William C. and Diane J.

Chapter 7

Idiopathic Pulmonary Fibrosis & Me

by Diane J.

Hello, my name is Diane, and I was diagnosed with idiopathic pulmonary fibrosis (IPF) in 2004. Yes! I said 2004. My family doctor sent me for a chest x-ray after having laryngitis for three months. I knew I was in trouble when the x-ray technician came out and told me to call my doctor the next morning for results.

My family doctor sent me to a local pulmonologist who had me do a hall walk and spirometry tests, along with a thorough physical exam. Afterwards, he was sorry to tell me that I had idiopathic pulmonary fibrosis. Then he called a friend of his, Dr. F. at the University of Michigan in Ann Arbor, and asked him to take me as a patient. I made an appointment for as soon as possible. Needless to say, I was very distressed. My father had died of IPF in 1990, so I knew the outcome.

After getting home and pulling up IPF on the computer and seeing the prognosis of a three to five year life expectancy, I was deeply depressed. I saw Dr. F. the next morning while I was in the hospital for a bronchial lavage. It was inconclusive, so I was scheduled for a lung biopsy. The biopsy confirmed my diagnosis of IPF.

My next step was to start in with research studies. I was determined to fight with all my strength. With the help and encouragement of the staff, I began my journey.

First, I had injections three times a week. Then, when that was not feasible, we went to a double-blind research study of a new medication. Then in 2008 I began receiving the new medication for real, and I took it for some 250 or so weeks.

Most of that time I was not on oxygen until 2013 when I had a sudden medical problem. I was on oxygen in the hospital, and I have been ever since. I have had great support from the staff and, of course, from my family and friends - and lots of prayers along the way.