

What's true cost of medications?

Lisa Schencker | Chicago Tribune

When Marathon Pharmaceuticals' \$89,000 price tag for a year's supply of its newly approved muscular dystrophy drug sparked outrage earlier this month, the company's CEO responded with another figure: \$20.

That's how much he expected Duchenne muscular dystrophy patients would pay per prescription of the drug, he wrote in a letter posted on the company's website. Insurers would cover the medication, and patients would pay only their typical copays. He touted the company's patient assistance program to help patients defray out-of-pocket costs.

"I want to reinforce that every patient who needs this drug will have access to it, and that price should not be a barrier," Marathon Chairman and CEO Jeffrey Aronin wrote.

It was a line of defense from a company within an industry besieged in recent years by criticism over drug prices. Martin Shkreli of Turing Pharmaceuticals took heat for raising the cost of a drug by 5,000 percent. Mylan faced vitriol over its EpiPen prices and now it's Marathon's turn in the hot seat.

But the arguments that insurance will cover much of a drug's cost and that patient assistance programs will decrease out-of-pocket expenses don't always reflect the reality patients face when it comes to pricey drugs, experts say.

Those who need costly medications can face thousands of dollars in deductible and co-insurance payments, depending on how their insurance plans cover drugs and whether they get help from patient assistance programs. Even with insurers covering most of the expenses, that coverage can come at a cost to all con-

sumers in the form of higher premiums.

"This idea that the vast majority of people out there are just paying flat \$20 copays, it's based on an old understanding of what insurance (does)," said Rena Conti, a University of Chicago associate professor of health policy who studies drug prices.

When asked to comment for this story, Marathon gave a statement saying, "We are focused on providing access to this important drug to every young patient who needs it."

On average, people with insurance through large employers spent about \$144 out-of-pocket in 2014 for retail prescription drugs, according to a Kaiser Family Foundation analysis.

But some people pay much more. About 2.8 percent of people with insurance through large employers paid more than \$1,000 out-of-pocket. Those people were much more likely to be diagnosed with conditions such as diabetes or mental illness, according to the analysis.

It's true that some insurance plans charge \$20 copays for prescription drugs, said Katherine Hempstead, a senior adviser at the Robert Wood Johnson Foundation. But other plans may require patients to pay the full cost of their prescriptions out-of-pocket until they meet their deductibles.

Still other plans may require consumers to pay a percentage of the full list price until they meet their

deductibles or out-of-pocket maximums. "There are many, many permutations," Hempstead said.

About 39 percent of Americans with nongovernmental insurance had high-deductible plans in 2016, according to the federal Centers for Disease Control and Prevention.

It's true that patient assistance programs may help patients cover out-of-pocket expenses. Aronin wrote in his letter that Marathon has "developed the most robust patient access program allowed by law," and a document on Marathon's website says it will offer a copay assistance program to people with nongovernmental insurance who face out-of-pocket costs for the drug, but it doesn't say how much that assistance will be.

Aaron Kesselheim, an associate professor of medicine at Brigham and Women's Hospital and Harvard Medical School, called patient assistance programs a "classic marketing strategy" that doesn't solve the larger issue of high drug prices. Some patients might not benefit from assistance programs because they don't know about them, don't qualify for them or the programs last only a limited time.

Plus, they still leave insurers on the hook for most of the cost — an expense that can get passed down to consumers, he said.

"Somebody's paying for that," Kesselheim said. "In the case of private insurance, it's everybody who's paying for it in terms of higher premiums, and in the case of Medicaid and Medicare, it's taxpayers paying for it."

Aronin has defended the \$89,000 price, even as he pledged to suspend the drug's commercial launch to further discuss the pricing issue with "community leaders." Babar Ghias,

Marathon chief financial officer, told the Chicago Tribune earlier this month the company expects revenue of about \$54,000 for each year's worth of the drug it sells, after rebates and assistance it provides to uninsured and underinsured patients.

Aronin said the company set the list price of deflazacort, which will be sold under the brand name Emflaza, at \$89,000 based on resources it invested to bring the drug to market and complete clinical studies, as well as to fund future research and ensure broad patient access through insurer reimbursement and its own assistance programs.

Much of the controversy over the drug's price arose from the fact that the drug has been available outside the U.S. for years, and some Americans have been importing it for as little as \$1,200 a year. Marathon did not develop the drug, though it had to usher it through the U.S. Food and Drug Administration approval process to sell it in the U.S.

The drug's price is also in line with prices for medications for other rare diseases — called orphan drugs. The top 100 orphan drugs in the U.S. cost an average of \$111,820 a year per patient in 2014, according to a report by Evaluate, a market research firm.

"Prices are set in the U.S. market at whatever the market will bear, and we've shown time and time again that the market will bear very high prices for noninnovative products," Kesselheim said.

But Paul Howard, director of health policy at the Manhattan Institute, a conservative think tank, said Marathon did something important by ushering the drug through the FDA approval process.

When considering the price,

Howard said people and policymakers might want to look at how the drug was approved — and question why it had to go through the full FDA process when it already was approved abroad.

"This is just one of those cases that highlights we've got to find better solutions to these problems," Howard said.

But for patients with diseases such as Duchenne, it can be difficult not to focus mainly on the numbers, and what those dollar figures might mean for access. Duchenne is a muscle-wasting disease affecting mostly boys that typically leads to death in a patient's 20s or 30s.

Jose Galvez, a 28-year-old Chicago-area man with Duchenne, said he worries about whether the cost of deflazacort will keep families from accessing it.

Galvez isn't sure if deflazacort could help him at this point — he uses a wheelchair and a ventilator to help him breathe, and has a feeding tube — but he hopes it can help others. Had it been available when he was younger, he probably would have tried it, he said. He didn't take steroids to treat his Duchenne, and he stopped walking at the age of 11.

Galvez is on a personal mission to help those with disabilities and diseases, running his own foundation to raise money for those causes. He wonders, if Marathon really wanted to help sick kids, too, why it set the price of deflazacort so high.

"Families should be very happy there's a medication out there, but we have to make sure it's at a price where it can be afforded by families," Galvez said.

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