Heather Snyder

PULMONARY FIBROSIS

"To this day, I always tell doctors: 'A patient's will to live is stronger than a doctor's opinion. Don't give up on someone who has not given up on herself.'"

I am a double-lung-transplant survivor of pulmonary fibrosis, which has affected my whole life, starting with my father. He was diagnosed with IPF and was given oxygen for palliative care. With three children, he was not about to give up. So, he participated in drug studies and even posed as a doctor to research his disease at the library of the National Institutes of Health. He would have a hard time breathing and would stop a lot to catch his breath. His back was covered with severe acne as a result of the high doses of pednisone and the drug studies.

He pushed himself to the limit, and although he prepared us as much as possible, nobody understood how this disease would continue to haunt our family.
I was nine when he died. The divorce rate was not like it is now, so I didn't have too many friends that I could identify with. My mother worked 10-hour days, six days a week, which left my two sisters and me home alone fairly often.

I loved track-and-field in middle school, but that came to a halt in high school because of my breathing issues. In college, I would work out and run short distances, but I stopped often to cough and catch my breath. I switched to kickboxing, but the more I worked out, the more out of shape I felt.

In 1998, an allergist diagnosed me with asthma, loaded me up with meds and inhalers, and sent me on my way. After years of struggling to breathe with routine tasks, I finally said enough, my father died of lung disease—I need a chest X-ray. HCRT shortly followed.

My pulmonologist took one look at my "clubbed" fingernails and referred me to a cardio-thoracic surgeon for a thoracotomy. The lung biopsy indicated fibrosis.

PULMONARY FIBROSIS

Pulmonary fibrosis describes a group of lung diseases in which thickening of the walls of the air sacs (called alveoli), caused by scarring, can result in cough, shortness of breath, fatigue and low blood oxygen levels. It can be caused by an identifiable irritation to the lungs, but in many cases the cause is unknown, which is described as idiopathic pulmonary fibrosis (IPF). Idiopathic means there is no known cause at this time. Symptoms include:

- Dry cough or shortness of breath
- Abnormal breath sounds—crackles (like Velcro) can be heard by your health care provider when you take a deep breath
- The ends of your fingers and/or toes have changed to a club shape (called "clubbing")

Learn more: ATS Patient Information Series. "Idiopathic Pulmonary Fibrosis (IPF)" New York, NY: American Thoracic Society 2011. patients.thoracic.org

In 2011, I went into full respiratory failure during an ice snowstorm in Hershey, Pennsylvania. When the storm finally let up, I was flown to University of Pittsburgh Medical Center with only a couple of hours to live. I was placed on a Veno-Arterial ECMO and waited for a donor. Five days later I received a double lung transplant. A week after transplant, I had an emergency partial colectomy and contracted the C-Diff virus. My chance of survival became extremely low.

Just like my father, I do not give up easily. I actually told my surgeons when I planned on going home. They were surprised, but I had a goal to reach. Not only was I discharged the following week, I was out one day earlier than I even planned. To this day, I always tell doctors: "A patient's will to live is stronger than a doctor's opinion. Don't give up on someone who has not given up on herself."

The day I was diagnosed in 2009 with PF was like a bad dream. How do we not have a treatment for something that killed my father 28 years before? It was a hard pill to swallow. My father had no hope, but I had some hope for a lung transplant. Looking at the future generations of my family I know there will be more options. I am now very blessed to witness a treatment on the horizon and the progress that has been made in genetic testing.

As a patient, I have a personal interest in the future of medicine. I have become a strong advocate for PF research and know that our hard work will pay off in the long run. As doctors and researchers move forward, I hope they remember my story. I am one of the many faces of pulmonary fibrosis.

I am not just a number, I am a life.

Heather Snyder was a patient speaker at the ATS 2014 International Conference in San Diego.