Best Kept Secret: Drug Company Assistance Programs

Many of us know about private insurance, ADAP, Medicaid and Medicare—but how many know about programs run by pharmaceutical companies intended to defray the high cost of HIV treatment? An advocacy group called the Fair Pricing Coalition has been fighting to make these programs a reality—and they want you to know about them.

March 31, 2009 By David Evans

Do you lack health insurance, but make too much money to qualify for government assistance? Are your prescription co-payments so high that you can't afford other basic necessities? Have you begun to question whether antiretroviral (ARV) therapy is beyond your financial means? There is another alternative, and it could be one of the best kept secrets in health care: the pharmaceutical industry's patient and co-payment assistance programs.

AIDS activists have been fighting to ensure access to medications for people with HIV ever since Burroughs Wellcome (now GlaxoSmithKline) introduced the first ARV—Retrovir (zidovudine)—back in 1987. The most public and successful of these fights resulted in joint federal- and state-funded initiatives such as AIDS Drug Assistance Programs (ADAPs) and expanded Medicaid services, which today serve nearly 75 percent of people living with HIV/AIDS in the United States.

Quieter, however, have been the fights to ensure access to medication for people who make too much money to qualify for government programs, but do not have private health insurance and cannot cover the full retail costs of pricey HIV medications. For such people, who would otherwise slip through the cracks in our fractured health care system, each of the pharmaceutical companies has offered patient assistance programs (PAPs) and some offer co-payment programs.

The PAPs aren't perfect—they all have income and other eligibility criteria—but they do provide free ARV medications, and sometimes other meds as well, to some people with HIV who can't otherwise afford them. More recently, several companies that make ARVs introduced programs that help offset the cost of the co-payments that most people with private health insurance have to pay when they pick up their HIV medications at the drug store.

Such programs have been fought for largely behind the scenes by a group of AIDS activists known as the Fair Pricing Coalition (FPC) and have, until now, flown under the radar. That's all changed. The FPC, according to one of its founding members, Lynda Dee, from AIDS Action Baltimore, is dedicating itself to spreading the word. "We need to make sure that the information about the

programs is disseminated widely so people know about them," Dee says.

What They Offer

Every company that makes ARV medications has a PAP for its own HIV drugs. The programs are set up to cover people who don't have any other affordable alternatives to pay for their medication. To qualify, recipients must prove that they have exhausted options like government programs and that they cannot afford to get private health insurance. Income criteria vary according to how many people live in the household. Usually, those criteria are not made public, but are calculated based on a person's income in relation to the federal poverty level, which for a single-person household in 2009 is roughly $10,800. Most companies will usually help people who make several times that.

Not everyone qualifies for the PAPs, and the programs aren't necessarily easy to access. Lei Chou, a longtime HIV activist who now works on hepatitis B drug development with the Treatment Action Group in New York City, warns people to be prepared to roll up their sleeves, bare their souls to the customer representative at the company and to jump through some hoops. "It's not going to be a situation of you making one phone call and the company says, 'Okay!'" Chou says.

The programs, nevertheless, are a potential solution for a person who has no other options.

Because of pressure by the FPC, several HIV drug companies have introduced what are known as co-pay assistance programs. These are available to people who have private health insurance but steep co-pays for their HIV drugs. The programs vary a great deal from one company to the next.

The first company to publicly announce its program, GlaxoSmithKline (GSK), offers up to $100 per month in co-pay assistance for each GSK-product prescription for people who meet its eligibility criteria, starting at the first dollar that a person pays. For example, if a person takes Lexiva (fosamprenavir), Norvir (ritonavir) and Epzicom (abacavir and lamivudine) and the normal co-pay is $75 for each prescription, then the co-pay total comes to $225 per month. With GSK's program, the person's Lexiva and Epzicom co-pays would now both be covered 100 percent, dropping their total monthly co-pay for HIV drugs to $75, for the Norvir, which is made by Abbott.

Abbott, Gilead and Tibotec have also announced co-pay programs. Bristol-Myers Squibb (BMS) and Boehringer Ingelheim are working on programs and might announce them within the next few months. Merck does not have a specific co-payment program but says that it might offer some co-pay support through its traditional patient assistance program. Pfizer and Roche do not have co-payment programs. (For a brief summary of the all the programs see the table below, or call Project Inform's hotline, beginning April 1, at 800-822-7422.)

A number of the nation's pharmaceutical companies have also banded together to form a prescription savings program called Together Rx Access. This program offers discounts from the retail price on a number of medications—including HIV meds and drugs for other diseases—to people who do not have health insurance.

Abbott, Gilead and BMS have announced that their co-pay programs will not cover all of their HIV drugs. Because Gilead and BMS collaborate on the manufacturing and sales of Atripla (efavirenz, tenofovir and emtricitabine), they do not yet have an agreement on how that drug should be included in any co-payment programs.

Abbott, which does offer a co-pay program for Kaletra (lopinavir and ritonavir), does not offer one for Norvir, which is widely used in low doses to boost the blood levels of all other popular protease inhibitors. When asked why its program won't cover Norvir, Abbott gave the following statement: "Abbott's Positive Partnership Co-Pay PLUS program is to support patients taking a Kaletra-based regiment, including Kaletra plus the other medicines in their HIV treatment regimen. Abbott has a significant and long-standing patient assistance program in place for Norvir, which includes a commitment to provide free Norvir to patients, regardless of income, if not insured or on an ADAP wait-list, and free Norvir, when used for high doses, of 400 mg or greater."

In other words, Abbott may help people with insurance co-payments obtain free Norvir, but only if they are taking 400 mg or more of it. People taking low-dose Norvir to boost blood levels of other protease inhibitors are simply out of luck.

This angers Dee, who says, "The fact that Norvir is not included in the Abbott program is disgusting and typical of Abbott. Remember, Abbott raised the price of Norvir approximately 400 percent some six years ago to take advantage of the fact that all currently marketed protease inhibitors (PIs) need Norvir to boost the levels of these PIs in patients to effective levels. Norvir is one of the top three utilized HIV drugs on the market. Not including Norvir in its co-pay program shows us that Abbott has not changed its stripes."

Why So Secret?

Some HIV drug companies, such as GSK and Tibotec, now feature their PAP and co-pay program information prominently on their product websites. Other companies either feature the information less prominently or do not display it at all.

Ken Fornataro, executive director of the AIDS Treatment Data Network (ATDN) in New York City, whose organization provides assistance to people with access problems around the United States, says that a PAP has rarely turned someone down once his group began to advocate for the patient and helped document the person's monthly expenses and need for treatment. Even when the person's income was higher than the eligibility criteria, his group has been able to secure access, though he says companies have asked him never to disclose that fact. Fornataro thinks the companies fear that such information would open the floodgates to people seeking free medication.

Fornataro and his staff have gained a fairly good sense for what the income cutoffs are for most companies, but he says that his group won't publish that information, partly because the formulas are fairly complex, and also because he doesn't want people with higher incomes to read the information and automatically assume that they won't qualify for the programs. Most of the co-pay programs do not have income limits and so are likely to be more widely available to people.

Chou points out that most people on treatment in the United States either qualify for government assistance or have private health insurance. Thus, he says, although it's good that the PAPs are there, they aren't set up to help very many people. This is especially true of the programs with income eligibility requirements that are not much higher than the requirements to qualify for ADAP or Medicaid. He also worries that the most restrictive co-pay programs may ultimately reach too few.

Dee acknowledges that the FPC turned to the idea of the co-pay assistance program when the companies stopped agreeing to price freezes for their HIV drugs and the coalition wanted to do something that would have an immediate impact on the lives of people with HIV.

Since the programs are not all the same, with some being more generous than others, there's also the unfortunate aspect that some people may lean toward one regimen, compared with another, simply because it's more affordable. "I hate the idea of people choosing drugs because it's what they can afford, but it's better than not picking up the drugs at the pharmacy at all," Dee says.

Fornataro says that given the state of the economy, and the high costs of health care today, the number of people falling through the cracks is growing. Thus, both PAP and co-pay programs might be both a saving grace for more people as time goes by and an area for renewed advocacy focus.

Dee says that getting the companies to get the co-pay programs in place took a lot of work on the part of the FPC and that getting the word out about the programs is going to be an even greater task. Regardless, Dee and her fellow FPC members are hard at work on the next pricing and access battles, including widening access to the PAPs and expanding the reach of the co-pay programs. Given the FPC's previous successes, and the public appetite for controlling health care costs, such efforts might ultimately prevail.

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