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Bill to ban limits on prescription drug co-pay help remains stalled in Ohio House

Darrel Rowland, *The Columbus Dispatch*

Sara Sharpe, 34, has a pretty basic wish: She doesn't want to suffer a potentially fatal allergic reaction "because of insurance company paperwork" foul-ups.

She is one of millions nationwide caught up in a money-saving move by health insurance companies with the unwieldy name of "co-pay accumulators." People in this diverse group, many suffering from rare diseases, are casualties of the ongoing battle over prescription drug prices among multibillion-dollar pharmaceutical manufacturers, health insurers and the obscure middlemen in the drug-supply chain, pharmacy benefit managers.

More than a dozen states and Puerto Rico have banned the controversial practice. Ohio appeared set to join them when the House Health Committee, in a rare show of bipartisan support for a substantive bill, unanimously approved a measure.

But that's been almost a year ago: March 16, 2021. Despite the across-the-aisle accord, House Bill 135 has not even been scheduled for a vote by the full House.

A copay accumulator works like this: To help needy consumers pay copays (including deductibles or co-insurance) for very expensive drugs, the manufacturers often provide financial aid. However, in recent years health insurers started stepping in and declaring that consumers cannot count that drug-maker aid toward their insurance policy's maximum for copays/deductibles or out-of-pocket spending.

Essentially, that means the consumer doesn't benefit from the aid, but the insurer reaps both the drug company's co-pay grant and the patient's actual co-pay on future prescription drug purchases.

The use of co-pay accumulators is growing rapidly, from 44% of Americans' commercial health insurance policies in 2018 to 80% in 2021, said Adam Fein in his Drug Channels blog.

Since the patient co-pays usually are based on amounts that approximate a drug's undiscounted, pre-rebate list price, the high-cost leads to fewer people taking needed medications, he said.

Carl E. Schmid II, executive director of the HIV+Hepatitis Policy Institute, told Ohio lawmakers last year: "The only players that this policy is good for are the insurers and the PBMs."

Bill Seitz: The one-man logjam holding up Ohio's bipartisan co-pay revamp?

House Speaker Bob Cupp, a Lima Republican, won't say why he won't put the legislation up for a vote. "I don't have any updates to report on the bill," his spokesman, Aaron Mulvey said earlier this month.

But Health Committee Chairman Scott Lipps pins the responsibility on a fellow southwest Ohio Republican.

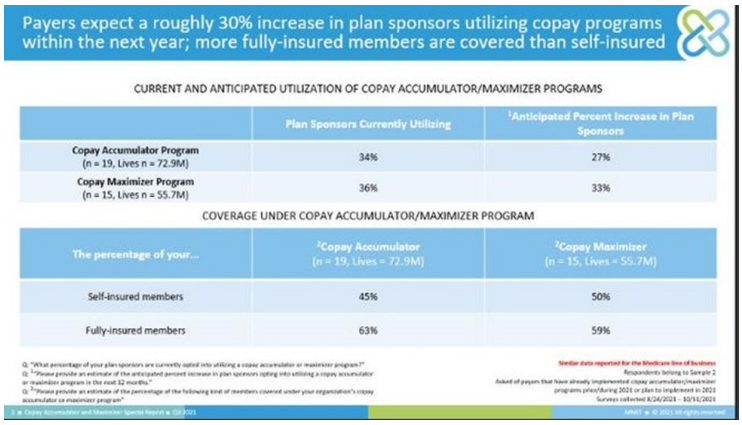
"There's one single person in the Statehouse who has stopped this bill, because the support is overwhelming," Lipps said.

That person is Cincinnati Rep. Bill Seitz, a lawyer whose role as majority floor leader is the No. 3 leadership post in the House.

"Bill has played tremendous defense," Lipps said. "In my lifetime I've never seen anything so accepted (get delayed like this). I see no justification for this."

If House leadership would allow a vote on the proposal, "it

Sara Sharpe, needs a regular medicine that has a list price of about $123,000 per use. The pharmaceutical company that makes the drug pays her insurance co-pay, but her insurance company keeps that money, as it will any co-pay that Sharpe must cover herself. Sam Greene/The Enquirer



Managed Markets Insight & Technology, which calculates analytics on the pharmaceutical industry, shows how co-pay accumulators and maximizers will grow. Managed Markets Insight & Technology

would pass with a dramatic majority," Lipps said.

A spokesman for Seitz said the veteran lawmaker is not a one-man logjam, but simply would like a couple of questions answered and assurances given.

Jonathan Fausey, majority policy adviser, said Seitz outlined the amendments he wanted in a June 2021 email to fellow Republicans.

"I do not have a problem with what is in the bill. However, I have three suggestions," Seitz wrote as he listed his desired changes.

"First, since you concede that 'nothing in this bill requires a health insurer to cover a medication outside the insurance formulary' (the list of prescription drugs the health insurer covers), I would like that to be expressly stated in the bill to avoid doubt."

• "I would like to have the bill affirmatively state that nothing in the bill shall be construed to prevent a health insurer from redesigning its formulary in any manner it deems fit in response to manufacturers' copay assistance plans, so long as the assistance is in fact credited towards the patient's copay while the drug is included in the formulary."

• "Finally, the concern has been expressed to me that some manufacturers will offer discounts for a limited period in an effort to drive patients into a more expensive drug that is part of the formulary, for which there is no generic equivalent. Then, once the patient is 'hooked' on the more expensive drug, they will withhold future coupons." The goal is to prevent manufacturers from "just trying to gain market share through promotional pricing."

But Lipps said bill co-sponsor Rep. Susan Manchester has "put her heart and soul into this" and "answered every objection" from Seitz.

Manchester, a Republican from Waynesfield in northwest Ohio, said she has spoken with Seitz and said, "I'm confident we're going to get to a good place" on what she calls a "patient-centered bill" that is backed by over 60 patient advocacy groups.

Ultimately, if Seitz won't go along , Manchester said she is confident the bill still will get widespread support in the House.

New study: Health insurers preventing medical care with their rules

If Ohio decides to regulate co-pay accumulators, that vote will come despite opposition from the powerful health insurance industry. Manchester said the Ohio Association of Health Plans turned down an offer to make the bill like one in Kentucky that won the support of that state's insurers.

Dan Williamson, a public relations veteran hired as a spokesman for the Ohio association, said he suspects that the year-long hold-up occurred because "after some research, House members have realized HB 135 is a PhRMA proposal that will increase costs for small businesses and consumers." PhRMA stands for Pharmaceutical Research and Manufacturers of America, which represents the nation's largest biopharmaceutical research companies

Before the bill was approved by the Health committee a year ago, association president and CEO Kelly O'Reilly asked legislators: "If a drug manufacturer can afford to give out coupons for their product, why don't they just lower the price of the drug?"

Many drugmakers have stepped in to cover the cost of those increasing co-pays. But when the insurers counter that move by refusing to give consumers credit for co-pays that don't come out of their own pocket, it is the patients who suffer, says a 2021 report by the AIDS Institute updated this year.

"Health insurance is meant to protect us from high, unexpected medical costs; but when health insurance becomes the very thing preventing us from getting the medical care we need, we must make changes," said Stephanie Hengst, the institute's manager for policy and research.

The problem was exacerbated in May 2020, the report said,

State Rep. Bill Seitz, a Cincinnati-area Republican, has been cited as a one-man logjam on a measure to ease consumers' health insurance co-pays that passed the House Health Committee unanimously nearly a year ago. Fred Squillante/Dispatch

Rep. Scott Lipps, R-Franklin Fred Squillante/Dispatch

Susan Manchester, R-Waynesfield, talks with Ohio House colleagues when the legislature reconvened at the beginning of 2019. Fred Squillante/Dispatch

when the Department of Health and Human Services finalized a rule essentially allowing health insurance companies to use co-pay accumulators at their discretion, even where there is no medically appropriate generic drug available.

$123,000 list price for treatment she needs every three or four weeks

Sara Scharpe gets co-pay assistance from companies that manufacture the pricey drugs she needs. Her health insurer recoups that drugmaker money for itself — leaving Sharpe and her husband, James, to come up their co-pay maximums: $4,200 for in-network care, $8,400 for outside the network.

"We budget every year for the out-of-pocket maximum," she said. "We've just always known that's our reality."

Still, Sharpe counts herself lucky because she's well aware that "families have to make heartbreaking decisions or try to figure out how they're gonna find this medication that could change their life or their child's life."

She suffered various medical maladies since she was in college: Miami University for undergrad, University of Kentucky for her graduate degree to teach psychology. Doctors weren't able to put together the whole picture until the past few years.

So now Sharpe, forced to quit her job teaching psychology at eight Cincinnati public schools and go on disability, takes 20 medications daily and about 15 more on an as-needed basis.

Her primary diagnosis is Hypermobile Ehlers-Danlos Syndrome, an inherited connective tissue disorder that causes everything from allergic reactions to to gastrointestinal issues to joint hypermobility. No treatment exists, although Sharpe takes medication for symptoms.

She also has a type of Mast Cell Disease, which can cause allergic reactions ranging from minor skin swelling to life-threatening anaphylaxis.

To combat the disease, Scharpe receives a sub-cutaneous injection of Xolair, a brand of omalizumab about every four weeks. It has a list price of $2,478.78 apiece, with a co-pay of $1,000.

She also has Common Variable Immunodeficiency, which causes low levels of the proteins needed to fight infections. It also increases risk for digestive disorders, autoimmune disorders, blood disorders and cancer.

For treatment, every three or four weeks Scharpe receives an infusion of Asceniv, which has a list price of $122,993.42 each, but her co-pay is $405. The medicationwas approved by the Federal Drug Administration in April 2019.

Insurance company paperwork snafu puts her life in danger

Her insurer doesn't even give her a chance to cover the co-pay personally. She found out the hard way when a new vendor hired by the insurance company to handle co-pays somehow lost her information.

When it came time for her Xolair treatment for Mast Cell Disease, she offered to cover the co-pay on her own, and sort things out later. The insurer refused.

By the time she got it sorted out her treatment was three weeks late.

"I didn't have anaphylaxis in that time period, but I could have," Sharpe said. "What I was experiencing were those chronic hives again. It's not like it's going to kill me but it's miserable.

"And I shouldn't have to experience it because of insurance company paperwork."

She's becoming more and more impatient with Ohio lawmakers because of the year-long delay.

"I think it's it's incredibly frustrating for patients, and I think that as a citizen it's really frustrating," said Sharpe, who's become an advocate for people with rare diseases.

"It just seems like things like this, that really have bipartisan support, could be a win for everybody."

Stephen J. Ubl, Pharmaceutical Research and Manufacturers of America CEO, says co-pay aid from drugmakers provides a "valuable source of assistance for many commercially insured patients who are facing rising out-of-pocket costs because of deteriorating insurance coverage for medicines." Max Taylor

Sara Sharpe shows an infusion port in her upper chest. She relies on a number of medications, the most expensive of which are six-hour infusion treatments. Sam Greene/ The Enquirer

Sara Sharpe keeps a stock of medical supplies and medications at her home in Springfield Township. Sam Greene/The Enquirer