Heather Kagel

IDIOPATHIC PULMONARY FIBROSIS (IPF)

Heather Kagel was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

I'm 51 years old and was diagnosed with idiopathic pulmonary fibrosis (IPF) in February of 2013. My symptoms before diagnosis included a persistent dry cough that would not go away. I went to the doctor thinking I had lingering bronchitis. She took an x-ray and told me she was referring me to a pulmonologist because it was not normal.

Because my dad and my granddad both had IPF, the first words out of my mouth were, "Please tell me it is not scarring." It was, in fact, scarring.

My diagnosis of IPF was confirmed shortly after that. I began using supplemental oxygen in June 2015. The three most common challenges I've faced are travelling with oxygen, getting the appropriate oxygen for home use, and exercising with oxygen.

Most oxygen providers will provide a home concentrator and either tanks or a portable oxygen concentrator (POC). Initially I ended up purchasing a POC out of pocket because it was difficult to get through insurance. Tanks are very heavy and, depending on your flow rate,

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you may have to carry more than one tank with you. Last fall I was prescribed a POC with a low continuous flow capability and it took over two months, and several follow-up calls by me, in order to get the machine. In addition to that, oxygen deliveries can be unreliable and sometimes require that you be home for a full day.

Plane travel requires a battery-operated POC. Most POCs have little to no continuous flow option, which prohibits those with continuous flow needs from air travel. If you don't own a POC or get one through insurance, the rental fee for a POC is almost cost prohibitive. Oxygen companies also require advance notice in order to access home concentrators and tanks while traveling, and if you give less than two-weeks-notice, there is a significant charge to arrange for the oxygen. I have also been required to pick up and drop off oxygen during weekday business hours. Otherwise, there are significant charges for delivering and picking up the oxygen. This requires factoring into travel the extra time and scheduling to pick up and drop off oxygen.

My hope is that oxygen companies will realize that oxygen needs are not a "one size fits all' across patients and will work more closely and compassionately with patients to ensure their oxygen needs can be met in a way that allows as much quality of life and as little frustration as possible. ■

Idiopathic 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. Pulmonary fibrosis can be caused by an identifiable irritation to the lungs, but in many cases the cause is unknown. In cases when the cause of PF is unknown, the diagnosis is idiopathic pulmonary fibrosis.

- Most people with IPF develop symptoms of cough and shortness of breath between the ages of 50 and 70 years.
- IPF is not common under the age of 50 years.
- Historically, more men have been diagnosed with IPF than women, but IPF in women appears to be on the rise.
- Occasionally, IPF occurs in members of the same family. When this happens, the disease is called Familial Pulmonary Fibrosis.

Learn more: ATS Patient Education Information Series. Idiopathic Pulmonary Fibrosis (IPF). ***www.thoracic.org/patients/patient-resources/resources/idiopathic-pulmonary-fibrosis.pdf***