

## HEALTH

# Michigan lawmaker wants to stop health insurance companies from using copay accumulators

**Kristen Jordan Shamus**

Detroit Free Press

Published 6:04 a.m. ET May 17, 2023 | Updated 9:09 a.m. ET May 17, 2023

A battle between pharmaceutical companies and health insurers is escalating over high-priced specialty drugs used to treat conditions like cystic fibrosis, hemophilia, autoimmune disorders, HIV and cancer.

In many ways, patients who are the most vulnerable say they are in the crosshairs — left struggling to figure out how to pay for medicine they need to survive or have a better quality of life.

“Drug prices are too high. It's not a secret,” said Emily Schaller, 41, of Detroit, who has cystic fibrosis, an inherited genetic disorder that can affect the lungs, pancreas and other organs, causing a build up of thick, sticky mucus.

Just one medication in her 10-drug regimen costs \$300,000 a year. “So the fight between the pharmaceutical companies for drug pricing and the insurers, they're taking it out on the patient.”

Insurers say the pharmaceutical companies' assistance really is a money grab, while advocates fault insurers' contention that less-expensive drugs are available for most of the conditions in question.

The medicines Schaller and others with rare and chronic diseases take “are 100% saving patients' lives and if you don't know how to get it, if you don't have resources and you can't get the medication, you could be very sick,” she said.

## Insurers take money from drug companies, don't apply it to deductibles

A freshman lawmaker — state Rep. Carrie Rheingans, D-Ann Arbor — plans to introduce legislation in the Michigan House later this month to take aim at "copay accumulator" adjustment provisions being used by as many as 80% of Michigan plans available in the Health Insurance Marketplace, according to a report released in February by the AIDS Institute.

When insurance companies use copay accumulators, they collect money from drug manufacturers' copay assistance programs, which help patients like Schaller afford expensive specialty medications, covering the gap between what patients' insurance policies will fully cover and copays, deductibles and coinsurance. But they don't count the copay assistance dollars toward the patient's annual deductibles or out-of-pocket maximums — costing patients, in many cases, thousands of dollars more each year for their medication, said Gavin Clingham, director of public policy for the national nonprofit Alliance for Patient Access.

"It's becoming increasingly common and it's becoming increasingly public — this fight between patients, insurance and manufacturers — on this issue," he said.

If the bill passes, Michigan would join 16 other states and Puerto Rico in prohibiting state-regulated commercial insurance companies from using copay accumulators. Similarly, legislation was introduced in Congress, which, if approved, would ban copay accumulator policies in federally regulated self-insured health plans, such as those provided by large employers.

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Rheingans said the legislation would ensure that "any copay that is contributed for a patient's care counts toward their out-of-pocket maximum and counts as a copay in the eyes of the insurer."

"We are looking at successes in other states and building on that momentum," she said. "I have talked to my direct constituents who really struggle to try to pay a \$22,000 bill a month if they have a specific rare disease and there's only one treatment ... to keep their symptoms under control.

“An insurance company doesn't need to be double dipping on the back of a person who is struggling to afford to eat and be housed.”

## **Average new drug cost \$2.3 billion to develop in 2022**

Pharmaceutical manufacturers say the high cost of prescription drugs is driven by the expensive process of researching new treatments, developing and testing them in clinical trials, and going through the regulatory approval process, which altogether can take a decade or more.

The cost to bring a single new drug to market averaged \$2.3 billion in 2022, according to the Deloitte Center for Health Solutions' annual Pharmaceutical Innovation Report.

It can be even more expensive to create new specialty drugs, such as biologic medicine, cell and gene therapies. They tend to be structurally more complex, use living organisms or components of live cells, and are not easy to replicate. That means few, if any, generic options exist for many of them.

To help patients who need those high-priced drugs, pharmaceutical companies offer discount coupons or copay assistance.

Jaime Moy has depended on copay assistance over the years. Both she and her son, Andy Moy, have psoriasis and a related form of autoimmune arthritis that can make daily tasks difficult. Some days, Moy said, she can't drive because it's too painful to grip the steering wheel of her car or turn her head to check for oncoming vehicles.

And for her son, whose psoriatic arthritis is more aggressive, "if he didn't have the biologic medication, there's no doubt that he would be in a wheelchair," said Moy, 46, of Waterford Township. "And that severely impacts your daily life and what you can do."

For years, both of them got injections of a drug called Stelara, which cost more than \$132,000 annually. Although their family's health insurance plan covered the bulk of it, without copay assistance from the drug's manufacturer, Janssen Biotech, the Moys would have had to spend \$16,000 out of pocket each year (\$4,000 quarterly) to cover their portion of the cost.

"Without that copay assistance, we just couldn't afford it," Moy said. "Two in the family with the disease, it's not going to work. So we're very, very grateful for that."

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## 'Without it, we would be in lots of trouble'

Still, her health insurance company didn't apply that copay assistance from Janssen Biotech toward Moy's out-of-pocket annual maximums. So when she needed gallbladder surgery a few years ago, it was an unexpected blow to her bank account.

"Had the money that the manufacturer had paid for our Stelara gone toward my copays, my out-of-pocket maximum for the year would have been met by that point and my gallbladder surgery would have been covered completely," she said. "Instead, we needed to find thousands of dollars more to cover that.

"Luckily, we could do it. But if there was an emergency, if there was a car accident or something more catastrophic, I can't say that we would have had more to be able to pay out."

Moy is among several Michigan patients who have gone to the state Capitol to lobby for legislation that would ban the use of copay accumulators.

"It's just so important that we have these medications," she said. "There isn't a generic alternative. We need it, and without it, we would be in lots of trouble. I feel sometimes like the insurance company is trying to find a way to keep us from succeeding because there is a medication that will work, but we can't afford it.

"So we are asking, as the patients, for the copay assistance being paid on our behalf to be counted. We spend so much time managing our disease and now we have to go even further just to make sure that we can afford it."

## Copay accumulators have become 'industry standard'

Leaders of health insurance companies and industry associations see the issue far differently.

Atheer Kaddis, vice president of pharmacy services and chief pharmacy officer for Blue Cross Blue Shield of Michigan, said copay accumulator policies and copay assistance programs have become "industry standard." Both Blue Cross Blue Shield of Michigan and Blue Care Network plans use them.

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"These programs protect our members from skyrocketing prices for drugs they need to maintain optimal health," Kaddis said.

Brian Mills, deputy director of commercial market affairs and communications at the Michigan Association of Health Plans, said copay accumulator policies aren't the problem. Rather, the cost of the drugs themselves are out of control.

Drug manufacturer coupons, he said, "are kickback schemes to drive consumers to purchase their most expensive drugs."

"In the commercial market, where these unscrupulous coupon tactics haven't been banned yet, health plans are putting co-pay accumulator adjustment policies in place to keep customer premiums affordable," Mills said. "When coupons are used, drug manufacturers are the ones dipping into customer premiums and collecting more money for their higher-cost brand-name drugs."

## **'Profit maximizers for drug manufacturers'**

Rather than ban copay accumulators, Mills said, the Legislature ought to prohibit manufacturer coupons, pass drug price transparency laws, allow prescription medicine to be imported from other countries and create a state affordability review board.

He pointed out that the federal government prohibits the use of drug manufacturer coupons or copay assistance for people who have Medicare or Medicaid coverage.

And in 2020, the U.S. Department of Health and Human Services issued rule called the Notice of Benefit and Payment Parameters, which allowed health insurers to use copay accumulators on commercial plans, granting "flexibility, when consistent with state law, to determine if and how to factor in direct drug manufacturer support amounts towards the annual limitation on cost sharing."

In issuing the rule, the federal agency suggested copay accumulator policies could serve as a tool to drive down prescription drug prices by preventing consumers from using manufacturer coupons and copay assistance to choose high-price brand name drugs over equally effective but cheaper generics.

In a legal brief supporting the HHS rule, AHIP, a national health insurance trade organization formerly called America's Health Insurance Plans, called co-pay coupons "profit

maximizers for drug manufacturers," raising health care costs for everyone, "including the patients who are ostensibly helped."

"Even when there is no alternative drug, coupons mask the immediate pocketbook impact of extraordinarily high drug prices from patients, while ultimately shifting the higher prices back to patients through higher insurance premiums."

Last year, three patient advocacy groups — the HIV+Hepatitis Policy Institute, the Diabetes Leadership Council and the Diabetes Patient Advocacy Coalition — sued HHS and the Centers for Medicare and Medicaid Services in the U.S. District Court for the District of Columbia, aiming to overturn the rule.

The advocacy groups say that many of the specialty drugs patients with rare and chronic diseases need lack less-expensive alternatives, and that when insurance companies refuse to apply copay assistance toward deductibles and other out-of-pocket maximums, they're violating the Affordable Care Act's cost-sharing limits.

The case has yet to be resolved.

## **High drug prices force difficult choices**

"The health plans will often say that copay assistance is a marketing tactic that it's used to push patients towards high-cost drugs, that it's problematic," said Sarah Procario, co-director of the Hemophilia Foundation of Michigan. "What we know is ... 99.6% of copay assistance is used for drugs that do not have a generic alternative.

The bill Rheingans plans to introduce in Michigan will contain language that allows health plans to continue using copay accumulators if a generic alternative exists and the patient hasn't already tried the lower-cost options through step therapy, Procario said.

When copays don't count toward deductibles and out-of-pocket maximums, patients must make hard choices, said Clingham, with the Alliance for Patient Access.

"Once a patient gets a diagnosis and they get a treatment that is working for them, it becomes a cost question to them: Can they afford their treatments? And you know, as cost increases, we know that people stop their treatments," Clingham said. "People will change their therapy. They will abandon their therapy.

"Those decisions have real-life implications for the patient. Their health care deteriorates every time they have to try something different. ... It's disruptive, in addition to the stress that

it causes. It's unclear what other side effects you may have, what comorbidities may be impacted, and how active the therapy might be.

“I think it has significant impacts on individuals who find themselves in the situation of not having payments made count towards their total expenses. It's very fraught for people, and time consuming, stressful.”

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## 'This drug ... gives me back tomorrow'

Ken Martin knows a lot about that stress.

He was diagnosed at age 5 with hemophilia, a life-threatening genetic bleeding disorder. At the time, doctors told his family he would be lucky to see his 12th birthday.

Now 56, Martin, who lives in Richmond Township, says he takes a drug called Hemlibra every week to prevent debilitating hemorrhages that cause intense pain in his joints.

The drug costs \$750,000 a year, but, he said, “it has been a life changer.”

Before he started taking Hemlibra, Martin had more than 40 hemorrhages in a year. Each time, if the bleeding couldn't be stopped or occurred in a vital organ, it could have been deadly. Now, he said, he averages about two per year.

As long as he remains on his employer-based insurance, and continues to qualify for the Michigan Children's Special Health Care Services program — which extends supplementary coverage into adulthood for people with for certain qualifying conditions, including hemophilia — Martin's out-of-pocket costs are mostly manageable.

He knows he is among the lucky ones, and that his circumstances could easily change. Martin is advocating along with Moy and Schaller to ban the use of copay accumulators in Michigan.

"I'm not a fatalist, but I'd never planned living this long," said Martin, whose brother also had hemophilia and died in 2002. "If I'm in a car accident, if I trip or fall — anything could have done it. I have kind of lived my life like, 'All right, let's enjoy it while we can' because I could never predict whether there might be an accident or whether I would be able to walk tomorrow, feed myself tomorrow.

"With this new medication, I don't want to say those concerns have gone away, but there's opportunity. I'm not going to start playing baseball. I'm not going to start running. The damage is done. But what this drug does, though, is it gives me back tomorrow."

At least for as long as he can pay for it.

*Contact Kristen Shamus: [kshamus@freepress.com](mailto:kshamus@freepress.com). Follow her on Twitter @kristenshamus. Subscribe to the Free Press.*