What’s in a Name?

The debate over who qualifies as a long-term survivor is in the spotlight.

January 6, 2025 By Victoria Noe

In 2015, I learned that long-term survivor Jeff Berry was forming The Reunion Project to address the needs of long-term survivors. A lot of my friends and women I was writing about, particularly in my book Fag Hags, Divas and Moms: The Legacy of Straight Women in the AIDS Community, are HIV-positive long-term survivors, so I asked whether I could attend the group’s first gathering and observe. He said I was welcome—not to observe but to participate.

I argued that I’m not living with HIV or AIDS, so I’m not a long-term survivor. But he insisted that I was. Of the early days of the epidemic, he said: “You were there.”

At that time, the needs of long-term survivors were only beginning to be addressed. The death in 2012 of ACT UP New York’s Spencer Cox due to AIDS-related illness after he stopped taking his medications is cited as a wake-up call, one that revived ACT UP. His death showed that the complacency in the community since the 1996 advent of effective treatment had consequences. Those who had lived through so much had been forgotten, neglected and even dismissed, inconvenient reminders of those dark, early days. That community was now mobilized.

It took me years to embrace Berry’s definition, though I can’t say I’m comfortable with it. I’m an ally, a title I wear proudly. A straight, cisgender woman who is HIV negative. I’m just not sure I have the right to consider myself a long-term survivor.

Over the years, I did many of the same things my friends living with HIV did: marched; advocated for funding and policies on the local, state and federal levels; raised money; made hospital visits; attended memorial services; raged; grieved.

The conversations on this topic ramped up as I worked on my book. One of the women I reference in it, Terri Wilder, told me something I saw in myself and others: “We are all damaged.”

But what are we? And does it matter how we identify?

In his September 2024 “Who ‘counts’ as a long-term HIV survivor?” essay on the San Francisco AIDS Foundation (SFAF) website, long-term survivor Hank Trout enumerates various definitions. For the first time, Trout notes, the federal government this year defined some key populations through the HIV/AIDS Bureau of the Health Resources and Services Administration to identify Ryan White HIV/AIDS Program recipients:

Older adults are people with HIV ages 50 and older.

Long-term survivors are adults who acquired HIV prior to the availability of antiretroviral treatment.

Lifetime survivors are adults who acquired HIV at birth or as young children.

The Ryan White Program’s mission demands that its definitions include only those living with HIV. At the same time, it makes a clear distinction between people who have lived with the virus for decades and those who have acquired HIV more recently. But for programming at SFAF, the nonprofit considers anyone who lived through the height of the AIDS epidemic a long-term survivor. SFAF recognizes that HIV-negative long-term survivors experienced the same loss and grief as those living with HIV. Indeed, we are included in the landmark San Francisco Principles:

“We embrace in our definition of ‘long-term survivors’ our HIV-negative sisters and brothers who faced the same fears, suffered the same losses, and endured the same grief as we HIV-positive survivors. And to this day, they continue to suffer the same PTSD [posttraumatic stress disorder], especially those caregivers and activists who rushed to the front lines of the fight against AIDS.”

I took a very unscientific poll, in person and on social media, to find out where people in the HIV community stand on this topic. Their perspectives varied as much as their locations:

“My brother buried his partner of 13 years and cared for him during the last horrific two years of his life. Please don’t tell me that my brother, who is HIV negative, doesn’t know what it is like to live with AIDS. My brother survived, as we all have, and is just as haunted by those years as most long-term HIV survivors.” —Mark S. King, Atlanta

“I do not consider myself to be a long-term survivor, not because I haven’t been impacted by HIV

and AIDS, because of course I have, but because I feel it would be disrespectful of me to presume that the challenges of people who aren't HIV positive are in any way identical to the challenges of those who are.… I am not going to be in a situation where, like Spencer Cox, I will be so deep in the depths of despair that I choose to just stop taking my meds and allow immune deficiency to take me.… Unless I walk in those shoes for decades, I can't in any way rank myself as someone who deserves the respect due to them for having lived the life experience of truly being a 'long-term survivor' of an HIV-positive status. That is a term that deserves great respect. It is a kind of respect that someone like me simply does not merit." —Tony Arena, New York City

"I'd say HIV-negative long-timers have important roles and perspectives but probably should use a different term." —Liz Highleyman, POZ Science Editor, San Francisco

"I could see how people with HIV would want us to use a different term and not co-opt theirs. We're all long-term survivors of the HIV and AIDS crisis, if not AIDS itself." —David Hamburger, Boston

"The same term? Def no, though definitely worth a suitable descriptive moniker. One that honors your trauma, contributions and life of 'living alongside and contemporaneously with HIV and AIDS.'" —Patrick Smith, Palm Springs, California

"I consider myself incredibly lucky to be HIV negative and do not consider myself a survivor, but having not experienced the reality of living with HIV, I don't think I could publicly call myself that. I really do think, though, that as witnesses to the microbiological disaster, we have a place but would never want to belittle the life experiences of someone living with HIV." —Ian Johns, London

"As an HIV-negative man, I absolutely believe that I, along with any other HIV-negative person who struggled to end the AIDS crisis, should be included as a long-term survivor." —Jeffrey Griglak, New York City

"I sometimes take issue with the term 'survivor.' I'm not quite sure that reflects our experience. But I believe there must be some acknowledgement of what we experienced. We were there, in the midst of it all. We saw friends and family die; we were at funeral homes making arrangements; we were at the hospitals negotiating care. We acted as power of attorney for many, some of whom did not have other family members or friends to advocate on their behalf. We advocated for benefits and proper medical care. How can this go unacknowledged? So if 'survivor' is not an acceptable term, there must be another term to identify those of us who, while being HIV negative, still were impacted by the HIV epidemic." —Rosa E. Martinez-Colón, Chicago

Recently, I again discussed this topic with Jeff Berry and was surprised to learn that our 2015 conversation had partially sparked his decision to include people like me in the long-term survivor definition. But the question remained: Do we deserve to be included? I looked to the military community, oddly enough, for guidance.

My father and his older brother both served in the Navy in the 1940s. My uncle was in Normandy for D-Day operations; my father signed up several months after V-J Day and never left the coast of California. Normandy saw intense combat; California saw none. The federal government classified them both as World War II veterans. They enlisted, underwent basic training, gave up their lives at home and served their country. Their service ribbons, like their experiences, were not the same. But as far as the government is concerned, they were both WWII veterans, deserving of all the perks of that title.

It's technically true. But is it fair?

Trauma and grief are all too real for those who are HIV negative. Psychotherapy was not an option for most people in the 1980s and early '90s. Those of us who were not living with the virus, often straight, could not find people outside the HIV or LGBTQ communities sympathetic to our experience. Subjects were changed; no words of support were offered. We kept our trauma to ourselves, only to have it present in ways that often made no sense.

It took me a couple of decades to recognize how my trauma most often manifests. Those of us who were around during those first 15 years of the epidemic remember the pages of obituaries in the weekly LGBTQ papers. Unless you were close enough friends to be part of a phone chain, you often did not know someone was gravely ill until reading their obituary, because so much of the suffering happened behind closed doors.

Nowadays, I freak out if I don't hear from my friends, if they don't respond to my texts or emails within a few days. I immediately assume they're dead or dying, when the reason for the silence is almost always quite benign. A few years before the COVID-19 pandemic, I asked my closest friends whether they would tell me if they were sick: not with a cold or flu but something life-threatening. One who initially said no opened up to me in unexpected ways when she was dying. The most common response was "Why wouldn't I?" But I'd seen too much in the early days of AIDS to make any assumptions about them or their families.

That means, for good or bad, I know a lot about my friends' health. They know, based on what I've been through, that I will listen without judgment, that I will keep our conversations to ourselves and respect their desire for privacy, that I will have the hard conversations with them that they

cannot face having with their families. I think living through those awful early days made me a better friend.

This is not a trauma competition between long-term survivors living with HIV and those who are not. When fellow HIV-negative long-term survivor Gene Fedorko first told me about documenting the names of those he knew who died of AIDS, I was stunned that there were over 1,100 names in what he has titled The Book of the Dead—Bearing Witness. He explains:

“I started keeping this list in the late ’80s, and I just kept adding to it. I didn’t want to forget any of these people that were acquaintances, but I might’ve forgotten them years later was my thinking. It’s actually a work of art now. I’m leaving it to the New York Public Library when I die; it’s a historic document. Tabboo! [the New York City–based visual artist] did the cover. And it’s in the Museum of Modern Art here in New York. It’s a narrative, if you will, of my journey through the epidemic. At Dr. Paul Bellman’s office [a practice in Manhattan where Bellman treated people with AIDS starting in 1988], where I worked for 26 years, we were at the epicenter of inner-city HIV and AIDS, and we were at the front lines. It’s been quite a process for me—all kinds of emotions, severe emotions. It gives me comfort to know that I was able to help so many people. Lots of palliative memories. The survivor’s guilt was intense for a long time, but that has mostly dissipated by now. I was very surprised, and I’m glad I’m alive. Also, it’s a way of putting people to rest with dignity.”

Long-term survivor support groups, like those held at GMHC, do not include us, and I don’t disagree with that. But we need our own “I was there too” groups. Maybe we got lucky; maybe we weren’t truly at risk. But as Jeff insisted, we were there. And that experience has shaped our lives.

Back to a name for us. I threw out a couple of suggestions to the people who responded to my inquiry. For those uncomfortable being called a long-term survivor, “witness” was deemed too passive. “Ally” was a possibility. Maybe “long-term survivor ally”? That’s a mouthful.

Part of me wants to insist that people like me don’t need a name or title. We know all too well what we endured. We’re not looking for awards or applause. But it would be nice to be acknowledged.

Victoria Noe is an award-winning author, speaker and activist. Her HIV and AIDS activism inspired her to write Fag Hags, Divas and Moms: The Legacy of Straight Women in the AIDS Community, the first book to honor the ways women changed the course of the epidemic.
