AIDS 20 Years Later

Remembering the victims, celebrating the survivors

by Timothy Krause • Photos by Marty Davis

Protesters play dead during a demonstration against the state's new HIV names reporting policy

Twenty years have passed since the AIDS pandemic began.

In Oregon, fewer people each year have become infected with HIV. Fewer people have been diagnosed with AIDS. People have been living longer, often healthier and more productive lives, primarily because of sophisticated medications.

These "miracle drugs" have affected not only the day-to-day well-being of people living with HIV but also the very nature of organizations that support them. And the availability of powerful treatment has fostered a serious complacency among the general public.

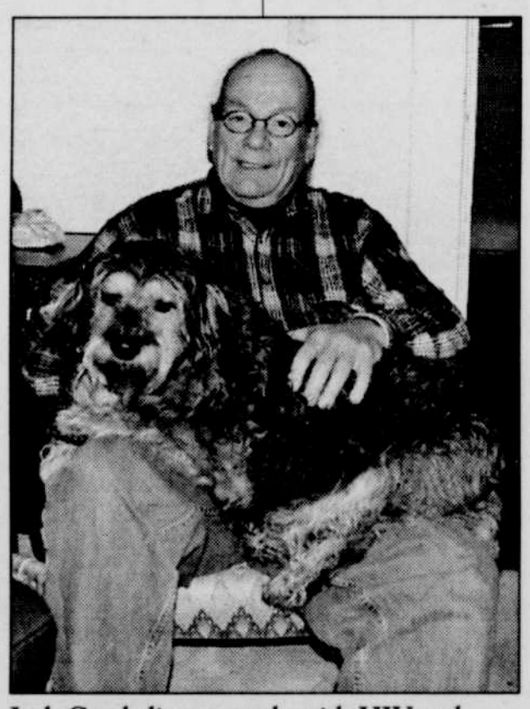
As World AIDS Day approaches Dec. 1, Portland-area caregivers and clients reflect on what's changed through the years, where they are today and what that means for tomorrow.

Thinking back

In 1985, when Jack Cox was diagnosed with HIV, nobody was talking about survivability.

"A lot of people were getting sick and dying," he says. "Nobody knew the right answer."

Cox already had seen his partner test positive and struggle to deal with the news. He thought it would be different if it should happen to him. But he found his own diagnosis to be just as difficult and strange, especially when disclosing his status to loved ones.



Jack Cox believes people with HIV and AIDS began to live longer once they became committed to engaging the disease

That part has not changed, he says. Even now, with all the talk of survivability, the first period after a person's diagnosis still is about coming to terms with mortality.

As time went on, more people with HIV and AIDS began to live longer, and Cox believes this was because of their commitment to engaging the disease. When doctors began believing that one could live with HIV, they began treating it differently. And patients began responding differently.

Today, Cox is a little scared. He watches friends who have been through an assortment of medications start to develop a wide range of complications.

And changes in public health policy, such as Oregon's recent implementation of HIV names reporting, have raised significant privacy issues. "There's a general fear about people with illnesses and with HIV in particular," Cox believes.

Taking responsibility

Dan Walz of Vancouver, Wash., who has been HIV-positive for 13 years, believes personal growth has contributed to his overall well-being. "I had to realize how important it was to take care of myself," he says.

But drug resistance issues and intolerable side effects led to a whole new set of health problems, so Walz changed regimens several times. He still works, volunteers and leads an otherwise active life, but he indicates his most effective treatment has not come in the form of pills.

"I really started doing a lot with alternative therapies, acupuncture, massage. Of all the things I've done for myself, alternative therapies were the best," he states, explaining they help minimize physical side effects and maximize the immune system.

Feeling better also has helped him take a longer-term look at his life. He says: "Before, it was like, I only have this short period of time, so looking forward to my future didn't make a difference. Now, it's like, I'm going to be around, and I need to plan for my future."

Lifelong struggle

Living longer with HIV also means rethinking relationships. Dan Bueling became infected by his partner shortly after moving to Portland from rural Montana in 1987.

His partner didn't want to address HIV and safer sex, and Bueling lacked the confidence to force the issue at the risk of losing the man he loved. Avoidance became an ongoing part of their relationship, which ended some three years later.

In 2000, he fell in love with a man who is HIV-negative, and life turned another corner. Bueling found himself leaving Portland—and his HIV medication—behind.

"I wanted to offer him and us the possibility of a long future together and felt I couldn't because I was damaged goods," he reveals. "It may be part of the reason I went off meds. I wanted to feel more like I was HIV-negative and didn't want my HIV to encroach on us."

With the support of his partner, Bueling has decided to resume treatment. However, he faces new challenges because the treatment that was so successful through the years has left him with physical complications that make it difficult for his body to accommodate other medications.

Yet, he maintains a positive outlook for change, both in his personal situation and in the larger community.

"HIV-positive people are in a lifelong struggle to control the impact HIV is going to have on their lives," Bueling observes. "Besides limited attention to physical needs, many are on their own to deal with psychological and spiritual needs that HIV often magnifies in their lives. After 20 years of fighting HIV, if we really care, this has to change."

Providing alternatives

Graham Harriman has been HIV-positive for 12 years and has worked for many years with long-term survivors and the newly diagnosed as a mental health therapist at Project Quest.

"For people who are newly positive, this is about trying to figure out what does it mean for my health? What does it mean that I'm positive?" says Harriman, who suggests social support is one of the biggest predictors of long-term survival for people with HIV. "A lot of people who have been positive for a long time will say you don't have to worry, but you do."

For himself, Harriman chooses to combine modern science with holistic activities. He believes patients need to be proactive with their doctors.

"I see HIV disease having changed the doctor-patient relationship," he says, noting how clients often go to their physicians with information in hand, asking to be put on or taken off a particular treatment. "It's incredibly important because you can't always be sure that your doctor will stay up to speed."

> *"HIV-positive people are in a lifelong struggle to control the impact HIV is going to have on their lives"*
> —Dan Bueling

Ron Robertson, an AIDS advocate diagnosed with HIV in 1996, agrees. He adds: "Most people won't argue with their doctors, but you can't rely on your doctor to know everything. And because they don't know, they are willing to take risks."

Still risky

John is a single gay man who found out he was HIV-positive in 1988.

"It was embarrassing and awful," he says, asking to remain anonymous. "The meds made me sick, and the care was very hands-off.