# Benefit Managers Profit by Specialty Drug Rights

Jessica Kourkounis for The New York Times

An anti-seizure drug used to treat Reegan Schwartz's epilepsy registered a fourteenfold increase in price last summer.

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Doctors treating children with a rare and severe form of epilepsy were stunned by the news. A crucial drug, H.P. Acthar Gel, that had been selling for $1,600 a vial would now cost $23,000.

The price increase, put in place over last Labor Day weekend, also jolted employers that provide health benefits to their workers and bear the brunt of drug costs.

As it turned out, the exclusive distributor of H.P. Acthar Gel is Express Scripts, a company whose core business is supposed to be helping employers manage their drug insurance programs and get medicines at the best available prices.

But in recent years, drug benefit managers like Express Scripts have built lucrative side businesses seemingly at odds with that best-price mission. A growing portion of their revenue comes from acting as exclusive or semi-exclusive distributors of expensive specialty drugs that can cost thousands of dollars. And the prices of such medicines are rising much faster than for the mainstream prescription drugs available through a wide variety of distributors.

Critics say that distributing specialty drugs with ever-higher prices runs counter to the best interests of the employers that hire companies like Express Scripts.

“We are headed right down into conflict alley with these exclusive arrangements,” said Gerry Purcell, an Atlanta-based health benefits consultant to big employers. As exclusive or semi-exclusive distributors of specialty drugs, the benefit managers “can raise the prices at will,” Mr. Purcell said, “and the employer will have little chance but to pay the bill.”

Express Scripts’ main competitors, CVS Caremark and Medco Health Solutions, have also built lucrative side businesses in specialty drugs. So have some of the biggest insurers that provide medical benefits to corporate America, including UnitedHealth Group, Wellpoint, Aetna and Cigna.

When asked about the potential conflicts, Express Scripts and the other companies — which are known as pharmacy benefit managers — tend to describe themselves as mere middlemen with little influence over what the drug makers choose to charge.

Steve Miller, an Express Scripts executive vice president, said of the H.P. Acthar Gel episode: “The increase was a manufacturing decision. I can’t comment on that.”

The pharmacy benefit managers say that keeping a lid on employers’ drug costs is still their top priority. And they defend their involvement with specialty drugs, saying it helps them keep better track of the medicines’ use.

“I don’t believe it is a conflict,” said Dave Rickard, an executive vice president of CVS Caremark. “We saved clients $115 million last year that would have been spent on specialty drugs that were not appropriate.”

But CVS Caremark, meanwhile, sold nearly $6 billion in specialty drugs last year through its pharmacy benefit management business — nearly 14 percent of the company’s annual revenue.

The main drug benefit managers make as much as 10 to 15 percent on each sale of a specialty drug, whose prices can range from $5,000 a year for certain anemia drugs to $389,000 in the case of Soliris, a drug for a rare blood disorder, whose distributors include Express Scripts’ specialty drug unit, CuraScript.

Spending on specialty drugs rose 16.5 percent in 2006, growing twice as fast as traditional drug spending, and totaled about $62 billion — which was about 23 percent of overall drug sales in this country, according to Charles Boorady, a Citigroup health care analyst.

Big employers and organizations including General Motors, Caterpillar and Calpers, the large California public employees health and pension group, say their spending on specialty drugs is growing at double the rate of the rest of their drug benefits for employees.

In some cases, employers are starting to push back. A group of large- and medium-size companies like Kinder Morgan Energy, a Houston pipeline company, and Enodis, an international restaurant equipment maker with United States headquarters in Florida, recently pushed CVS Caremark to agree to hand back $15 to the employers on each prescription filled for all specialty drugs listed in a Caremark contract.

The giveback is meant to let the employers share a portion of the rebates that the pharmacy benefit managers often collect from drug makers in addition to keeping a portion of sales. But the giveback is relatively minuscule, acknowledged David Dross, a drug benefits specialist at the Mercer benefits consulting group who helped organize the employer effort.

With specialty drugs, the pharmacy benefit managers are "getting a lot more than the $15 in rebates," Mr. Dross said.

Susan A. Hayes, a drug benefits consultant based in Lake Zurich, Ill., said she had seen rebate contract terms that give the pharmacy benefit managers rebates of 3 percent to 10 percent of the selling price.

Specialty drugs are aimed at diseases that include cancer, multiple sclerosis and hepatitis C. Some, for rarer disorders, may have federal "orphan drug" status that gives a manufacturer exclusive marketing rights for a certain period. Specialty drugs also include medications whose distribution is tightly regulated as federally controlled substances, like the narcolepsy treatment Xyrem, which is distributed through Express Scripts

Makers of specialty drugs can command lofty prices mainly because patients have few alternatives, and there is typically little or no competition — whether because the medicine still has patent protection or the drug is difficult to make. Or it may be, as with H.P. Acthar Gel, that the patent has long since lapsed but there is a relatively small number of patients.

With specialty drugs representing about 60 percent of the new medicines submitted for approval by federal regulators, their overall cost will probably keep pushing up drug expenses well into the future.

Express Scripts is smaller than Medco and CVS Caremark, but it gets a bigger share of its revenue from specialty medicines — 19.8 percent of its 2007 revenue of $18.3 billion.

That compared with about 13 percent of Medco's $44.5 billion total revenue last year. And it compared with about 13.9 percent of CVS Caremark's total of $43.3 billion, not counting $2 billion sales of specialty prescriptions filled at CVS retail drugstores.

Express Scripts also has a larger number of exclusive distribution deals, with sole rights to 7 specialty drugs, all of which have orphan drug designation, as well as 11 more that are available through only one or two other national distributors.

Medco's specialty unit, Accredo Health, lists 4 orphan drug exclusives and 21 more drugs it shares with one or two other distributors. CVS Caremark said it had one exclusive and 35 drugs available from a limited group of specialty pharmacies.

In the case of H.P. Acthar Gel, an injectable anti-seizure medication derived from hog hormones, the fourteenfold price increase came after the maker, Questcor Pharmaceuticals, gave exclusive distribution rights to Express Scripts' CuraScript unit last summer.

"This sort of puts the spotlight on the greed angle of the business," said Dr. Robert R. Clancy, a pediatric neurologist at Children's Hospital of Philadelphia. He has been using H.P. Acthar Gel to treat a severely ill 3-year-old girl, Reegan Schwartz. Employer health plans bear most of the drug's steep cost, with individuals in many cases making only a standard co-payment. In the case of the two courses of Acthar treatments for Reegan, the cost to her father's health plan was about $226,000. Her father, Mike Schwartz, who works for a large pharmaceutical company, Merck, that has no ties to Acthar or its manufacturer, said he ended up paying only $60 out of pocket for the Acthar therapy.

Steve Cartt, a Questcor executive vice president, said the new price was chosen by looking at the prices of other specialty drugs and estimating how much insurers and employers would be willing to bear.

"We did some market research," Mr. Cartt said. Talking to pediatric neurologists and others about various pricing options "gave us some comfort that the strategy would work, and physicians would continue to use the drug, and payers would pay," he said. "The reality was better than we expected."