through some of the scariest times of her life.

Davis says she loved organizing the event with Kincaid and the core TRP staff. “They were amazing,” she says. “All we had to do was show them the lay of the land [in New Orleans], connecting them to the health department and various nonprofits. It was a great success to see people with HIV from different parts of Louisiana show up. The community camaraderie and the sharing of personal stories in a safe space, without stigma or judgment, was very healing.”

Particularly moving, she says, was a final-day exercise in which everyone received a wooden heart with somebody else’s name on it and was then asked to say goodbye to that person with healing, affirming words while holding the heart. “It gave us a moment to show love to someone we may not even have had the chance to talk to during the event,” she says, “to say how proud we are of each other for this struggle that we’ve all survived.”

Indeed, Waheedah Shabazz-El cites TRP’s heart-holding ritual as one of her favorite things about the group. An esteemed long-term survivor and advocate based in Philadelphia, Shabazz-El, age

71, who was diagnosed in 2003, is TRP's part-time director of community engagement. She had long volunteered with TRP prior to being hired, bringing many Black people, trans people, women and people of faith into a group that initially consisted primarily of gay white men. "[The ritual is] a chance to say to someone before you leave 'I'm taking you with me, and I'm holding you,'" she says. "People need to be held. I know how good that feels."

Waheedah Shabazz-ElCourtesy of Waheedah Shabazz-El

Shabazz-El adds, "[Survivors] have a need to be heard, to have our voices centered. We need to be on the boards of the places where we get services. Nothing about us without us!" She credits the survivor community with helping her get through the death of her only daughter two years

ago. “I assumed she was going to be around to take care of me,” she says, but adds that, amid her overwhelming grief, “this community held me so tight I could feel people’s arms around me.”

“We’re the greatest generation.” That’s how Sanford Gaylord, 59, a Chicago-based actor, writer and HIV activist, characterizes the long-term survivor community. “We’ve survived one of the biggest wars that has been waged on humankind. I got so many nuggets of wisdom from men who’ve died,” says Gaylord, who was diagnosed HIV positive in 1989.

He’s also shared his own survivor wisdom via various roles in the HIV field, including as a featured voice in HIV and the Journey Toward Zero, a three-part docuseries coproduced by the Chicago Department of Public Health and directed by Emmy winner Chan C. Smith. Gaylord says he helped the producers of the series, which focuses on Chicago-area people living with HIV, assemble a diverse roster of subjects, including well-known activist Rae Lewis-Thornton.

Sanford GaylordCourtesy of Sanford Gaylord

Many folks featured in the series are long-term survivors. Among the major issues they discuss, he says, are “the guilt of having survived when others didn’t,” “finding and creating purpose, even as you mourn what you don’t have anymore or what could’ve been if HIV hadn’t come into the picture” and “acknowledging trauma and the benefits of therapy.”

Gaylord says most survivors, him included, need “to not be erased, to be listened to, to be honored and not put out to pasture.” Such folks also need practical support with housing and long-term care as they age, he says, because many of them are financially struggling and also, especially the gay ones, don’t have children to take care of them. “I don’t want to be found dead,

like one of my greatest inspirations, Joseph Beam." He's referring to the gay Black activist and poet who died of AIDS-related illness in 1988. "I don't want to die alone."

Gaylord says he's familiar with Chicago's Town Hall apartments—which opened in 2014 as the first supportive affordable housing center for LGBTQ seniors in the Midwest—so he knows there are options for him and other survivors as they move into old age. The federal Ryan White CARE Act—as well as myriad other federal, state and local programs—also help folks meet their housing, health care, nutrition and other needs. According to the LGBTQ senior advocacy group SAGE, the Town Hall Apartments constitute one of about 31 such affordable complexes nationwide serving LGBTQ elders; more are under development.

Long-term survivors who are not LGBTQ also have needs. Says Shabazz-El, who deals with diminished mobility as she ages, "We should challenge the federal government to lower the age for federal benefits for our community."

Research shows that people living with HIV age faster than those without the virus. It should be noted, though, that not smoking, minimizing alcohol intake, exercising regularly, eating a Mediterranean-style diet and staying in connection with other people can offset or mitigate this discrepancy, enabling HIV-positive people to live longer, healthier lives.

Gaylord says that, given the shifting political winds in Washington, DC, and nationwide—winds not always favorable to such vulnerable groups, such as people with HIV and LGBTQ people—the survivor community needs to be more organized and united than ever. "We can't become complacent," he says. "We don't need to be going back into the closet in a nursing home. If we're really a village, then let's take care of each other."

TRP is perhaps the best-known national network of HIV survivors. Others include Let's Kick ASS (AIDS Survivor Syndrome), which was started by survivor Tez Anderson, and local networks based at pioneering HIV groups such as San Francisco AIDS Foundation, where, as the head of aging services, respected survivor Vince Crisostomo coordinates survivor services, and New York City's GMHC, which has a hub for long-term survivors.

However, most of the advocates POZ spoke with for this article acknowledge that survivors vary in their ability or willingness to connect with such groups, noting that some individuals are stuck in a rut of isolation and depression so deep they can't even see it.

Says Jones, "I've been quite deliberate in trying to stay busy and engaged with the community, but the overwhelming majority of survivors I love and care about are increasingly isolated. Part of

that is ageism, but also quite a few are just not interested in being connected."

As Shabazz-El points out, some survivors never even really came out with their HIV status—even within their own community. She says it's always deeply moving when someone takes the mic at a TRP event and says it's the first time in their lives they've told a roomful of people that they're living with HIV. This usually happens at least once at every event, both she and Berry say.

For those held back by fear, isolation or depression, Shabazz-El asks that they consider starting by taking part in TRP's virtual events. "You don't have to turn on your camera, and we have a therapist at the event who can talk with you one-on-one if you feel triggered. Someone once said that it took courage to even come to the webinar with their camera off and that they were crying behind the camera."

Regardless, Shabazz-El says, pushing through the fear or other blocks is worth it. "We need to not live in shame, and I love TRP because it's the antidote to shame, which is empathy, which happens when we come together and share our stories. That's where many of us have learned to be powerful and to speak out." She pauses before adding, "I mean, who wants to die living in shame?"

If you'd like to contribute to the survivor oral history anthology, visit sfaf.org/get-involved/hiv-long-term-survivors-anthology or email AnthologyLTS@gmail.com. For more info on the networks in this story, go to reunionproject.net, letskickass.hiv and sfaf.org/communities/people-over-50, or email ltshub@gmhc.org. Also, The Reunion Project can help you identify and connect with long-term survivor networks in your city or state.
