

Chapter 2

The IPF Research/Support Group

by Deborah D., R.N.

Working with patients and families with IPF has been a passion of mine for the last fifteen years. I have had the opportunity to work within a health care facility that provides another option to patients who have been stricken with this life-threatening disease—and that is research.

The University of Michigan is a highly respected IPF research site and I was able to work with many patients who were enrolled in our clinical trials throughout the years. Within the last year, there have been two new drugs approved for patients with IPF. I feel proud to have helped coordinate three of the clinical trials over several years which, ultimately, assisted patients in receiving a commercial use drug.

I also have had the honor of leading the IPF support group in our area. It has been a humbling experience to listen to stories from patients and caregivers who are dealing with the fallout of an IPF diagnosis. I have been able to provide them with additional resources - speakers for such things as exercise, diet, medication, palliative care, and hospice. We have a very lively group with lots of laughter and inspiration.

This book has been a labor of love for those who have shared their stories. We are very grateful. We hope the stories that have been shared here will inspire those newly diagnosed patients and their families to understand that they are not alone. The information is out there - use it, stay informed and be proactive!