Judy Moore

PULMONARY FIBROSIS

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I am a third generation idiopathic pulmonary fibrosis (IPF) patient. I was first diagnosed about nine years ago when my brother said, "You sound like mom." An X-ray suggested pulmonary fibrosis, only the second case my doctor had seen in her practice. Other tests, including a lung biopsy, confirmed the diagnosis.

My grandmother died of IPF in 1968 and my mother in 1990. Imagine my surprise that there was still no cure, not even a treatment! Since as many people die from IPF a year as they do from breast cancer, I was shocked at the lack of progress.

My first doctor was brilliant, but he did not communicate well with patients. Before my biopsy he said, "Well, what we don't want is IPF." After the operation he came into the room, grinned and said, "Well, you've got it! See you in the office in three days." When my family and I returned, we were told, "You need to go home and get your affairs in order because this can go quickly." He did get me to National Jewish Health, where I have an attentive, caring pulmonologist whom I can approach with any question.

Early on, I attended an IPF convention where two newly diagnosed men were sent by their doctors to learn more about the disease. After the first session one of the men collapsed; no one had told either of these men that IPF was an incurable disease with no workable treatment. But now there are some tools and some hope. In October 2014, the U.S. Food and Drug Administration approved two medications for pulmonary fibrosis. I was in one of the trials, and I am now on one of the drugs. These treatments do not stop or cure the disease, but they often seem to slow the progress. My last CT did not show any additional damage.

I work at fighting the disease in several ways. Since I am third generation patient,

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Pulmonary fibrosis describes a group of lung diseases in which thickening of the walls of the air sacs (called alveoli), caused by scarring, can result in cough, shortness of breath, fatigue and low blood oxygen levels. It can be caused by an identifiable irritation to the lungs, but in many cases the cause is unknown, which is described as idiopathic pulmonary fibrosis (IPF). Idiopathic means there is no known cause at this time. Symptoms include:

- Dry cough or shortness of breath
- Abnormal breath sounds—crackles (like Velcro) can be heard by your health care provider when you take a deep breath
- The ends of your fingers and/or toes have changed to a club shape (called "clubbing")

Learn more: ATS Patient Information Series. "Idiopathic Pulmonary Fibrosis (IPF)" New York, NY: American Thoracic Society 2015. thoracic.org/patients/patient-resources/resources/idiopathic-pulmonary-fibrosis.pdf

my main reason for participating in research has been for my three children and four grandchildren. National Jewish Health has discovered several genes of interest for this disease, and I assume other research labs have done the same.

Besides taking my medications, I take supplements. I have been in pulmonary rehabilitation for eight years. This has served as a support group, a place where other patients and I see one another at our best and our worst! My Pilates for Cancer Survivors group started over ten years ago, and the exercise helps support the lungs. I am active in two other support groups, and they are my go-to sources for new research and patient information. I see my respiratory doctor at least every three months. Of course, my strongest support is my faith in God.

IPF requires a creative doctor, who is able to talk openly with the patient and not discourage him or her. It takes someone who is able to encourage patients to keep working at exercise and health, and getting out of bed in the morning. I struggle with constant cough, extreme tiredness, at times the need for oxygen, breathlessness, and rib pain. One summer my cough was so severe that I damaged the cartilage between my ribs.

I'd like to tell other patients that I've heard it said that you need to GET UP, GET DRESSED, SHOW UP! Attitude affects your life and those around you each day.