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The Price They Pay

ProPublica and The New York Times have partnered to tell the stories of Americans living daily with the reality of high-cost drugs. There are millions of others just like them.

by Katie Thomas, The New York Times, and Charles Ornstein, ProPublica March 5, 2018 *This story was co-published with The New York Times.*

THE BURDEN of high drug costs weighs most heavily on the sickest Americans. Drug makers have raised prices on treatments for life-threatening or chronic conditions like multiple sclerosis, diabetes and cancer. In turn, insurers have shifted more of those costs onto consumers. Saddled with high deductibles and other out-of-pocket costs that expose them to a drug's rising list price, many people are paying thousands of dollars a month merely to survive. For more than a year, President Donald Trump and Democrats in Congress have promised to take action on high drug prices, but despite a flurry of proposals, little has changed. These are the stories of Americans living daily with the reality of high-cost drugs. And there are millions of others just like them.

Skipping Drugs She Can't Afford

SAUNDRA JOHNSON, 57, MINNEAPOLIS, MINNESOTA

Katie Campbell/ProPublica

With an annual income of less than \$20,000, Johnson doesn't come close to being able to afford the 12 medications her doctors have prescribed for congestive heart failure, diabetes and related complications. She is one of the many who finds herself "in between," as one of her doctors described it, narrowly missing the requirements for assistance but making too little to afford her prescriptions. Here's a rundown of the math: Johnson's Social Security disability income of \$19,560 in 2017 placed her above the cutoff for receiving additional government assistance for her prescriptions, called Extra Help, even though nearly every dollar of her income is already spoken for, from paying Medicare premiums to food and other household expenses.

Medicare rules prohibit her from using drug co-pay coupons, which are commonly used by those with private insurance. And Novo Nordisk, the company that sells her fast-acting insulin, Novolog, and her diabetes medication, Victoza, requires low-income Medicare beneficiaries to first spend \$1,000 on drugs in each calendar year before they can qualify for free drugs through its program. In a cruel twist, Johnson doesn't have that \$1,000 to spend, so she resorts to not taking some drugs for months until she reaches the company's threshold. These are tough choices. Sometimes she stops taking the short-acting Novolog, staying on the longer-acting insulin, Tresiba, as well as her heart medications, like bumetanide and digoxin. "I prioritize the heart stuff over the insulin because the heart stuff is more immediate," she said. Johnson understands the risks; she was a health educator for people with HIV and AIDS, helping patients enroll in programs that lowered their drug costs. Her blood sugar has risen dangerously high, and a little over a year ago, she was hospitalized for three weeks because she said she wasn't on the right diuretic to reduce excess fluid.

Last June, she was approved for the Novo Nordisk assistance program, allowing her to begin taking the Novolog insulin again. As of mid-November, Johnson had spent \$2,782 on prescription drugs, not counting the cost of the free insulin, according to a report provided by her pharmacy.



Sandra Johnson (Katie Campbell/ProPublica)

For another drug, Entresto, an expensive treatment for heart failure, Johnson participates in a clinical trial that provides the drug for free. Once that ends, she faces another hurdle: “There’s going to be a discount or I’m not going to be on Entresto anymore.”

In January, she started all over again. “I’m stuck between a rock and a hard place, and I’m sure a lot of other people are as well.”

WHAT’S GOING ON HERE

Medicare’s prescription drug program, known as Part D, has been a lifeline for seniors and disabled people. Those with the lowest incomes can qualify for federally subsidized Extra Help to reduce their costs. But to be eligible, an individual must earn less than \$18,210 and a married couple living together cannot earn more than \$24,690. In a statement, Novo Nordisk said it provided some forms of insulin at reduced costs to help patients who are struggling. “This patient is an exceptional example, reminding us that we need to continuously evaluate how we keep our support programs sustainable while covering as many of those in need as possible.”

'We Always Seem to Fall Through the Cracks'

ABIGAIL BOSTWICK, 37, OF TOMAHAWK, WISCONSIN

Bostwick was diagnosed with multiple sclerosis in 2013. Insurance covered the first drug she took, Tecfidera, but required her to contribute \$1,000 a month. "I didn't cry when I was handed the diagnosis of M.S.," Bostwick said. But after learning how much prescriptions would cost, "That was when I felt truly helpless." Bostwick, a former journalist, has coverage through her husband's employer because she can no longer work. They hit their \$4,500 annual deductible in the very first month of every year because Gilenya, the drug she had been taking until last fall, carried a list price of about \$5,500 a month. The couple put aside \$375 every month to make sure they could cover that deductible.



Abigail Bostwick (Narayan Mahon for The New York Times)

The Bostwicks, who recently decided to divorce, have drained their savings, given up family vacations, and sold a motorcycle, a car, furniture and other belongings. Changes to her husband's employee benefits this year means another \$1,000 out of pocket annually. Bostwick, who is disabled, said she plans to sign up for Medicare coverage after she loses access to her husband's insurance.

Bostwick suffered severe side effects that led her to stop taking Gilenya, and she's recently been approved to begin a new drug, Ocrevus.

"This is such a huge bill and it's not really something that we can forgo," she said. "We're your basic middle-class couple. We don't have an extravagant lifestyle or anything like that. But we always seem to fall through the cracks."

WHAT'S GOING ON HERE

The prices of several multiple sclerosis drugs have shot up in recent years. The cost of Gilenya, the drug that Bostwick took, has nearly doubled to almost \$92,000 a year since Novartis got approval for it in 2010. In a statement, Novartis pointed to its patient assistance program that eliminates monthly out-of-pocket costs for most commercially insured patients (Bostwick said her family income is too high to qualify for most assistance programs). There are also signs that companies may be getting the message. Ocrevus, the drug Bostwick will soon begin taking, was approved in 2017 and Genentech, its manufacturer, announced it would price the new drug at 25 percent below the list price of Rebif, the older drug that it beat in clinical trials.

A Father Crosses the Border for His Son

JONATHAN YEAGLEY, 61, BERWYN, PENNSYLVANIA

Aaron Ernst for ProPublica

Every three months, Yeagley, a stock trader, hops into his car and drives seven hours — 390 miles — from his home outside Philadelphia to a Walmart half a mile across the Canadian border. There, he buys Xeljanz to treat his son Jonathan's alopecia areata, a type of hair loss caused by an immune disorder. He drives back the same day.

In 2016, Independence Blue Cross, Yeagley's insurer at the time, rejected coverage of the drug because Xeljanz is approved to treat rheumatoid arthritis, not alopecia. Yeagley appealed and lost his case; an outside reviewer wrote that there's not enough evidence that the drug is effective against alopecia. In 2017, Yeagley switched to another insurer that does not cover prescription drugs. There are no approved drug treatments for the condition, and Yeagley's son's doctor at Yale University, Brett King, has found Xeljanz effective at regrowing hair for some patients. (King is a consultant for the drug's maker, Pfizer.) Once a year, Yeagley uses a coupon from Pfizer that covers about three months of the drug, but for the rest of the year he is on his own.

In the United States, Xeljanz costs about \$50,000 a year (through a drug discount website). That's after Pfizer raised the price of Xeljanz by nearly 8 percent in

January. In Canada, the price tag is \$15,000. "I don't have that kind of money to throw away," said Yeagley, who has made five trips so far. Yeagley's son spoke on FaceTime with a Canadian doctor who asked for pictures and reviewed laboratory results before writing a prescription so the Yeagleys could legally obtain the drug in Canada.

Jonathan, who is 20, worries about shouldering the costs in the future. "I don't tell him that I think about it a lot but I do think about it a lot," he said. "I'm so grateful for what he does for me but I don't know how long it can go on."

WHAT'S GOING ON HERE

Drug prices are cheaper in Canada, where an independent quasi-judicial body is supposed to ensure that pharmaceutical companies do not charge excessive prices. In another twist, the price of Xeljanz has come under scrutiny because it was developed in part based on research by the National Institutes of Health, a federal agency. Some consumer groups and lawmakers have questioned whether drugs developed with taxpayer money should carry lower price tags.

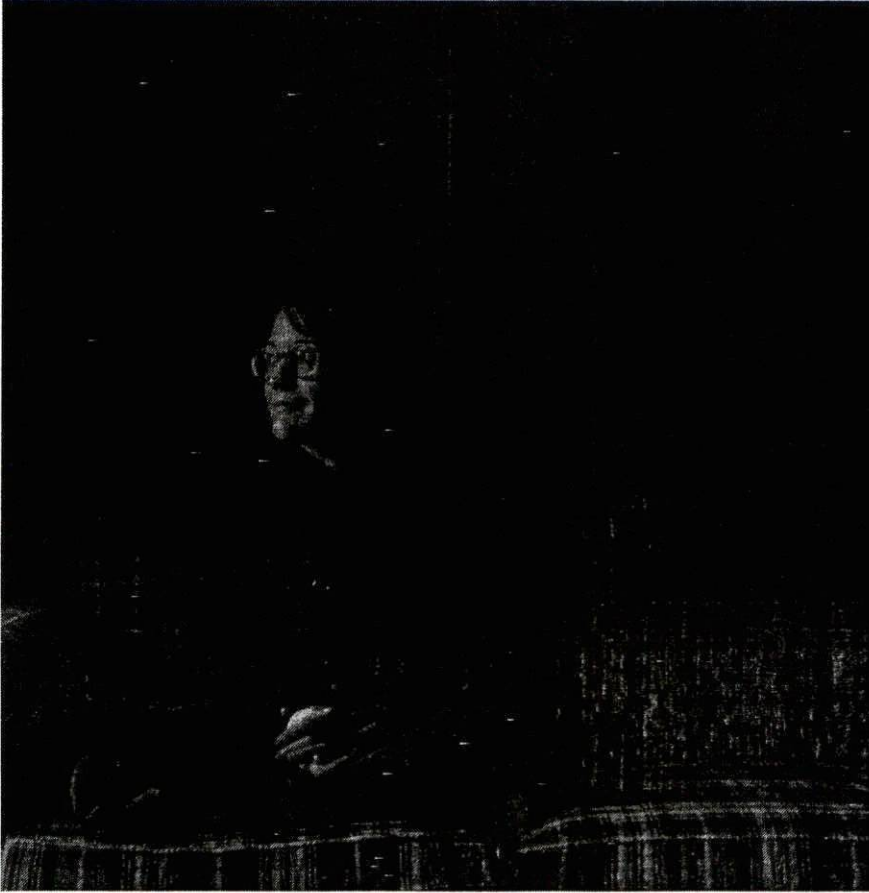
In a statement, Pfizer said it is studying medications to treat alopecia. It has said it spent more than a \$1 billion on "the discovery, development and commercialization of Xeljanz."

Stockpiling Insulin

AMANDA WALKER, 34, OF MEMPHIS, TENNESSEE

Diabetes has driven nearly all of Walker's adult life. Walker, who was diagnosed with diabetes at age 9, dropped out of college, forgoing her aspirations to be an artist, in part because she needed health insurance. She sought out retail jobs with coverage, selling suits at Men's Warehouse and Jos. A. Bank. She got an insulin pump, helping keep her stable. Even then, she struggled to pay her out-of-pocket costs, spending \$300 a month for insulin and other supplies.

Last fall, she became unemployed after taking a new job that didn't work out. Without coverage, Walker stockpiled empty vials of insulin in her refrigerator, using a syringe to suck out whatever drops were left. She once turned to Facebook, pleading for help, and within 45 minutes a nearby resident offered her two insulin pens.



Amanda Walker (Andrea Morales for The New York Times)

By December, Walker obtained subsidized health insurance through the Affordable Care Act. She pays a premium of \$3.95 a month and \$25 a month for insulin. But even though her health coverage is more secure, she still worries that she could wind up rationing her insulin again if the health care law were repealed. “I think in an alternate universe, there’s a me that’s not diabetic,” she said. “And I wonder what she’s doing. What life is she living? I’m stuck.”

WHAT’S GOING ON HERE

In the United States, three manufacturers dominate the insulin market — Eli Lilly, Novo Nordisk and Sanofi — and a recent study found that prices nearly tripled from 2002 to 2013. The drug makers have been accused of price-fixing in several patient lawsuits, and several states are investigating. In response, the companies have rolled out programs, such as one through CVS Health, that reduce costs for the uninsured or those with high-deductible coverage.

Despite the uproar, all three manufacturers raised their list prices again in 2017, according to the Gold Standard Drug Database from Elsevier, an information analytics company.

Two Battlefields: The Illness and the Bills

CARTER KNUTSON, 68, BLOOMINGTON, ILLINOIS

At the Mayo Clinic in Rochester, Minnesota, Knutson had begun a two-pronged treatment aimed at attacking a large tumor threatening his pulmonary artery. As chemotherapy dripped into his bloodstream, he learned that his insurance company wouldn't cover the second phase, a pill called Xeloda that he could take at home. Doctors at Mayo wrote to the Knutsons' prescription benefits manager, CVS Caremark, to explain that Knutson's kidney disease made him a bad candidate for the usual treatment, with the chemotherapy drug cisplatin. After a denial and failing two appeals, Knutson, a retired farm equipment salesman, and his wife Julie, decided to pay for the drug themselves. "We felt like we didn't have a choice," Julie Knutson said. After using a coupon they found online, the pill cost \$1,000 per prescription. After three courses of the drug, Carter Knutson's tumor shrank enough to enable surgery. He is now in remission.



Carter Knutson displays a photo on his phone that was taken during his treatment at the Mayo Clinic in Rochester, Minnesota. (Eric Ginnard for The New York Times)

After the operation, the Knutsons appealed again — this time through the state's insurance commissioner. Within 24 hours, the reviewer ordered CVS to cover the pills. The Knutsons received a check in July 2016 for \$2,790.81; they turned around and donated \$3,000 to the Mayo Clinic.

The fighting took its toll, Carter Knutson said. "When you are in that situation, you are really fragile, not as capable as you are when you are healthy in an everyday situation," he said. "It's like they're trying to make it so difficult that you just give up."

WHAT'S GOING ON HERE

Knutson's situation is a good reminder that even if your insurer rejects a treatment or drug, you have the right to appeal — often more than once. He only won when he appealed to an outside reviewer through the Illinois insurance department, an external process required by the Affordable Care Act. While CVS Caremark said in a statement that it respected the care provided by the Mayo Clinic's oncologists, it added: "This case illustrates that medical experts can disagree on whether experimental therapy may work for a patient, and we certainly hope it has for Mr. Knutson."

A Common Childhood Ailment Carries a Big Price Tag

AVIVA WILLIAMS, 42, LOS ANGELES, CALIFORNIA

Katie Campbell/ProPublica

Last year, Williams' 4-year-old daughter, Amy, began complaining about an itchy bottom — a classic sign, her doctor later informed her, of pinworms. Williams gave Amy an over-the-counter medicine and her daughter's symptoms seemed to improve. When the pinworms returned a while later, the doctor prescribed albendazole, a prescription treatment that has been around for decades. Williams thought little of it, until she checked the price with her pharmacist. The drug cost \$724 for a four-tablet treatment, and according to her drug plan, she had to pay about \$250. Because her doctor recommended that all four family members be treated, she was suddenly facing a \$1,000 bill.

To save money, Williams decided to fill prescriptions for her daughter and herself, but to buy the over-the-counter treatment for her husband and younger daughter, who did not have symptoms. A few weeks later, Williams found pinworms in her younger daughter's diaper, and had to pay \$250 for another round of albendazole.



Aviva Williams' four-year-old daughter, Amy. (Melissa Lyttle for The New York Times)

She said she is furious that she was forced to pay \$750 for an old drug. "They price it because they can," said Williams. "Wall Street decided they could make money off prescription drugs, which is just scary and depressing."

WHAT'S GOING ON HERE

Although albendazole lost its patent protection years ago, just one company, Impax Laboratories, sells the drug. Its high price dates to 2010, when a company called Amedra Pharmaceuticals — later acquired by Impax — bought the right to sell it from GlaxoSmithKline, and raised the price to about \$120 a pill from roughly \$6. A spokesman for Impax Laboratories declined to say why Amedra raised the price.

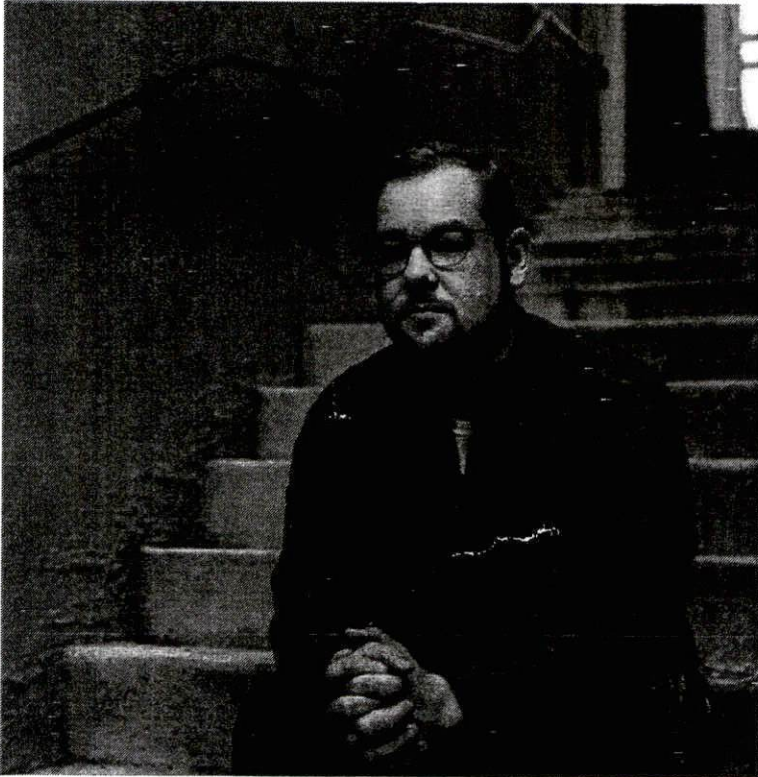
Williams saved her bottle of albendazole as a bitter reminder of how she once had to pay hundreds of dollars for a handful of pills. The other day she noticed a detail she had not seen before: Impax does not even make the drug. It is still manufactured by GlaxoSmithKline.

A Shell Game of Debt

MATTHEW BOTTS, 34, OAKLAND, CALIFORNIA

In 2007, Botts was 24 and three weeks into his first year at the University of San Francisco School of Law when he was diagnosed with chronic myelogenous leukemia, a blood cancer. His doctor prescribed Gleevec, an effective but expensive medication that until recently cost more than \$140,000 per year. The price recently began to go down in the face of generic competition.

Botts had no money to spare. For the first months of his treatment, he was able to take another patient's unused medications that were no longer needed (she was dying and his oncologist had connected them). Then, after receiving coverage through a former employer, Botts moved up his wedding date so he could switch to his wife's policy. But between his deductible and out-of-pocket costs, his expenses added up. Botts applied for assistance through a program run by Gleevec's maker, Novartis, but said he was rejected because his wife made slightly too much.



Matthew Botts (Andrew Burton for The New York Times)

Without options, Botts tapped into his law school loans. "At 24, when you're really not making any money, you don't really have any options other than that," he said. Botts dropped out of law school. "When everyone else is 24, 25 and going out and partying," he was worried about ensuring he had money "so I could make sure I paid for my chemotherapy meds and still go to class."

Today, he owes more than \$73,000. He works at a debt collection company in the Bay Area, managing corporate relationships for banks. The irony is not lost on him. “We have a huge pile of medical debt that resulted from all of this. It just hasn’t been paid,” he said. “I will be paying those up until the day I die.”

WHAT’S GOING ON HERE

There’s no dispute that Gleevec is a breakthrough cancer drug. It is also a very expensive one whose cost has increased sharply over the years. When it was launched in 2001, Gleevec cost \$26,000 a year. That price increased significantly, to about \$146,000 in 2016, before the drug lost its patent protection and began facing generic competition. The drug’s price has been falling since then, though not as quickly as some hoped.

In a statement, Novartis, the maker of Gleevec, said it was not familiar with Botts’ situation, but that it “offers one of the most significant patient assistance programs (PAPs) in the industry.” The company suggests that patients contact its assistance program, Patient Assistance Now Oncology.

Overall, cancer drug prices are increasing at a rate much faster than inflation.

Charles Ornstein is a senior editor at ProPublica, overseeing the Local Reporting Network. From 2008 to 2017, he was a senior reporter covering health care and the pharmaceutical industry.

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