

# HIV Long-Term Survivors Declaration

With courage and compassion long-term survivors of HIV strive not only to survive but also to thrive into full, meaningful, productive, independent and connected lives, free from stigma, ageism and discrimination regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socioeconomic circumstance.

A VISION FOR  
OUR FUTURE

**LetsKickASS.org**  
**AIDS SURVIVOR SYNDROME**

We are long-term survivors of the AIDS pandemic, the most devastating health crisis of the modern era. We are all affected by, and many of us are infected with, HIV.

We come from diverse races and ethnic backgrounds, genders, incomes, ages, and physical abilities. We are all impacted differently by decades of living with HIV and surviving the AIDS pandemic.

Since the first instances of "gay cancer" posted in our community in 1981, we rallied together against an indifferent world to care of each other and collectively fight back against HIV. With courage and compassion, we strive not only to survive HIV but also to thrive into full, meaningful, and productive lives. In the face of significant adversity, individually and collectively, we learned that we are resilient.

### **There are a few definitions of Long-Term Survivor (LTS)**

- **Pre-HAART LTS**—Longest-term survivors are individuals who acquired HIV in the 1980s and 1990s, before the advent of highly effective antiretroviral therapy (pre-HAART) when having HIV was considered a death sentence. Those living longest with HIV have physical and psychosocial implications that are vastly different from those who acquired HIV later in the epidemic.
- **Post-HAART LTS**—those who tested past 1996 and living with HIV for over 10 years.
- There are long-term survivors of a different stripe that are often left out of the discourse. They are the survivors who remain HIV-negative. They were lovers, caretakers and frontline healthcare workers. They were lesbians who stepped in to take care of people with HIV and AIDS. They too suffered enormous losses.

It has been over thirty years since the Denver Principles began the self-empowerment movement for people living with HIV but long-term survivors now find our voices muted. Our issues are sidelined by the agencies we helped to form. Conferences devoted to HIV are focused on newer topics while relegating long-term survivors to the sidelines and affinity sessions off the main stage.

Our marginalization exacts a toll our mental health, which in turn affects our overall physical health and quality of life. The White House updated the National HIV/AIDS Strategy for the U.S. in July 2015 with no mention of the experiences or the lived reality of long-term survivors.

Now is the time to reclaim our silenced voices and insure that long-term survivors' perspectives are not ignored. With talk about the End of AIDS and campaigns like Getting To Zero, it becomes vital that we take care of and acknowledge long-term survivors.

We are into the fourth decade of the HIV epidemic and half the people living with HIV are age 50 and older. By 2020 that number will be 70%. This is a wakeup call to focus on the needs and reality of older individuals aging with HIV. Because we had the audacity to survive we now face a host of challenges few of us could have predicted.

## **The Challenges**

Long-term survivors face a myriad of interconnected psychosocial, practical, and medical challenges rooted in HIV-stigma, aging, ageism, and economic distress that impacts functional health-related quality of life (HRQoL) issues.

## Psychosocial

The AIDS epidemic has been a series of traumatic events. We now know that surviving can also have trauma-related implications. The legacy of our past is having an effect on our lives now, and too many survivors are unaware of what is happening to them.

The effects of sustained trauma now present in combinations of depression, anxiety, emotional numbness, anger, survivor guilt, insomnia, nightmares, hypervigilance, hopelessness, substance abuse, sexual risk-taking, emotional numbness, low-self esteem, avoidance, social withdrawal and isolation, and/or a lack of future orientation.

*We call this **AIDS Survivor Syndrome (ASS)**. It exists on a spectrum and varies by degrees of intensity and it affects long-term survivors differently at different times.*

It is a natural response to posttraumatic stress (PTS). It often occurs years after the trauma ended. We stand with the movement to Drop the D in PTSD because a perfectly human response is not a "disorder".

Healthcare practitioners do not look for ASS among older clients thereby missing the bigger picture and impacting the quality of care survivors receive. They treat individual symptoms without seeing the larger dynamic at play.

We need to let our tribe know the problematic feelings people are experiencing are authentic and legitimate and that they are shared by many among us. We need to inform the people charged with our healthcare that underneath our depression may lay a forest of co-occurring psychological symptoms that are easily misunderstood. There is an urgent need for cultural competence training for everyone working with older individuals with HIV including trauma-informed care with an awareness of the experiences of the early days of the HIV epidemic.

*Often hidden behind an angry mask is a person terrified by the idea of growing old after decades not imagining it would happen.*

There are a substantial number of women long-term survivors who are often left out of the current HIV discourse. Trauma-related issues specific to women include intimate partner violence. Especially vulnerable are transwomen and women of color. Medications are most often studied on men; few have been conducted on dosing women.

As survivors age, we tend to isolate. Those living longest with HIV pull away just when we need to lean in and lean on our community. If we still have any semblance of a community left after so many extraordinary losses, we must make every effort to build new social networks that were once the hallmark of our response to HIV.

Living in isolation makes finding a sense of meaning and purpose difficult. It can breed a despair that can be devastating and may lead to suicide. Isolation increases the tendency toward depression. Survivors also feel a sense of guilt that they lived when so many of their loved ones and community died.

HIV stigma remains an onerous, hideous problem. Stigma resulting from fear of contagion has morphed into laws criminalizing sex with HIV-positive individuals. Combating stigma requires employing active, multipronged strategies, not just simple slogans.

To battle it we need to reject stigma and strengthen empowered networks of long-term survivors. Being HIV positive is nothing to be ashamed of—it never has been. Though disclosure for some, especially HIV-positive women of color and transwomen can be especially perilous. But when it is safe, we need to stand bravely in the light and not hide our HIV-status. The more visible we are the stronger we combat stigma.

The face of stigma may be changing now due to the new prevention options, Pre-exposure Prophylaxis (PrEP), Post-Exposure Prophylaxis (PEP), Treatment as Prevention (TasP) has joined condoms in the new prevention toolbox that has that added potential for reducing stigma is opening the door to a kind of connectedness possible before HIV made sex fearful. In that environment, the ones being stigmatized may well become the ones who do not testing and do not know their HIV status. We need to make HIV testing as routine as testing for cholesterol and CBC.

Long-term survivors are now encountering ageism. We never imagined we'd live long enough to that face that "ism", so it is challenging when it occurs. It is too easy to feel invisible and useless in a youth-obsessed culture. But, again, we do not have to participate. Much of ageism has to do with our own perception, given that the majority of people with HIV are older. We must make an effort to acknowledge one another and not treat each other as invisible and yet any older adult has felt the sting of invisibility.

People who were once courageously at the forefront of activism years ago are now feeling invisible as we age. Since many people with HIV have returned to health, the community has shifted its priorities. The assumption is that we have regained our physical wellbeing and no longer need support, attention, or resources. Those assumptions however are far from our lived reality.

There's an urgent need for affordable, culturally-aware mental health services from professionals who understand our rich, complicated histories as well as the possibility of trauma. We need to insure that the peer-to-peer support services that have long been a staple of HIV stay focused to the changing realities of older individuals with HIV.

## **Socioeconomic**

Long-term survivors never imagined living long enough to reach "retirement age" and many if not most have no money saved. For years retirement was a euphemism for being on disability. Often survivors live below the poverty level crippling their ability to be engaged citizens of the world. For many that only gets worse after they reach 65. If they have been on disability for years (or in some cases for decades) the future looks frightening. Without "paying into the system" they only qualify for the minimum Social Security benefits once they reach retirement age.

Supplemental Security Income (SSI) is antiquated and in need of major reforms. It doesn't allow for saving of more than \$2000 in assets. As if it were possible to save on a limited income. Social Security Disability (SSDI) income is not enough to live on. Our options are limited. Living month-to-month and not living well are the soul-crushing reality survivors face today. Survivors on disability are treated as suspect and forced

to prove ongoing disability to insurers. We are guilty until proven innocent because our disability is often invisible. That suspicion creates stress that affects healthy aging.

The long gaps in our work histories and lack of skills to work in the modern digital world present a high hurdle to reentering the work place. Combined with ageism, returning to work for the majority of survivors nearly impossible. Even survivors who have remained working are ineligible to purchase long-term care insurance, making their financial future distressingly precarious.

In urban settings, the lack affordable housing impacts our lives and our ability to stay in treatment. Many people are isolated from biological families and have lost many of their "logical families", lovers and friends, and therefore face these challenges alone.

Long-term care is only available to those of financial means and not those living on disability incomes. It will be up to the community to care for older individuals with HIV.

## **Medical**

Our ongoing economic distress is correlated with poorer health outcomes and impacts our ability to get to and stay "undetectable" or virally suppressed. Treatment as prevention (TasP) is an important component in the Getting to Zero campaigns, yet getting to undetectable attainable for those without the means and determination. Class, race, gender, access, and poverty remain barriers to the goal of getting to undetectable.

Detectable or not, survivors are dealing with accelerating aging from persistent inflammation. We have ramifications from years taking medications that were often ineffective as well as toxic. In those years before highly effective antiretroviral therapy (HAART) combination therapy was available many individuals took mono therapy and built resistance. Today many long-term survivors are on "salvage therapy" and are left with limited drug options.

For decades we have lived with stress that would break the hardiest of people. Untreated and often hidden stress can become a killer. Unfortunately, many survivors self-medicate with alcohol and substances that do more harm than good. We need to revisit proven, healthier ways to deal with stress.

Long-term survivors are once again on the medical frontier, facing accentuated aging and increased frailty before our time. Comorbidities factors like Hep C, diabetes, increased cardiovascular disease and strokes these and other HIV related ailments all present a complicated medical situation that continue to have a devastating impact on survivors' health. It is well known that ongoing gastrointestinal problems occur early in HIV infection and many long-term survivors live with debilitating neuropathy. Contradictory and ever-changing predictions about our life expectancies are enough to make our heads spin. We survived the odds before so must remember that as we age.

In the U.S., the majority of people living with HIV are over 50. There is a strong need for understanding of the scientific and medical complexities associated with the biology of HIV and aging. We need more research that requires ongoing and sustained funding as well as stronger leadership on LTS issues. We face a crisis in long-term health care sensitive to long-term survivors.

# A VISION FOR OUR FUTURE

Let's Kick ASS was formed to raise awareness about the invisible but very real effects of AIDS survivor syndrome and posttraumatic stress. However, raising awareness is not enough. The reason for our formation was to overcome ASS so that we can make the next decades the best they can be.

Long-term survivors often have a hard time wrapping our brains around the idea of a future. Decades of believing that that our lives would be cut short have trained us not to consider "what if", yet here we are facing the conundrums of midlife and aging with HIV.

*Ours is not a movement simply about nostalgia, pain and grief. It is also a testament to the resilience of the human spirit, to humans who rolled up their sleeves and refused to accept our death sentences.*

The result of that resilience is we are living longer. It presents tremendous opportunities and our calls on us to be creative, compassionate and passionate. If you are not yet in touch with that idea that you are resilient, it is ok. You have to notice it for it take root. If we stop focusing on all the times we nearly died and the loved ones we lost but recall instead at how we got back up, how you survived. That begins to change our perspective. We need a more nuanced view of resiliencies and focus on the ways to increase resilience as we age.

It becomes important for those who survived to tell our stories, to speak our truth with compassion. Our legacy rests in our hands. We must write new, more accurate narratives that reflects the complexity of our history and the richness of our lives ones that honor our past, but does not weigh us down in it. Our histories are more than simply our histories, because the stories we tell ourselves about our survival are an important part of the healing of our lives. Our stories hold the key to richer, fuller lives. Re-writing our stories are vital to our survival.

We must engage in intergenerational dialog in a meaningful, respectful conversation that stresses our example of resilience and survival as well as our struggles then and now. The generations we have much to learn from each other.

We find ourselves underrepresented in the decision-making AIDS institutions, boards of directors, or executive positions, reminiscent of the earliest days of AIDS. Yet we have the knowledge, experience and

wisdom to make a meaningful contribution to the discussions and programs affecting our lives. This requires long-term survivors to speak up and demand a seat at the table. Not just an advisory board for show but meaningful inclusion about matters related to our lives.

We must battle against cynicism, judgment and infighting because we are all in this together. We need the most creative ideas for tactics and strategies for healthy aging and what it means to live a good life. We will no longer be ignored as we empower each other and ourselves to find meaning and purpose in the aftermath of the HIV epidemic. We assert our right to return to work, volunteer, and be involved productively in society.

It is critical that AIDS survivor syndrome (ASS) and the effects of PTS be acknowledged, evaluated, understood, and studied. We know enough to know the phenomenon is real. While we see it among our cohort every day. We are the catalysts to creating change.

In the quest for the End of AIDS, the lives and experiences of those longest affected by the epidemic must be prioritized, not minimized or ignored. It is now time to become fully engaged elders, teachers, and leaders. We've learned valuable lessons about survival and community empowerment that implores us to share it with the world.

The realities of the older generation are excluded from the decision-making bodies as younger, well-intended, often HIV-negative individuals have taken the helm at HIV service organizations. They are ill-equipped to provide services to the now majority of those living with HIV. We must insist that providers of all stripes, including aging providers, become culturally competent so that our needs and issues are placed front and center.

We must come together to defeat the twin scourges of stigma and ageism. Studies suggest the best approach to reducing stigma is focusing on personal contact, education, and empowerment. It also happens when we refuse to be shamed. We must revisit the idea of empowerment and what it means now. We reduce stigma by building strong connected networks of long-term survivors. We owe that to each other by working together and being strong in the places we hurt most.

If our history teaches us anything, it is that when we come together we can make a difference in peoples' lives. With courage and compassion, we strive not only to survive HIV but also to thrive into full, meaningful, productive, independent and connected lives. We want to continue a respectful conversation among peers and educate the world about the existence and power of survivors. The power of a grassroots movement is that it is from the bottom up not the top down.

This declaration is a call for additional ideas, dialog, solutions and action for long-term survivors and those aging with HIV. Use what you want to of this document to help create dialog and action. We do not have the luxury of time. This is urgent that we improve the lives of survivors. Our work will continue as long as there is one isolated survivor left in that lonely room.

**#LTSVisionForOurFuture**

Let's Kick ASS is a bona fide grassroots movement of long-term survivors both positive and negative to defeat AIDS survivor syndrome and raise awareness about what it means to be a long-term survivor. We have chapters in Portland, OR, Palm Springs, CA and Austin, TX and are rapidly expanding. We are based in San Francisco.

If you are interested in starting a chapter in your area, please contact us at [LetsKickASS.org@gmail.com](mailto:LetsKickASS.org@gmail.com). We created a toolkit to help you start a chapter: <http://letskickass.org/chapter-toolkit/>.

Find us on the web at: [LetsKickASS.org](http://LetsKickASS.org) | Twitter: [@LetsKickASS\\_org](https://twitter.com/LetsKickASS_org) | Facebook: <https://www.facebook.com/AIDSSurvivorSyndrome> and Instagram: <https://instagram.com/letskickass/>

See our Let's Kick ASS PSA here: <http://letskickass.org/video/>.

**June 5 is National HIV/AIDS Long-Term Survivors Awareness Day.** It is a day to spotlight long-term survivors and our issues. Theme for 2016 is **We Are #HIVResilient**.

Find us on the web at [NHALTSAD.org](http://NHALTSAD.org) | Twitter [@AIDSSurvivors](https://twitter.com/AIDSSurvivors) | Facebook: [facebook.com/NationalHIVAIDSLongTermSurvivorsAwarenessDay](https://facebook.com/NationalHIVAIDSLongTermSurvivorsAwarenessDay)

You can also read this on **Medium**: <http://bit.ly/LTSVisionForFuture>. Reddit: <https://redd.it/3i94uk>.

*Final version written by Tez Anderson, founder of Let's Kick ASS from data that was compiled from the large community of long-term survivors in San Francisco and around the country. Tez also sits on ACRIA's ROAH 2.0 Research Advisory Committee.*

**#EverySurvivorCounts**



**We Are #HIVResilient  
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