



Karen Allison

Idiopathic Pulmonary Fibrosis

My life before IPF was full, but simple. I've been married for 48 years, raised four sons with all our hearts and not much money. I worked several part-time jobs to help financially, but the cost of daycare for four was too much. I retired when IPF and COVID-19 hit simultaneously in 2020.

For about two years I had a nagging cough and general feeling like I was always on the verge of starting a common cold. I lived on pseudoephedrine.

My husband insisted I go to my primary care physician for a chest x-ray.

As previously, my primary care physician thought my problem was postnasal drip and /or a viral infection. I asked if I needed a chest x-ray. He listened to my lungs and said he didn't think so but gave me a referral to an ENT.

The ENT didn't find anything unusual about my sinuses, but he listened. He prescribed an inhaler for my cough and ordered the chest x-ray.

In March of 2020, the results came in, and I googled every word. The conclusion was not good. Next was a CAT scan, which confirmed the findings of Interstitial lung disease/usual interstitial pneumonia / idiopathic pulmonary fibrosis. It was a death sentence. Life expectancy is three to five years with no cure or treatment that has been proven to extend your life, other than a lung transplant.

I researched every article I could find. Due to Covid-19, getting an appointment with a pulmonologist was going to take some time. It was hard to be patient but knowing there were people very sick and diagnosed with COVID-19, I waited. I remember feeling a bit like I was set aside on a shelf, with an expiration date.

I knew I was terminally ill. IPF was FATAL. How long would I last?

COVID-19 and IPF kept me isolated at home, but not lonely. I decided to get a puppy! I thought it would be good to have a special kind of friend to lay on my bed with me on bad days and listen to my every word with a smile, and hopefully take me for walks, who wouldn't offer advice, or wishful thinking, or unrealistic expectations of my future days. My Bernese Mountain Dog puppy, Bella, was a ball of fur with a wagging tail and just what I needed.



I was also constantly out planting things my son brought because he knew it would keep me busy and happy. My flowers would help me start conversations with strangers at a distance, and I would tell them about my joy of gardening and the reality of my disease. Strangers listened. Strangers shared their stories and lifted my spirit.

Once I finally saw a pulmonologist, my IPF diagnosis was confirmed. I wasn't far enough along to be considered for a lung transplant. At that point, I was just short of breath, constantly coughing and tired. I knew I would need supplemental oxygen in the near future, but I didn't want to start it yet because it felt like "the beginning of the end."

I saw an ad in our little local paper about Wescoe Pulmonary Fibrosis Support Group and I called late the next night. This wonderful lady called me right back and instantly I felt her warmth and caring. I knew she was an angel. The Wescoe PF group was a collection of beautiful people who were walking along a similar path, who shared their experiences and reached out with open arms. This disease has brought so many beautiful caring people into my life. It feels like oxygen for my soul. I'm so grateful to feel this joy more than I feel the sadness.

I started pulmonary rehabilitation and needed to have supplemental oxygen to walk or do any activity. I had put it off as long as possible, but I needed oxygen. If I wanted to stay active, I had to breathe.

The supplemental oxygen was delivered to our home. At first, it felt like I was connected to a 50-foot hose that felt like a dog leash to reach around the house. I was constantly tangled, tripping, it got caught on everything, our cat would chew holes in it, and my husband was always trying to keep the tubing unkinked. It was terrible.

I decided I had to think of it as the beginning of better breathing, instead of the beginning of the end. My doctor gave me the idea of putting my oxygen in a baby stroller! I put a tank in the stroller, my sweet husband stabilized it with bungee cords, and I connected a 50-foot tubing so I could continue to do my gardening. I was finally free to move.



It wasn't pretty, but it worked. I even learned to take Bella for a walk with the stroller and oxygen tank. It was difficult at the beginning. Bella would pull and not heel. Eventually, though, I got that huge puppy trained and together we met the challenge. We walk several evenings a week at least a mile or more. Medicare wouldn't pay for anymore respiratory therapy, so I needed to keep moving.

“This disease has brought so many beautiful caring people and circumstances into my life. It feels like oxygen for my soul. I'm so grateful to feel this joy more than I feel the sadness.”

The more I moved, the more oxygen I needed. The medical supply company constantly got it wrong. I explained I needed more tanks; they would deliver fewer. One customer service person even said that because I had a home oxygen concentrator it wasn't like I didn't have any oxygen. I responded “Well, how should I take that down the sidewalk?” They told me I had to have a new six-minute walk test in order for them to supply enough supplemental oxygen. Their records were not up to date. They had me at two liters when I had been using between three and five liters for months. I just wanted to breathe the best I could and for as long as I could.

I cried, I called my doctor and the next day received a call from the supervisor at the supply company. I was only able to get 30 tanks of oxygen a month, as a result of Medicare rules. My doctor's office did their best to make sure I got what I needed.

That winter, one of my sons did some research and found a clinical trial in its third phase that looked hopeful. I read as much as I could, and I decided to give it a try. I didn't want to just put my time in and die. I was excited to be a real part of science and be useful.



To participate, I had to be sick enough, but not too sick. I had no other medical problems. I pre-qualified as a candidate for the trial, but everything was on hold due to COVID-19.

Finally, once we were fully vaccinated, we headed to Temple Lung Center in Philadelphia. I had to pass testing before I would start the infusions. I assumed there would be no problem. I was healthy other than the IPF.

A couple of weeks later I got a call with an unpleasant surprise. My testing showed my liver enzymes were acutely elevated, and I could not participate in the clinical trial unless my liver was healthy.

After more tests and gastroenterologist consultation, I still have no symptoms and no real diagnosis, just acute liver disease for now. Even the doctors are puzzled. There seems to be some fibrosis in my liver now also. Could it be in connection to lung fibrosis?

My story continues... ●