



Eileen O.

Chapter 8

A Family Affair

by Eileen O.

My IPF journey probably started over 20 years ago when my mother was diagnosed with idiopathic pulmonary fibrosis (IPF). I believe it must have been sometime in 1989 when we discovered not only this disease but also the grim prognosis that went along with it. I remember asking my physician at the time if this was hereditary. I was told that they did not know the cause of the disease, but they did not believe that it was hereditary. My mother died in 1993, and within the next 10 years she also lost a half-brother and a full brother to the disease. Two other full siblings also had the disease, and though they have passed on, it was not from IPF.

In December of 2011, I began going to a new physician, and when I mentioned to her that I had shortness of breath from time to time and the fact that my mother had died from IPF, she sent me to get a chest x-ray. Approximately a month later she called me and asked for a follow-up x-ray as there were some things that weren't clear on there and suggested that maybe I wasn't feeling well on the day of the original x-ray. My concern started to rise because I knew I was feeling okay during the first x-ray, and I had just hoped that she would tell me that I needed to lose some weight. After the second x-ray, she said there were still some anomalies and they could do further tests, but because of my family history maybe I should see a pulmonologist.

Naturally, I did what most people do; I got online to see what changes had been made in the treatment of this disease in 20 years. I was dismayed to see the same life expectancy as my mother had. I was also the same age as my mother when she first had the disease

and I felt like there was a rock in my stomach as I started to believe that I could figure out at what age I was going to die.

I met with a pulmonologist who had several tests performed and said that he could say with 95% accuracy that I had IPF. However, he had no further advice for me and I felt as if he didn't really know how to help me any further. He was depressing and discouraging.

My mother's sister was still living and we started communicating regularly. She lived in St. Louis and was one of the most positive people I could have connected with. She had been living with IPF for eight years. When she next went to see her doctor, she asked about a doctor in my area and was given the name of a doctor at the University of Michigan. She told me that I should go to see him. I've never been one to change or switch doctors or go for a second opinion, but this time I did, and I've been grateful ever since. When I met with the doctor, I told him I knew the outcome of the disease, but I would appreciate him offering any encouragement that he could. If I participated in research studies, he was careful to say that I would not only help others, but maybe even myself. I loved the feeling that he cared about me. The other thing he did for me was to tell me about patients he had seen recently who had been living eight, 10, or 12 years. Patients need to hear that it is possible to live with this disease.

I even learned that though the Internet seemed to still proclaim a short life span for those with IPF, there was much going on as far as research and strides were being made. So my assumption that nothing had been done in the last 20 years since my mother died was not necessarily true, though there is still a long way to go.

I believe that my IPF was diagnosed very early. Every MRI or CT scan showed something different, but they were not able to definitively state that I had IPF until a lung biopsy confirmed it. The doctor said it would be my decision as to whether or not to have the biopsy, but at this point I needed to know for sure. In late March of 2013, I had a lung biopsy, which proved that I did indeed have IPF.

Because of that diagnosis, I was also allowed to participate in some trial research studies and I did get to participate in an intensive study

that involved re-inhaling carbon monoxide, which made for lots of jokes with the family and co-workers.

I am not on oxygen, and at this point, probably the only real effect of my disease is shortness of breath, perhaps on stairs, long climbs, etc. Last April we took a trip to the Smoky Mountains and I tried to climb a high point. I did not get far because of both my knees (another story) and my lungs. I was disappointed, but am not going to complain if that's the worst that happens.

Because of my faith, I try to rely on trusting God and prayer a lot. I figure that God is in charge of my life and he knows how many days I have left and it doesn't mean that this disease is what will end my life. I have just recently received one of the new, approved drugs to begin taking. I will be starting it soon and like everyone else, I am hopeful that this will help to lengthen my life.

I retired from my job this past September and though my children thought I would retire when I first got the diagnosis, I tried to explain to them that I wasn't ready to sit home and think about my disease. I needed to work to keep my mind off of the disease and I didn't want to sit home and start feeling sorry for myself.

It was extremely difficult to tell my children because they saw my mother succumb to this disease and they also knew the outcome. I also felt bad because since there may be a genetic influence in my family. I worried about what I may be passing on to them. However, they also have a strong faith and I feel that they needed to know so that they can also pray for God to intervene if that is His will.

I am generally pretty positive about how I am doing, but that is probably because I am still doing well. I am attending a local support group and enjoy meeting together monthly to hear what is going on with others and hear about everyone's experiences.

Thank you for the opportunity to share my story.