# Sleeping With the Enemy

As sky-high drug prices bankrupt ADAPs, AIDS advocates and pharmaceutical reps make strange bedfellows

June 1, 1998 By Ken Silverstein

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November 2 was a jubilee for the ADAP Working Group (AWG), a coalition of AIDS advocacy groups and drug companies that fights to increase funding for a federal program that last year allowed states to give free meds to some 80,000 under- and uninsured PWAs. On that day, Congress boosted the AIDS Drug Assistance Program (ADAP) budget to $285 million, nearly double the 1996 allocation. “It was a real feeling of accomplishment,” says Dorothy Keville, the pharmaceutical industry’s cochair of the AWG. “There was a shared feeling of ’Isn’t it great?’” To AIDS advocates, the victory was even sweeter because it had been Newt Gingrich’s House of Representatives that led the parade to expand funding substantially above President Clinton’s request of $167 million. The future of ADAP seemed bright.

Yet for some community reps in the AWG, the triumph left a bitter aftertaste. Just weeks before, following fierce lobbying by the very drug companies that share their AWG table, Congress killed a law that would have dramatically lowered drug prices for numerous health care organizations, including ADAPs. “We were furious at how the drug companies were giving with one hand and taking away with the other,” says Mike Shriver, AWG rep for the National Association of People With AIDS (NAPWA). “It’s still very painful.”

This setback came while many ADAPs, drained by astronomical AIDS drug prices, were capping admissions or rationing meds (see sidebar). Peter Arno, professor of health economics at Einstein Medical College in New York City and coauthor 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 for AIDS drugs than by going to Congress every year, hat in hand, to ask for more money to subsidize the profits of the drug companies.”

Arno’s view reflects a growing debate about the AWG, where reps from such community fixtures as AIDS Action Council, Project Inform, Treatment Action Group, San Francisco AIDS Foundation and NAPWA sit cheek by jowl with officials from Abbott Laboratories, Bristol-Myers Squibb, Glaxo Wellcome, Hoffmann-La Roche (Roche), Merck, Pfizer and other drug giants. While members portray the AWG as a success, some observers wonder if this tactical alliance makes advocates reluctant to challenge the industry on vital issues such as pharmaceutical pricing.

The congressional effort to stretch drug-purchase dollars -- a key aim of a law called the Federal Acquisition Streamlining Act (FASA) -- was buried last year, largely by the pharmaceutical lobby. Originally passed in 1994, FASA would have allowed state and local agencies to pay the same prices as the feds for everything from paper clips to drugs. (Drug companies price on a sliding scale: Big buyers, such as Medicaid and large HMOs, get steep discounts. Retail druggists pay the highest rates, while prices for states, ADAPs and others fall in between.) By most estimates, the program would have saved ADAPs (and many other local health programs) 25 percent to 40 percent on pharmaceuticals. The net result? More drugs for more PWAs.

AIDS advocacy groups were among FASA's most enthusiastic supporters. But a coalition of businesses -- led by the drug industry and the U.S. Chamber of Commerce -- launched a counterattack. "We already offer a wide variety of discounts and rebates," Jeff Trewhitt, spokesperson for the Pharmaceutical Research and Manufacturers of America (PhRMA), says. "There's got to be a cutoff point."

The drug companies initially focused their fire on the Department of Veterans Affairs (VA), which negotiates prices for the 23,000 medications bought by federal agencies. A VA white paper obtained by POZ said, "Passage of [FASA] prompted numerous phone calls and visits from the pharmaceutical industry to the [VA]." The "substance of all the calls and visits was the same," the document said: If the companies had to extend discounts to state and local agencies, they would evade the hit by raising prices for the feds.

In the face of such pressure, Congress imposed an 18-month moratorium on the program while its feasibility was studied. The investigation, completed in spring 1997, was inconclusive, recommending that FASA move forward slowly. But last May, Sen. Kit Bond, a Missouri Republican, slipped an amendment to repeal FASA into a disaster-relief bill. Within six weeks, Bond's campaign had received checks for $1,000 from political action committees (PACs) affiliated with Bristol-Myers Squibb, Merck and Pfizer. FASA won a reprieve when the House forced a compromise.

Yet the drug companies and their allies weren't through. Rep. Ann Northrup, a Kentucky Republican whose campaign, like Bond's, had been well padded by the drug barons, tacked an identical amendment onto the postal appropriations bill. That measure was passed and signed into law by Clinton last October. An amendment by three Democratic representatives, supported by the White House, would have saved FASA for drugs needed to treat "life-threatening conditions" such as AIDS and cancer. The amendment was killed by a full House vote.

The source of the drug lobby's vaunted power in Washington is no mystery. During the 1995-1996 election cycle, pharmaceutical companies ponied up $6.1 million in "soft money" (contributions made to political parties). Drug industry PACs tossed in another $3.2 million in campaign money. That buys a lot of calling cards in the capital, and the industry magnifies its beltway might with squadrons of high-powered lobbyists. In 1996, industry reps shelled out $37 million to lobby the federal government. Among the big-name shops retained by PhRMA are Barbour, Griffith & Rogers, whose partners include former Republican National Committee chief Haley Barbour; and Akin, Gump, Strauss, Hauer & Feld, home to Vernon Jordan, Clinton's golfing pal and the would-be

benefactor of Monica Lewinsky.

FASA is hardly the only example of drug companies flexing their muscle to battle benefits for PWAs. In 1995, the industry tried but failed to dismantle a federal program that discounts drug prices for public agencies that serve low-income people. “The drug companies have hammered away against many legislative efforts to expand access and lower prices,” says Ted Slafsky, a lobbyist with the Public Hospital Pharmacy Coalition.

All of this makes the AWG collaboration troubling to some activists. The fact that most of the advocacy groups take industry handouts renders the alliance even more controversial. Stephen LeBlanc of ACT UP/Golden Gate, which refuses drug company money, says he was stunned when he first saw the AWG membership list. Recalling his days as an organizer with the Massachusetts Public Interest Research Group, a Ralph Nader-affiliated consumer organization, he comments, “If people had found out we were working so closely with chemical manufacturers -- and being funded by them -- it would have destroyed our credibility.” In LeBlanc’s view, advocates can’t help but be compromised by working so closely with drug companies. “There’s no quid pro quo, but there’s no critical distance between advocates and drug companies. The AIDS community needs truly independent voices.”

But community members defend the AWG coalition. “Working with the companies has resulted in far more money for the ADAPs, even if they’re in it for self-serving reasons,” says Martin Delaney of Project Inform. “They’re big business and that’s who the Republican Congress listens to.” NAPWA’s Shriver admits to mixed feelings about the alliance with the companies, but argues that it has paid big dividends. “The prices they charge are too damn high and that makes our participation a challenging experience,” he says. “But you have to choose between holding on to your beautiful principles or helping PWAs.”

Dennis DeLeon, president of the Latino Commission on AIDS in New York City, applauds the AWG for winning more money for ADAPs but worries that such alliances “make people go soft in their willingness to confront industry. Some groups have such a symbiotic relationship with the companies that it’s impossible to distinguish them from the companies’ policy and outreach departments.”

Community advocates in the AWG vehemently deny this. Delaney says that Project Inform has received substantial money from Roche, while remaining a loud critic of saquinavir. “In the end, I don’t give a fuck whether I get money from the drug companies,” he says. Advocates add that their own underfunded lobbying programs are miniscule next to the millions spent by the companies. AWG member Richard Jefferys of the AIDS Treatment Data Network (ATDN) says his group organized an e-mail and phone campaign to save FASA. AIDS Action also pressed hard for the law, says Javier Salazar, one of the group’s lobbyists. “We put the issue of drug prices on the radar screen of many members of Congress,” he says. “The primary reason we lost was not because we rolled over and did nothing, but because we were confronting the leviathan that is the drug industry.”

Some, though, question the ardor of AIDS advocates in the battle to save FASA, and they fault the AWG alliance. “There’s a conflict of interest, and it was revealed by FASA,” says a health care lobbyist who asks to go unnamed because of continued collaboration with advocates in other efforts. “Outside of AIDS Action, the other groups were not at the forefront of the issue.”

Some advocates say they pressed the pricing issue at AWG meetings. “We’ve been very aggressive in confronting the companies about their prices,” says Shriver. AIDS Action’s Salazar agrees: “We’ve made it clear that our participation in the AWG would not prevent us from speaking out about prices. That’s created a high level of tension at times.” But AWG cochair Dorothy Keville tells a different tale. A former government affairs manager for Burroughs Wellcome (now Glaxo), Keville denies that FASA ever caused bad feelings. “People bring issues up all the time, but if it’s not something that we’re going to vote on, it’s just a point of information. FASA was never a divisive issue.”

Concludes economist Peter Arno: “The active co-optation of segments of the advocacy community leads to higher drug prices, taxpayer subsidies of the industry and inadequate access to lifesaving treatment.”

While the controversy over AWG rages, various interim measures have been proposed. Arno advocates that ADAPs form joint purchasing agreements to leverage better prices from manufacturers. “Everybody talks about letting the marketplace find the answers,” he says. “This would help make the marketplace responsive to the monopolistic practices of drug companies.”

Other community reps propose using ADAP funding to buy health insurance policies instead of medications, an idea backed by Clinton’s AIDS advisory council. “That would allow people to buy medical care as well as drugs,” says Shriver.

One option in the works is a set of draft regulations issued by the Department of Health and Human Services (HHS) that, if approved later this year as expected, would make an existing federal drug discount available to more -- but not all -- ADAPs. (Fourteen ADAPs already access that discount program.) Advocates say the HHS initiative is a step in the right direction.

But some observers say that all these efforts miss their mark. A congressional staffer, who asked not to be identified because he works with AIDS advocacy groups, sums up the problem: “The pharmaceutical companies are happy to lobby for more funding, but they don’t want to talk about their prices. That’s why we have an ADAP Working Group. But we’ll never see a Working Group to Reduce the Cost of Protease Inhibitors.”

**ADAP or Perish**

*Loot to the companies, boot to the PWA’s*

The ADAP Working Group controversy comes as many ADAPs are floundering. Always stretched for cash, their situation grew more serious with the recent advent of combination therapy. For the estimated 30 percent of HIV positive Americans who have no health insurance (another 20 percent

have private insurance and the rest rely on Medicaid), enrolling in an ADAP can literally be a lifesaver.

Now, the increased demand for pricey drugs has pushed many programs into crisis. At presstime, 10 ADAPs had halted admissions, while seven others were rationing or no longer dispensing more expensive drugs, notably protease inhibitors. In Florida, 2,200 people were on the ADAP waiting list. Following a public uproar, Mississippi reinstated 640 people it had bumped, but none get combo therapy. Wes McComas, a case manager at Project Connect in Jackson, says, “We’re still so tight for money that I’ve had to suggest that some PWAs to move to Memphis or New Orleans, where the programs are in better shape.” Even with both federal and state governments greatly increasing ADAP funding,the crisis can only worsen. A 1997 report by the Kaiser Foundation estimated that 280,000 people may be eligible for ADAP benefits, three and a half times the number that participated last year. “There are many, many people who can’t get into the ADAPs, and many who are in are not getting optimal treatment,” Mike Shriver of NAPWA says.

From the start, high drug prices have meant that the government gets little bang for its ADAP bucks. Indeed, the program was inaugurated in 1987 partly in response to activist protests over AZT, which was priced beyond the reach of anyone without health insurance. Antiretrovirals remain among the most expensive drugs on the market, sparking renewed charges of pharmaceutical price-gouging (see “The Price May Not Be Right,” *POZ*, April 1997). Triple combos run to about $12,000 a year. Average annual wholesale protease prices range from about $5,400 for Crixivan (marketed by Merck) to $6,700 for Viracept (Agouron) to $6,900 for Fortovase (Roche) to $8,200 for Norvir (Abbott). And pharmaceuticals comprise the nation’s most profitable legal industry, with returns to investors in recent years four times the average for the Fortune 500. Protease manufacturers Merck, Roche and Abbott racked up 1996 profits of $3.8 billion, $2.9 billion and $1.8 billion, respectively. The question some are beginning to ask is: When PWAs are literally dying for access to drugs, should the taxpayers be subsidizing such high pharmaceutical profits?

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