Connell Rodden

IDOPATHIC PULMONARY FIBROSIS

"When I was first diagnosed, I felt like time was on our side. Unfortunately, time is running out for me and many others who wait (not always patiently) for new lungs."

In January 2008, I was diagnosed with idopathic pulmonary fibrosis. My nurse practitioner heard "crackles" in my lungs while I was being examined. The first thought was pneumonia. She sent me to have a chest x-ray, and later she called to say that I had better see a pulmonologist as she suspected something much worse. IPF is a chronic, progressive disease that usually results in an average survival rate of three to five years. To know that you have a terminal disease with no cure or treatment is devastating.

Because there is no cure or treatment for IPF, the only option is lung transplantation, and I was recently listed for transplant by my doctor at Temple University Hospital who I have been with for five years. I participated in several studies and clinical trials through Temple Health to explore both the effectiveness of trial medication and to track the progression of the disease. I would do most anything to assist in finding a cure or treatment for IPF. I certainly appreciate the efforts of all the doctors, scientists, and medical personnel and hope someday they will find a treatment and eventually a cure.

Initially, I was able to function relatively well–resting more than usual–but I was able to accomplish normal tasks and hobbies. As the disease and my symptoms worsened, I had to give up many hobbies and interests. I could no longer hike the trails to go hunting with my buddies. Fishing became a chore, as I no longer had the strength, breath, and endurance to reel in the big ones.

These days, I can't I swim and snorkel with my youngest daughter (one of our favorite vacation activities), and sightseeing and most outdoor hobbies have become

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Pulmonary fibrosis (PF) describes a group of lung diseases in which thickening of the walls of the air sacs (called alveoli) caused by scarring (fibrosis). Scarring in alveoli prevents oxygen from passing into blood vessels. This can result in coughing, shortness of breath, fatigue, and low blood oxygen levels. The scarring also makes the lungs "stiff" and difficult to inflate, which means they hold less air than normal lungs.

- The diagnosis is idiopathic pulmonary fibrosis (IPF) when the cause of the PF is unknown.
- The amount of scarring can increase with time, making the lung even stiffer, further limiting its filling capacity, and limiting the ability of oxygen to pass through air sac walls.

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

a thing of the past. I need oxygen 24/7. Even going to dinner with the family and playing with my seven-year-old grandson is no longer easy, as I experience shortness of breath. It is a horrible and frightening experience not being able to breathe.

When I was first diagnosed, I felt like time was on our side. The feeling was, "Five years is a long time, anything can happen." I thought, "They are finding cures for many diseases—why not IPF?" Unfortunately, time is running out for me and many others who wait (not always patiently) for new lungs.

Connell Rodden was a patient speaker at the ATS 2013 International Conference in Philadelphia.