



My HIV Story

Joe De Hoyos reflects on coming out and his journey with HIV.

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I came out when I was 15, which is the first time I went to a gay disco. It was the night I went to see Donna Summer in concert. I loved disco music and dancing. This was in Houston in the late '70s. Eventually, I found a club where underage gays could sneak in. I went for the dancing, but older men were always drawn to me. It would be a few years before I started having sex. My friends and I would leave the club and go as a group to “dirty bookstores” for a laugh and, eventually, the bathhouse. By then, it was the early '80s, and I was 18 or 19.

I met Tim at a bathhouse. He was 33. It was the first time I had sex with someone on a regular repeat basis. I was a senior in high school, and we became boyfriends. As soon as I graduated, I moved in with him. We only lasted a year though. A couple of years later, he called to tell me he had AIDS. I must have assumed he got it after we broke up because I don't remember feeling concerned for myself. He moved back to Florida to be with his family, and we lost touch.

In 1985, I noticed what looked like a lesion on my arm. I had a biopsy done and an HIV test. It was two long excruciating weeks before my follow-up appointment. When I was told I was positive, it was as if my soul left my body. I guess it must be what being in shock feels like. I didn't tell my family for 10 years. I went through many years of fear and anguish, but I was fortunate to get assistance from organizations like AIDS Healthcare Foundation Houston, Desert AIDS Project in Palm Springs, Positive Resource Center in San Francisco and also from the AIDS Drug Assistance Program (ADAP), all of which have helped at one time or another.

The year after I moved to San Francisco, I got sick. It felt like the flu, but it was fatigue. A blood test showed I had AIDS—only 10 T cells! I had only taken Zerit and Epivir because the other drugs scared me. I had to start a full cocktail of drugs and go on disability. I stayed on disability for 18 years. In the meantime, I went back to school, got a degree in merchandising and eventually went back to work. But I was in and out of jobs for a few years because I kept getting sick. I thought I'd never be able to work full-time again.

I have been able to work full-time since 2018. I'm now looking forward to retiring when I'm 70,

which is in six years. At this point, I have nothing saved for my old age, but I'm optimistic it will work out. It always has!

What three adjectives best describe you?

Optimistic, creative, insecure.

What is your greatest achievement?

Surviving and keeping a roof over my head despite years of financial insecurity.

What is your greatest regret?

Not being in a long-term relationship.

What keeps you up at night?

Leg pains.

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

The shame that comes with it.

What is the best advice you ever received?

Always make sure you can afford to feed yourself and have a roof over your head.

What person in the HIV community do you most admire?

André De Shields. He proves that being HIV positive and being a senior are not reasons to slow down. He has the right spirit!

What drives you to do what you do?

The urge to be creative. I can't turn it off.

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

My two cats.

