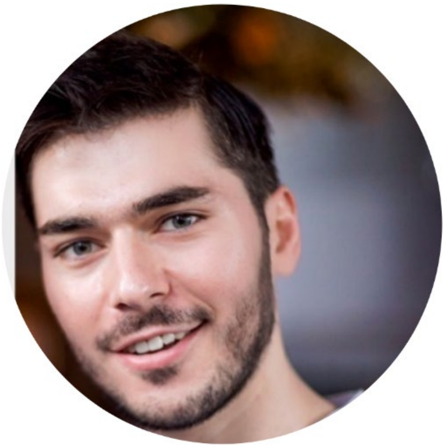
Eitan Kling-Levine's Story

(New York, NY)



I was 21 years old, healthy, active, and pursuing a degree in drama at NYU when I was diagnosed with ulcerative colitis, a type of inflammatory bowel disease (IBD). My doctor started me on steroids and other oral drugs right away, but they didn't help. I felt hopeful when he recommended a stronger, targeted biologic therapy, but my insurance company said I'd have to try and fail on other less costly medications before they would pay for the new one.

I dedicated six months of my life to trying and failing on the medications my insurer preferred, a protocol they call step therapy. That was half a year of continued symptoms—urgency, bleeding, weight loss, inflammation, and ulceration—causing permanent damage to my colon.

Over those six months, I missed my final semester of college and my graduation. My social life was reduced to conversations with my mother through the bathroom door. The fulfillment of acting on stage was no longer part of my life, and I transformed—mentally and physically— into someone who was unrecognizable to both my loved ones and to myself.

By the time my insurer approved the medication my doctor originally prescribed, my colon was in bad shape. I spent 15 weeks on the treatment but saw no improvement—the damage that was done was irreversible. That summer, my colon was surgically removed, and I began life with an ostomy bag. In November, my rectum was removed, and the following February, my ostomy was reversed. During that surgery, the end of my small intestine was reshaped into an internal pouch to replace the organs I no longer had.

Today, I know what triggers my colitis and I'm never panicky about knowing where a bathroom is. My life is sort of normal again, but my body will never be the same. I missed out on so many simple joys, and I have to deal with the effects of long-term steroid use, including cataracts and weakened bones. I often wonder whether I could have avoided pain, hospitalizations, surgeries, and emotional struggles if I had been allowed to follow my doctor's earliest medical direction.

I don't want other IBD patients to go through the struggles I did. That's why I'm joining the Crohn's & Colitis Foundation in raising awareness of the New York-passed step therapy reform laws and calling for the U.S. Congress to pass step therapy reform. I believe all patients with health insurance should have access to an expedient and medically reasonable appeals process.

Learn more at www.crohnscolitisfoundation.org/steptherapy.