

Oregon is home to 5,200 people with HIV/AIDS, many of whom cannot afford the extremely expensive medications that can increase the quality of and prolong their lives.

The federal government, through the AIDS Drug Assistance Program, provides financial help to states to give low-income people better access to these medications. In Oregon, this money is disbursed by the state-run program CAREAssist.

CAREAssist now is being challenged by a budget shortfall, as the funds formerly provided by ADAP have been cut. In order to stay afloat, the state program has proposed expelling 300 clients, potentially leaving 300 people suddenly without access to their medications.

But those affected by the shortfall might have another option—to be rescued by a new organization called the AIDS Service Access and Accountability Coalition. Headed by facilitating director Steve Carroll, it aims to provide financial help to people with HIV who can't afford their medications, including current and former clients of CAREAssist.

The grassroots organization was formed in response to the deplorable ways in which CAREAssist proposed to manage its financial troubles. The consequences of cutting someone with HIV/AIDS off from access to medications are severe. "Obviously, this was an appalling and unprecedented concept," says Carroll, noting that never before had a state ADAP suggested removing people from an active program.

But a group of concerned citizens wouldn't stand for this. "The result was a gathering of individuals to discuss and confront the absurd ideas coming out of these offices," Carroll says. The emerging organization saw its mission as twofold: to demand accountability from the state and to provide access to medications for those in need, especially those cut off from CAREAssist funding.

Toward its first goal, the coalition began investigating information disclosed by the state relating to ADAP funding. However, it has been hampered by the dearth of statistics released by CAREAssist.

"The state, by holding back critical information, has hindered the collective ability of this community to mitigate circumstances," Carroll says. "This has created a dangerous and life-threatening situation for HIV/AIDS patients."

Toward its second goal, the coalition designed a medication aid program and has applied to various foundations for funding. However, Carroll says, "We are still waiting for approval and the grants funds necessary to implement our financial assistance plan."

The proposed aid plan has three major parts. Firstly, the coalition plans to provide supplemental assistance to CAREAssist clients.

## GRASSROOT GOALS

Coalition pushes for AIDS drug assistance by Caitlin Smith



Fred Schaich (left) and Steve Carroll recently returned from Washington, D.C., where they lobbied for HIV/AIDS funding

Beginning in January 2003, CAREAssist plans to require clients to pay a monthly fee. But making this payment is difficult for people in the program. As Carroll comments, "It is not hard to imagine people living at 100 percent to 325 percent of the federal poverty level as having a couple of bad months financially, but that shouldn't mean they should be denied drug treatment for AIDS."

Secondly, the coalition plans to help people on the CAREAssist waiting list until a space opens for them. A total of 23 people are on the waiting list, with more applications under review.

Lastly, the coalition wants to offer assistance without rigid income restrictions, by assessing each individual application for need. CAREAssist only provides aid for people who earn less than 325 percent of the federal poverty level (\$28,795 a year), and new clients can make no more than 200 percent. This is a severe restriction, considering AIDS drug treatments can cost up to \$20,000 a year.

According to the coalition, one of the main flaws of CAREAssist is that it didn't communicate well with the HIV/AIDS community. Carroll stresses the importance of reaching out to people in need who might not know where they can go for help. He thinks coalition volunteers

can do this much more effectively than can CAREAssist.

The coalition "consists, at this time, of people living with HIV/AIDS helping others of our community living with HIV/AIDS," Carroll says. "We have an entirely different network to reach people because we are those people."

Carroll also stresses that, despite his intense involvement in the coalition, helping people live with HIV/AIDS is a community effort: "It is essential for everyone to understand that this is a coalition of individuals and service-related organizations. We depend on each other to make the decisions, and we pass information freely among our group to all and any who want to be involved. We like to approach our position in the community as one that hears and acts upon the suggestion of our community."

The spirit of the coalition is in contrast to the experience of its members with the Oregon Health Division, which is guilty of "concealing information and/or misdirecting [CAREAssist] until a crisis occurs," another coalition member says. "It is an uphill struggle trying to enter into credible relationships with an agency whose leadership is committed to obstructionist positions or even just having underlying reluctance to engage in open conversation."

When asked about the coalition's criticism

that CAREAssist is poorly run, a representative of spokeswoman Bonnie Widerburg simply said that changes were being made to allow the program to operate for the rest of the grant year. Furthermore, it "is continuing to meet with our advisory committee to review the implementation process and to develop strategies to address issues [that] will arise if adequate funding is not obtained for the next grant year."

The Department of Human Services points out that the costs of HIV treatment and health insurance have grown significantly, while federal funding has not. "In addition," state epidemiologist Mel Kohn said in a recent press release, "Oregon's program has had a dramatic increase in enrollment, created by the state's economic downturn and loss of jobs."

Working with Carroll at the coalition is Fred Schaich, founder of the International Foundation for Alternative Research in AIDS, a Florida-based organization with a strong presence in Oregon that aims to "foster new paradigms and integrative treatment concepts and conduct comprehensive treatment education programs in HIV/AIDS." The two men recently returned from Washington, D.C., where they joined about 30 people from other states, members of the AIDS Treatment Activist Coalition, lobbying for an additional \$162 million in funding for people with HIV/AIDS.

Securing more funding is especially challenging now, Schaich notes, because "with the 'war mentality' and consequential 'flat funding mentality' circulating...it will be most difficult to expect Congress to appropriate any or all of the \$162 million needed to save ADAP."

Like Carroll, Schaich says that as long as he is well, he puts most of his time into activism and HIV/AIDS treatment education. "I am a survivor. I survive and thrive because I participate in my health care.... I'm not lucky for having survived AIDS since 1980, I just work hard at it."

The time and energy Schaich puts into the foundation and the coalition come from firsthand knowledge of what it's like to live with HIV/AIDS. "I respect and admire anyone who has developed the coping skills to live with this lifelong disease, its stigmas, opportunistic infections/diseases and treatments."

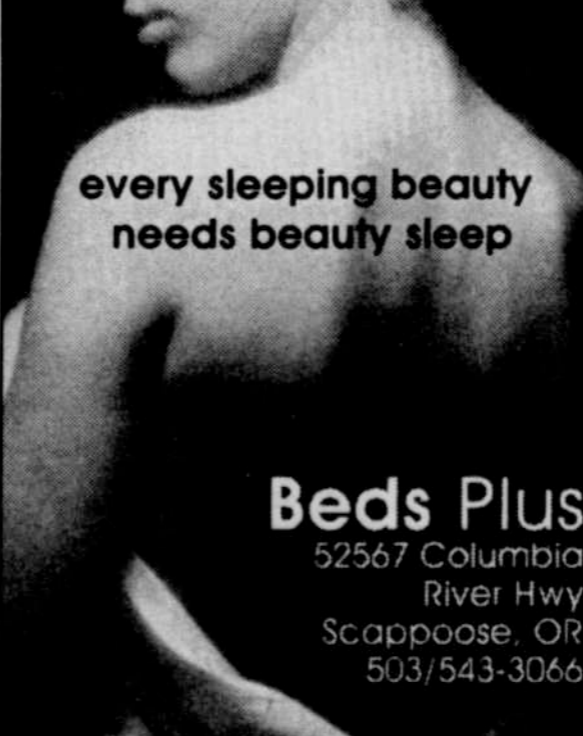
But Schaich vehemently encourages people to take control of their own health care. "Why don't others become at least interested in what it is that may save their lives? I just take it a step further and like to help others with treatment options and concepts that I find useful."

"Remember," Schaich adds, "it's not easy to live with HIV/AIDS, but it is possible!"

For more information contact the AIDS SERVICE ACCESS AND ACCOUNTABILITY COALITION at 503-288-6582 or asaac@atbi.com.

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