31 at 30

Thirty-one Long-term Survivors on Thirty Years of AIDS

May 2, 2011 By Laura Whitehorn

Click here to read a digital edition of this article

June 5, 2011, marks 30 years since the first published accounts of what became known as AIDS. The history of AIDS entails the excruciating loss of more than 25 million lives globally. But it also offers the powerful survival tales of many who returned from the brink of death to inspire, protect and advocate for others. Survival involves many issues: how quickly you learn your status after contracting HIV; whether you can get, afford, tolerate and keep taking meds (if needed); whether you have emotional support, safe housing and help dealing with substance use (if needed); empowerment and enlightenment about health care; and an enduring will. For this 30th anniversary, we asked 31 long-term survivors who've appeared in POZ what moves and sustains

them and whether they think they'll live to see a cure. Here is a sampling of their sage advice. Read their complete responses on "30 Years of AIDS" here. Each person here is equally wise and wonderful—they appear in no particular order. Why 31? One for each year, and one more for good luck. May we all survive together to see the end of AIDS!

1. Sean Strub

Innovator, rule-breaker, POZ *founder, senior adviser to the Positive Justice Project, HIV criminalization fighter, positive for 31 years.*

The best advice I ever got was, “Be skeptical, especially of anything presented as beyond question. Seek health as an ongoing journey, not a destination.” Overcoming stigma is a challenge that never ends, and for those trapped in disenfranchising burdens like racism, poverty, addiction, incarceration and mental illness, it’s much more difficult.To someone just testing positive, I’d say, “Study. Fall in love. Be of service. Be kind to all.”

2. Robert Chodo Campbell
Buddhist counselor, peacemaker, cofounder of New York City's Zen Center for Contemplative Care, positive for 28 years.

The best thing anyone's said since I tested positive is, "You look fabulous." An HIV treatment

advance was that I stopped taking Zerit and halted the progress of facial wasting. My refuge is the knowledge that everything is impermanent, including my virus. It is constantly changing, as am I. My advice? Never ever ever feel less than the person standing next to you.

3. Kim Hunter

Manager of the Office for Women's Health at New Jersey's Hyacinth AIDS Foundation, ex-prisoner, freestyle cruiser, positive for 25 years.

Accepting my HIV has often been the deciding factor in my treatment compliance. I am grateful that the worst, early days of this epidemic are gone. The quality of my life has improved because of my commitment to taking my meds. When I got my diagnosis, I had no idea I'd be around to tell you this today. For anyone afraid of having tested positive, I say, "Just follow me."

4. Sylvia Young

Woman of the WORLD (peer advocate program manager at Women Organized to Respond to Life-threatening Disease), positive for 16 years.

My refuge is music. I go with my husband, a guitarist who plays R&B, jazz and rock, to gigs—and I dance. My challenge is fatigue. I've had to learn not to overextend myself. My family has aided my survival the most—my daughters, grandson and of course my husband. From them I have never encountered a bit of stigma. I tell newly diagnosed people, "Forgive yourself."

5. Dab Garner
Teddy bear–tender (creator of Dab the AIDS Bear Project), positive for 29 years.

At the end of the movie Longtime Companion, all your friends who died from AIDS complications show back up on the beach. I still cry every time I watch it. It would be a dream come true to have all of my friends back again. If a cure is found in my lifetime, I would benefit—no more costly medications every day. But the greatest gift would be knowing no one else would have to die from AIDS.

6. Stacey Latimer

Gay minister (Love Alive International Sanctuary of Praise NYC), believer, positive for 24 years.

My major economic challenge has been recovering from the “last days”mentality. Living as if there was no tomorrow created a financial nightmare. Facing reality was the curse that tagged along with the blessing of survival. My faith is my refuge. The Creator has already surpassed so many of my expectations over the last 30 years—a cure in my lifetime seems a small milestone for the Spirit.

7. Sharon Wagner

Mother and grandmother, churchgoer, cancer survivor, positive for 24 years.

The most helpful thing anyone has said is, “Take your medicine and stay positive.” I don’t think I will see a cure in my lifetime, and if I do,I won’t benefit from it—I’ve had HIV too long. My advice to

anyone who tests positive is, “Get all the information, see a good doctor, change your lifestyle, eat right, exercise, and if you choose to go on HIV meds, be consistent in taking them.”

8. Bamby Salcedo
Mexicana immigrant, transgender warrior, coordinator of the Children’s Hospital L.A. transgender youth program, positive for 16 years.

Someone told me, “If you let having HIV make you depressed, it will kill you. Ignore the negative stuff about your disease and don’t let HIV stop you from being who you are.” We are beautiful the way we are.Change is good—it’s just hard to understand. Being positive is just a change in our lives. Helping in my community, bringing trans issues to the fore, sustains me.

9. Peter Staley

AIDSmeds founder, crystal-kicker, ex-Wall Streeter, positive for 28 years.

Shortly after my diagnosis, I told my closest friend and former piano teacher the news. After a long pause, he said, “Well, OK then, will you leave me your grand piano?” A sense of humor can add years to your life. I tell newly diagnosed people not to live in an HIV closet. While it might help prevent some hard moments, it’s a form of self-loathing that will keep you from living life to the fullest.

10. Jane Fowler

Graceful and gracious voice of HIV over 50, founder, HIV Wisdom for Older Women, positive for 25 years.

After my HIV diagnosis, I spent four years in semi-isolation. Then my son said, “You’re positive, so

do something positive," urging me into the role that has empowered me—public speaker on HIV/AIDS. I'm a fanatic reader of biographies. It's useful to be reminded that all people face obstacles and endure setbacks. I'll turn 76 in July. If we have to wait another 30 years for a cure, I won't live to see it.

11. Fred Hersch

Jazz pianist and composer, coma survivor, AIDS fund-raiser, positive for 25 years.

I've been on "salvage therapy" for many years. Fortunately, new drugs came along each time I was crashing on a regimen. My CD4 count hasn't been above 200 for years, but my virus is undetectable—HIV and I are at a standoff. Being out as gay and positive helps me overcome stigma.Jazz has a rep for being macho and homophobic, but when I was near death in 2008, the whole jazz community was caring and supportive.

12. Mechelle Jones

Crack-habit code cracker, inspirer, admissions coordinator for HELP/PSI in the Bronx, New York, positive for 16 years.

When I tested positive, someone told me, “You are a fighter. You willrise above HIV/AIDS.” My refuge is God; my children are my biggest supporters. It’s important to express your feelings, bad as well asgood, but to have people in your life who won’t let you stay stuck on abad feeling. My job

helping others dealing with AIDS and drug abuse is a blessing.

13. Lisa Tiger

Muscogee Nation role model, speaker, mom and adopter of abused kids, positive for 23 years.

In 1992 my doctor said, “If you want children, don’t let HIV stop you.” I now have three. My refuge from HIV (and Parkinson’s disease) is running—at least a mile every day for more than four years. I

post it on Facebook, and people write, “If you can do it with AIDS and Parkinson’s, then I have no excuse.” Time is precious. Spend it making plans for your fabulous future.

14. Loreen Willenberg

HIV controller, former landscaper who started the Zephyr Foundation to promote controller studies, positive for 19 years.

It’s hard to fathom where my life would have gone if HIV hadn’t found me. In 1995, my physician

said, “One of these days, scientists are going to want to study you, because your immune system holds back this infection.” I have more hope than ever for a cure in my lifetime. The benefit to me will be gratitude that I was able to make a small difference by participating in studies of HIV controllers and nonprogressors.

15. Hydeia Broadbent

HIV's knock-your-socks-off baby girl, award-winning public speaker,positive for 27 years (her whole life).

At birth, the doctors told my parents I wouldn't make it past the age of 5. Then I had to take 35 to 50 pills a day, or wear a pump all day because I couldn't take medicines by mouth. Now I only take nine pills a day, and HIV-positive women can have negative babies! Growing up I worried about not being able to be a mother. My economic challenge:meeting the requirements to keep my state-subsidized health care.

16. Larry Bryant

Rebel rouser, former all-star footballer, Housing Works' national field organizer, positive for 25 years.

Trust and acceptance from my family and friends defined my survival.The stigma I impose on myself is most damaging and damning. I have self-destructed in the face of close friendships because of my own fear. As important as it is to find a cure, it's equally important to identify

strategies to address homelessness, poverty, homophobia and sexual violence. A cure will be needless if these persist—we will just sit and wait for the next epidemic.

17. David Lee

Welcoming shoulder and master of social work at Culturally Compassionate Counseling, positive

for 16 years.

The words that have helped me most came from my own mouth: “I got HIV being a human being doing human things.” Knowledge has helped my survival, and having great friends has helped me emotionally. I’m not concerned about a cure, because I believe I’ll live a normal life with the treatments already available.

18. Shawn Decker

Positoid rock star, educator and author (My Pet Virus), POZ *blogger, positive for 25 years.*

When I was diagnosed at age 11, my uncle said, “Don’t let the bastards get you down.” For me, well-designed treatment interruptions (one week on, one off) boost energy without letting HIV mount an assault. Playing and writing music with my band, Synthetic Division, offers a change from speaking on sexual health and HIV. My soul medicine is my loving negatoid partner, Gwenn. Love yourself and let HIV weed poisonous people from your life.

19. Susan Rodriguez
SMART starter (founder, SMART University, New York City), positive for 16 years.

Side effects and aging are challenging, but at least I’m alive to deal with them. Walking my greyhound Ollie and carrying my little Chihuahua Mork in Central Park or along the East River clears my head. Keeping the doors open at my HIV/AIDS organization, SMART University, presents my economic challenge.

20. Tracy Bruce
Georgia peach of a mom and grandmother, HIV prevention specialist, positive for 26 years.

I feel the world passed me by while I struggled to control HIV. After 15 years on disability, the insurance company said I should work full-time. But fatigue and the economy proved them wrong. My drive to see my children grow to adulthood aided my survival. If a cure is found, I won't know whether to be elated (for all of us living with HIV) or depressed that my husband isn't alive to

benefit.

21. Latrischa Miles

Champion adherence counselor (at the Kansas City Free Health Clinic), positive for 16 years.

Early on, I refused to leave my doctor’s office until he answered all my questions about my regimen. He did, and he directed me to more information (and to my first copy of POZ so I could self-educate). I speak at organizations, schools and churches. Stigma is often the fear of the unknown—dispelled when we talk about it.

22. Eric Sawyer
Ambassador of activism, UNAIDS adviser, cofounder of ACT UP New York and Health GAP, positive for 30 years.

What’s allowed me to live is deciding to manage my health in partnership with my doctor, not as a passive patient. We need a renewed demand for cure research on the global agenda. Cure in my lifetime? I’m skeptical. Too many pharma companies make too much money keeping HIV-positive people relatively healthy. I tell newly diagnosed people, “Manage your health so you can live a normal life span. And have a lot of great sex—it gives you something to live for!”

23. Tom Duane
Openly gay and HIV-positive New York State Senator, community champion and hero, positive for 30 years.

Along with loving family and friends, every positive person I have met—closeted or not—who has whispered “thank you” to me for being open about my HIV has helped me survive. Mental health services aid my health; recovery programs are my refuge. Maintaining health insurance is a challenge. As a male, Caucasian elected official, my experience with stigma can’t begin to compare with what others face every day. I tell those newly diagnosed, “Keep working to stop others from becoming positive.”

24. Jorge Delgado
Impassioned and empowered minister, HIV/AIDS ministry director at Metropolitan Community Church in DC, positive for 23 years.

In 30 years, nearly 30 million people around the world have died. Medical advances have changed my death sentence to a more treatable long-term disease. My challenge has been the countless thousands of dollars spent on deductibles for doctors and meds. My faith has helped me deal with the anxiety and depression that can affect those of us with HIV.

25. Jack Mackenroth
Project Runway contestant, advocate and athlete, positive for 22 years.

When I was diagnosed, I expected to be dead at 25. As treatments improved, so did I. For refuge, I swim competitively with Team New York Aquatics and design fashion, write and make art. If there

were a cure in my lifetime—I'm not counting on it—it would be odd because HIV has become such an integrated part of my life. But I'd be more than happy to let it go.

26. Linda Scruggs

Program director, AIDS Alliance for Children, Youth and Families, survivor of incest, sexual abuse and cocaine, positive for 21 years.

I was on 15 pills a day, then eight or 10, and I had trouble taking them. In 2004, a doctor asked, “If I can find a regimen of three or four pills will you take them?” I committed to that combo, and now, seven years later, my CD4 count is above 900. I wish I could afford dental care to make my smile as beautiful as I feel my life is today.

27. Monica Johnson
One of our favorite HEROES (she founded Helping Everyone Receive Ongoing Effective Support in Columbia, Louisiana), positive for 27 years.

I know a college degree and career are useless if you can’t get health insurance. Too many people with HIV are forced to live below poverty level in order to have affordable treatment options through government programs. Saying, “I don’t have time or T-cells to waste” keeps me grounded. It helps me decide quickly if something is worth the hassle.

28. Imani Harrington
HIV drama-writing queen (Bitter Fruit, for example), positive for 26 years.

Socially responsible designers and artists inspire me. I think I will see a cure—with science and biology, the natural world might surprise us. We should dream. I would tell someone newly diagnosed with HIV, “Find what gives you meaning. Can you see this working for you even when it might not seem to be? Can you accept life as you have been born into it?”

29. Dawn Averitt Bridge
The Well Project founder, mother (her older daughter was POZ's first cover baby, celebrating an HIV-negative birth), positive for 23 years.

Someone said, “HIV isn’t the death sentence you think, so don’t rob a bank—you’ll likely be here to pay for it!” The rest of the world grossly underestimates the challenges of getting meds and staying on them (all the time!). My daughters are my refuge—amazing little people,the children I was never going to have because of HIV.

30. Greg Louganis
Diving board Olympian, trainer of divers and dogs, positive for 23 years.

My challenge has been sponsors pulling support because they didn’t think I’d live this long. Yoga helps me maintain physical, emotional and mental flexibility and a positive outlook. What I’d say to a newly diagnosed person? “You idiot, what were you thinking!” No, really,“Just take a breath, take responsibility, live your life with passion.”

31. Mary Fisher

Artist, world-rocker (her speech at the 1992 Republican Convention broke the don’t-say-AIDS barrier), energetic educator, positive for 20 years.

My treatment advance was learning to listen to my doctor and finding a doctor who listens to me. Stigma isn't a knife that slashes through your throat; it's more like someone rubbing sand paper on your skin,wearing off your resistance. I tell newly positive people, "You now have a chance to start your life over on much better terms than you had before." The irony is, it's true.

Click here to read more of our "30 Years of AIDS" coverage.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/30-AIDS-HIV-20350-5441