



# The Kansas City Foundation for **PULMONARY FIBROSIS**

13725 METCALF AVE, BOX 286  
OVERLAND PARK, KS 66223  
KCFPF@KCPULMONARYFIBROSIS.ORG



by Matt Shanahan

## Monthly Newsletter April 2021

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KCFPF Website

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

Facebook

<https://www.facebook.com/kcspf>

## National Volunteer Month



The Foundation would like  
volunteers for these committees.

- Fundraiser Committee
- Patient Initiative Committee
- Media Committee (Website,  
FB, News, Newsletter)

For more information go to [page 7](#).

or to sign up [click here](#)

# Idiopathic Pulmonary Fibrosis (IPF)

## WHAT'S THE DIFFERENCE BETWEEN IPF AND COPD?

"It can be easy to confuse IPF and COPD. Both diseases affect the lungs, are progressive, and share many symptoms. These common symptoms include shortness of breath that gets worse with time, chronic cough, and fatigue. However, the way they damage the lungs is different.

In IPF, your lungs become scarred, stiff, and thick, and this damage isn't reversible. In COPD, the airways and air sacs in your lungs become blocked, but you can control the symptoms, even in later stages of the disease."

Source: Raremark.com, Emily Armstrong, Raremark Community Manager

[Click here for complete article.](#)

Dr. Rae Osborn wrote an article on the difference of IPF and COPD on [DifferenceBetween.net](http://DifferenceBetween.net). On the right is her comparison chart.

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

Table comparing  
**COPD & Pulmonary Fibrosis**

Characteristics	COPD	Pulmonary Fibrosis
Definition	COPD is a chronic obstructive Pulmonary disease in which the flow of air through the lungs becomes very limited	Pulmonary Fibrosis is the disorder in which the lungs become very scarred
Symptoms	Difficult breathing, productive coughing, wheezing, barrel chest, hyperinflated lungs	Difficulty breathing, nonproductive cough, clubbing of fingers and toes, fatigue, muscle aches, weight loss
Diagnosis	Physical exam, Pulmonary function tests, chest X-rays	Physical exam, chest X-ray, high-resolution CT scan showing opaque and honeycomb areas in lungs
Causes	Cigarette smoking and alpha-1 antitrypsin disorder	Genetics and environment, especially metal dust, some chemotherapy medicines
Risk factors	Having alpha-1 antitrypsin disorder, smoking cigarettes, exposure to smoke	Exposure to metal dust, cigarette smoking, certain viruses, certain genetic mutations
Life expectancy	8 to 14 years	4 to 5 years
Treatment	Bronchodilators, corticosteroids, supplementary oxygen, lung transplant	Pirfenidone and nintedanib, supplementary oxygen, lung transplant



## Managing your IPF



When a person is diagnosed with IPF, their quality-of-life changes. They should start managing their life with IPF. Below are a couple resources which will help them with living with PF.

Living with Idiopathic Pulmonary Fibrosis by Boehringer Ingelheim

<https://www.lifewithpulmonaryfibrosis.com/sites/default/files/Living%20with%20IPF%20eBook%202020.pdf>

Life with Pulmonary Fibrosis by Pulmonary Fibrosis Foundation.

<https://www.pulmonaryfibrosis.org/life-with-pf>

## Connections to IPF



On Heathline.com, Marjorie Hecht has an article about IPF and Obstructive sleep apnea (OSA). Many IPF patients use a CPAP for their OSA.

[Click here to see article.](#)

On Heathline.com, Marjorie Hecht has an article about IPF and gastroesophageal reflux disease (GERD). Many IPF patients are on anti-acid therapy.

[Click here to see article.](#)



On Pulmonary Fibrosis Foundation, Forest Ray, PhD has an article about the risk of Air Pollutant risks of causing acute exacerbations in IPF.

[Click here to see article.](#)

## Autoimmune Interstitial Lung Diseases (ILD)

### Rheumatoid arthritis with interstitial lung disease (RA-ILD)

"RA is a systemic autoimmune disease. Besides the joints, it also affects other parts of the body, including lungs.

Rheumatoid arthritis (RA) is a condition that affects about 1% of the population worldwide. Of these people with RA, 10-20% will develop lung involvement known as interstitial lung disease (ILD). In this form of ILD, scarring of the lung tissue might develop. This scar tissue is known as pulmonary fibrosis and affects the tiny air sacs and blood vessels responsible for providing oxygen to all parts of the body. As healthy lung tissue is replaced by scar tissue, it becomes harder for oxygen to pass through the lungs and into the bloodstream."

(source: Boehringer Ingelheim)

<https://www.lifewithpulmonaryfibrosis.com/understanding-pulmonary-fibrosis/conditions-pulmonary-fibrosis/ra-ild>

### Sjögren's syndrome with Interstitial Lung Disease

"Sjögren's syndrome is a rare autoimmune disease that primarily affects the salivary and tear glands. It can also affect the lungs.

Only 6 people per 100,000 each year develop Sjögren's syndrome, with about 9-20% of these people developing ILD.

In Sjögren's syndrome with ILD, scarring of the lung tissue might develop. This scar tissue is known as pulmonary fibrosis and affects the tiny air sacs and blood vessels responsible for providing oxygen to all parts of the body. As healthy lung tissue is replaced by scar tissue, it becomes harder for oxygen to pass through the lungs and into the bloodstream. This results in shortness of breath." (source: Boehringer Ingelheim)

<https://www.lifewithpulmonaryfibrosis.com/understanding-pulmonary-fibrosis/conditions-pulmonary-fibrosis/sj%C3%B6gren%E2%80%99s-syndrome>

## Treatments

### Oxygen Therapy



A person with Pulmonary Fibrosis (PF) could have the symptoms: Shortness of breath, Cough, Tiredness, or Blue fingertips or lips. In time these symptoms might require a person to need supplemental oxygen.

Getting supplement oxygen can be a complicated process. Always talk with your doctor about the process.

Here are a couple of resources explaining supplemental oxygen.

The CHEST Foundation provides a detailed resource.

<https://foundation.chestnet.org/lung-health-a-z/interstitial-lung-disease-ild/interstitial-lung-disease-ild-oxygen-therapy/interstitial-lung-disease-ild-oxygen-therapy-complete/#>

The Pulmonary Fibrosis Foundation provides another detailed resource.

<https://www.pulmonaryfibrosis.org/life-with-pf/oxygen-therapy>

### Pulmonary Rehabilitation



Pulmonary Rehab is a specialized program to combine exercises and education to people who have a lung disease such as PF. The exercise can help you breath better and provide quality of Life.

The Pulmonary Fibrosis Foundation recently added a Pulmonary Rehabilitation Toolkit page to their website. This toolkit is in partnership with the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR).

<https://www.pulmonaryfibrosis.org/life-with-pf/PRToolkit>

AACVPR Pulmonary Rehab resource.

<https://www.aacvpr.org/Pulmonary-Patient-Resources>

## Care Partners



On Raremark.com, Pravin Pant, MSN, NP provides helpful tips on being a Care Partner. It has Patient Tool available.

[Click here to see article.](#)

In the European Respiratory Society (ERS) magazine Breathe,

Liam Galvin talks about providing care to his wife who has IPF.

[Click here to see article.](#)



## VOLUNTEER:

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 an annual 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 main role of the Media Subcommittee will be to spread awareness, distribute educational and grant information, advertise events which are developed by the other subcommittees. The primary focus will be on website and Facebook updates, but other media will be used dependent upon the target audience.

Sign Up using link below.

[HTTPS://WWW.KCPULMONARYFIBROSIS.ORG/WANT-TO-HELP](https://www.kcpulmonaryfibrosis.org/want-to-help)