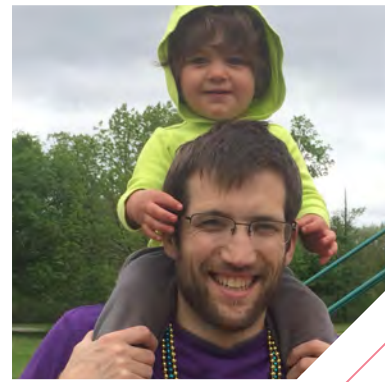
Chris Kvam

CYSTIC FIBROSIS



My name is Chris. I am 37 years old, and happen to have Cystic Fibrosis. I am also an avid cyclist and runner, assistant district attorney, and husband. I ran competitively in high school and college, and continue to push my limits athletically. I have made exercise the keystone in my CF care, and strive to live fully by setting healthy goals.

I was diagnosed with CF in 1984. My doctor told my parents to treat me like a normal kid, and when I got sick, we'd deal with it. I was never sick or disabled. I grew up maximizing health, regardless of what my lung function was. Enzymes, chest physical therapy, nebulized treatments and other drugs became part of my normal, the small price for having the chance to participate and excel.

I spent much of my young adult life trying to avoid hospitalizations. I viewed the prescription of IV's as a failure on my part. My lung function would decline, but I would convince my care team to give me a few weeks before ordering the cleanout. I'd spend that extra time doing everything possible to raise my lung function just enough to prevent the hospitalization.

Chris Kvam was a patient speaker at the ATS 2018 International Conference in San Diego, California.

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Ultimately, I became very sick, and couldn't climb up two flights of stairs. I realized that my attitudes towards CF, my CF self-care and goal-setting had to change. I became focused on maximizing my health status, and recognized that cleanouts were a tool in that effort.

Today, I direct my own care, and I collaborate with my care team to make my health care decisions. I can't remember the last time a pulmonologist told me something about my lungs I didn't already know.

Adherence to care is not easy, and at times, life with CF is not easy. Not everybody is passionate about exercise, but everyone with CF can be passionate about something, and can learn to use that passion to drive their adherence to care. This doesn't mean adherence is easy, this means that adherence is worth it. ■

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 carries 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 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.
- 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.***