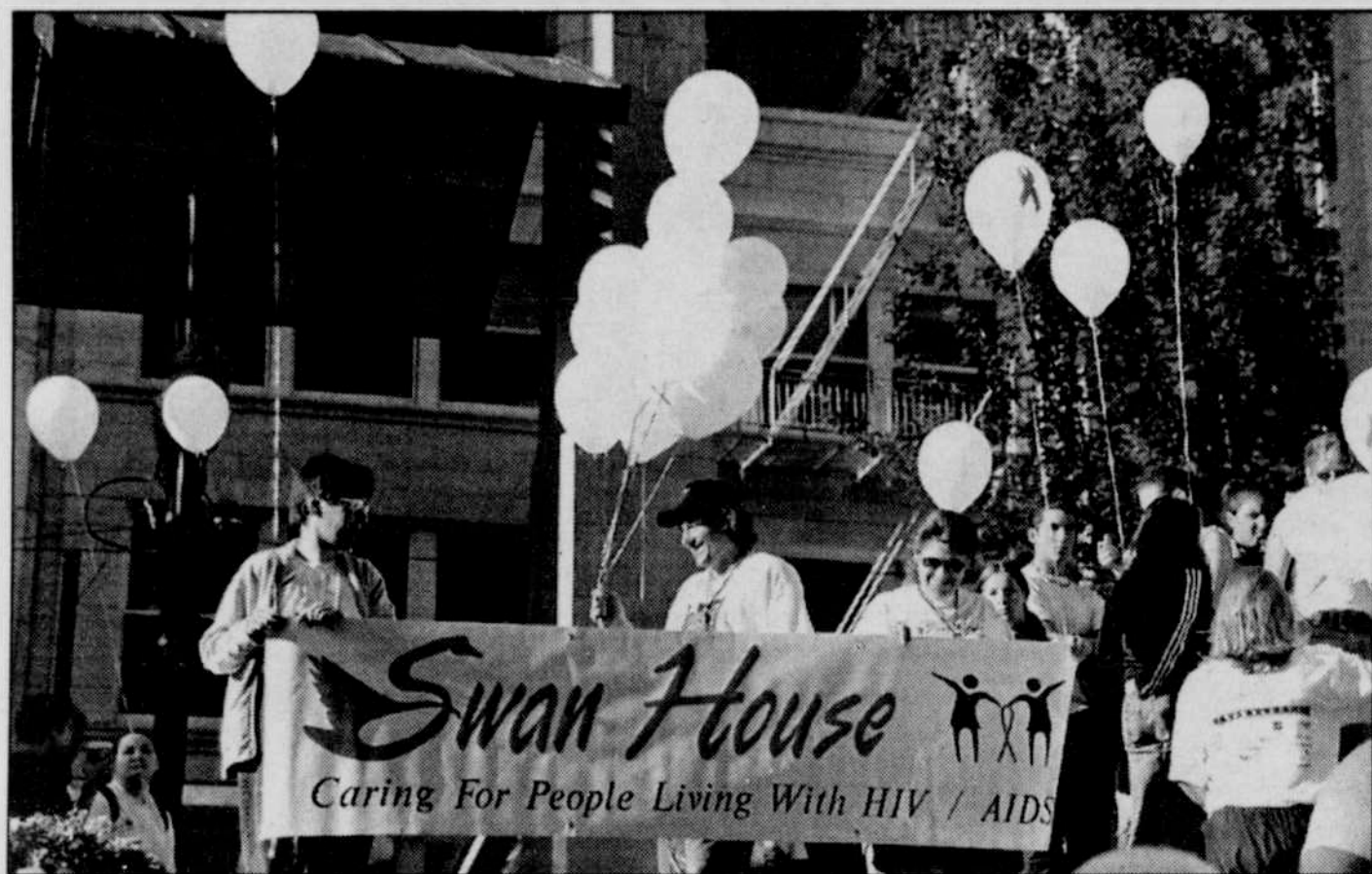


AIDS 20 Years Later



Swan House, a nonprofit adult foster care home in Milwaukie, serves HIV-positive people with low incomes

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For better or worse

Pamela Alvey has been in the HIV field since she was 17 years old. Last year, she opened Swan House, a nonprofit adult foster care home in Milwaukie for HIV-positive people with low incomes. As a nurse, Alvey has witnessed firsthand the progress that has occurred in treatment options, and she wanted to create a place for patients who needed help but were still somewhat independent.

"Until protease inhibitors came out, everybody just died—and died pretty quickly," she remembers. "Today, people who were at death's door are still alive. It wasn't a cure, but it felt like one."

These new drugs came with their own side effects, however, such as peripheral neuropathy. And these were side effects of the medication—not HIV or AIDS—in addition to things like nausea and fatigue.

For those who don't tolerate these medications well, the side effects can be debilitating to the point of not being able to work or carry out daily activities. In turn, when drugs make patients feel ill, it affects how well they adhere to a regimen, some of which involve dozens of pills each day.

Despite recent drug combinations with simplified dosage, adherence remains a serious issue. If a drug's course of therapy is not strictly maintained, it's possible for the virus to mutate, becoming resistant to the treatment. The virus then might carry with it resistance to a whole class of drugs, even eliminating future alternative treatments.

"Until protease inhibitors came out, everybody just died—and died pretty quickly. Today, people who were at death's door are still alive. It wasn't a cure, but it felt like one."

—Pamela Alvey

Local research

Some drug regimen changes are being studied by a Portland-based nonprofit.

The Research and Education Group operates as part of a national network of sites looking into HIV management issues. Support coordinator Steven Pierson says the organization initially offered studies as a way to provide clients an advance opportunity to try new therapies, especially those offering immediate treatment for opportunistic infections. Today, researchers assess different types of treatment strategies for managing HIV during the long term.

One such study just getting under way will follow two groups. The first will continue to use

existing treatments, changing regimens as necessary, according to current practices. The second will follow a "cycling" method in which patients take medication only when T-cell counts drop below a certain level. Although the dangers of repeatedly dropping to low T-cell counts are not known, cycling has the advantages of reducing toxicity, costing less and potentially keeping open long-term drug options.

Feminine perspective

"When I first started, most women were well and working or sick and wasting. Then, all of a sudden, we're at this place where they're not either. They're not well, and they're not sick and wasting. They're in limbo," says

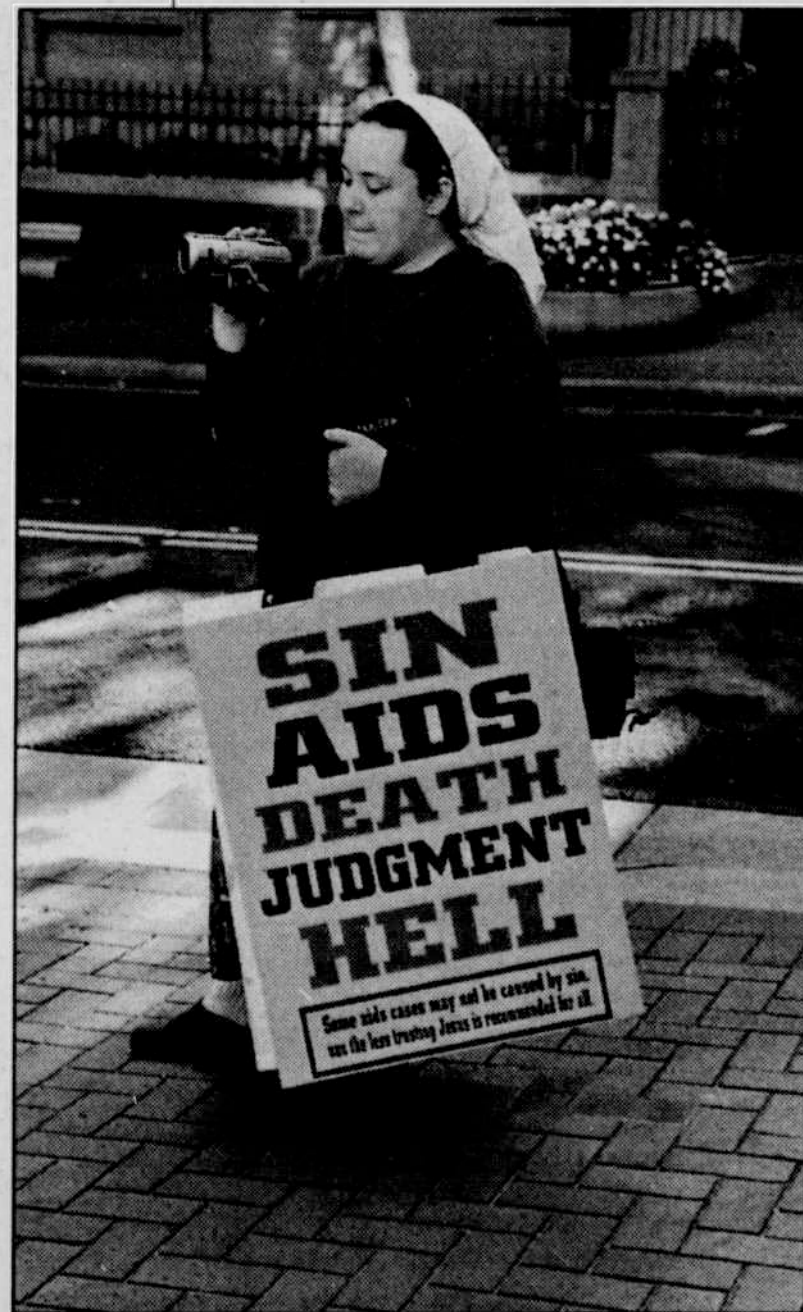
Lisa Gates, a mental health provider and outreach specialist with Women's Intercommunity AIDS Resource.

Like their positive brothers, the needs of women with HIV now center less on opportunistic infections than the side effects of what they call their "toxic meds." In fact, Gates says clients tend to identify drugs more by how they make them feel than by their names. For some, she adds, "This boils down to quality of life vs. quantity of life."

The organization has seen its clientele change significantly, too. Most notable is the rise in number of young women, women of color and trans individuals.

However, one support group's advice to the newly diagnosed is universal: Don't screw up your credit, because you're going to have to pay it back. Gates remarks, "Essentially, they're saying life is going to go on." □

TIMOTHY KRAUSE is a writer and editor in Portland.



Even today, ignorance remains the most harmful risk factor in fighting AIDS

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