

Hannah Grauso's Story (Reno, Nevada)



I was two years old when I was diagnosed with ulcerative colitis, a chronic, incurable inflammatory bowel disease (IBD). My childhood wasn't exactly "normal", but I managed okay until my symptoms flared in high school. The pain was horrible, but things got even worse when I couldn't take the medication my doctor believed had the best chance of helping. I needed to try and fail another medication first — a practice known as step therapy.

I imagine it was tough for my parents when I was a toddler, when I was unable to communicate how I was feeling except to cry from pain in my stomach. I have no memory of spending four weeks in the hospital after being diagnosed with ulcerative colitis, but I know the medication I started taking relieved the pain and diarrhea, and I went into remission for four years.

Eventually, the medications stopped working. When I was eight years old, I had surgery to remove my entire colon. The surgery helped; my symptoms went away and although I occasionally experienced inflammation around the j-pouch that was created to replace my colon and rectum, it was never too serious. Then, when I was 14 years old, I started suffering from severe abdominal pain and frequent diarrhea. Antibiotics helped at first, but when my symptoms worsened, my doctor did a colonoscopy and diagnosed me with Crohn's disease.

My doctor wanted to put me on a specific biologic medication, but he said our insurer would require me to try and fail on another medication first. I was constantly going to the bathroom, I had bad stomach pain, and low appetite, which led to weight loss. Half-way through sophomore year of high school, I had to stop competing on my school's debate team. I was missing school and my social life was essentially non-existent. There were days I could barely get out of bed, and I didn't think I was going to be able to go away to college. Finally, after a year of failing on the medication my insurer preferred, I was able to start the original treatment my doctor had wanted me to take.

It's been almost two years, and the injection I take at home every eight weeks is working to keep my symptoms at bay. I did go away to college, and I am enjoying it immensely. I just can't shake the frustration knowing that I, and so many other IBD patients, needlessly suffer and miss out on so much. That's why I'm advocating alongside the Crohn's & Colitis Foundation as they call on Nevada and federal legislators to pass step therapy reform, so that all patients with private insurance have access to an expedient and medically reasonable appeals process.

Learn more at www.crohnscolitisfoundation.org/steptherapy.