

A Difficult Diagnosis Sparks Hope and Support for Others—Maybe You

(NAPS)—In 2022, Lisa Reed was eagerly anticipating her 70th birthday. She had plans to travel to Italy and was looking forward to spending more quality time with her grandchildren. But a persistent cough, worsened by a bout of COVID-19, led her to the emergency room in her hometown of Sante Fe. There, a series of tests, including a high-resolution chest CT of her lungs, revealed something unexpected: pulmonary fibrosis (PF).

Symptoms of PF, such as chronic dry cough, fatigue and shortness of breath, can often be confused with other more common illnesses, making it difficult to diagnose. In Reed's case, her chest CT showed the presence of white tissue on her lungs—a characteristic sign of scarring and inflammation.

Like many others diagnosed with PF, Reed had never heard of the disease. Her internet search was startling, revealing that PF causes progressive and irreversible scarring in the lungs. It is part of a family of over 200 interstitial lung diseases (ILD) that affect more than 250,000 Americans.

Fortunately, Reed was diagnosed in the early stages of the disease. She quickly immersed herself in learning everything she could about PF. She discovered the Pulmonary Fibrosis Foundation's (PFF) website, absorbing fact sheets, watching webinars, and exploring clinical trials and opportunities to get involved.

A friend of Reed's who is a nurse practitioner suggested she reach out to the ILD clinic at National Jewish Hospital in Denver, a PFF Care Center Network site. She now receives care there from a multidisciplinary team of doctors including a pulmonologist, rheumatologist, cardiologist, and oncologist. She began an antifibrotic treatment to slow the progression of the disease.

As Reed started her treatment, her family received more unexpected news—both of her brothers were also diagnosed with pulmonary fibrosis. The siblings believe their condition is familial, with each of them at different stages of the disease. One of her brothers has since undergone a double lung transplant and is doing well.

Reed firmly believes that self-advocacy is essential in getting the right care as quickly as possible. She has volunteered for clinical trials, participates in online support groups, and actively



Lisa Reed and a quarter million other Americans have pulmonary fibrosis, a serious lung disease, but early treatment can make a big difference.

engages with the PFF. Throughout her journey, Reed has found the PFF to be a vital resource for trusted information and tremendous support.

“Whether it’s getting the right diagnosis, learning what treatments are available, or finding resources for caregivers, there are answers and support,” she said. “It’s impressive and wonderful.”

Now, Reed volunteers as a PFF Ambassador, sharing her story and helping others along their journeys. “The way to help myself is to help others,” she says.

Reed plans to attend a virtual PFF Education Symposium. She looks forward to learning about the latest research studies, how to live better with PF, and to connect with others navigating life with PF.

“Whether you’re newly diagnosed, or you’ve been living with PF for years, no one should face this journey alone,” said Reed. “There are so many ways we can help each other, both big and small. And there’s a whole community of people, resources, and support ready to help you through the PFF.”

The PFF Education Symposium is a virtual conference taking place Nov. 7-8. To learn more about PF and to register for the Symposium, visit pulmonaryfibrosis.org/symposium.