



Brother of Mary F.  
with his grandchild

## Chapter 10

### What is IPF?

by Mary F.

When I took a new job in the University of Michigan Health System Pulmonary and Critical Care Medicine Division in 2004 I had never heard of idiopathic pulmonary fibrosis (IPF). At that time the division was home to a large NIH grant entitled, *Specialized Center of Research (SCOR) in Occupational and Immunological Lung Diseases*. I dealt with the business end of the grant, but I really did not know what the scientists were studying.

Around 2005/2006 I participated in the *Quest for Breath* fundraiser, which was organized by a family that was devastated by the disease and was trying to raise money to support research and awareness of IPF. I was walking with one of my new colleagues at the event and sheepishly asked him, “Exactly what is IPF?” He told me that it is an uncontrollable scarring of the lungs with no cure or treatment, and they don’t really know how it starts. I also learned it can run in families.

My brother, a retired firefighter, had a chronic cough and was sent to a University of Michigan pulmonologist after his primary care doctor became concerned about him. There was concern that he might be at the very early stages of pulmonary fibrosis, and the doctor sent his case to the interstitial lung disease (ILD) conference. The radiologist, pathologist, and pulmonologist reviewed his case in the ILD conference, and interstitial lung disease was ruled out. What a great relief!

Several years later a different brother had his knee replaced and was a patient in a local facility for extended physical therapy. He had a

complicated medical history starting at four years old when he was diagnosed with polio. In his late 50's he endured multiple rounds of chemotherapy and radiation therapy for prostate cancer. He picked up a bug while in the rehab facility which turned into pneumonia. He was very ill and was admitted to his local community hospital. When I learned he was in the hospital for pneumonia, I asked if he could be transferred to the University of Michigan to be cared for by the doctors in my division.

He came here and was diagnosed with pulmonary fibrosis. I was floored. I thought he had pneumonia and with a hearty dose of antibiotics he would be back on his feet, playing with his grandkids and following the Detroit Tigers.

The doctors did what they could for him to be comfortable and he was able to eke out another year of semi-high quality of life. His health then failed miserably and quickly, and he ended up in the hospital again. His daughters called me terrified. We worked on transferring him to the University of Michigan where he was in isolation in the critical care medicine unit for about a week, and then transferred to a general floor bed. They made it possible for him to have a few months of manageable life. He then opted to go into hospice in March of 2014 and passed on April 30, 2014.

I'd like to say he was an ideal and stoic patient, but that really isn't true. He was angry; he couldn't breathe, and did not want to use the oxygen. He wanted a lung transplant and was angry that he didn't qualify.

So now I know what idiopathic pulmonary fibrosis is. I know that it can run in families, and I am scared for my brothers, my son, nieces, nephews, and myself. At the first hint of shortness of breath after working out or playing tennis, I think it's going to be my fate as well. I live with an attitude of gratitude each day that I am able to enjoy good health, because I know this disease is out there and it has struck in my family.

There is no cure. New treatment has come recently that will prolong a patient's life, but it isn't the miracle that is needed to eradicate

pulmonary fibrosis. I hope the National Institutes of Health continue to commit funding for more research around this insidious disease so future generations do not have to gasp for their last breath in the midst of their golden years. I absolutely hate this disease.