Drug Bust

One in three HIVers depends on ADAP for meds. But sky-high prices, exploding enrollment and new national priorities are bankrupting the program. Welcome to post-9/11 AIDS.

February 1, 2002 By Lawrence Goodman

In November 2000, HIVer Jeff Crafford got word that his federal disability benefits were going up by $45. Good news, right? Of course not. The increase bumped up his income just above the cutoff level for Medicaid. Suddenly, Crafford, 35, found himself without health insurance. Not to panic -- this was the very type of bind that the AIDS Drug Assistance Program, or ADAP, is intended to fix. ADAP is a unique government program that covers the cost of AIDS drugs for HIVers who make too much money to be eligible for Medicaid and too little to afford private insurance. But when Crafford, who lives near Little Rock, went to apply for ADAP, he discovered that he was out of luck. Arkansas' ADAP program was closed to new enrollment. His name would go at the end of a long waiting list.

Here Crafford's tale turns Dickensian. In order to scrape together enough money to pay for the HIV regimen that was keeping him healthy, Crafford resorted to extreme measures -- fishing recyclable cans and bottles out of garbage bins to redeem at grocery stores for nickels, eating nothing but $1 microwaveable meals. But even that wasn't enough -- for five months he had to take an unwanted drug holiday. Within three months, he came down with a severe case of cryptococcal meningitis and ended up in the hospital. "I felt like I just wanted to go ahead and die," he recalls. "I was beyond desperate."

Crafford is now receiving assistance from a charitable fund set up by the drug industry. But this lifesaver covers far fewer meds than ADAP -- and skimps on antibiotics. "If I get another opportunistic infection, I don't know what I'm going to do," he says. "I'll just have to do without something -- like food." He is not joking.

Literally scores of PWAs are finding Crawford's tale more than a cautionary one now that chronically cash-strapped ADAP faces its worst-ever budget crisis. This year not only Arkansas but eight other states have closed their ADAPs to new enrollees. As a result, activists estimate that some 1,500 HIVers are languishing on waiting lists. Thousands more may join them now that Congress has failed to boost funding as needed.

But even those already enrolled in ADAP -- a total of 125,000 HIVers, or one in every three on treatment -- have reason to lose sleep. There is a growing fear among activists that some states will subject their ADAPs to Draconian cuts. Government officials may decide that certain drugs --

human growth hormone, for example, the priciest AIDS med -- are not “essential” and drop them from the program. The worst-case scenario has other states following Michigan’s lead by offering a reduced selection of antiretrovirals as a way of holding down costs -- leaving drug-resistant HIVers out in the cold. “This is a very dire situation,” says Arnie Doyle, a top official at the National Alliance of States and Territorial AIDS Directors. “You have treatments available that can prolong life, and a number of people may soon find themselves unable to get them.”

There has always been a crisis aspect to ADAP. It was launched in 1987 when AZT hit the market and activists demanded that Congress do something exceptional to ensure that HIVers without health insurance could afford the long-awaited first treatment. And Congress did. But while two-thirds of the money came from the feds, a third was ponied up by the states. In turn, each state got wide latitude to implement its own program -- a logistical nightmare for advocates and lobbyists working to change ADAP policies.

Until 1996 funding for ADAP was relatively modest, but when the protease revolution came along, introducing $15,000-a-year triple-drug combos as standard of care, enrollment and costs surged. The program’s beneficiaries typically had an annual income that was less than the annual price of the cocktail. Some were among the working poor who did not got health benefits at work, yet made too much money to be eligible for Medicaid. Others, such as Jeff Crafford, were jobless but received federal disability payments that also restricted them from Medicaid.

At first, state and federal legislators responded to the increased demand for ADAP services by funding the program generously. Between 1996 and 1999, ADAP’s total budget went from $188 million to $665 million, a 350 percent increase. But by 2000, amid cries of “AIDS exceptionalism” -- special treatment for this one disease -- and a general dimming of AIDS as a cause, Congress’ enthusiasm had waned. “The thinking was ’We gave them money last year and the year before. Now there are other needs out there,’” says one state ADAP official. So that year the ADAP Working Group (AWG), a unique coalition of activists and drug company reps, called for a $130 million hike in ADAP funding. Congress approved only $61 million. Last year, AWG predicted the program would require a $120 million increase. Then came 9/11, the official recession and a radical shift in priorities inside the Beltway. Says William Arnold, AWG chairperson, of recent lobbying efforts: “You start talking about the AIDS problem in the U.S. and it becomes, ’What about our boys in Afghanistan getting shot up?’” In December, Congress passed a $50 million increase in ADAP funding -- once again, less than half what AWG deemed necessary.

The current shortfall will only intensify the crisis triggered by last year’s funding gap, according to advocates. “It’s a snowball effect,” says Ryan Clary, a community organizer at Project Inform, an AWG member. The writing’s on the wall -- longer waiting lists, shorter drug formularies. “Even with $60 million in new funding, the existing waiting lists would grow,” says James Driscoll, the federal affairs advisor for the National AIDS Treatment Advocacy Project, another AWG member. Driscoll warns that seven more states may cap enrollment.

The Florida program -- the nation’s third largest with 15,000 enrolled -- may be in the greatest jeopardy. Tom Liberti, chief of the Bureau for HIV/AIDS at the Florida Department of Health, reports

that his state's ADAP will likely be hit with an unmet need of $6 million in 2002. Closing the program to new enrollment, which would create a waiting list of several hundred within six months, is a distinct possibility. "We're very, very concerned," he says. "We've not had to close the program yet, but I can't tell you what's going to happen by the end of March."

Worse troubles loom for ADAP in the near future. Several major advances in AIDS treatment, such as the anti-HIV fusion inhibitor T-20 and the hepatitis C med Pegasus, may soon hit the market. Given the current budget trauma, advocates are at a loss as to how they will persuade all 50 states to add these lifesaving drugs with their hefty price tags to the ADAP formulary.

Yet such new therapies will be in high demand with ADAP enrollees -- hep C, for example, is a serious co-infection that disproportionately strikes African-American HIVers, many of whom depend on ADAP. Driscoll says that California alone would need an additional $145 million from the feds to add Pegasus and the few other hep C drugs to ADAP's roster. "So right now, that's not even on the table," he says. "And minorities are going to suffer the most."

Welcome to hard times. As the ADAP Working Group contemplates bankrupt ADAPs, the uneasy but effective symbiosis between AIDS activists and the drug companies is increasingly strained. Some advocates are calling for a tactical turnaround -- time to target Big Pharma more aggressively. Antiretrovirals alone consume more than 80 percent of ADAP's budget. These activists believe that begging the government for more money no longer suffices; the drug industry must bite the bullet and curb prices -- at least until ADAP's budget debacle passes. "If prices continue to escalate," says Anne Donnelly, Project Inform's public policy director, "it's a recipe for ADAP's failure."

But pressuring pharma to lower drug prices has never been a leading AWG strategy -- in this strange-bedfellows union, it's tough to hold your partner's feet to the fire while keeping them in bed with you. Still, the community groups represented by the activists who sit cheek by jowl with drug company officials at AWG meetings are among the most vocal opponents of drug profiteering. While critics grumble that AWG skirts the pricing issue, AWG advocates counter that the rising cost of AIDS drugs accounts for only a third of the increase in ADAP expenditures. The main cause of the coming ADAP bust is due to exploding enrollment and -- the good news -- the longer life expectancy of HIVers. "Even if you cut the price of every single drug covered by ADAP 33 percent, the program would still be in trouble," William Arnold says.

Under current federal law, pharmaceutical companies can increase prices they charge ADAPs by no more than the cost of inflation. Arnold worries that asking Pharma to reduce its profit margins even further could make it averse to the financial risks entailed in developing new drugs -- which is the industry's own argument. "As an AIDS advocate, I don't have the luxury of beating up on the drug companies," Arnold says, adding, "I feel that the drug pricing ADAP gets from the industry is quite attractive."

But some experts and activists -- and even several of the state officials who run ADAPs -- see a shift to a price-lowering offensive as the only way to keep ADAP from bottoming out. Peter Arno,

professor at Albert Einstein College of Medicine in Bronx, New York, and author of *Against the Odds: The Story of AIDS Drug Development, Politics and Profit*, says: “The strategy of the AWG is bad public policy. The public interest would be better served by working to bring down prices than by going to Congress every year, hat in hand, to ask for more money to subsidize the profits of the drug companies.”

PWA Linda Grinberg, a member of the Fair Pricing Coalition, a group of activists and ADAP officials, says that Pharma may be willing to lower its prices in limited cases, but it’s unlikely to take any drastic measures -- such as enacting an across-the-board freeze on prices. Grinberg doesn’t see the Fair Pricing Coalition taking a more aggressive stance. “You can ask for the moon and the stars, but is it reasonable?” she asks. “I’m not sure how much leverage we really have.”

There is no happy ending to this chapter -- possibly the last -- of the ADAP story. With AWG unwilling or unable to win price cuts, federal funds and enrollment both largely capped, and demand rising, more and more HIVers will face a Sophie’s Choice: between meds and food -- or, at least, quality of life. Although interim measures have been proposed by outsiders -- that ADAPs form joint purchasing agreements to leverage better drug prices, say, or that they use funds to buy health-insurance policies instead of meds -- such stopgap measures have found little favor. For now, activists have decided to keep on keeping on -- a little pressure on industry here, a little lobbying of Congress there. The only other option, it seems, would be for the feds to ensure that the working poor and disabled HIVers on ADAP were able to afford health coverage. As one state ADAP official puts it, “Most of us would gladly see this program go away if we could get universal health insurance.” But even before 9/11 no one was holding their breath for that one.

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