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November 4, 2016

Boston, Massachusetts

Positive since 1983

In 1979, I started getting sick.

In 1983, I was seeing Dr. Groopman at Beth Israel Deaconess Medical Center. I was not scared. I felt relief because now we knew what was going on with my body.

Only in 1990 did the antibody test go positive. I fought for good health care at Fenway Community Health.

When AIDS Action started having groups for people with AIDS, I fought to get in. I told them, “What do I have to do? Wait until I get sicker to get help?” I was getting sick often. I had herpes that lasted six months.

When AZT first came out, I waited about six months. My T cells were at 500. Dr. Mayer offered to put me on it, and eventually, I took the offer. It is one reason that I am still alive.

Over the years, I did many combos. But until last year, none of them worked well. I tried lots of other things: AL-721, super hot baths, Chinese herbs prescribed by Dr. Mim Tat Wong, mirror work and meditation. I told my virus not to kill me, and I would not kill it.

I’ve lost over 200 friends. I was treated like a subhuman at the hospital. Back in those days, they would throw out everything in a room that a person with AIDS had died in. So near a friend’s end, we would take back the stuffed bears because we knew they would be thrown out. I saw young men grow old in months. Healthy men reduced to walkers and wheelchairs. A friend, Michael, at 6 feet 2 inches, was down to 87 pounds. Even as a premed guy, I had to look up the infections that my friends were getting. Nobody had ever seen so many rare infections.

One mom had to bribe an orderly to sneak out her son’s body in the trash and put it into her trunk. They were burning bodies as medical waste. A woman I knew was told she could not have it even though her husband had died of it.

Sustiva turned my nightmares into a living hell. I still have dreams that are just as real as any other memories. I spent two and a half months in a psych ward because they were afraid that my

mind would never heal. I walked around with a ruptured appendix because I had no fever.

When my dad died, my family turned against me, leaving me homeless while I was sick with bacterial diarrhea.

Since then, I've lived in rest homes. Now, I'm in assisted living. My family is forcing me to live with a huge hump and a huge belly [called lipodystrophy] from the meds or HIV. I was on the street when I got triple pneumonia and nearly died. I was in the intensive care unit for 10 to 14 days. It is all fuzzy.

The huge problem is, there are guys like me being forgotten and rotting away because old gay men do not count. Blue Cross Blue Shield and Express Scripts make your life hell. Because I own one fifth of my family business, I do not get anything. I have to pay for everything: deductibles, copays and other fees.

Now, as a diabetic, food is harder to get and make. If it were not for Peapod's food delivery, I would be totally out of luck.

It's sad, but our stories are not heard. We are the forgotten.

What three adjectives best describe you?

Hard, demanding and fuzzy.

What is your greatest achievement?

Running Gay Pride Boston for many years as its treasurer.

What is your greatest regret?

Not having kids.

What keeps you up at night?

Pain—lots of pain. Worrying that the young will just repeat all our mistakes.

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

That we would be treated with compassion.

What is the best advice you ever received?

Stay alive to tell the stories of the ones who died.

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

None.

What drives you to do what you do?

To be the last one standing.

What is your motto?

To the doctors who told me I would die, I told them I would piss on their graves.

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

My artwork.

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

Yorkshire terrier. My favorite dog. Cute but still a ratter.

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