Chapter 5

I Wish I Had Better News

by David D.

These were the last words I remember the pulmonologist saying as we left his office that cold January day in 2014. "I wish I had better news." It had started out as a diagnosis of pneumonia in mid-December by my family doctor but failed to show little improvement over a two-week regimen of potent antibiotics. This is what brought me to the specialist that day. It all seemed like a nightmare as my wife and I tried to comprehend his statements. "Idiopathic Pulmonary Fibrosis…a progressive, degenerative disease with no known cure…may be weeks, months or years…likely a respiratory infection will land you in the hospital and *IF* you survive it, your quality of life will be greatly diminished…need for more tests and second opinion…." We left that day confused and numb but with an appointment scheduled with pulmonologist Dr. G. at the University of Michigan in April. With plans to go to Florida for two months, the only encouraging words from the doctor's office were, "Go enjoy yourselves; you control this disease, don't let it control you." We informed our two grown children who have families of their own of the doctor's news, and after some tears, many prayers, and words of encouragement we left for our Florida vacation.

Looking back over the year prior to my diagnosis of IPF, there were perhaps some telltale signs of the disease—the "crackling" noise reported when the doctor listened to my breathing; the oxygen levels dropping to the low 90s, and a slight cough during cardiac rehab exercise. But I was not experiencing any shortness of breath.

Upon return from our Florida vacation, we checked in for my first complete pulmonary workup at the University of Michigan in April, 2014; the six-minute hall walk test, various breathing analyzer tests, a

CT scan, and finally the first visit with Dr. G. My wife and I liked the guy the instant we met him. He asked a ton of questions, thoroughly reviewed our records, and confirmed the diagnosis of IPF. The big difference was his attitude toward the progression of this disease. Instead of, "I wish I had better news," it was, "We are going to do everything we can to fight this." My wife and I left that day at least with hope, and hope is the one thing you must always cling to.

Summer progressed nicely with the disease causing little interruption to my daily routine, with the exception that extra exertion such as lawn work or washing the car would bring on the nagging cough. In the fall of 2014 there were more tests and another visit with Dr. G. He had three suggestions: 1) Start oxygen therapy during exertion; 2) enroll in the university's IPF support group; and 3) take part in the research study of a new drug. The last two I did willingly, but the first was more difficult. Oxygen therapy with the familiar nasal cannula and oxygen tank, to me it seemed, would mark me outwardly as a sickly person.

Enrolling in the support group helped my wife and I understand that we are not the only ones going through this life-changing challenge. Under the leadership of Deb D. we have found that she and the others in the support group to be a source of strength and encouragement. IPF can affect each person quite differently, so sharing ideas on practical exercise and breathing techniques, quelling a disturbing cough, and the myriad of challenges presented by the disease has been informative and helpful - not only to the person with the disease but the caregiver as well. I also started taking a new drug as a participant in the research study group. The drug was later approved by the FDA in October of 2014.

My first major setback came in November 2014. Having been a heart patient for over 10 years, I recognized that the pain between my shoulder blades could be heart related and I sought treatment at the emergency room. Two days later I left the hospital for home with a new stent and no pain, but was surprised by my weakened condition.

Most of November seemed to be spent recuperating. Then in early December, both my wife and I got mild cases of influenza and were

quite sick the remainder of the month. (Fortunately we had gotten flu shots or it could have been much worse according to our doctors.) We kept in contact with the pulmonary clinic at the university because with IPF it is very important to avoid respiratory infections. Thankfully I had none, to my knowledge. Nevertheless, by year-end I was experiencing more shortness of breath and more coughing than I had prior. I began using my oxygen more frequently as this would ease the symptoms.

Another set of breathing tests in January 2015 and a visit with Dr. G. revealed a slight decrease in lung function. Overall he was pleased and felt that the new medication was slowing the progression of the disease. He encouraged me to continue with exercise and pulmonary rehabilitation. He pointed out that people with compromised immune systems can require much longer periods of recuperation and that my health issues from November and December could have been a major reason for the letdown in my overall feeling of wellness.

Today as I write my story from Florida, we are on our second annual trip since being diagnosed with IPF and I am feeling stronger. But I still am noticing the need for more oxygen therapy. Not all the time, but certainly for exertion, walks, and intimate moments with my wife. The nasal cannula and oxygen tank is becoming more a part of what defines me. Surprisingly, it has prompted opportunities to discuss my condition with others and increase their awareness of IPF and the need for more research.

Upon our return to Michigan, I will have another complete set of pulmonary tests and meet again with Dr. G. in April. The future remains uncertain. But so it is for all of us. Being diagnosed with IPF has forced my wife and me to think and plan more purposefully. For example:

1) We set intentional goals. We are planning a trip to California via Route 66 in our Mini Cooper convertible this September; our first grandchild's high school graduation in 2016; and our 50th wedding anniversary in June of 2016.

2) We take care of business. We are completing the necessary documents for palliative care we wish to receive. We are finalizing funeral plans, directives, and assuring our legal affairs are in order. This will ease the burden and decisions our children would otherwise have to make.

During those times when I am slightly more contemplative about my IPF disease, I realize how incredibly fortunate I am. My disease is not ravaging my body with pain. Nor has it messed with my mind and made me forget those who love me most. So, I will continue to hope, pray, and work for the best possible outcome with fighting this disease. And I will not despair! Faith has always been important to me, but faith is pretty easy when we are on the mountaintop. It is in the valleys of life that your faith is put to the test. If I am going to thank God in the good times, I am going to thank him in the bad times as well. I do not know how the remaining chapters of my story will be written, but more than anything I want the final sentence to read, "He finished well."