Chapter 4

My Journey with IPF

by Peter M.

Hi, my name is Peter M. I would like to tell you about my journey with idiopathic pulmonary fibrosis, or IPF.

I'm no stranger to lung disease. My grandfather died from pulmonary fibrosis the year I got married (1984), and his sister three years later.

I've been healthy all my life except for some asthma and hay fever. I was running almost as soon as I could walk and have always played hard. My mom gave up trying to get me to sit still. She just directed my energies to where she could and handed me peanut butter and jelly sandwiches as I ran by. As an adult, those energies were directed toward flying, which got its hooks in me in eighth grade and reeled me in when I took flying classes in college. In three years I was a certified flight instructor teaching pilots how to respond safely no matter what happened with their aircraft. Flying is one of the greatest loves of my life.

My wife and I live on a small farm near my hometown. In late summer of 2012 I noticed that when I would take a walk out back I'd get out of breath. I figured I was out of shape; I needed to walk more. It didn't bother me when I split wood; that was all burst energy. In October one of my business partners had a serious cold. Like a good friend, he shared it with me. By the second week in November, I had developed a barking cough. I went to the urgent care center and they put me on a corticosteroid drug and a cough suppressant. Those helped a little.

We had moved back to the farm from a different city, so I went to see a doctor in town that I didn't know. He upped the dosage of the medications that urgent care had prescribed for me and that helped. But a couple of weeks later I was back in the emergency room with chest pains and I was unable to breathe. My coughing was so violent that I was pulling muscles in my chest.

After a couple more visits to that doctor and a CT scan, I received a call from the doctor's receptionist saying he wanted to see me that week because, "You have lung disease." I was stunned - and angry! - that she'd just dropped that information on me like a bomb into my life. During my appointment, the doctor explained that I needed to see a pulmonologist, but it would take four to five weeks to get an appointment. At that point, my wife and I decided I needed to see another doctor.

Luckily, our previous doctor still had my records and would see me. The difference between the doctors I've seen has been incredible. The first doctor talked *at* me, the second talked *with* me. It was important to me that he was engaged with me because this is *my* life that is involved. I know he has a lot of other patients, but when I am with him I want to be the focus. I learned a great line once: Be HERE, now. If your doctor isn't, he is not serving you. The first doctor sent me in the right direction, but I wasn't comfortable with him. If things don't seem right, don't hesitate to do some research and look for other options.

My new doctor told me that if I weren't able to get an appointment with a pulmonologist within two weeks, he'd get one for me. As it happened, the pulmonologist had an opening the very next morning, so my wife and I were there with bells on. The pulmonologist looked over my CT scan, which I had brought on a disk, and reviewed my other information. She said it could be idiopathic pulmonary fibrosis and spelled out what it was, along with the good and the bad that was involved with it. But she wasn't willing to diagnose me definitively until she'd consulted her colleagues at their weekly review board.

Immediately my thoughts went to my grandfather and the last years of his life. I grabbed onto, 'it could be something else,' for dear life.

There *had* to be another diagnosis for my condition… Something curable…

I was at my daughter's home visiting my grandchildren when my pulmonologist called to tell me the diagnosis was definitely IPF. It was like a kick in the gut. I sat down hard on my daughter's couch and my daughter immediately started doing online research. The first few things she turned up were quite depressing; no cure and a life expectancy of three to five years.

I was one of those guys who didn't want to wear that oxygen hose on my nose. In fact, I had just talked to my wife about that about six months before. I didn't want to stand out in a crowd as a person with a disability and wonder what they were thinking or saying.

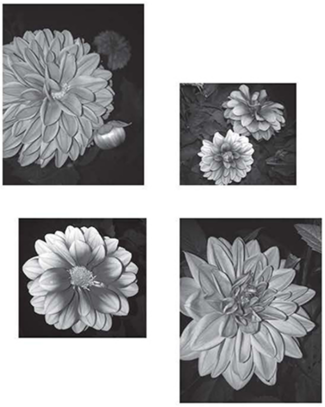
After the call, I felt alone. But in flight school I was trained - and had trained others - to identify the problem and move forward with the best available option. You can't take time in the pilot's seat to wonder about the what-if's and why-if's, so I didn't allow myself to do it then. I reminded myself that technology has come a long way in the last thirty years since Granddad's death and that I was not alone. "Stop," I told myself. "Take a breath or two. Don't worry about the short life expectancy. We caught it early, and we'll manage it. Take a couple more deep breaths, then take the next step." I realized that other people must be suffering with IPF, so I went looking for support groups.

Support groups are wonderful. We are all in the same boat. Granted, we are at different levels of the condition, but the attitudes are great. Different people try different things and may have a solution for an issue that you may have.

The IPF diagnosis has changed the way I look at life. It has put a finiteness to it, where it was open-ended before. But these days, I am getting more active about getting back to my flying, and I'm going to create some recreational time for myself (hunting, fishing, two wheeling, etc.) and my wife.

I am a Pulmonary Fibrosis Foundation ambassador, and they are a very good resource for information and have listings for support groups across the country. The Foundation is also a very strong advocate for people with pulmonary fibrosis. Please see the Resources page in this book for a listing of many excellent and reliable sources of information and support concerning pulmonary fibrosis.

The thing to remember is that you are not alone. There are treatments now and people who want to help.



Sharon and David D.