

## Patients for Affordable Drugs Share Their Stories

### Ramae Harmin, Bemidji, MN

In 2018, I was Ramae Harmin — a 47-year-old single mother, long distance runner, and high school math teacher. Then I was diagnosed with an incurable blood cancer called multiple myeloma. Now, for the rest of my life, I will be a cancer patient.

I took a leave of absence from my job as a teacher to undergo several surgeries, radiation, an induction chemotherapy regimen, and a stem cell transplant. My slow recovery from the transplant coupled with the intense fatigue from my daily maintenance regimen has prevented me from returning to work. I have just enough energy to take care of myself and my son.

I also have just enough money to live. For now, I receive long-term disability from my former employer and from SSDI. I am currently still on my private insurance plan through Cobra, but I will make the switch to Medicare at the end of the year. My only income is 60% of my former teaching salary and some child support that will end when my son turns 18. I also have two college-aged daughters that I help to support as well. Other than a high yearly deductible and the monthly Cobra premiums, I have paid very little out-of-pocket for my medical treatments and medications. My maintenance drug, Revlimid, is not fully covered by my insurance plan, but I do qualify for \$25 copays through my drugmaker's assistance program. The drug maker charges my insurer between \$15,000 and \$25,000. My assistance will evaporate once I start on Medicare. I'm terrified.

**Myeloma patients on Medicare are paying as much as \$3,000 out-of-pocket per month for Revlimid and other drugs.** There are grants available for some, but not all qualify. I don't know if I will qualify or if the grant money will be there when I need it. What I do know is that I won't be able to afford this monthly cost without selling my home and using every penny I've managed to save — and even that will only last so long.

### Margaret, MN

My name is Margaret and I'm from Minnesota. When I was 19 years old, I was diagnosed with Crohn's Disease. Because I was on my parents' insurance, I had no clue how to navigate insurance coverage for my care and medications. For a number of years, the price of my drugs never crossed my mind. But when I turned 26 and was no longer eligible for my family's insurance plan, things got tricky.

I was ultimately added on to my husband's insurance, but the switch was far from seamless. In addition to switching insurance I had moved to a new state, and my first infusion in California came with a copayment of \$6,000. When I called to see why my patient assistance program wasn't paying for the drug, I was told that my membership had lapsed. While I eventually regained membership, Janssen Pharmaceuticals won't

retroactively cover that first infusion — meaning I'm stuck with a bill for \$6,000 that is rapidly accumulating interest.

**\$6,000 per dose is a number no patient should have to pay just to control their debilitating symptoms. The price of my drugs is high, and that's without even mentioning the high cost of my other medical care, like trips to the Mayo Clinic and appointments with chronic care specialists.** Because of these expenses, I've been forced to move back to Minnesota and go back to living with my parents at the age of 30. This isn't the life I imagined for myself — but it's something many patients are experiencing because the medications we need are simply too expensive to keep up with.

Years after my initial experience with the drug Remicade, I've been switched to Stelara and am once again struggling to get Janssen Pharmaceuticals to cover that medication through patient assistance. Drug companies advertise patient assistance programs, but the hoops I've had to jump through clearly show that even with these programs, patients are slipping through the cracks and ending up in debt.

This issue is difficult for me to rehash — it triggers a lot of depression and anxiety for me to talk about what I went through and continue to go through. But I think it's important to speak up. Statistically, many young girls like me get diagnosed with Crohn's Disease in college, when they have financial support from family and health insurance. It gets more complicated once you turn 26, and I want more patients to know how to work as their own advocates. This issue is serious, and it's impacting a lot of people.

### **Travis Paulsen, Eveleth, MN**

My name is Travis Paulson and I am from Eveleth, Minnesota.

I have been a Type 1 diabetic for many years, but affording insulin wasn't that difficult as a child — it was about \$8 a vial. The problems came when I was in my late twenties and early thirties. I was working in finance full-time and going to college full time, and my insurance had a deductible of \$7,500. **Insulin at the time ranged from \$300 to \$350 a vial, and I required about five vials a month.**

There were times I couldn't scrape together \$5 and was just plain poor due to these costs. On several occasions I starved myself and took less insulin than I was supposed to so my vial would last longer. Unfortunately, even doing that, I would run out of insulin. I wasn't involved in diabetes groups and knew no other diabetics. I don't even think there was a name for rationing insulin at the time. I thought I was in a unique situation, so I didn't reach out for help.

**All those years of rationing insulin have caused diabetes retinopathy, insulin resistance, and long-term complications that never would have occurred if I had access to affordable insulin.**

I would stay in bed and call into work sick until my paycheck cleared the bank. I'd then force myself up and get to a pharmacy and get insulin. It's really hard to move when your blood sugar is that high. I remember feeling like I wasn't going to make it, but somehow I did. Ten years ago, I had never heard of anybody dying from rationing insulin, so I figured that while it wasn't a good thing, it wouldn't go so far as to kill me. I've learned since then that I was just very lucky at the time — I easily could have died. It was during the financial crisis of 2007 to 2008 that I was forced to ration insulin again. Times were tough for lots of people. I remember camps of ex-financial services workers living in tents. But aside from just finding housing during the financial crisis, I had an additional problem: I had to afford my insulin. I traveled around the country working odd jobs to afford insulin and rationed what I had, living a meager existence and working warehouse jobs wherever I could.

It was after I came back home to Minnesota to get back on my feet that I decided I would no longer tolerate the abuse and hold on my life Big Pharma had. I realized I could get insulin from Canada for less than a tenth of the price I was paying in the U.S. From then on, I have been getting my insulin in Canada and helping others to do the same.

The unfortunate thing is that all those years of rationing insulin have caused diabetes retinopathy, insulin resistance, and long-term complications that never would have occurred if I had access to affordable insulin. My health is what paid the price.

### **Lija Greenseid, St. Paul, MN**

A few years after my daughter was diagnosed, I heard Nicole Smith-Holt talk about losing her son, Alec, after he rationed his insulin because of the price. I knew then that I needed to get involved. Nicole's story was similar to other people's stories, and I worried it could be mine too if someday my daughter couldn't afford or access her insulin.

Four years ago, my family and I traveled around the world and bought insulin at one-tenth or less the price we paid at home. I grew frustrated thinking of all the families like mine who were paying unreasonably high prices for our insulin, and especially of the families like Nicole's who had lost loved ones because of the price gouging on insulin. The United States is unique, in a bad way, in how expensive insulin is here. Other countries pay a fraction of what we pay for our insulin. I started sharing my story and took an active role in the fight for affordable insulin.

Though I work part-time as a program evaluator, I began spending more and more of my time advocating for affordable drugs and health care changes. Living in Minnesota, just five hours from Canada, I and several other people with diabetes organized a cross-border trip to raise awareness of the unaffordability of insulin and to purchase the drug at one-tenth of the US price. There have been multiple of these "Caravans to Canada" trips and they have gained national media attention, pressuring elected officials and drug companies to acknowledge the unreasonable price gouging on insulin.

January 2023

Additionally, it brought attention to the thousands of people every year who travel to other countries just to afford their life-saving medications.

When it comes to cheaper insulin prices, Canada isn't an outlier. Their prices could be our prices here in the United States. If our lawmakers allowed Medicare to negotiate with drug manufacturers as the Canadian public insurance does, the price would decrease significantly. We need lawmakers with the courage to prioritize patients and work to decrease the cost of prescription drugs like insulin.

Because of our advocacy in Minnesota, some insurers in our state have capped their prices, allowing some people to only pay \$25-30 a month for insulin. Additionally, we passed the Alec Smith Insulin Affordability Act which provides a safety net for Minnesotans who can't afford their insulin. But this is not enough. Insulin is just one drug. We need solutions both at the state and national levels to address the system-wide greed of drug companies. Drug companies continue to charge ridiculous prices, further exacerbating already existing racial and economic inequities in our health care and prescription drug systems. High prices disproportionately affect black and brown communities, the same people hit hardest by the COVID-19 pandemic. In such a critical moment in our country, I'm inspired to refocus my activism and continue advocating for a more just system.

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