

# In our own words

Dec. 1 marks World AIDS Day, and long-term survivors and activists share firsthand how HIV has changed their lives

Compiled by Floyd Sklaver

**H**aving HIV sucks. There's no other way to put it. I have known that I have had HIV for almost 20 years. And yet during that time, I have rarely spoken about it because of my fears and my shame. Then I was assigned to interview these courageous people, each of whom has been affected by HIV/AIDS for as long as I have or longer.

How I wish I had more space because there were so many other people I wanted to call and stories I wanted to share—for instance, the woman who made herself get clean and sober when she had just one month to live because she refused to die an addict.

HIV/AIDS is frightening, humbling and all-consuming. And yet these extraordinary people have managed to use their experience as an opportunity to expand their capacity to love. Let their own words move and inspire you, and let them give you hope and courage as they have me. But, most importantly, let their stories be a gentle reminder of where we've been and where we must never go again.

*David Eisen was practicing Chinese medicine in a community health center in Boston at the beginning of the crisis.*

I got involved with HIV/AIDS when it was still HTLV3. At that point people were coming in and doing 1,600 milligrams of AZT and still dying in three months. We were seeing emaciated, malnourished people with constant tidal fever. Extreme low energy. Not just the blahs [but] people who couldn't even walk a block. We were seeing a lot of advanced [Kaposi's sarcoma]. It wasn't uncommon for KS lesions to overcome internal organs. And the symptoms were usually in groups. And no one even knew what it was because they were dying before anyone could test them.

*Eisen is director of Portland Alternative Health Center, a program of Central City Concerns.*

*Tabor Porter is a 50-year-old artist and activist who has been diagnosed as HIV-positive for almost 20 years.*

I found out I sero-converted to what was called Gay Related Immune Deficiency in 1985, and luckily I was at the time also just bottoming out on alcohol and drugs. I didn't remember a lot of the '70s—that proves I was there. It was a great time, but we had no idea what was going on.

I remember watching TV and seeing something in New York and San Francisco about GRID. I wasn't feeling very well. I had stopped the drugs and alcohol, but I still wasn't feeling good. I had been living in Alaska [from 1979 to 1982] and so I thought I was safe. I later found out that a lot of airline stewards were unknowingly transmitting the virus [as they traveled around the country] and I slept with a lot of them.

I decided that HIV was just like alcohol and all I could do was deal with it one day at a time. My first doctor was at Kaiser, and she told me that people like me were going to be a huge burden on the medical profession and she was going to keep me comfortable but not to ask for anything miraculous. I was livid. Anger is a good motivator and so I got involved in a lot of activism. I think that kept me alive.

I began taking classes at Project Quest. I considered the classes woo-woo. They were classes in strong feelings, and psychoneu-

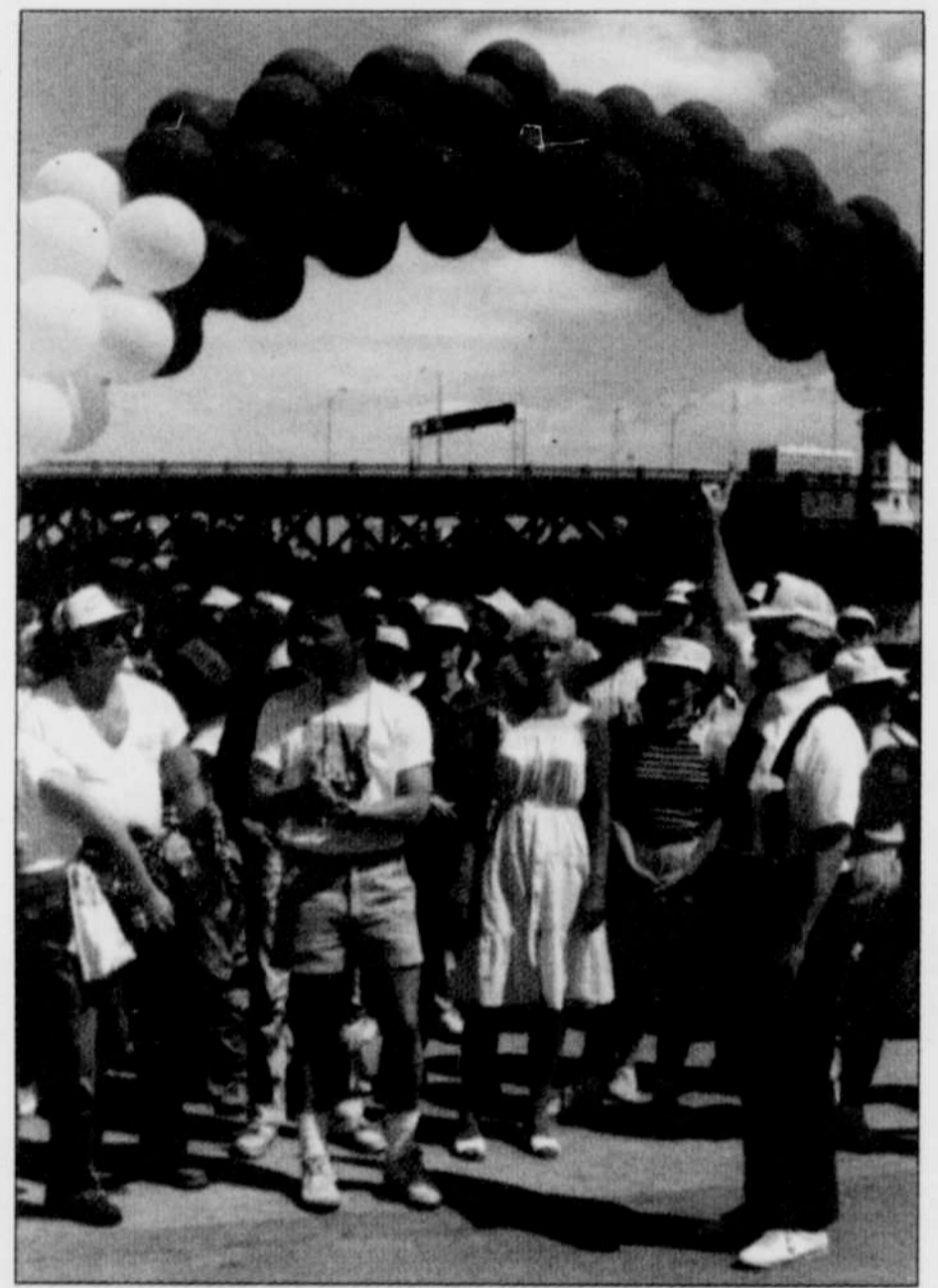
roimmunology—an image class like hypnosis where you go into a guided imagery and see yourself fighting against the HIV and winning—but they kept me alive. I didn't see any other choice. It was mind over matter for just about a year with 16 to 18 T cells until the cocktail came.

*Porter remains an activist today and was recently profiled on KGW-TV when the Oregon Health Plan tried to eliminate coverage for AIDS drugs.*

*Tom Koberstein was executive director of Cascade AIDS Project from 1986 to 1989.*

If you look back to 1986 when there was one treatment [AZT], no federal money for services and prevention as we know it now, no one knew where this was heading. It was largely a white gay man's disease and everybody was dying. So the challenge was to bring some comfort and dignity to people for whom medicine could do nothing.

Some of the heroes of those days were the



Former Portland Mayor Bud Clark (right) joins Tom Koberstein in the 1988 "From All Walks" fund-raiser for Cascade AIDS Project

doctors who early on provided care. Bob Lawrence, Jim Sampson, Doug Biers and Mark Lovelace. Those guys along with a couple of new people in public health saw immediately that this was a disease that had issues that went beyond the disease that needed to be addressed. They were issues of confidentiality, quarantine and how to get the word out so that people reduced their risk. Also, how to identify people who have the disease. Issues like life insurance, health insurance, could people be thrown off of their insurance, employment discrimination.

The doctors worked with the state health division on a task force that brought together physicians, lawyers, insurance professionals, church representatives, public health officials and people with HIV to hammer out policies around these issues. And Oregon really came together early in that respect, whereas a lot of states dissolved into factions and rivalries between competing community-based organizations and public health officials. There was plenty of rage and give-and-take, but Portland really saw the wisdom of unifying around central issues.

The huge number of volunteers from literally all walks of life who came forward always continued to astonish me.

*Koberstein is experiencing health difficulties and living on disability.*



Tabor Porter, who found out in 1985 that he was HIV-positive, shares a moment at home with his mother

PHOTO BY MARTY DAVIS