David and Bonni S.

Chapter 6

My Life With IPF

by David S.

Diagnosis: How did you feel when you were first diagnosed, and how did you tell your family and friends about your diagnosis?

I first learned of my idiopathic pulmonary fibrosis (IPF) diagnosis five years ago at the age of 55. I had gone to my regular doctor to get an antibiotic for a recurring cough. He listened to my lungs and said he heard a faint crackling sound. To my questioning look, he explained that in his experience this crackle was often associated with IPF. After a bit of discussion about what IPF is, he asked if I wanted to have it checked out with a CT scan or just not worry about it because it was probably nothing. Since my philosophy is that it's better to check and find nothing than to not check and wish I had, a CT scan was done. When the results came back, he referred me to a pulmonologist who ordered a lung biopsy for verification - and verified it was!

My initial reaction was, "Wow, what does it mean?" As my wife was with me every step of the way, I had a loving and caring support person already in place. This did not lessen our concern that all of a sudden our future together became much less than what we were planning for. After looking up IPF on the Internet we were stunned to learn that the average life expectancy after diagnosis is three to five years. It isn't an exaggeration to say that I was a bit down after seeing this information on the Internet.

Upon further discussions with my pulmonologist I was referred to the Division of Pulmonary and Critical Care Medicine at the University of Michigan. There, I underwent a verification

bronchoscopy. With this further verification I spent a considerable amount of time with the doctor discussing IPF and what to expect. Through this very frank discussion of what probably lay ahead during the progression of the disease, my state of mind became much more settled. He explained that IPF does not always progress at the same rate and many patients have much longer life spans than three to five years, especially if their diagnosis is made early in the life of the disease, which mine was.

The next hurdle was to share my IPF diagnosis with my family and close friends. This was not as hard as I expected. My wife already knew, and my father was the next to know. Even before the confirmed diagnosis, I talked to my dad since I have always sought his advice on important events in my life. Then, upon receiving the CT scan result I called each of my children, my siblings, and my wife's siblings to let them know what was going on. Through the years they have also been kept up to date on the results of each successive test to monitor my IPF progression.

Symptoms: What do you like, or not like, about your IPF and how does your IPF make you feel?

In all honesty, I can't really say I like anything about having IPF. That said, there have been some things it has encouraged me to do that I do like. My wife and I have done more travelling than we otherwise might have, and I have renewed some family ties that I had let lie dormant for many years. I don't mind being able to park closer to buildings with my handicap sticker, especially during the winter, and at my job as a substitute teacher I am no longer required to be outside to watch the kids before school and at recess when the temperature is below 40. On the flip side, I do not like having a frequent cough, nor the diminished stamina I have for walking, especially being much slower on stairs.

Treatment: What is being done to treat your IPF, how does it make you feel, and what are some things you like, or don't like, about being treated?

After my diagnosis I asked to participate in IPF treatment studies. The reasons are twofold: 1) You never know what might work and

honestly, what do I have to lose?; and, 2) Anything that can be learned from my participation may very well be of benefit to my children someday if they ever develop IPF. This is especially of concern to me as my father was diagnosed with IPF just one month after I was.

I have been involved in treatment studies continuously since the reconfirmed diagnosis at U-M. One of the studies I participated in was a blind study involving either a new drug or placebo, then a follow-up study knowing that the drug was being administered. As this drug has recently been approved by the FDA, I am currently taking it. It seems to be helping as my IPF has not progressed as rapidly as originally expected. I don't mind taking the drug, though getting acclimated to the recommended dosage took some time. I also am tired a lot, but that goes with the territory.

Advice: How do you manage your IPF at home, and what advice would you give to somebody who has just been diagnosed with IPF?

Around the house I have learned to do things a little slower. I take the stairs one at a time instead of two or more; I take frequent breaks when working in the yard; I have put the washer, dryer, and my easy chair up on 3.5" platforms to reduce the stooping, bending and lifting; and I even (occasionally) listen to my wife when she says she will do something to make it easier on me.

For somebody who has just been diagnosed with IPF, the best advice I can give is to find a close and caring person who will laugh with you, cry with you, and support you every step of the way. I am very fortunate to have already had this person in my life - my wife.

Reflections: How has IPF changed your life, and any additional information you'd like to share.

IPF has changed my life in that I definitely have a greater understanding of my mortality. Of course, some of this also comes just with the addition of years. In addition, I have also become very familiar, and comfortable, with hospitals and doctors' offices, especially the University of Michigan Health System. This familiarity

has become a wonderful part of our support system as the care, concern, and honesty of the U-M staff has kept my wife and I well-grounded on a day-to-day basis and when looking into the future.

For the most part I have been able to keep a very positive outlook on life and living. This has been, and is being accomplished through the use of humor, belief in God, living each day to its fullest, and being grateful every day that I have another day to live and spend with my wife and family. On the rare day that the IPF does get the better of me, my wife is generous enough to take just a little more of that day's burden off my shoulders.