Chronicling Idiopathic Pulmonary Fibrosis:

A Collection of Personal Stories

Edited by

Sara K. Whisenant

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This book is dedicated to Arianna,
the bravest person I know.

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FOREWORD

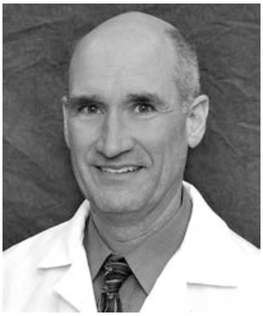
I have had the honor and privilege of helping to care for patients with pulmonary fibrosis for nearly two decades. During that time there have been improvements in diagnosis, a better understanding of the pathobiology of disease, and the approval of the first two drugs to treat the disease. These are important milestones and should be celebrated. Yet there is much work to be done!

The stories in this book give a personal account of the struggles that many patients encounter. What it feels like to be diagnosed with a terminal illness and having to share that news with family and friends; the changes in lifestyle the disease mandates over time; managing symptoms; the hopes and fears of participating in clinical trials or looking into the possibility of receiving a lung transplant. These are stories every caregiver needs to read!

Our healthcare system is becoming more complex and electronic. Physician practices seem busier than ever. It can be very impersonal. The stories in this book highlight the importance of resisting this impersonality. The importance of talking *with* and not *at* patients; the impact of giving, or not giving, hope and encouragement is clearly evident! The role of support groups, as a source of information, strength and encouragement is also clearly articulated.

Nearly 700 individuals, with approximately one third being patients and caregivers, attended the biannual Pulmonary Fibrosis Foundation 2015 Summit (www.pulmonaryfibrosis.org). I cannot emphasize enough how critical it was to hear from patients what they thought about the status of clinical care and research – helping us set priorities moving forward. This book is another example of how patients can be active, vocal and engaged. Patients and their caregivers are warriors fighting a terminal illness. They are heroes that participate in research and enroll in clinical trials.

I believe being a physician is the best career anyone can have, and the stories in this book are an affirmation. These stories also remind me of how great it can be when we 'get it right' and how detrimental when we 'get it wrong'. We have made progress in fighting pulmonary fibrosis but much work needs to be done to improve access to care, diagnostic accuracy and to eventually find a cure. Listening to our patients and hearing stories like those in this book is a critical piece of that equation!



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PREFACE

I have worked in the Pulmonary Division at the University of Michigan Health System (UMHS) for fifteen years in many different roles. For the past six years I've worked in an administrative assistant role, where I have the privilege of supporting seven faculty Pulmonologists, including Dr. Flaherty, who wrote the Foreword for this book. I worked with the research coordinators in the past and in that position I was able to meet and get to know many people who had been diagnosed with idiopathic pulmonary fibrosis (IPF), along with their families. This is what solidified my interest in the disease process. That exposure plus my training and interest in psychology led me to pay special attention to the family dynamics related to the coping skills developed by individuals whose lives are touched by this intimidating diagnosis.

The idea for this book was brought to me by the publisher in the Medical School Information Services Learning Design & Publishing department. She showed me one of her previous book projects; a collection of patient stories about a different diagnosis. I thought something similar might be a very interesting and helpful resource for idiopathic pulmonary fibrosis patients. I pitched the idea to Dr. Flaherty and he agreed.

This book will be a great resource for our patients and their families because it fills a gap in the currently available literature. The stories in this book are written *by* IPF patients, *for* IPF patients. While there is a lot of valuable literature available about pulmonary fibrosis, it does not necessarily answer everything that a newly diagnosed person wants to know. These stories talk frankly about the problems that these people and their loved ones face.

People who have already experienced this diagnosis have much to share with people who are newly diagnosed. There are also some questions answered here that people may find hard to ask in the clinic (or even in the support groups) because it does not seem like there is enough time or because the questions feel too personal.

Finally, writing about one's personal experiences can be a cathartic and therapeutic exercise for people suffering from any diagnosis. Books like this provide an outlet so that the world can hear their voices.

It is important to realize that even with a diagnosis like IPF, the journey is not all about gloom and doom. As you read these stories you will see that a lot of people take this as an opportunity to put their affairs in order, to spend more time with family, to count their blessings and to enjoy their lives. They deliberately spend more time doing what they enjoy instead of putting things off. This is a big part of the 'beauty in the darkness' that an IPF diagnosis brings.

My hope is that this book will help people who are newly diagnosed to understand that they are not alone. To help them to realize that there are resources, therapies and ways of battling the disease that are available to them. Maybe reading the stories will also help patients and family members get to better know their healthcare team and to understand that they are also human beings with hopes, fears and, sometimes, even a very real and personal connection to IPF.

We will keep printed copies of this book in the Pulmonary clinic at UMHS and will hand them out to every new and return patient. Books will be available upon request as well. This book is available for purchase on Amazon.com. And, finally, the University of Michigan Patient Education Clearinghouse plans to make this book available in patient libraries and upon request.

I hope you will enjoy reading these stories as much as I have enjoyed putting this collection together.

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ACKNOWLEDGMENTS

I do not think anyone produces a book all by himself or herself. In my case, the entire Pulmonary Division has been behind me and helped me all along the way while putting this book together. The research nurses suggested potential authors to me. Dr. Flaherty wrote the Foreword and supports the project. Our division chief, Dr. Standiford, also supports the project. My boss and our Division Administrator, Mary Freer, allowed me to take time to work on this, even though it is not strictly part of my job. Without their support I would not have been able to do this.

Thanks to Jasna Markovac and especially Karen Kost from the Learning Design & Publishing department in Medical School Information Services. They supported me every step of the way. This project would not have been possible without their guidance, in-depth knowledge and oversight. I would also like to give a special thanks to Arianna Whisenant for providing the beautiful flower photographs. I also want to express my appreciation to Nancy North for doing a fine job on the initial copy editing; any errors that slipped through are mine alone.

The University of Michigan Patient Education Clearinghouse and Awards Committee has generously funded this effort and they also championed the idea to provide this sort of new resource to patients. A huge thanks goes to them.

Last, but certainly not least, I would like to give a special thanks to all of the author-contributors for having the courage and for taking the time to tell their stories. Without you, this book would not have been possible.

Sara Whisenant