

# Katie O'Grady

## Cystic Fibrosis



I was born in relatively good health in New York in 1995. As a child, I had some gastrointestinal (GI) issues that just seemed to get worse, with no explanation. They thought it was Crohn's Disease (because an aunt of mine had it), then thought it might be lactose intolerance when the tests came back negative. Eventually, I was diagnosed with cystic fibrosis (CF) at the age of six.

Early on, I felt like a normal kid. My symptoms were limited mostly to just GI issues. But then I started missing a lot of school because of my health issues. I couldn't leave the bathroom, pretty much. I started getting all these medical treatments and I didn't really understand it. My thinking at that age was that I had this problem, and a doctor would give me medicine that would make me better – much like treating a cold. But I soon realized how invasive treatments could be. It was frustrating when I'd have to do my nebulizer and other medical treatments, sometimes for hours.

As a child and adolescent, I remember being very embarrassed by my disease. Early on when my symptoms were mostly GI, I felt ashamed as I thought CF was a bowel movement disease. I did not tell any of my classmates and never talked much about my medical condition. If I had friends or family over, I just would just refrain from doing my treatments. But as I started to get older and moved into middle school, I started to get a lot of chronic sinus infections. These sinus infections then became lung infections for which I was hospitalized several times. That was a very confusing and disorienting time for me as no one else I knew needed to go for surgery. I felt isolated and very alone.

There was one instance when my science teacher was talking about CF, and I remember I immediately froze up. No one in class knew about my disease except my teacher. At one point, she said, “Right, Katie?” indicating to everyone that I had it. And I sat there in silent embarrassment with everyone staring at me. It was mortifying. Kids came up to me afterward asking if I was okay, if I was going to die.

In another incident on the school bus, a classmate mentioned that his mom underwent an ultrasound to see her baby. I chimed in that I had had an ultrasound (for surgery), but the other kid didn’t understand and then all the kids started laughing at me. Situations like those were hard to deal with as a youth as I tried to navigate my health issues while also dealing with the emotional challenges of fitting in.

When I started high school, my mom was unfortunately diagnosed with Stage 4 colon cancer. In my senior year of high school her health really started to deteriorate. She was my best friend, and I never left her side other than when I went to school and after-school sports. As she got more ill, my health also deteriorated. My doctor ended up telling me that since I was under so much stress and anxiety my body could not handle it anymore. While my mom was in hospice, I came down with pneumonia. Thankfully, because we had a hospice nurse at our house, I was also able to get IVs at home so I could be with her. It was the most ill I had ever been, and I can only imagine how my dad must have felt having to take care of my mom and I.

Stress and anxiety are so much more powerful than I think a lot of us realize. Having a support system is important for your mental health but also your physical wellbeing, especially when you have a chronic illness. I didn't get mental help during this time, but my family was always supportive. The other thing that really helped me cope was discovering my passion for running. I started running in middle school and subsequently joined the track and cross-country team and ended up being good at the sport – often coming in first place in competitions.

I kept running throughout high school and beyond. It was not without its challenges and there were times when I placed last in some competitions, which coincided with my symptoms getting worse and the stress of my mother's worsening health. But running did enable me to be a more

empowered and confident version of myself than I would have been without it.

Running changed everything for me. It improved my symptoms and cleared out a lot of the congestion I had to deal with in living with CF. It gave me something to look forward to and it enabled me to connect with others with CF. I even participated in the Boston Marathon in October 2021, on a team of 10 runners to raise funds for the CF Foundation. It was an amazing experience—everything from pre-race training to the post-race activities. I am still in touch with many of my fellow runners today. I would encourage anyone living with CF to get the mental help they need, find a passion they love, and develop a support system that works for them. ●

## Cystic Fibrosis (CF)

Cystic fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. While there is no cure, life expectancy has steadily improved in the United States. Some other facts about cystic fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
- CF individuals have abnormally thick mucus, which blocks the airways (obstruction) and leads to repeated infections and damaging inflammation in the lungs. Treatments are directed at trying to prevent.

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