

Hi. My name is Rowan and I am going to be three in September. I've had IBD almost since birth. My big brother, Aidan, also got IBD as an infant. He's going to be six soon and he's been doing very well on Pentasa. My parents went through a lot with him and thought they'd learned what they needed to know, but boy did I show them!

My mom thinks I probably started having diarrhea some time in my first two weeks, but when she found blood in my diaper the day before my 2-month birthday she could no longer deny there was a problem. My mom was nursing me so the doctors told her to stop eating food that can cause allergies. She wasn't really happy with this—for a while she wasn't eating much more than potatoes—but she would do anything for me. There wasn't very much blood at first, but it kept getting worse and worse. By the time I was 7 months old, I was bleeding very badly. My doctor wanted me to stop nursing and drink an elemental formula but I did NOT want to do that. My parents tried and tried and tried to get me to drink the formula, but I refused. After ending up in the hospital severely dehydrated (when I say I don't want to drink something, I mean it!), I got a feeding tube. I hated that thing! My mom would hold my head between her knees and my arms in her hands while my dad sat on my legs to put it in. I would scream and cry the whole time. That whole episode was so traumatic that after it I refused to eat or drink anything. Meanwhile, since Pentasa worked so well for my brother I started taking that. I ended up being allergic to it so I had to stop it. Since I still wasn't getting better my doctor started steroids. Everyone hoped I would start improving quickly, but I just continued to get worse. The steroids made me feel awful, too, and I didn't want to laugh, talk, or play anymore. I cried if I wasn't being held all day long. I got really fat and stopped growing. I plummeted off the growth chart and stopped being able to do many of the things I had learned to do. I spent six weeks of my first summer in the hospital. I got so anemic that the doctors wanted me to get a blood transfusion. My doctors tried vancomycin, metronidazole, probiotics, and complete gut rest. Only gut rest seemed to help and I finally was able to go home. But I quickly started to relapse. My doctor started 6-MP, but that gave me pancreatitis--what a miserable first birthday!

I was so little that everyone was nervous about trying new drugs on me. There just isn't any information about using many of the IBD drugs in babies and no one really knew how they might affect me. But something had to be done. Finally, after a lot of consideration and consultation with different specialists, my doctor started me on Leukine. This isn't a common treatment for IBD, but it was one of the safer options. Miraculously, after about 6 weeks, it worked! I was doing great! Unfortunately, my insurance company didn't want to pay for it and at about \$100 a day it wasn't an expense my parents could afford for very long. After four months of appeals, lots of help from the doctor and my favorite nurse practitioner, and the involvement of a great lawyer the CCFA referred us to, the insurance company was finally forced to pay for it. But that relief was short-lived because I had a bad relapse when I was about 17 months old. I spent two more weeks in the hospital. Once again, steroids didn't work. I got a PICC line so I could start TPN and gut rest. But this time it took a long, long time for the gut rest to help. After about 2 months of TPN I still wasn't all better so the PICC line was pulled and I got a Broviac catheter. That line didn't stay in place properly so a month later I had to get it replaced.

By last summer I was finally doing really well and my doctor told me I could eat again. But I didn't want to eat or drink; I was still traumatized by my horrible experience with the formula. So I spent a month at the CHOP feeding clinic learning how to eat and drink. That was a lot of hard work for me and my parents. I'm a really good eater now. I was doing so well that by the fall my doctors started weaning me off the TPN. But just as I was about to stop the TPN and have my catheter pulled in

time for Christmas, I had another bad relapse. I had to restart TPN and my doctor increased my Leukine. I also restarted some probiotics. I had a scare and another week in the hospital during the big snow storms when I got a line infection. Luckily that infection wasn't something really bad. I slowly started getting better after that, though I never got as well as I was last summer. My doctor thought I was doing OK enough to try weaning off the TPN though, so I started eating more and more until my TPN was finally stopped.

Unfortunately, it seemed like I was starting to get worse again. It's wasn't too bad at first so my parents were just nervously monitoring the situation. I ended up back in the hospital for another week with yet another line infection. I got a little sicker that time, but once again I was really lucky that the infection responded easily to treatment. My doctor and parents were torn about what to do with my catheter. They were afraid I could get a bad infection if it stayed in, but also afraid that I'd need it again soon if it got taken out. They decided to leave it in and see how I did. I just kept getting worse. My doctor tried increasing the Leukine again, but that didn't do anything so my doctor decided it was finally time to stop that medication. After lots of consideration and consultation with other specialists, my doctor and parents decided to start Remicade. So far it doesn't seem to be helping, plus I got an infusion reaction on just my second dose. My parents are really worried that Remicade is not going to be an option for me and since the list of remaining options is growing increasingly smaller and less appealing they aren't sure what to do next.

When I think about my short life, it's easy to get lost in all the medical stuff I've been through. I've spent months in the hospital (I even left some of my toys in the playroom so there would be more fun stuff for the little kids), I had a year of therapy to help me catch up on my development, I've had three sigmoidoscopies, six colonoscopies, and six upper endoscopies, I get my blood drawn ALL the time (I'm so good for that that I'm better behaved than my big brother!), I used to get injections every night, still get dressing changes every week, and when I was on TPN my parents had to wake me up every night to change my diaper so it didn't leak from all that fluid. But I've been growing up, too. I learned to carry my own TPN bag around so my parents didn't have to follow me everywhere. I've learned how to hold my arm out for a blood pressure and how to pick it up for my temperature. I learned to hold still for my injections and to not wiggle or cry during my weekly dressing changes. I've learned to tell my mom and dad when my tummy hurts and when I have to go potty. I'm trying really hard to do as many normal things as possible. I started school last fall and I love it! I've learned how to use scissors and how to hold a pencil. I know my shapes and colors, the letters in my name, and I can almost count to 20. I'm really lucky to have teachers that don't mind having me at school with my IV catheter. And when I'm home I like to go to the playground, play with my train tracks, and goof off with my big brother.

It is a privilege to be a Team Challenge honoree. I hope my story will help raise awareness of IBD and make people understand why it is so important for us to raise money for research. My brother and I hope we can grow up and have our own kids, knowing that they won't have to go through what we've been through.