

Macy Stahl's Story (Charlottesville, VA)



When I was 15 years old, my Crohn's disease flared, and I lost half my body weight within six months because I couldn't eat normal foods. I was so relieved when the nutrition shakes my doctor recommended allowed me to gain weight and get my Crohn's under control. But I couldn't believe that our insurance company wouldn't pay, just because the nutrition wasn't coming through a tube inserted in my body.

I was just eight years old when I was diagnosed with Crohn's disease, a chronic, incurable inflammatory bowel disease (IBD). At first, my symptoms weren't too bad. I rarely missed school, and I enjoyed training as a competitive dancer and contortionist. Then, in high school, I began experiencing frequent flare ups. Eating caused extreme pain and diarrhea. It was so bad I had to sleep on a blow-up mattress in the hall to be close to the bathroom. My doctor prescribed steroids to control the inflammation, but they didn't work. It was a vicious cycle -- the less I was able to eat, the harder it was for my body to fight Crohn's.

I missed school for months at a time and had symptoms of malnutrition, like hair loss and brittle bones. When I was a sophomore in high school, I was admitted to the hospital for a few weeks. I was put on total parenteral nutrition (TPN), which delivered nutrition through a line to an artery near the heart. That was only a short-term solution to help me gain the few pounds necessary to transition to oral nutrition.

After my hospital stay, my doctor recommended nutrition shakes, which I relied on for a year while I slowly integrated regular food back into my diet and got to a stable weight. I can't understand why insurers would have paid for a feeding tube, but wouldn't cover the medically-necessary foods that allowed me to regain my healthy weight. I am fortunate that my parents could afford the shakes, but not all families are able to pay up to \$60 per day for this treatment.

My junior year in high school, I was able to start the process of finding the right biologic treatment to further address my Crohn's symptoms. This was only possible because the shakes had helped me gain enough weight to take the medication. I'm able to dance again, and I am preparing for a career in nutrition.

My experience is why I'm working with the Crohn's & Colitis Foundation to urge members of Congress to co-sponsor the Medical Nutrition Equity Act, so that all Crohn's and colitis patients have access to medically necessary foods like the ones that helped me thrive again.

Learn more about the Medical Nutrition Equity Act [here](#).