

Bonnie Deane
Appleton

My name is Bonnie Deane and I live in Appleton, Maine.

My son, Dakota, was diagnosed with severe Crohn's Disease and juvenile arthritis in 2014 when he was 14. When he was diagnosed with the disease, he began receiving Remicade infusions every six to nine weeks to treat the rheumatoid arthritis and severe Chron's Disease. The cost of each Remicade infusion is \$78,000.

When my son was first diagnosed, I was working four jobs and had health insurance through my employer, but the coverage was not good. We had to meet a deductible and after the deductible was met, we were responsible for a copay for the infusions. Each and every year since, we've had to pay \$10,000 or more toward our deductibles and copays and have hit the maximums every year. These medical and insurance expenses have placed our family into deep financial distress. All of the bills have ended up in collections, which is stressful. There is no choice with these bills. We're trying to pay these medical bills off to the best of our ability. These are life and death decisions parents have to make when a child has a disease.

We signed up for a discount program through the drug manufacturer, but even with that, my husband and I have medical debt in the six-figure range because of the cost of Remicade and other family medical expenses. Our medical debt is more than what we paid for our house. My husband and I are almost 60 and we're going to be dealing with this medical debt for the rest of our lives.

My son has to have this drug or he'll die. He's 20 years old now and has just recently qualified for MaineCare after losing his job, but I worry about how he'll afford these infusions once he's back on his feet and working again. It's definitely an eye-opener. I pity anyone who has a child who has any kind of disease. It's financially devastating for people. There's no help, but he has to have it to live.

What I want you to understand is that it doesn't matter whether you're blue collar, you're a millionaire or you're on welfare. If you're really sick and you need a drug like Remicade to survive, you're going to lose everything — and there's something wrong with that. I don't want anyone else to ever go through what we continue to go through.

Thank you.

Bonnie Deane
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