Jennifer Eisenmann

CYSTIC FIBROSIS

Jennifer Eisenmann was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

I'm 48 years old and I have cystic fibrosis. When I was 12 months old, doctors told my parents they would be lucky if I lived to my teens.

Despite having two protein-processing mutations, I was not very sick as a child. My mom did hand percussion on me to loosen mucus and I took enzymes to help digest my food. I started noticing deficiencies in my breathing when I was in college, and I got scared. I attended my first real cystic fibrosis clinic when I was 22, and began twice-daily breathing treatments as well as frequent hospitalizations to deal with infections.

In 2014, I had a typical blast of IV antibiotics, but I still got worse. It took weeks to get over. I decided it was time to accept I needed a double lung transplant, so my husband and I moved to North Carolina to be close to two great transplant centers. It took another bad infection in July of 2016, which nearly cost me my life, to be deemed "sick enough" to start the listing process. I received my transplant that December. Those five months were the longest of my life. Sometimes I wasn't sure I would live long enough to get a transplant. I worried about what the surgery recovery would be like. But most of all, I dreamed of what it would be like to take a full breath.

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While I am very grateful for my transplant, it truly is trading one set of problems for another. I have struggled with my weight, undergone multiple surgeries. All of this, and the average life expectancy five to nine years after transplant is only 50 percent. I've seen many of my friends die from rejection, pneumonia, kidney failure, and cancers that are common to post-transplant recipients.

The average life expectancy for someone born with CF in the U.S. is now 44-46 years old, but it is still widely known as a pediatric disease. I hope this perception changes. I am happy to report that I have been feeling well for several months now and enjoy time doing "normal" things like spending time with my family, going out with friends and taking my dog to the park. Most of all, I enjoy being able to take deep breaths once again. Without the medical and research community I would not be here today. ■

Cystic Fibrosis

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. Those with only one CFTR mutation are carriers and do not have it. If both parents are carriers there is a one in four chance their child will have the disease. While there is no cure, life expectancy has steadily improved the median survival exceeding 45 years in the United States. Some other facts about cystic fibrosis are:

- There are now more adults than children with CF in the U.S.
- 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.
- Older children and adults are usually diagnosed based on symptoms, such as frequent respiratory infections, malnutrition, and/or male infertility.
- 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 and treat these problems.

Learn more: ATS Patient Education Series 20 Facts about Cystic Fibrosis. New York, NY. ***www.thoracic.org/patients/patient-resources/resources/cystic-fibrosis-facts.pdf.***