Live and Love

POZ asked readers, “How did HIV change your life?” In an opinion piece titled “Determined to Live and Love,” long-term survivor John Reams shared his story of profound loss and immense gratitude. Below is an edited excerpt.

May 18, 2020 By John Reams

In 1991, I had a bacterial pneumonia. I was scared to death. I began thinking about the possibility I might have AIDS. It was a few long difficult weeks until I returned to get my results. I tested HIV positive. Soon after my diagnosis, my partner tested HIV positive.

In 1994, I received a frantic call from my father. He told me that something was wrong with Michael, my older brother by 10 years. My parents and I decided to see what was wrong.

I remember my brother answering the door naked and then returning to a sofa bed, where his partner lay asleep. Michael wasn’t himself. He was childlike, and his partner, Arnold, had lesions on his face.

They both had AIDS-related illness. My brother had wasting syndrome and AIDS-related dementia. Arnold was diagnosed with Kaposi sarcoma (KS). I remember the term “full-blown AIDS” being used at that time. I hate that term.

My brother and Arnold were both intelligent, talented and full of life. Now they were fragile, gaunt and afraid. My mother and father asked if I would consider moving to San Diego to care for my brother. I did—without hesitation.

Just before Christmas of 1994, it was obvious to me that Michael was no longer able to care for himself or his partner, whose KS was taking his right eye. I told Michael that Arnold needed skilled nursing. Michael agreed.

Soon after that, Patrick, my husband of 33 years, and I moved in with my brother. I spent a total of eight months caring for him before he died, followed by two of their close friends and, lastly, Arnold, my brother’s partner of 15 years.

This experience changed everything. My husband and I reevaluated our lives. We became closer and more in love. Because of this experience, I didn’t want to die anymore. I was determined to live.

A year after my brother passed, I witnessed my father having a fatal stroke, and I also ended up

moving in with my grieving mother. In 1996, my T cells were just 76, and I got an opportunistic infection. I now had an AIDS diagnosis. Denial was not an option for me anymore. I was ready to fight.

Eventually, it was clear that we were not dying and that the new classes of HIV drugs were working. Patrick and I decided that we needed to do something besides being on disability. Neither one of us wanted to wait too long to start back in the workforce, so he became a truck driver.

As a driver, Patrick had medical and prescription coverage, but the job wasn't perfect. I didn't get to see him very much, since we still lived in California, and his runs took him from Texas to Pennsylvania to throughout the Midwest.

Eventually, he asked if I wanted to move to Indiana to his childhood home. Soon we moved and even bought a house. Five years later, my mother died. I hope it gave her peace of mind to see us growing and living.

It's now just my husband and me. I still have physical challenges, but even with these struggles, I wanted more.

I saw a listing for a two-day-a-week job as a front desk person at our local HIV/AIDS nonprofit. I interviewed for the position and got it. Over four years later, I'm still working there.

I thank all who have helped me through my journey. I look forward to sitting at the front desk for many more years, talking and listening to clients and helping staff.

In 2020, Patrick and I celebrate 34 years together. I'm so grateful. I'll end with a line from the sci-fi movie Galaxy Quest that Pat and I live by: "Never surrender, never give up!"

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