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Chapter 12

My IPF Story

by Lori F., B.S.N., R.N.

I have been a nurse for over twenty years; the majority of my time was in the thoracic surgery clinic. There, amongst the patients seen, were patients who had interstitial lung disease. They would come to be seen for their thoracoscopic lung biopsies (VATS) to get lung tissue in hopes of making a definitive diagnosis. Generally they only had a few appointments with us - the initial appointment, surgery, and a post-operative appointment.

It was during these evaluations that I started to learn about idiopathic pulmonary fibrosis (IPF). I do think idiopathic pulmonary fibrosis is one of the harder diseases for me to understand. For me, it is important to understand a disease so I can help the patients and family dealing with the disease or getting ready for surgery to understand.

In thoracic surgery, we dealt with a lot of cancer, and many times (not all, of course) there was a history of smoking or reflux to help determine why the cancer developed, but with pulmonary fibrosis, there is no known cause. So that makes it even harder to explain, understand and accept.

A few years ago I decided to make a change, and there were only a few places I wanted to go - a benefit of being here for so long. Since I had worked with and knew many of the lung doctors (pulmonologists), pulmonary medicine was my top location. I feel fortunate to have worked with the thoracic surgeons, and now I feel the same about the pulmonologists with whom I work. I continue to learn every day about all the different pulmonary diseases.

Pulmonary fibrosis is one disease that I have become more familiar with after working on the surgery side and seeing those that have, or are about to have, a lung biopsy. However, it is one I continue to try to learn more about. One positive on the IPF front over the past few years since I have been here is the introduction of two anti-fibrotic medications to the public. These medications have shown hope in slowing the progression of IPF. There is still much to do, of course, and my hope is they are able to continue to do the research that is needed (many research studies are done at the University of Michigan), as it is important to keep moving forward to find a cause and a cure.

After running the support group in thoracic surgery (the esophagectomy support group) for over ten years, I developed a strong interest in support groups and their importance to patients and families. I was fortunate enough (even though it was because Deb D. was leaving) to be given the opportunity to lead the IPF support group here at the University of Michigan. It is hard to measure how much the support group can help all of us. But being able to share with one another and learn how to deal with the disease, the medications, and even end-of-life care is, I feel, invaluable to all involved.

I realize these topics can also be difficult to discuss; I feel strongly that the support group can help. And the support groups help not only the patient and family, but they also help the group leader (currently me). Many times when patients call the nursing office I share what has been expressed at the support group meetings by those who have already gone through similar situations. I will continue to work to make the IPF support group what it needs to be so that we can help those who are dealing with, and affected, by IPF.

I hope that as you read this and other stories in this book, it may help you deal with your upcoming tests, appointments, and/or surgery, as your doctor figures out your individual disease and situation and then prepares a plan for you. At the very least, know that there are resources out there for you, including the Pulmonary Fibrosis Foundation.

I realize that the time it takes to figure out exactly which pulmonary disease you have is a difficult period of adjustment. And the hardest part is learning to live with it at the same time that you are helping the rest of your family adjust. As difficult as this can be, remember to ask questions and remember that it is okay to seek support, whether it is within your family, circle of friends and any of the IPF support groups. They all can help you along this journey that you have begun, living with idiopathic pulmonary fibrosis.