“Nothing About Us Without Us”

Long-term survivors release a statement detailing their challenges and demands.

November 16, 2020 By Trent Straube

What are the struggles and needs of long-term survivors, those who were HIV positive before the arrival of effective treatment in 1996, who buried their friends, suffered extreme stigma and acted as guinea pigs for drug companies only to find their needs ignored and taking a back seat to HIV prevention efforts? Well, a group of long-term survivors and advocates met over Zoom during the summer and crafted the San Francisco Principles, a statement outlining five challenges and seven demands.

“As we age with HIV, we face the debilitating physical and mental health effects of aging at an accelerated rate,” coauthor Hank Trout, an activist and editor at A&U magazine, said at a press event announcing the document. “Even though we make up over 50% of adults living with HIV in the U.S., we are nowhere to be found in state or national AIDS policies. The president’s ‘Ending the HIV Epidemic’ program doesn’t even include us.

“We survivors in San Francisco,” he continued, “set the global standard for compassionate care for people living with HIV and AIDS, and we intend to do the same for long-term survivors.”

In general, the San Francisco Principles demand health care that is better tailored to the aging HIV population and that addresses mental health issues, such as isolation, depression, substance abuse and the trauma of surviving AIDS. Further asks include allocated resources for the needs of long-term survivors, a place at the planning table—“nothing about us without us”—and an alignment with other social justice movements.

You can read and endorse the statement online. It’s inspired by the 1983 Denver Principles, a groundbreaking manifesto of empowerment by people living with AIDS.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/nothing-us-without-us