

Jan. 13 was a day of wrath, a day of mourning for R. David Meador. That was when he received a letter from the state of Oregon informing him that his HIV drug assistance benefits would end in two weeks. The state's Medically Needy program had run out of money.

"All hell broke loose," Meador recalls, remembering how he was "cussing, cursing, crying, shouting and throwing things."

The form letter had cut a critical lifeline for Meador and many low-income Oregonians with HIV and AIDS—including a large number of gay men—whose lives depend upon prescription medication.

After first contacting his county caseworker, Meador jumped on the phone to call Salem legislators. He wanted to put a face on the impersonal numbers of an unwieldy state budget that led to the program's demise. The few legislative aides that responded were sympathetic, but not helpful.

"Government should not control people's lives, but it should help to preserve life. You just don't go around killing people," Meador says, "especially when the government sets the precedent to start paying for the drugs in the first place."

Meador, a 38-year-old gay man, lives with his partner in Northeast Portland. He was diagnosed with HIV in 1989 and AIDS in 1993. He remembers when newly developed drugs, such as anti-retrovirals, changed his existence from one of dying of AIDS to that of living with HIV. Meador was one of many patients that benefited from these drug regimens with the assistance of state and federal health funding, such as the Medically Needy program of the Oregon Department of Human Services.

"Now, the threat of being ripped off them is a nightmare," he shares.

Meador has been in the process of filling out about a dozen different applications for patient assistance programs available through individual pharmaceutical companies that assist people who can't afford to buy the drugs they need. Each program has its own paperwork to complete and conditions to meet.

"It's all-consuming," he notes. "I get up, fill out forms, go to bed, fill out forms."

But flipping through this pile of paperwork may provide his only hope for maintaining his health.

Meador's regular regimen of 13 meds includes not only the life-saving anti-retrovirals but also treatments such as antifungals and antibiotics that allow him to enjoy a reasonably functional life. Together, the monthly prescriptions cost \$2,000.

Even if Meador is accepted onto all of the necessary patient assistance programs, making ends meet won't be easy. These programs commonly require a user co-payment. Although nominal, the co-payment eats into the \$900 a month he receives from Social Security, which is his sole means of support. That leaves few resources for other necessities, such as food, rent, clothing and frequent trips to his case manager, doctor and pharmacy.

"You take it one day at a time," he says, uncertain but still hopeful, knowing it won't be long until he runs out of medication. "As long as I can get the anti-retrovirals..."

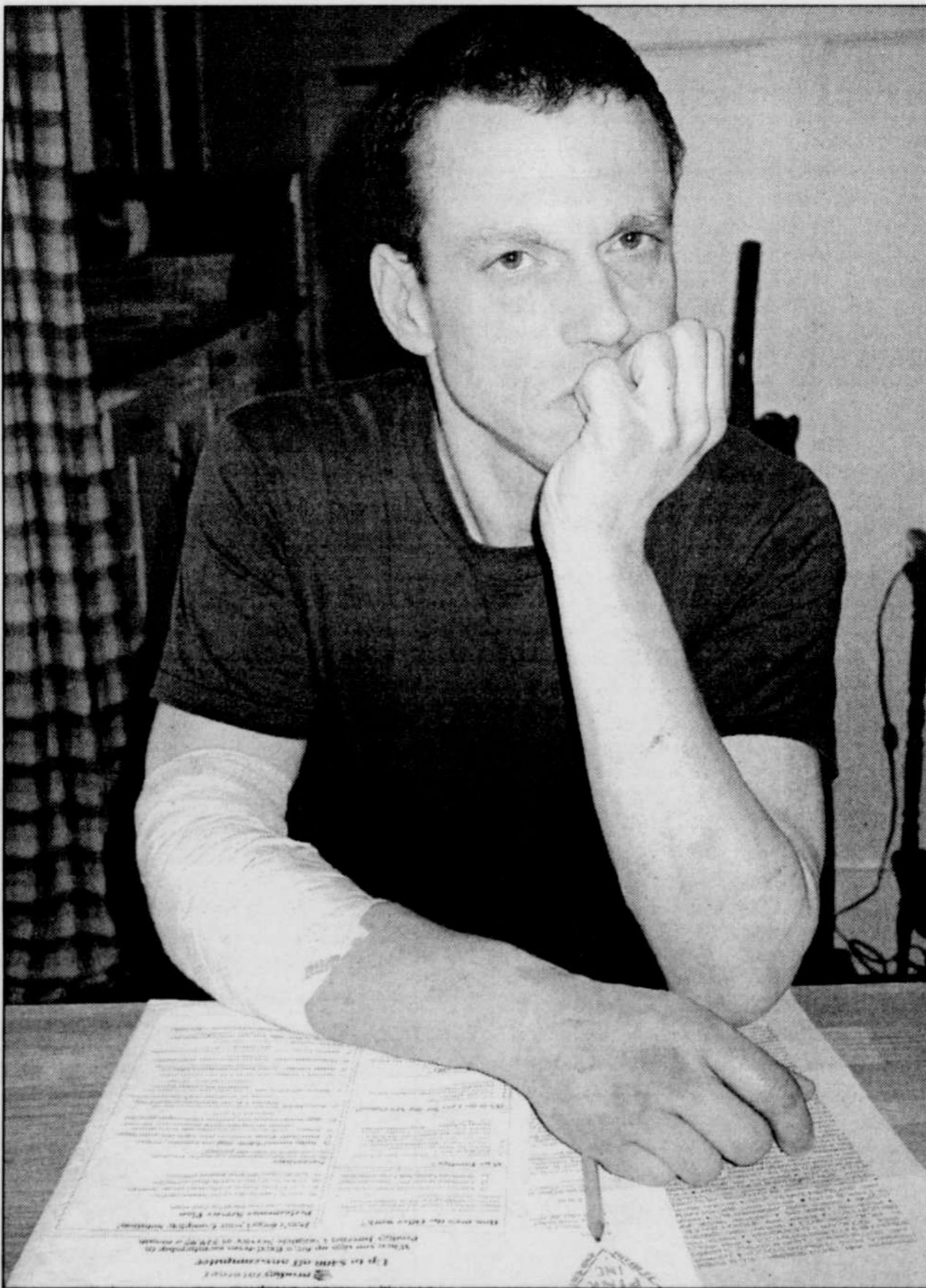
Meador continues to look at other sources of support, too, but the funding crisis is so widespread that even the AIDS Drug Assistance Program, funded through federal Ryan White Comprehensive AIDS Resources Emergency Act Title I monies, is now an unlikely source of assistance. Like the unbalanced economy, too much demand is chasing too few dollars.

"I blame social complacency," Meador states. Everybody was experiencing "smooth economic sailing with a 'me, me, me' attitude. There was

A STATE OF RECKONING

Feeling abandoned by legislators and fighting complacency, Oregonians living with HIV make grassroots efforts to seek accountability

by Timothy Krause



Ever since the state cut off his HIV drug benefits, R. David Meador has been busy filling out applications for patient assistance programs

no feeling that the floor could cave in. Now that it did, no one knows where to turn."

While Meador understands the basic economics—no cash, no programs—he argues that legislators could have prioritized more effective-

ly and provided better information to voters about funding options, such as the recent Ballot Measure 28.

"I think government—and society as a whole—has forgotten a sense of community and

sense of responsibility toward community," Meador remarks. The government has "a huge responsibility to spend money wisely. They may have to stop worrying about re-election and be bold enough to propose a tax increase."

The media also focused on school closures, he says, making Measure 28 look like an education initiative. Journalists neither illustrated the life-and-death nature of the measure's impact nor explored the complex issues tied to the changes that have been implemented as a result of a bankrupt state.

But as nonprofit organizations and government agencies alike scramble for ways to maintain services to the HIV community, Meador hopes they'll keep in mind their ultimate mission of serving individuals and worry less about maintaining the status quo.

"No one is focusing on the consumer's need," he says. "Whatever happened to the client determining what is right for them?"

Common at the onslaught of AIDS, this self-determined, individual-oriented grassroots approach is on the rise again in Portland with the January formation of AIDS Action Project Northwest.

In a setting more akin to a Sunday afternoon football game, four gay HIV-positive guys sit around a living room off Northeast Broadway, determined to give consumers a vehicle for self-advocacy. They are laying the groundwork for this new statewide nonprofit organization that will keep consumers of HIV/AIDS services informed and encourage them to provide input, direction and monitoring of services and funding in Oregon.

AAPNW grew out of two different local efforts. One was interested more in activism, while the other sought quality assurance. As the state's budget crisis grew, participants began to close in on similar goals of accountability, seeking to empower individual consumers as watchdogs of service providers that sometimes are thought to put organizational needs ahead of client well-being.

Board member Eric Landon compares the past year with a "perfect storm," describing how Oregon's formerly compartmentalized HIV services were becoming more integrated into the state's health care system just as the system collapsed. He says, "Everyone was running for cover asking, where are we going to get our medications?"

Then, during the course of the year, as the state began its roller-coaster ride of cuts, refunding, more cuts and more refunding, public doubt grew for the need of Measure 28 to maintain vital services. While funding cuts have not been limited to HIV programs, AAPNW organizers say the impact is greater than for other diseases because drug costs are so much higher.

There already was some truth to the joke that twists the prevention motto of "Get tested, get treated" into a more realistic "Get tested, get in line." Now, these community leaders ask what kind of incentive there is even to get tested if there's no affordable treatment.

Fellow board member Fred Schaich tells how the state's health care plan for low-income people living with HIV is dependent upon a sustainable government with accountability in place. "Once that system begins to fall apart," he comments, "it's like a huge house of cards that collapses."

Even while AAPNW continues to organize as a formal nonprofit, the group already has held a meeting to initiate a dialogue among consumers and stakeholders.

"Everybody talks about a stakeholder in these scenarios, and a lot of times, they're actually referring to the institutions around the stakeholders," says Steve Carroll, also on the board of directors. "But we were going to people