

The Kansas City Foundation for Pulmonary Fibrosis

Inside this issue

- Recordkeeping for Patients with PF..... 2
- PFF Pulmonary Rehabilitation Toolkit..... 3
- Research Publications 4
- Stories by Persons with PF.....5
- Call for Volunteers..... 6



Join the KC Foundation For Pulmonary Fibrosis for a **fun evening of music, dancing, casino games, and food.** **Support the foundation's** mission of improving the lives of people with PF and Transplant recipients in KS and MO.

The Gatsby Gang Jazz Band 5-Piece provides the music. Listen to the Gatsby Gang Jazz Band [here!](#)

The foundation is looking for volunteers to help with the silent auction before and during the Gala and other areas. If you can volunteer please complete the form [here](#).

Schedule of Events

Registration/Cocktails	6:00 pm
Welcome by Dr. Hamblin	6:45 pm
Music/Dancing	7 – 10 pm
Food	
Cash Bar	
Silent Auction	
Casino Games	
Photo Booth	

See the website for more information. Click [here](#).

Recordkeeping for Patients with PF

PF Now: Part Three

PF Now discusses the many reasons to keep track of your own medical records because of PF.

The column provides some of the information you should consider gathering and organizing.

Click [here](#) for the full article.

PF Now: Part One

"Research has shown that patients who self-advocate by personally managing their medical records have also enjoyed better health."

PF Now has created templates to help you measure your progress.

PF Now provides a **Weekly Update template**.

Click [here](#) for the full article.



PF Now: Part Two

In this PF News column, it provides a **Treatment Plan Template**.

Click [here](#) to read the full article.

PFF Pulmonary Rehabilitation Toolkit

Virtual Pulmonary Rehabilitation Exercise Instruction Series

The Pulmonary Fibrosis Foundation created an exercise Instructional program. This is a series providing instructions for these levels:

- * Beginner Level
- * Intermediate Level

Click [here](#) for the Beginner Level instructions.

Click [here](#) for the Intermediate Level instructions.

Virtual PR—Preparing for At-Home Exercise

"In a roughly 15-minute webinar, Aimee Kizziar, respiratory therapist supervisor at UC Davis Health System, prepares viewers for three 30-minute exercise videos designed to be performed at home and to progress participants from beginning and intermediate levels"

To view the article click [here](#) .

Virtual PR—Starting At-Home Exercise (Part 1)

The Pulmonary Fibrosis Foundation created an at-home exercise program. This is the first of a series describing their program.

It covers:

- Get "SMART" with goal setting
- Ensure your safety

To view the article click [here](#) .

Virtual PR—Starting At-Home Exercise (Part 2)

The Pulmonary Fibrosis Foundation created an at-home exercise program. This is the second of a series describing their program.

It covers:

- ⇒ Selecting exercise equipment
- ⇒ Choosing the right exercise program
- ⇒ General exercise guidelines

To view the article click [here](#) .

Research Publications

PF Now: Research Publication for PF Patients

PF Now completed a research study about symptoms and quality of life for PF patients.

The column discusses:

- * What was the latest study
- * What did the study show

Click [Here](#) for the story.

PF Now: Understanding Research Publications

Pulmonary Fibrosis Now discussion how you can interpret Research publications. They discuss three areas:

1. How to Find Research about PF
2. How to Understand Research about PF
3. The Structure of a Research Publication

Click [here](#) for the full article.



PF Now: Finding Published Research

Pulmonary Fibrosis Now provides various links and way to finding publicized research.

Click [here](#) for the full article.

PF News: Stories by Persons with PF

Stories by Samuel Kirton

I'm Grateful for Doctors Who Understand IPF

Sam wrote "The gravity of my diagnosis hit Susan (his wife) especially hard, to the point where every time I walked into the room, she burst into tears. Fortunately, we found good information at the Pulmonary Fibrosis Foundation "

- ◆ My diagnostic team
- ◆ My transplant team

Click [here](#) to read the full article.

Identifying and Avoiding False Health Claims

Sam states "Scams have become particularly rampant in rare disease communities, and are spreading rapidly via social media platforms, web pages, and unsolicited text messages.."

Click [here](#) for the story.

An IPF Patient Perspective on What It Means to Be Rare

Charelene Marshall states "For most of my adult life I was blissfully unaware of rare diseases. This lasted until 2016, when I was diagnosed with idiopathic pulmonary fibrosis (IPF), a life-threatening and progressive lung disease"

She discusses:

- 1) Being an educator and an advocate
- 2) Suppressing our needs
- 3) Dealing with medication side effects
- 4) Navigating insurance and extra medical costs

Click [here](#) to read her column.



A Day in the Life: When Laughter Is the Best Medicine

Ann Reynoso says "Laughter brings people together. It can lead to positive emotional changes, especially when you're having a rough day. It can also boost the immune system, which enables our body to fight infections. Laughter can help us feel relaxed and vibrant and make our spirits soar."

Click [here](#) to read her article.

The Kansas City Foundation for Pulmonary Fibrosis (KCFPF) is a nonprofit organization dedicated to improving the lives of patients with pulmonary fibrosis and other rare lung diseases through education, technology, and research.

Volunteers Wanted!

The Foundation would like volunteers for these committees.

Fundraiser Committee: Subcommittee will be to make recommendations to the Board on the annual fundraiser. The subcommittee will also explore additional fundraising opportunities outside of a yearly event.

Patient Initiative Committee: The purpose of the Foundation Patient Initiative Committee is to be good listeners and observers of the Pulmonary Fibrosis Community and identify, research, and propose opportunities the Foundation can financially support to make life easier.

Media Committee (Website, FB, News, Newsletter): The primary role of the Media Subcommittee will be to spread awareness, distribute educational and grant information, and advertise events developed by the other subcommittees. The primary focus will be on website and Facebook updates, but the use of different media will depend on the target audience.

Visit Here to sign up: <https://www.kcpulmonaryfibrosis.org/want-to-help>

All images on proceeding pages are either property of KCFPF or licensed under Creative Commons.

Kansas City Foundation for Pulmonary Fibrosis

13725 Metcalf Ave, Box 286
Overland Park, KS 66223

kcfpf@kcpulmonaryfibrosis.org
<https://www.kcpulmonaryfibrosis.org>

