Billy Anton

PRIMARY CILIARY DYSKINESIA (PCD)

Billy Anton was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

On the outside I look pretty normal, but there's a battle going on in my lungs: primary ciliary dyskinesia.

I had most of the classic PCD phenotypes shortly after birth which allowed for early diagnosis and treatment. Many PCD patients go decades without a definitive diagnosis. At first, PCD didn't prohibit me from being a kid. Though I did get sick and required antibiotics, I always bounced back quickly. I was very active, playing upwards of 100 basketball games per year, and never felt that I was physically inferior to other kids.

My teen years didn't come as easily. I was almost willfully ignorant to PCD, not always complying with my treatments. Then I stopped playing sports, and I started getting sick more often. I missed school, had more courses of antibiotics and got increasingly frustrated. I refused to accept PCD as a part of my life, so I pretended that it didn't exist, allowing it to take over my life on its own terms.

I was hospitalized for the first of 7 times when I was 17. I felt physically depleted. My doctors insisted this was just the cycle of PCD, even though my rapid decline was atypical. With college approaching and my health in question, I decided to stay local, missing out on the "college experience." I finally sat back and considered how much PCD was affecting my life.

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I began doing my treatments with a purpose, twice a day, and saw small improvements. I incorporated physical activity again. I gained confidence in my ability to fight and find stability in my health care. In 2015, I got involved with the PCD Foundation as a volunteer, and I now serve as vice chairman of the board.

Currently, my lung function hovers around 50 percent, and I have a chronic cough. I have sinus issues, and moderate pain caused by severe bronchiectasis in my lower lobes. I often consider how quickly my health will deteriorate or how PCD will affect my quality of life. I know what potentially lies ahead: sinus surgery, hospital admissions, PICC lines with IV antibiotics, oxygen supplementation, and potentially a double-lung transplant. Hopefully some of those things are many years away. I try my best to stay present, but you can imagine how easy it is to look back and question some of my past health choices.

It's an honor to represent the PCD patient community and I also want to express how grateful I am for researchers who work tirelessly to better understand PCD. PCD is a serious disease. It's not "similar to asthma or allergies," or even a "milder CF." It's a progressive respiratory disorder that can be debilitating. ■

Primary Ciliary Dyskinesia (PCD)

PCD is an inherited disorder, meaning that people born with the disease receive a mutated (abnormal) gene from both parents. In PCD, mutations in the genes responsible for building cilia and controlling their function result in cilia that do not work effectively. PCD causes frequent respiratory infections starting at a very early age that result in lifelong, progressive lung, sinus, and ear disease.

Symptoms of PCD start very early in life, usually during the first year, and include:

- Neonatal respiratory distress (trouble breathing shortly after birth) in full-term babies, usually requiring oxygen therapy, and often lasting days to weeks.
- Daily, year-round, nasal congestion.
- Daily, year-round, wet (mucus-producing) cough.
- Chronic middle ear fluid and ear infections that can lead to hearing loss or speech difficulties
- Chronic sinus infections.
- "Sidedness" differences (situs inversus totalis or situs ambiguus/heterotaxy), including congenital heart defects.
- Male infertility (inability to make a woman pregnant), since sperm tails use the same genes as motile cilia.
- Reduced fertility in women (inability to get pregnant) related to cilia dysfunction in the Fallopian tubes.

Learn more: ATS Patient Education Information Series. "Primary Ciliary Dyskinesia (PCD)." ***www.thoracic.org/patients/patient-resources/resources/pcd.pdf***