Resources

Pulmonary department, University of Michigan Health System
https://medicine.umich.edu/dept/pulmonary-critical-care-medicine/

Pulmonary Fibrosis Foundation
http://www.pulmonaryfibrosis.org

National Heart, Blood and Lung Institute
http://www.nhlbi.nih.gov

American Lung Association
http://www.lung.org/#

National Jewish Health
http://nationaljewish.org

National Jewish Health –
Participation Program for Pulmonary Fibrosis
www.pfresearch.org

Coalition for Pulmonary Fibrosis
http://www.coalitionforpf.org

Pulmonary Fibrosis Doctor (a blog)
http://www.pfdoc.org

American Thoracic Society
http://www.thoracic.org/

Clinical Research Studies, University of Michigan Health System
https://umclinicalstudies.org/

Patient Education Clearinghouse, University of Michigan Health System
http://pteducation.med.umich.edu

“Every Breath Counts” (video)
http://everybreathcountsfilm.com
(Inclusion of this resource does not constitute endorsement of products offered by the video’s sponsoring organizations.)

CarePages (free websites/blogs for patients and families)
https://www.carepages.com

Thanks to author Peter M., an ambassador for the Pulmonary Fibrosis Foundation, for recommending many of the resources shown here.

If you are interested in knowing how you can help advance research on pulmonary fibrosis and other conditions, please contact the University of Michigan Health System Office of Medical Development at (734) 998-7705.

Telling Your Story

There is growing interest in clinical departments in creating books that share personal stories that are written *by* patients and *for* patients who share a common diagnosis. Most people do not expect to become authors and may not have this kind of writing experience. To help them get started, the contributing patient-authors were given a list of questions to help them start thinking about how they might like to tell their story. Those questions are reproduced here in hope that they might be helpful to others.

\- Sara Whisenant, Editor

<u>Story-Telling Ideas/Talking Points</u>

1. Diagnosis
    a. How did you feel when you were diagnosed?
    b. How did you tell your friends and family about your diagnosis?

2. Symptoms
    a. What do you like or not like about your IPF?
    b. How does IPF make you feel?

3. Treatment
    a. What is being done to treat your IPF?
    b. How does treatment make you feel?
    c. What are some things that you like about being treated?
    d. What are some things that you don't like about being treated?
    e. How do you keep your spirits up during treatment?

4. Advice
    a. How do you manage your IPF at home?
    b. What advice would you give to somebody who has just been diagnosed with IPF?

   c. What kinds of things would you want your healthcare team (doctors, nurses, family, friends etc.) to know about what it's like to have IPF?

5. Reflections
   a. How has IPF changed your life?
   b. Anything else you would like to share about your story of the IPF experience?

Please Take Our Survey

I am interested in knowing what you think about this book. To that end, I have created an online survey and I invite you, the reader, to participate.

This survey is anonymous and confidential. Your identity will not be collected, tracked nor shared. Your survey responses will never be associated with your health records in any form. There is no penalty for not taking the survey nor for stopping at any point after you begin.

Your feedback will be used to improve the patient experience at the University of Michigan Health System.

Thank you for participating.

http://umhealth.me/ipfbooksurvey

Sara K. Whisenant

About The Editor

Sara Whisenant grew up in southeast Michigan and she still resides there with her husband and daughters. She has worked for the University of Michigan Health System for fifteen years. She holds a Bachelors degree in Psychology. While she has held many different roles at the University of Michigan, she is currently working as an Administrator in the Pulmonary Department. In this role she works closely with the Pulmonary faculty, administrators, research staff and patients. These connections are what inspired her to create this book.

Sara loves spending time with her friends and family and enjoys planning family outings and vacations. Sara and her family have a soft spot in their hearts for animals. The current menagerie includes two cats, a Beta fish and a Robo Dwarf Hamster. The family dream is to one day live on a big farm, where they can have many more animals.

This is Sara's first book.