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Close to home: the effect of rising insulin costs on diabetics in Auburn-Opelika

Brittany Cannon Dement, 32, hasn't slept through the night in more years than she can count. A Type 1 diabetic, she wakes up multiple times throughout the night to check and regulate her blood sugar. Sometimes, she's fine. Other times, she wakes up shaky and pale, drenched in a cold sweat that can only mean her sugar is low.



She's well used to this by now. She was diagnosed with Type 1 diabetes at 14 after watching her sister, Brooklyn, suffer from the disease since the age of 8. But sometimes it's not the disease that keeps her awake. Sometimes she's lying awake thinking about the \$6,000 she spends every year on insulin alone.

Dement is an adjunct professor of government and economics at Southern Union Community College. Her husband, Russell, is a manager at TruBridge, a prominent Mobile-based healthcare company. Through these jobs, she and her husband have what she described as

very good health insurance. But she is still required to pay this expense out of pocket every year before she meets her insurance deductible.

“Thank goodness my husband has a good job, and I have good health insurance,” Dement said. “But \$6,000 a year is a lot of money, especially for a disease I didn’t bring upon myself. I think all the time about the things I could have done with that money.”

That’s not to mention the costs she incurs that insurance doesn’t cover, such as alcohol swabs, juice boxes and snacks to fight low blood sugar, adhesive patches to keep her glucose monitor attached to her arm and copays for doctor’s visits and lab work.

And she’s one of the lucky ones.

“I feel really blessed that it only costs me \$6,000 a year, because for a lot of other people it’s so much worse, especially for those that don’t have health insurance,” she said. “I hear so many stories about people who start to ration their insulin and end up in the hospital with diabetic ketoacidosis, and it just makes me sick. It’s not like people with Type 1 can just go without insulin. If we don’t get it, we die.”

According to MayoClinic.org, [diabetic ketoacidosis](#) is “a serious complication of diabetes that occurs when your body produces high levels of blood acids called ketones”—a condition that develops when the body doesn’t receive enough insulin. Though it can also be caused by illness, the most common cause is “missed insulin treatments or inadequate insulin therapy.” The condition can cause loss of consciousness and, if not treated, can become fatal.

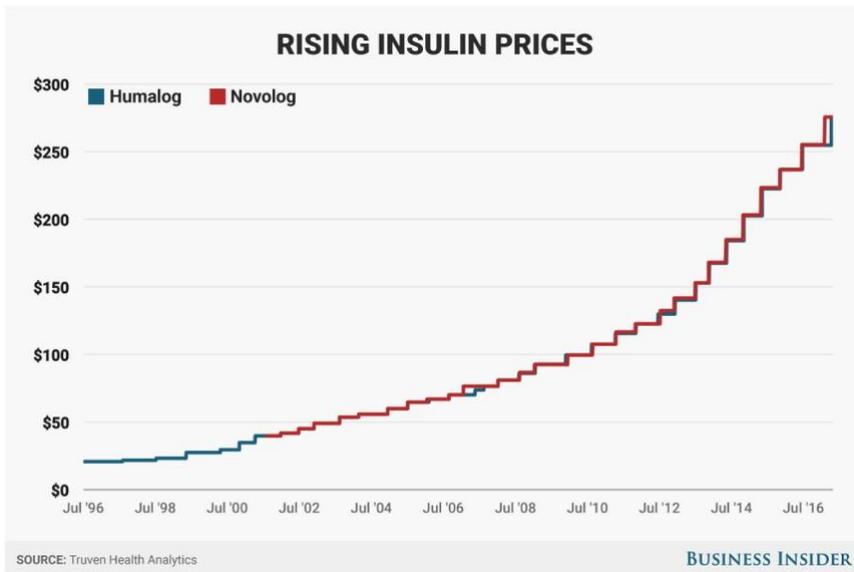
In the past two years, there have been 10 reported deaths from insulin rationing in the United States. [According to RightCareAlliance.org](#), the most recent victim, Jesimya David Scherer, was only 21 years old. He was working two jobs and still could not afford to buy the amount of insulin needed to keep himself alive.

There have been no reported insulin rationing deaths in the Auburn-Opelika area. However, Anna Carter, an RN/BSN at the Diabetes and Nutrition Center of East Alabama Medical Center, said that she sees someone admitted to East Alabama Medical Center with diabetic ketoacidosis every day.



“It’s very frustrating,” she said. “Our role at the Diabetes and Nutrition Center is to teach people to live with and manage diabetes. But, if they can’t get their insulin, there’s only so much we can do.”

Carter, a Type 1 diabetic herself, said she has noticed a marked increase in insulin prices over the past few years. And she’s right. According to Lydia Ramsey of Business Insider, prices of Humalog and Novolog, two prominent insulin brands, [rose 250% from 1996 to 2017](#). From 2016 to 2017 alone, the price of Humalog increased 7.8%.



[A study done by BMJ Global Health](#) shows it costs drug companies between \$2.28 and \$3.42 to produce a vial of human insulin. It costs between \$3.69 and \$6.16 to produce a vial of analog insulin.

“Pharmaceutical middlemen are crooks,” said Noelle Stewart, a dietician and certified diabetes educator at the Diabetes and Nutrition Center. “I get so upset about it. I ask all these pharmaceutical reps why prices are so high and none of them can ever tell me. They’re supposed to be helping people, but they just want to make money.”

Although Carter and Stewart both agreed that the issue is prevalent among low-income diabetics without health insurance, they both said the problem they run into the most is people like Dement who have health insurance and still can’t make ends meet.

“A lot of times our patients are on a fixed income. At the end of the month they just don’t have enough left to pay their deductibles,” Carter said. “That’s when rationing comes into play, which leads to a hospital visit, which leads to more bills they can’t pay.”

Even when the diabetic ketoacidosis caused by rationing insulin isn't fatal, it can cause life-altering problems. Stewart said it can affect a patient's vision and energy levels and often lead to kidney failure or neuropathy that makes it difficult to live a "normal life."

"It's heartbreaking to see," she said.

Why are insulin costs so high?

T1International, a non-profit whose mission is to "support local communities by giving them the tools they need to stand up for their rights so that access to insulin and diabetes supplies becomes a reality for all," lists [a few different reasons for the high cost of insulin](#) in the United States. One of these is the fact that three companies—Eli Lilly, Novo Nordisk and Sanofi—control 90% of the world insulin market and as such can dictate prices as they wish. Another is that there is no generic insulin as there is with other common drugs.

T1International also claims that the issue lies in patents. According to their website, "pharmaceutical companies take advantage of loopholes in the U.S. patent system to build thickets of patents around their drugs which will make them last much longer (evergreening). This prevents competition and can keep prices high for decades."

The T1International website also states that the patent for insulin was sold for only \$1 in 1921.

There is also the fact that insurance companies dictate which insulins patients must use if they want the cost to be covered.

"A lot of times insurance companies don't dictate what's best for the patient but just a specific brand that's most expensive," Carter said.

And this isn't specific to just insulin. Dement said that her insurance dictates she buy Acucheck testing strips, which are some of the most expensive on the market. She also said that

some insurance companies will only cover the cost of enough testing strips for a patient to check their blood sugar once a day (even though it's recommended that they check it as many times as eight).

“To me, it's just immoral,” said Dr. Rene Mceldowney, a professor in the Health Services Administration program at Auburn University who holds a doctorate in comparative health care policy. “A lot of people say that drug companies have to charge such high prices for insulin because of research, but a lot of studies have been done that prove companies spend most of their money on advertising. So it's a catchy phrase they like to throw around, but it's not really true.”

Dr. Mceldowney also said her foreign colleagues often express amazement at what she refers to as a fragmented health care system in the United States.

“We're the richest country in the world, and yet people are dying because they can't access insulin,” she said. “It just doesn't make sense to them. It doesn't make sense to me, either.”

What can be done?

For Dr. Mceldowney, the answer to the insulin crisis in the United States is simple—centralized price negotiations, a system almost every other country in the world has in place to control drug costs.

“We don't have to reinvent the wheel,” she said. “Other countries have already done it. And the United States is already doing it with Veteran Health Administration and the Department of Defense, the only two entities in our country that are allowed to negotiate drug prices. Let's take that and apply it to the general population.”

Dr. Mceldowney is aware that this will have a negative effect for those in the United States who hold stock in pharmaceutical companies. But for her, the positives far outweigh the negatives.

“The point of health care isn’t for stockholders to get rich,” she said. “They can buy another stock. There’s something unusually uncomfortable about those who get rich off the pain of other people.”

In the meantime, many insulin companies offer patient assistance programs for those struggling to afford insulin. They’re not always foolproof. According to Carter, the guidelines for the program are strict and exclude many patients from qualifying for the program, and the online forms are often difficult to interpret. Patients also have to repeat the process every year. But, for the people who qualify for the programs, she said, it is a beneficial resource.

Patients without health insurance also have the option to purchase insulin over the counter at their local Walmart. Each vial costs \$25.

“It’s not the best for prolonging life and managing diabetes, and we definitely don’t recommend it,” Carter said. “And that’s still \$75 a month if you buy three vials, which isn’t enough for most people. But it’s better than nothing.”

There are also organizations in the Auburn-Opelika area working to aid those in the community who struggle to afford their insulin. [Mercy Medical Ministry](#) is a donation-based clinic in Auburn that offers medical assistance to those without health insurance or financial resources. Their volunteer staff also offers one-on-one assistance to those struggling to apply for patient assistance programs.

But in the minds of many diabetics in the community, there is still more to be done. Ava Michl, a 21-year-old student at Southern Union Community College, won't be satisfied until the health care system in the United States changes.



“I’m in a Facebook group with other people who are Type 1 diabetics, and I’ve seen people begging for insulin or diabetes supplies,” she said. “I actually sent an old transmitter to a stranger on the internet once. It’s extremely upsetting, and our policy makers need to be doing more to fix the problem.”

Dr. Mceldowney agrees.

“At this point, it’s a humanitarian issue,” she said. “Everyone likes to say that this health care reform can’t be done because America is different, but Eisenhower saw the interstate system in Germany during World War II and brought it back to the United States, and now we can’t imagine a world without four-lane highways. So people like to think we can’t borrow from other countries, but we’ve done it. We just need to get moving.”