



## WHO WE ARE

We are artists and musicians, healthcare providers and essential workers, community organizers and entertainers, writers and caregivers. Among our ranks are long-term HIV/AIDS survivors. Although myriad definitions of “long-term HIV/AIDS survivors” exist, for our purposes, we are The AIDS Generation, diagnosed with HIV during the 1981-1996 fifteen-year period before the advent of HAART. We bore the brunt of the AIDS pandemic from the very first, and today people over the age of 50 comprise the largest segment of people living with HIV. We are the ones who suffered the first diagnoses and the unmitigated fear of catching or spreading the disease; we are the ones who buried our friends after watching them slowly disintegrate, some of us losing our entire social circle; we are the ones ignored by our public health officials, laughed at by politicians, condemned by religious leaders, and shunned within our own communities; we are the ones who put our bodies on the line as unpaid guinea pigs for pharmaceutical companies; we are the ones who submitted to the first toxic trials and research programs; we are the ones still living with PTSD from the early, horrendous days of this pandemic.

Now we are in our fifties, sixties, seventies and beyond, living lives we never expected to have, lives that have been riddled with isolation and loneliness, the expense of medications and healthcare visits, declining physical health, untreated substance use and mental health problems. We live with a sense of having been forgotten, shoved to the side by AIDS researchers and service providers, unknown to geriatricians. We survivors are routinely ignored at HIV/AIDS conferences, while funding for research and services is consumed by prevention techniques and programs. While we recognize the importance of prevention, and heartily support the goal of ending the AIDS pandemic, we insist that prevention not drain resources from caring for those of us who have lived with HIV for thirty, thirty-five, forty years. Our surviving still faces an economic system that continues to evict, separate, and destabilize us. The burden of compounding healthcare costs, a fragmented healthcare system, and increasing costs of living continue to export many of us away from adequate healthcare delivery systems.

As the first generation of people to age with HIV, we face the debilitating physical and mental effects of aging at an accelerated rate.

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, especially those caregivers and activists who rushed to the front lines of the fight against AIDS.

We acknowledge that we proffer this Statement in the midst of the COVID-19 pandemic. We never imagined that we would experience the second viral pandemic of our lives. For many of us, this debilitating pandemic has triggered more PTSD, intensified our isolation, and interrupted our access to healthcare — enhancing the urgency of our mission.

Nearly everything the world knows about HIV/AIDS has been learned on the backs of us long-term survivors. **And we will no longer be ignored.**

## CHALLENGES

From the research on the effects of HIV on aging, we know the following —

- Today people over the age of 50 comprise more than 55% of the people living with HIV in the U.S.; in some cities, like San Francisco, that percentage is about 65%, and experts predict that people over fifty will comprise 70% or more of the U.S. HIV community by 2030.
- Long-term survivors experience accelerated aging due to the ravages of HIV on the immune system. Comorbidities can appear in long-term survivors some twelve years earlier than in their negative counterparts. At age 50-54, cognitive and physical abilities diminish much more quickly in long-term survivors. We are more prone to cardiac arrest, frailty (osteoporosis), balance issues, diabetes, CMV infection, and innumerable other conditions.
- These health concerns are exacerbated by the intersectional problems of poverty, depression, the costs of and access to healthcare, unstable housing, mental health concerns including substance use, racism, sexism, homophobia, and transphobia.
- While some ASOs have begun to offer programs and services to long-term survivors, there remains a severe dearth of those services and programs, which reach only a small fraction of the long-term survivors in the country and provide little geriatric healthcare.
- Long-term survivors are routinely relegated to the sidelines at national and international AIDS conferences, both in planning and in presentation.

## OUR DEMANDS

In solidarity with the 1983 Nothing About Us Without Us dictum of the Denver Principles, we proffer the following San Francisco Principles for Long-Term HIV/AIDS Survivors —

- There are severe shortages of HIV/AIDS specialists and geriatricians in the US. Given the escalating costs of medical education, the lack of government subsidization for medical education, the lack of respect for and prestige often associated with these specialties by the American healthcare system, and the time and physical demands required by the practice of these specialties, the majority of medical students have gravitated away from these specialties. Therefore, all medical professionals serving long-term survivors and/or older adults living with HIV must be trained in the proper care and to ensure state-of-the-art geriatric healthcare specific

to their needs. Providers, especially non-HIV-expert ones, must be made cognizant of the physical, mental, and psychosocial indignities faced by aging long-term survivors.

- Mental health services for older people living with HIV must be provided on demand, at a reasonable cost and free and without judgment and stigma.
- Mental health professionals serving older people living with HIV **MUST** be trained to address issues of the psychosocial damage suffered by long-term survivors, primarily but not limited to isolation and loneliness, depression, and alcohol and substance use, including psychological services and harm reduction services.
- Long-term HIV/AIDS survivors **MUST** be included in the planning and implementation of any programs and services offered to them. Again, **Nothing About Us Without Us**.
- Long-term HIV/AIDS survivors **MUST** be given a prominent seat at the table in planning all national and international AIDS conferences to ensure that we are not the “forgotten majority.”
- Resources must be allocated to programs and services grounded in the information and data gathered in HIV and aging studies.
- We must align the fight for long-term HIV/AIDS survivors with other social and healthcare justice movements, such as Black Lives Matter, LGBTQ rights movement, the women’s movement, the Native Americans’ movement, and all other movements and organizations working to end racism, sexism, ageism, homophobia, and transphobia around the world.

With these principles in mind, we are ready to lead the fight for health and social justice for long-term HIV/AIDS survivors everywhere. From San Francisco to the world, we invite you to join us in this fight.

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