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April 1, 2016

Gladstone, Oregon

Positive since 1985

I was probably infected with HIV shortly after coming out in 1980. I tested HIV positive in 1985 and was immediately diagnosed with AIDS Related Complex (ARC), a now-defunct term. My physician told me that my immune system was fully compromised and that I probably had less than two years to live. I was told that I should prepare for blindness within six months due to an untreatable cytomegalovirus (CMV) infection. At the time I was a divorced, 29-year-old gay dad. My kids were 8 and 9.

My employers told me they wanted to fire me and had discovered that they could have fired me for being gay, but because they were made aware of my HIV status, they'd be open to a huge lawsuit due to the Americans With Disabilities Act. They chose to eliminate insurance coverage for anything that might be HIV related. Instead of quitting, I found a gay attorney who was looking into establishing corporate case law regarding HIV group insurance coverage. He donated his time and sued them for discrimination.

On a daily basis I'd look in the mirror for signs of my approaching death. I sought out others like myself who were diagnosed with ARC and AIDS. In truth, I felt pretty sorry for myself and others like me. I lived in fear and felt shame for what I'd brought on my family. As the months went by, I started losing friends to AIDS from my support group. I became fixated on reading the obituaries to find out who else had died, and my life seemed totally focused on death and dying.

In the early days I feared being quarantined and never seeing my kids again, as public health departments and the CDC were deciding how to protect society from the "gay plague." My ex-wife and I decided not to tell our kids until it was absolutely necessary, out of fear that they would be stigmatized by friends, neighbors and schoolmates.

Two years went by and I didn't die. I met someone who was also HIV positive. Love bloomed. We partnered up, and from 1988 to 1994, we lived in denial and pretended that love would protect us. Like so many others, we opened our home in 1991 to hospice a friend whose family wasn't up to the task. We watched and waited while all of our close male friends fell to the disease. In 1994 my partner, Bob, became ill with non-Hodgkin lymphoma, and in 1995 I lost my best and last friend. I

became bitter and angry. My friends were all gone. I directed my anger outward at acquaintances in the gay community for turning their backs on us. I called death to me daily and by 1996 I almost got my wish. My T-cell count dropped to 20 and yet I was still turned down for Social Security disability; I wasn't sick enough, though I was too ill to qualify for the promising drug trials that were happening at the time. I temporarily lost the ability to speak. My doctor told me I had less than six months. I laughed when three months later he told me my T-cell count was 1. It seemed so ironic and unfair. I didn't want to keep living, yet I wouldn't die. And all my friends, who had such a lust for life and fought so valiantly, didn't make it.

I chose to attend my daughter's graduation from high school in 1996. I wasn't supposed to live long enough see her turn 11, and nothing would stop me from seeing her graduate. She hadn't seen me in about six months. She later shared with me that she hadn't recognized me. She wondered as I walked up the hill whose uncle or dad was it that was dying, because she felt sorrow for them. Then she realized it was her dad climbing the hill. It was one of life's bittersweet moments.

Then the FDA chose to do a rapid release of a new class of antiretrovirals due to the extremely promising results in the drug trials. I soon began my slow physical recovery. Every three months my labs looked better and continued to improve. I threw myself into volunteer work with our local HIV support organization, Cascade AIDS Project (CAP). I was a support person for clients. I helped people move. My son and I became personal perspective speakers and shared with groups of students what living with HIV/AIDS was like. My son started his own nonprofit organization focused on kids who were HIV positive or affected by HIV . We went through a 10-week training course on HIV testing and harm-reduction counseling in high-risk populations.

Even though my story is filled with sorrow, loss and suffering, my real story is one of miracles, blessings and healing. I'm a long-term HIV/AIDS survivor. I live daily with survivor's guilt and I channel it into making a difference for others. In 1999, I decided it was time to return to work and to try and get off of disability. I was blessed to be hired by the Multnomah County Health Department to do HIV testing, harm-reduction counseling and needle exchange in our local STI clinic— the same place I received my own life-altering test result. I found a sense of purpose and meaning.

I later transferred into our health department's early childhood services and for 10 years I did "Welcome Baby" visits in four local hospitals as part of our state Healthy Families Program. It was nice to get away from HIV and AIDS and to focus on new life and new beginnings. My immune system stabilized at around 600 T-cells, give or take 100. My viral load has been undetectable for the last 13 years. But I was still scarred emotionally. I isolated myself from the gay community, and I secretly still longed to die. I presented a happy appearance, but I still saw myself as a broken man, killing time on planet Earth waiting to die and to be reunited with those I'd loved and lost.

Then something amazing happened: I decided I was done being angry. It served no purpose other than making me feel hurt, and it only pushed others away. I started letting people in again and decided that life is what we make it. The world we perceive is the world we experience. Even my

darkest moments—and I've had many—have been filled with treasures and pearls of wisdom. I am blessed. I am a long-term HIV/AIDS survivor. Like my fellow survivors, I am filled with wisdom and experience. I have much to give and to share with others. I have NOTHING to be ashamed of. We long-term survivors, both negative and positive, men and women, we all need to reach out and help to remove the stigma around HIV and AIDS.

In December of 2013, I started a new job with the health department, and found a passion and purpose that I hadn't felt since the day I was diagnosed in 1985. In November of 2013, my T-cell count was 640. Five months later, in April of 2014, my T-cell count was 1,051. It was a total surprise to both my HIV specialist and me. I had made no change in medication, no change in diet, only a newfound sense of passion, purpose, desire, and belief that I can and will make a difference. That my life does have meaning.

I decided later that year to try to connect with other long-term survivors. I wasn't quite sure how to do it, but I knew that I needed to do it. I decided to put a personal ad on POZ Personals.

One day a straight friend I work with sent me a link to a new nonprofit called Let's Kick Ass (ASS stands for AIDS Survivor Syndrome) that was started by Tez Anderson in San Francisco. When I went to the site, letskickass.hiv, I cried for over an hour. I saw that June 5, 2014, would be the first-ever National HIV/AIDS Survivor Awareness Day, and here was a group of people experiencing my very same symptoms: isolation, chronic depression, PTSD, a focus on death or dying, and HIV-related lipodystrophy. I no longer felt alone.

As an employee of Multnomah County here in Portland, my first response was to send a letter to our County Chair and Board of Commissioners requesting that we be the first county in the U.S. to recognize June 5 as National HIV/AIDS Long-Term Survivors Awareness Day. Eighteen days later, with the wonderful writing talents of Jim Clay, a fellow long-term survivor who wrote the proclamation, we jointly presented before the County Board. For the first time in my life, I proudly came out publicly—and on camera—as a long-term HIV/AIDS survivor. I've asked that the county change its employee health plans to specifically address the difference between how we treat cancer survivors and how we treat HIV/AIDS survivors. It was one of the most liberating experiences of my life.

We are now forming our on local chapter of Let's Kick ASS. I encourage all of you to go to letskickass.hiv or lka-pdx.org, to learn more about this wonderful grassroots movement and its mission.

I've gone from someone who was angry and bitter and supposed to die by 31 to someone whose kids are now 36 and 37. They are married with loving partners. I've been blessed with two wonderful grandsons. Life is so much better when it's shared. It's never too late to reach out, or too late to envision a future you never thought possible.

What three adjectives best describe you?

Resilient, passionate, purposeful.

What is your greatest achievement?

Living long enough to see my kids grow up and have kids of their own. Also, being alive to provide support and love to my mom during her final years.

What is your greatest regret?

Waiting so long to reach out to others for friendship and support.

What keeps you up at night?

Passion and bad sinuses

If you could change one thing about living with HIV, what would it be?

Allowing myself to feel ashamed and isolated for so long

What is the best advice you ever received?

Live by the Golden Rule.

What person in the HIV/AIDS community do you most admire?

Tez Anderson

What drives you to do what you do?

My hope for a brighter future for at-risk kids and my desire to reach out to other long-term HIV survivors

What is your motto?

We can change our life experience by seeing life differently.

If you had to evacuate your house immediately, what is the one thing you would grab on the way out?

A picture of Bob and myself during our first few years together

If you could be any animal, what would you be? And why?

The phoenix (death and rebirth)

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