Fiasco in Florida

Roughly 6,500 ADAP clients in Florida are about to be temporarily cut off from their HIV medications. Here's how a group of advocates, a nonprofit pharmacy and the pharaceutical industry banded together to prevent a catastrophe.

January 31, 2011 By Tim Horn

The Florida AIDS Drug Assistance Program (ADAP) is in big trouble. As if the program's ever-expanding waiting list—currently consisting of more than 3,000 HIV-positive state residents in need of antiretroviral (ARV) treatment—wasn't bad enough, Florida's ADAP is expected to exhaust all available funds and virtually shut down in early February. Given that new Ryan White CARE Act funding won't be available to the program until April 1, a large percentage of the state's ADAP clients are on the verge of a nightmare: nearly two months without access to lifesaving medication.

Enter the Fair Pricing Coalition (FPC), a national group of activists that has performed nothing short of a magic act to bridge the imminent gap in Florida. FPC has succeeded in brokering a series of agreements—with Welvista, a national, nonprofit mail-order pharmacy; major pharmaceutical companies manufacturing ARVs; and Florida's ADAP—that will allow about 6,500 of the state's 10,000 ADAP clients to continue receiving their ARVs, beginning February 14. With these agreements, Florida should have enough funds to provide medications to the remaining 3,500 ADAP clients.

Advocates of all stripes continue to scramble to prevent any disruption of services—for example, the ADAP Advocacy Association sponsored a crisis meeting in Florida the last weekend in January to discuss the $14 million shortfall in the program's funding and the emergency efforts under way to secure the breach. In addition, FPC has been working around the clock in recent weeks to ensure that the worst-case scenario doesn't involve thousands of people living with HIV going off therapy. AIDSmeds checks in with Murray Penner and Lynda Dee of the FPC about the group's efforts and the road ahead.

First off, Murray, can you explain how we got into this situation in the first place? How is it that 6,500 Floridians on ADAP were at risk of losing their ARV drug coverage for two months?

Murray Penner: This is something that's been brewing for years in numerous ADAPs across the country. We often refer to it as a "perfect storm." The federal ADAP appropriation through Ryan White was approximately 70 percent of the overall national ADAP budget years ago, and it's now about 50 percent. That indicates a trend of greater need and federal appropriations that haven't

kept pace with demand. States were making up most of the shortfalls prior to the recession, but in the last few years, that funding has also not kept pace with burgeoning enrollments, which are occurring due to increased unemployment and positive developments, such as more and more people living longer, more people knowing their status because of increased testing, and treatment guidelines which encourage earlier treatment to improve health outcomes. Meanwhile, already expensive drug prices continue to increase, even though some companies have frozen prices for ADAPs and federal law limits price increases for ADAPs to the rate of inflation. Add all of this together, and it's a perfect storm for ADAP crises across the country. Florida's situation is not unique. In particular, their state appropriates a much smaller percentage of their overall ADAP budget than many other states, which has contributed to this dire situation there.

To remedy this, the Fair Pricing Coalition has been working tirelessly with pharmaceutical companies and Welvista to essentially provide ADAP clients in Florida with emergency short-term coverage during the state's financial crisis? How did you go about this monumental task?

Lynda Dee: Over the years, we have pressured major HIV drug companies to set the lowest initial drug prices possible, to minimize price increases and to expand benefits and eligibility criteria in their co-pay and patient assistance programs (PAPs). Initially, we used our company contacts to broker a deal covering all ADAP waiting list patients. Thereafter, we floated a one-stop shopping concept. Welvista agreed to be the focal point where ADAP patients could obtain their drugs by applying only once, instead of having to apply to numerous company PAPs. When we learned about the Florida ADAP crisis, we attempted to broker a one-time deal whereby all companies participating with Welvista would cover the 6,500 patients being dumped by Florida [through to] April 1, 2011, as a result of state and federal budget shortfalls.

Penner: As a last ditch effort after we felt all other options had been exhausted, the FPC made an appeal to the companies participating in Welvista, requesting that they help bridge the gap in Florida. It took a great deal of explanation, arm-twisting and appealing to the moral obligation we all have—federal government, states, industry and community members—to ensure that people don't lose access to their medicines. We worked tirelessly with Welvista, the Florida ADAP and companies to broker this rescue effort.

Are all antiretroviral manufacturers participating in this effort in Florida?

Dee: Abbott Laboratories, Bristol-Myers Squibb, Gilead Sciences, Merck and Co., Tibotec Therapeutics, Boehringer Ingelheim and ViiV Healthcare are currently participating with Welvista to cover national ADAP waiting list patients. Abbott, BMS, Gilead Sciences, Merck and ViiV have also agreed to this one-time deal that would cover the 6,500 Florida ADAP patients. We are still negotiating with Tibotec.

I imagine this requires some level of cooperation from Florida ADAP officials. Has this been the case?

Dee: Abbott, BMS, Gilead, Merck, ViiV and Welvista are ready, willing and able to get the job done. Welvista CEO Ken Trogdon negotiated terms with Florida to ensure that the costs incurred by Welvista for serving these 6,500 patients would be covered. Remember, Welvista is a small

nonprofit mail-order pharmacy that serves many uninsured people around the country with various diseases. Welvista is not a huge company that is able to absorb the huge overhead costs associated with dispensing drugs to 6,500 people.

Ken flew to Florida to get the job done. When he got there, he was made to wait three hours and deal with a bevy of Florida lawyers. The contract terms were not in fact the terms that were previously agreed to by Florida. Ken has repeatedly requested the number of prescriptions that will need to be filled week by week, patients' medication needs, including medication doses and other relevant information so that they can be tracked and coded properly. Ken needs this elementary information so he can order the correct meds for people.

This is very basic information that Ken has been requesting for the last two weeks. You would think that Florida would have provided this information yesterday. Why are they dragging their feet and speaking from both sides of their mouths? Is it incompetence? Are these 6,500 people unimportant to them?

You would think Florida would be breaking its back to make this deal fly instead of continuing to insert flies in the anointment. Frankly, I'm baffled and quite appalled by what I'm hearing about Florida's ADAP administration. They have apparently known about this impending fiasco since October of 2010 and failed to remedy this situation. They haven't even applied for all the industry rebates the state was entitled to. What's going on down there? Who's minding the store?

Meanwhile, FPC and other advocates are doing everything possible to address this emergency situation. But this raises another important question: Will what happens in Florida stay in Florida? What's to stop other states that decide to underfund—or unfund—ADAP from taking advantage of the generosity being shown here by these pharmaceutical companies and Welvista? Doesn't this set a dangerous precedent?

Penner: There was a great deal of discussion in the FPC about whether this was the right thing to do and whether or not it was a precedent-setting plan that would relieve states and the federal government of their responsibility of ensuring that people living with HIV have access to their medications. Pharmaceutical companies were very concerned about this too. We have always known that we must increase advocacy efforts at the state and federal level to ensure that there are necessary funding increases for ADAP. But in this case that wasn't going to help in the short term. Meanwhile, the clock was ticking and 6,500 Floridians were set to lose access to their medicines, which we found unacceptable. We agreed that we had to go forward with this rescue effort and send a loud and clear message that this could not be repeated in Florida or anywhere else.

Dee: While the pharmaceutical companies have agreed to cover ADAP waiting list patients through Welvista, the 6,500 Florida patient Welvista program is clearly a one-time deal that will not be repeated by the companies or again attempted by the FPC. Florida is the exception. California, North Carolina and New Jersey have had similar crises and allocated additional state funds to their ADAPs in order to prevent such a fiasco. Other states will have to do the same.

That being said, we cannot ignore the astronomical cost of these drugs. The FPC will also continue to pressure companies to set the lowest drug prices possible, to freeze the price of drugs for ADAPs and to take price increases in line with the Consumer Price Index in markets other than ADAPs.

Let’s talk logistics. How do Florida residents currently receiving ADAP enroll in the Welvista program without risking unnecessary breaks in their HIV treatment?

Penner: Case managers at the local level in Florida will assist ADAP clients affected by this transition and provide explanations as to how it will occur. No application will be necessary for clients as Florida’s ADAP will securely transfer client information—including prescription information—to Welvista, which will then fill up to a 60-day supply of medications for each client. Each client will receive enough medication to last at least through April 1 when the clients will again be able to get their medications from Florida’s ADAP through the normal procedures. It’s a monumental task for case managers, Florida’s ADAP and Welvista, but we have faith that this can be accomplished as seamlessly as possible.

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