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LEADER (U.S.) | SUPPORT SYSTEM

## Through Charities, Drug Makers Help People – and Themselves

By Donating Money, Firms Keep Patients Insured And Medicine Prices High

By **GEETA ANAND** Staff Reporter of THE WALL STREET JOURNAL

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Nancy Oliva hadn't paid much attention to her insurance plan's requirement that she pay half the cost of prescription drugs. Then the cashier at ShopRite told her she owed \$636 for seven pills.

Ms. Oliva, 60 years old, was diagnosed with a rare type of brain tumor earlier this year. She was prescribed a new drug to be taken in combination with radiation. The retail price of a one-week supply of the pill, called Temodar, is \$1,272.

- Drug Extends a Life, But at What Price? (</articles/SB113210858490898540>) 11/16/05
- How Drugs for Rare Diseases Became Lifeline for Companies (</articles/SB113202332063297223>) 11/15/05

Ms. Oliva, who earns about \$40,000 a year managing a clothing store in Long Beach Island, N.J., pulled out her American Express card that day in September and paid, unsure where she was going to find the money for the next week's supply. Fortunately, the nurse at her doctor's office found help for her from a

charity, Patient Services Inc., which picked up her drug co-payments -- \$3,800 for a six-week course of treatment.

The twist: The money for her co-payments came from Schering-Plough Corp., the drug's maker.

To cope with rising medical costs, insurers are requiring patients to pay higher

expensive medicine free from drug companies, people with insurance are increasingly finding it difficult to afford these drugs. In response, drug companies are giving money to charities that are specifically set up to help patients pay such costs.

Under this support system, drug-company money keeps patients insured -- and keeps insurers paying for the high-priced medicine.

"It's a win-win situation," says Dana Kuhn, co-founder and president of Patient Services, a Midlothian, Va., charity, which solicits money from drug companies.

"Patients are helped and companies are helped. They make a small contribution to help the patient and get much more money back when the insurer pays for the drug."

Drug companies also often take a tax deduction for their donation.

But critics contend the arrangements unfairly let drug companies protect the prices of their most-expensive medicines. "I don't want to discount the legitimate help they provide to people in need," says Scott Howell, an internist who serves as vice president of pharmacy affairs at Highmark Inc., a Blue Cross and Blue Shield company in Pittsburgh. "But it's really a clumsy way for manufacturers to game the system so they can continue their high pricing."

The efforts, critics say, are a short-term fix that doesn't address the underlying problem: the soaring cost of ultra-expensive drugs. They argue that by paying patients' premiums or co-payments, drug companies are shifting most of the price of these medicines to the patients' insurers, who in turn spread the cost onto the other people they cover.

"This is not a sustainable level of spending," says Alan Garber, chairman of the Medicare Coverage Advisory Committee and director of the Center for Health Policy at Stanford University. "The idea of making drugs available to people who can't afford it is very appealing, but the net effect is for the drug company to appropriate most of the gain."

Drug companies say the high prices of new drugs allow them to recoup development costs and invest in research, as well as provide return for their shareholders. Donating to groups that make insurance payments helps people get their medicine.

A Schering-Plough spokeswoman says the company contributes to Mr. Kuhn's charity "as a resource for patients." She declined to say how much Schering-Plough donates to such programs.



Dana A. Kuhn

\$1,200?" says Ms. Oliva, who is now taking another round of Temodar. "But I'm so pleasantly surprised that someone is trying to help me stay alive and it's the drug company of all people."

The need for financial-assistance programs is growing. The biotechnology revolution has created hundreds of drugs for chronic, life-threatening illnesses. But many are coming to market at high prices. In May, the U.S. Food and Drug Administration approved a drug for a rare genetic disease, called MPS-VI, made by California-based BioMarin Pharmaceutical Inc., which costs an average of \$300,000 a year. Other new drugs cost less, but are still pricey, such as cancer drugs Avastin, at \$50,000 a year, and Erbitux at nearly \$120,000 a year.

Unlike traditional medicines that are made by mixing chemicals, many newer drugs are proteins grown in cells, which is a complex, expensive process. Companies say costly manufacturing also leads to higher prices. On the other hand, the gross profit margins on some of these drugs can exceed 90%.

While Patient Services developed the concept of soliciting drug-company money to pay insurance premiums, the National Organization for Rare Disorders, a Connecticut nonprofit, recently began performing the same kind of middleman role. "Everybody knows what has to happen -- that these prices have to come down," says Abbey Meyers, the group's president. For now, she says, "we're trying to work with drug companies in a way that's acceptable to them and that also helps patients. We're doing the best we can." A few smaller charities have sprung up recently with similar plans.

Companies including Amgen Inc., Genentech Inc., Genzyme Corp., Teva Pharmaceutical Industries Ltd., Baxter International Inc., Novartis AG and ZLB Behring also donate to these programs.

## Approaching Companies

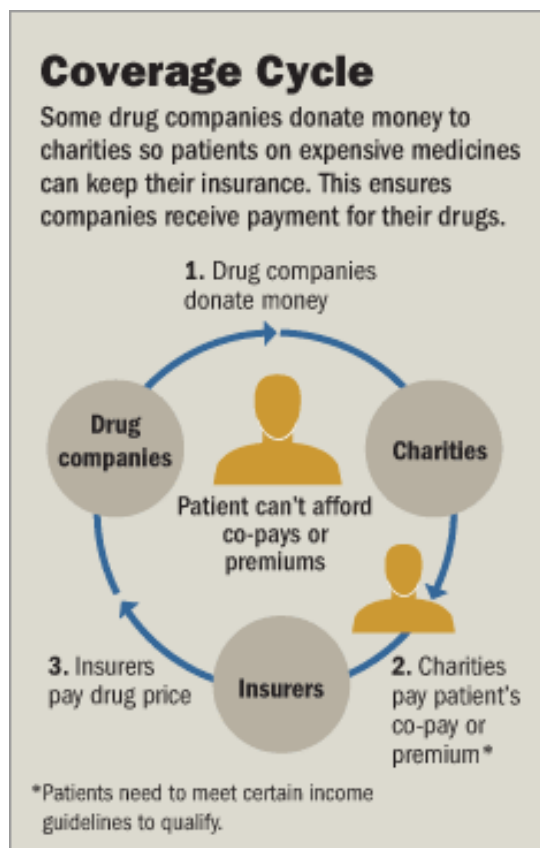
Mr. Kuhn, 52, who suffers from hemophilia, co-founded Patient Services, also known as PSI, in 1989 while working as a counselor at a Richmond, Va., hospital. He saw hemophiliacs struggling to pay rising premiums to maintain insurance coverage for Factor VIII, the blood-clotting protein they need to stay alive. The drug today costs about \$100,000 a year.

Mr. Kuhn approached companies making the drug for a donation to help patients pay premiums. "Our argument was, 'If you donate \$50,000, we can keep these people insured and provide revenue for you,'" he says.

Baxter and Armour Pharmaceutical Co., two of several companies that made the drug, each contributed \$50,000 the first year. The program has grown steadily, now assisting people with 19 different chronic illnesses.

Last year, Patient Services raised \$22 million, helping nearly 20,000 patients pay premiums and co-payments. About \$17 million of that came from 13 drug companies.

When he makes his pitch to companies, Mr. Kuhn says he emphasizes that they can make money by donating. During a 2003 visit to Genzyme, for instance, he brought along a chart showing how a donation would affect a patient who needs the company's drug, Fabrazyme. Genzyme says the drug typically costs between \$175,000 and \$200,000 a year. The chart showed that if Genzyme donated \$5,400 to cover the patient's premium for a year, it would bring in about \$185,000 by getting its drug paid for by the patient's insurance.



Genzyme signed up. "We wanted to do whatever we could to make sure all patients who needed our treatment could get it," says a spokesman for the company, based in Cambridge, Mass. He declined to say how much Genzyme donates to Patient Services.

### 'Who Can Afford It?'

One of the first to get help was Jeremy Taylor, a 25-year-old auto mechanic in Phoenix, who suffers from Fabry disease, a rare genetic disorder that can cause kidney failure, heart attacks and death. It costs about \$224,000 a year for him to receive Genzyme's drug. His insurance pays for most of that, but under the plan, he is required to pay about \$27,000 annually, PSI says. Mr. Taylor declined to be interviewed.

"It's a real miracle drug for us," says his father,

Patient Services says it provides \$27,000, all donated by Genzyme, to keep Mr. Taylor insured. Mr. Taylor's insurer pays the remaining \$197,000 cost of his treatment, according to PSI.

Until Mr. Taylor's drug was covered by insurance, Genzyme provided it to him for free, his father says.

Genzyme helps keep 167 patients with Fabry disease insured through its charitable program, PSI says. Genzyme is the only donor for PSI's Fabry program and it makes the only drug for the disease. The company donates less than \$2 million to the program, Mr. Kuhn says.

It isn't clear how much revenue Genzyme receives from the sale of the drug to these patients. Assuming each patient receives the low-end estimate for a year's dose, that could generate revenue of about \$29 million.

"Of course we get revenue from patients who are insured," says a Genzyme spokesman. But he declined to be specific on how much revenue the company receives for patients it helps stay insured, saying that would incorrectly imply the company makes donations "simply for financial gain." He says the company makes donations "simply to insure access to care for patients."

Genzyme struck a similar arrangement with the National Gaucher Care Foundation in 1993, soon after the company brought a drug to market to treat Gaucher disease. Genzyme makes the most widely prescribed treatment for this disease, which causes organs to swell and bones to deteriorate.

The foundation's patient-assistance budget this year is \$1.6 million. The biggest donor is Genzyme, according to Barbara Lichtenstein, program director of the foundation. It helps about 200 patients with insurance premiums and other medical expenses. Genzyme says its drug for this disease costs an average of \$200,000 per year.

Genzyme has a staff of 34 insurance specialists who try to keep patients who take its drugs insured. If no insurance can be found, the company gives the drug to patients free.

Gaucher patients "are like gerbils on a wheel," continuously finding and losing insurance, Ms. Lichtenstein says. Some who call her have hit their maximum lifetime caps of several million dollars on insurance coverage and have to find new jobs to get additional health-care coverage, she says.

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