We Are Lifetime Survivors

People born with HIV are reclaiming their experiences—and giving themselves a new name.

January 8, 2024 By Alicia Green

As a little girl, Porchia Dees and her family drove an hour from their home in San Bernardino, California, to Children's Hospital Los Angeles every month. These visits were routine for Dees, who was always sick and on medication. She had a team of doctors and social workers she saw often.

Dees knew something was wrong, but she couldn't figure it out. One day, she finally learned the truth.

"I had always heard the word HIV," says Dees, now a 37-year-old health educator and HIV advocate. "I just didn't know what it was."

When Dees was about 11 or 12 years old, a social worker gave her an HIV 101 lesson. Dees learned about the different ways the virus could spread. Once it was over, the social worker broke the news to her.

"She finally told me that I had HIV, then asked me if I had any questions," Dees recalls. "I didn't really know what to say. I kind of froze up. I just remember feeling like that was a lot to take in."

That was the day Dees learned that she was born with HIV. She had always known that her mother struggled with addiction and was sick. That was also the day she learned that her mom was living with HIV.

Making it to her preteens was a big deal because Dees wasn't supposed to live to see age 5. Year after year, she surprised her doctors. At the height of the AIDS epidemic, children born with HIV were not expected to survive. A diagnosis was considered a death sentence. However, some beat the odds and grew up.

The road to adulthood wasn't always easy. Many struggled along the way, and today, some feel forgotten.

Porchia Dees Kevin McDermott

“Compared to the entire population of people in the United States, there are not very many people living with HIV,” Dees says. “Not a lot of people know someone living with HIV. But then, even in our own community, not a lot of people living with HIV know someone who was born with it. We feel isolated even within our community.”

But now these adults born with HIV are making it known that they’re still here and want to be recognized. They don’t want to be called verticals or perinatals, terms that identify them according to how they acquired the virus. Rather, they prefer to be known as lifetime survivors or dandelions—in honor of the late lifetime survivor and writer Mary Bowman, whose poem “Dandelion” was a tribute to her mother and others with HIV. (Bowman’s mother died of AIDS-related illness when Bowman was 3 years old.)

Last September, the largest group of lifetime survivors convened at the annual United States Conference on HIV/AIDS (USCHA) held in Washington, DC. During the first day of USCHA, they demonstrated onstage and introduced themselves to the HIV community as lifetime survivors.

“We gave statistics about how prevalent we are around the United States and worldwide, how many of us are dying each year and why we continue to fall through the cracks,” Dees says. “Then we brought our mothers who we lost into the space,” she says, referring to the moment when the survivors took turns saying the names of their deceased mothers. “It was powerful.”

That demonstration at USCHA was years in the making. It all started about five years ago, when

Dees applied for a scholarship to attend the national conference. The scholarship was for long-term survivors aging with HIV.

“I’m not 50-plus, but I’ve been living with HIV for my entire life,” Dees says. “I was 32 and living with HIV for as long, if not longer, than a lot of the folks who were 50 and older. So I applied and wrote my essay on why I should get the scholarship.”

Dees was awarded the scholarship by NMAC (formerly the National Minority AIDS Council), which produces USCHA. She was the only person under age 50 selected to receive it. The 50+ scholars program then developed the National HIV and Aging Advocacy Network, which Dees also applied to join.

She was allowed to form a special interest group for people living with HIV since birth or early childhood. The group was very small at first. But as membership grew, it took on a new life. It became the Lifetime Survivors Cohort, and Dees is one of its chairs. Helping her along the way was another lifetime survivor, Grissel Granados.

“Grissel has been mentoring me and helping me develop the programming for the cohort,” Dees says.

Grissel Granados Courtesy of Grissel Granados

People born with HIV have long been considered long-term survivors. Being born with HIV means they have lived long term with the virus. But Granados believes that lifetime survivors have unique distinctions.

“We’re long-term survivors, but we’re also lifetime survivors,” says Granados, a 37-year-old HIV advocate from Los Angeles. “Nobody else knows what it’s really like to be living with HIV from day one and to have complicated relationships with your parents around it.”

Granados explains that being raised in the shadow of their parents’ experience of stigma and secrecy caused emotional and mental trauma for many lifetime survivors. But being born with HIV also physically affected this group differently than other people living with HIV.

“A lot of us grew up experiencing pretty intense medical issues at a young age because of the effects of HIV on our bodies before antiretrovirals and then also the effects of the medications,” Granados says.

Growing up with HIV meant lifetime survivors had weakened immune systems from an early age, rendering them more susceptible to other health issues. For example, Granados was diagnosed with cancer at age 10. (Studies have shown a correlation between HIV and some cancers.)

What’s more, lifetime survivors tend to be left out of conversations about people aging with HIV, which tend to center people ages 50 and older, excluding the nearly 10,000 adults in the United States who were born with HIV.

“There isn’t clear information about what symptoms are arising because you’re over 50 and what symptoms are coming up because you’ve been living with HIV for 30 or 40 years, which is where we come in,” Granados says. “If you’re saying that all of this is happening because you’re a long-term survivor, then that applies to me, right?”

Lifetime survivors are experiencing some of the same issues as older people with HIV but at younger ages. Some have dealt with kidney failure, bone loss and HIV-associated cognitive issues, among other concerns.

“The virus has affected us all differently,” Dees says. “Some people in the lifetime survivors group can’t work.”

Lifetime survivors have also felt as though they’ve fallen through the cracks in the transition from pediatric care to adult care. Once they were older, they were immediately grouped with other adults living with HIV.

For Dees and Granados, one of the highlights of the lifetime survivors gathering at USCHA was connecting with one another. Twelve lifetime survivors had been awarded scholarships to attend the four-day conference. But by the end of USCHA, the cohort had grown to 20.

“It’s the biggest visual representation that people have probably ever seen,” Granados says.

“There hadn’t been a national gathering probably ever of this group outside of camps that we aged out of 15 to 20 years ago.”

Those camps connected kids born with HIV to others like them, often for the first time in their lives. As they became older, though, they lost these connections. Some lifetime survivors never experienced such communities. These survivors began to feel socially isolated and alone. But as they continue to organize, lifetime survivors are once again finding community or experiencing it for the first time.

“It felt very good for us to be able to reconnect and have a space to come together because we lost that from when we were children,” Dees says.

Richard Adkins was one of the lifetime survivors who connected with the cohort at USCHA. The 33-year-old accountant and HIV advocate from Gaithersburg, Maryland, was part of a panel at the conference. He met Dees as they happened to be walking in the same direction. The two started talking about their experiences as adults born with HIV. Subsequently, Adkins joined Dees and other lifetime survivors at a dinner.

Richard Adkins Courtesy of Richard Adkins

“I felt like this was something that was needed and was happy to be a part of the cohort in any way that I could,” Adkins says. “Knowing some of the people I met there for five minutes, it was like they get me, and I get them. Even though we lived our own separate lives, I understood because I was also walking in that same lived experience.”

Adkins grew up experiencing stigma from a young age. When he was 7 years old, he learned that he was born with HIV.

“I attributed my new life to the HIV diagnosis,” Adkins says. “Before we found out, I was a ‘normal’ kid. Now I was always in protective mode, not letting those around me know what was going on for fear that it would be used against me.”

But as he got older, camps and support groups helped him work through his stigma and to accept himself.

“What makes lifetime survivors different is that we grew up in a world where we were already judged for having HIV before we could stand on our own,” Adkins says. “Thanks to medical advancements now, there are not many kids born with HIV, so we are also forgotten about. But we’ve been dealing with the pain, trauma and medical side effects for years.”

Now, these lifetime survivors are advocating for themselves. And Adkins wants to do his part.

“We’re making a difference,” Adkins says. “There are people who think if you acquire HIV your life is over. Lifetime survivors know that’s not the case.”

Adkins and other members of the Lifetime Survivors Cohort meet virtually every two weeks to plan events and discuss how they can continue to expand the group. They have already opened up the group to include those who acquired HIV through blood transfusions at a young age.

“As a group, we’ve talked about different things, including having retreats and mental health workshops,” Adkins says. “We’ve talked about empowering us to do training to educate people on what lifetime survivors are going through.”

Coming together at USCHA was just the beginning for the Lifetime Survivors Cohort. The cohort is also dedicated to ensuring that lifetime survivors have a seat at every table. One of the areas in great need of their voices is the research field, Granados says.

“It’s being able to have dedicated research and to have better data come out of research that exists, even if it isn’t specific to our population,” she says. “It’s making sure that we’re always counted and that our data is significant.”

“We need support to continue keeping us organized, raising awareness around who we are and to ensure that we are not forgotten moving forward,” Granados says.

But it’s not just older lifetime survivors they want to recruit to their movement. Dees hopes that they can reach the babies still being born with HIV as well as adolescents or emerging adults living with HIV. They don’t want these young people to fall through the cracks like some of them did.

The one message these lifetime survivors hope reaches others like them is: You are not alone. There are thousands of lifetime survivors who have experienced the same things as you. They know what you’ve been through and are here for you.

Granados believes it’s the perfect time for lifetime survivors to organize. These survivors have grown up and gained the confidence that comes with adulthood to advocate for themselves. They have also accepted their HIV status.

“Our experiences matter and deserve to be represented,” Granados says. “Our issues deserve to be addressed. We don’t need somebody else telling us what we need, what we want, what we should do or how to do it. We’re at the point where we got this.”

Adkins agrees. “For us to have this lifetime survivors movement,” he says, “it’s the opportunity that we can define who we are ourselves without waiting for somebody else to give us the space or the opportunity.”

To connect with the Lifetime Survivor’s Network, click here to visit them on Facebook.