# 30 Facts
In 30 Days

PULMONARY FIBROSIS®
awareness month
SEPTEMBER

PRESENTED BY Pulmonary™ Fibrosis Foundation

The word “pulmonary” means lung and “fibrosis” means scar tissue. So in it’s simplest sense, pulmonary fibrosis means “scarring of the lung.” More than 250,000 Americans are living with PF, and more than 50,000 new cases are diagnosed annually.

**There is no known cure.**

# 30 Facts
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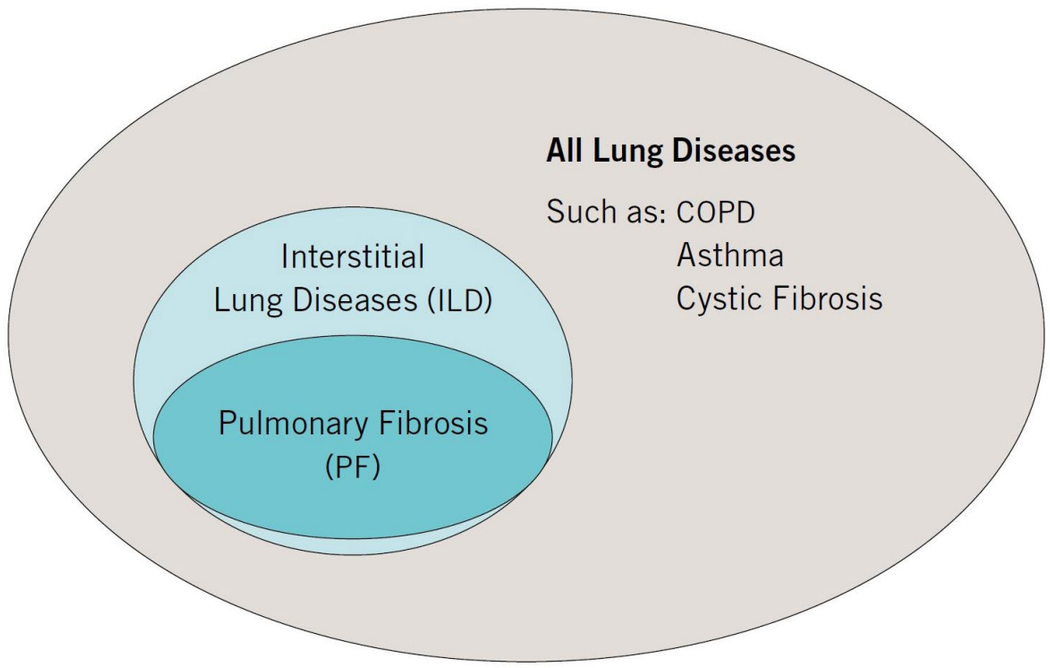
Interstitial lung disease, or ILD, includes all of the diseases in which there is inflammation or scar tissue in the walls of the air sacs. Many forms of ILD are called “pulmonary fibrosis.” But pulmonary fibrosis is not a specific disease. It’s the general term that describes ILD.



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The most common symptoms of pulmonary fibrosis are dry, persistent cough, shortness of breath, and fatigue. It's often a "progressive" disease, which means that it worsens over time. As PF progresses, patients may become breathless while taking part in everyday activities, such as showering, getting dressed, speaking on the phone, or even eating.

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There is no known cure for pulmonary fibrosis, but effective treatments are available. Commonly prescribed treatments include oxygen therapy, pulmonary rehabilitation, medication, symptom management, and, less often, lung transplantation. Not all PF treatments are appropriate for everyone; your doctor will determine the best course of treatment for you. Treatments for PF are aimed at **slowing the course of the disease, improving symptoms, and helping you stay active.**

# 30 Facts
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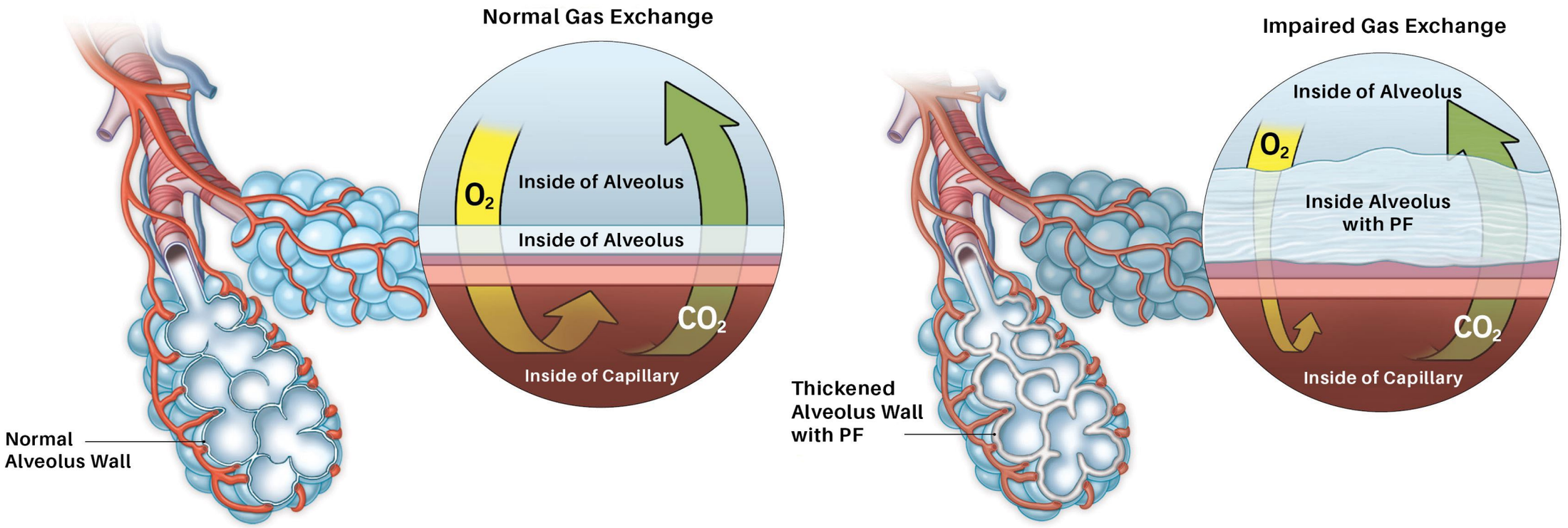
Your lung is made up of millions of tiny air sacs called “alveoli.” The wall of each air sac is 10x thinner than a strand of hair, allowing oxygen to move throughout the body. With pulmonary fibrosis, thickened scar tissue and inflammation builds on the walls of these air sacs. This causes shortness of breath and can trigger cough.



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Idiopathic pulmonary fibrosis (IPF) is a diagnosis in which the cause of the disease is unknown. This is only one kind of PF of unknown cause; other ILD diagnoses are also without known cause. Below are a few you might come across.

| Disease | Abbreviation |
|---|---|
| Idiopathic pulmonary fibrosis | IPF |
| Idiopathic non-specific interstitial pneumonia | Idiopathic NSIP |
| Respiratory-bronchiolitis-associated ILD | RB-ILD |
| Desquamative interstitial pneumonia | DIP |
| Cryptogenic organizing pneumonia | COP or BOOP |
| Sarcoidosis | Sarcoid |

# 30 Facts
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No one can tell you how long you will live with pulmonary fibrosis. You may have seen estimates online that people with the disease will live 3-5 years. Thanks to early diagnosis and better treatments, this statistic is outdated.

# 30 Facts
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There are five main categories of identifiable causes of interstitial lung disease. In the United States, environmental and autoimmune causes are the most common types of ILD of known cause.

| TYPE OF PULMONARY FIBROSIS | CLUES THAT DOCTORS USE |
|---|---|
| Drug-induced | Prior or current use of amiodarone, nitrofurantoin, chemotherapy, methotrexate, or other drugs known to affect the lungs |
| Radiation-induced | Prior or current radiation treatment to the chest |
| Environmental (called hypersensitivity pneumonitis) | Exposure to mold, animals, or other triggers |
| Autoimmune (called connective tissue disease-related) | Joint inflammation, skin changes (particularly on the fingers and face), dry eyes or mouth, abnormal blood tests |
| Occupational (called pneumoconiosis) | Prior or current exposure to dusts, fibers, fumes, or vapors that can cause PF (such as asbestos, coal, silica, and others) |
| Idiopathic | When no cause can be identified |

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One of the most common symptoms of PF is shortness of breath. Scar tissue and inflammation make your lungs stiff. Stiff lungs are hard to stretch, so your breathing muscles have to work extra hard just to pull air in with each breath. Your brain senses this extra work, and it lets you know there's a problem by triggering a feeling of breathlessness.

# 30 Facts
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Your doctor may measure your oxygen level in different circumstances: while sitting at rest, while walking in the hallway or on a treadmill, and during sleep. If your oxygen level drops below about 88%, your doctor may prescribe oxygen therapy. Your oxygen prescription will include:

- When to use your oxygen (during sleep, rest, or activity, or at altitude)
- How much oxygen you need for each activity
- What type of oxygen equipment fits your lifestyle and oxygen requirements

Using oxygen can be inconvenient and difficult to adjust to, especially outside the home. Sharing your concerns with your care team can help. Over time, most people find the benefits of using oxygen greatly outweigh the downside. Many people using oxygen report they have less breathlessness and fatigue and are better able to pursue an active lifestyle. Contrary to a common misconception, oxygen is **not** addictive.

# 30 Facts
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Cough is one of the most common symptoms of PF. Studies estimate that people with PF can cough anywhere from 200-500 times per day.

# 30 Facts
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Most people with pulmonary fibrosis can and **should** exercise. Simply walking or doing light strengthening exercises can improve your quality of life. Pulmonary rehabilitation, a monitored exercise program tailored to your abilities, is a great option. PR includes exercise training; breathing exercises; anxiety, stress, and depression management; nutritional counseling; education; and more. It's been found to improve physical function, breathlessness (dyspnea), mood, and quality of life in people with IPF and other types of PF.

# 30 Facts
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Palliative care means treating the symptoms of a disease to help you feel better on a day-to-day basis. It doesn't directly treat the underlying disease. Talk to your doctor about medications for cough, breathlessness, anxiety, and depression. Palliative care, delivered by a multidisciplinary team, focuses on relieving symptoms and improving quality of life throughout your disease course.

# 30 Facts
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No two cases of PF are alike. Every person experiences the disease differently, and not all treatments are right for everyone. Your doctor is the only person who is qualified to provide **you** with medical advice.

# 30 Facts
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Drug therapy for pulmonary fibrosis is often specific to the type of PF a person has. Because of differences in the causes of PF, a medication prescribed to treat one form of the disease may not be right for another form. It's important to discuss drug therapy with your doctor to learn what medications may be appropriate for your form of PF.

# 30 Facts
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Pulmonary fibrosis is considered sporadic when there are no known relatives with the diagnosis. When two or more blood relatives are affected, this is considered familial pulmonary fibrosis (FPF). It's estimated that as many as 20% of people with ILD have FPF.

# 30 Facts
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Transplant centers have strict criteria for being a candidate, including weight, the health of your other organ systems, your history of medical compliance, and your support system, among many other factors. If, after extensive evaluation, the transplant center determines that you're a candidate, you'll be placed on a waiting list and assigned a lung allocation score (LAS) that determines the order of priority for waiting candidates. Using several criteria, the LAS tries to predict the likelihood of each candidate's survival in the next year without a transplant, and the likelihood of surviving one year after a transplant.

The average wait time for an IPF patient is 3-6 months, but it can be much longer. The transplant surgery is followed by an extensive recovery time. Most people with PF who have successful lung transplants feel better, reporting that cough and breathlessness are gone. However, lifelong risks after transplantation are serious and include infections, rejection of the new lung, and medication side effects.

# 30 Facts
In 30 Days

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Stem cell therapy is **NOT** an FDA-approved treatment for pulmonary fibrosis. There have been serious medical complications reported from patients living with PF who underwent unapproved treatments. Learn how to protect yourself from stem cell centers' deceptive marketing at **pulmonaryfibrosis.org/stemcell**

# 30 Facts
In 30 Days

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There are many causes of the cough that can accompany pulmonary fibrosis. Talk to your doctor to see if post-nasal drip, heartburn (gastroesophageal reflux disease, GERD), low oxygen levels, or another issue may be contributing to your cough.

# 30 Facts
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Researchers have made great strides in better understanding and treating the disease. But there is much more to learn—and the best way to help ensure these important discoveries will continue is to join a clinical trial or research study.

People living with PF may find several advantages to joining a clinical trial. Participants may obtain access to a potential new PF medication and receive valuable education about improving their health. Increased clinic visits and testing usually associated with a clinical trial may give participants a clearer picture of the state of their disease and progression. Many PF clinical trial participants say that even if joining a trial doesn't directly benefit them, they view it as an important step on the road to helping future patients with PF.

# 30 Facts
In 30 Days

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There are countless advertisements for products offering a natural or herbal cure for pulmonary fibrosis, but none of these remedies have scientific data to back up the claims. Any product you take, including supplements, will have an effect on your body and could result in side effects and interactions with any current medications. Always check with your doctor before starting any new treatment.

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The **PFF Community Registry** is the Foundation's largest investment in research. This powerful research tool enables researchers to explore what treatment strategies work best for patients and to find new ways to prevent, diagnose, treat, and potentially cure pulmonary fibrosis. Patients, caregivers, and family members can enroll in the Registry today and help researchers at **pffregistry.org**

# 30 Facts
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Caregivers must take care of themselves, too. It can be physically and emotionally draining to care for someone with a chronic illness. You can take care of yourself by asking for help when you need it, keeping up with your own responsibilities, and making time to do the things you enjoy. Further, you can join PFF Caring Conversations, the PFF's support group for caregivers.

# 30 Facts
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PRESENTED BY Pulmonary Fibrosis Foundation™

Finding a healthcare provider who has knowledge and experience with the treatment of pulmonary fibrosis can result in better care. To help you find doctors who are experts in PF, the Foundation established the PFF Care Center Network. Currently, there are 81 centers nationwide. To see if there's a PFF Care Center near you, visit **pulmonaryfibrosis.org/medicalcare**

# 30 Facts
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It is not uncommon for people living with PF to struggle with anxiety and depression. Your emotions are valid. If you are struggling with your mental health, talk to your doctor about seeking a counselor who can help guide you through your journey with pulmonary fibrosis. Additionally, a support group can help you feel less alone. You can find a support group near you, either in person or virtually, at **pulmonaryfibrosis.org/supportgroups**

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The PFF has provided more than $4.5 million in research funding through the PFF Scholars program. This program supports researchers at an early stage in their field to help them pave a path for a career in ILD research. This grant also enables them to receive even more ILD research grants throughout their work.

# 30 Facts
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In order for a drug to be available on the market, it must be tested on humans through a clinical trial. A lack of patient participants is one of the most common reasons a clinical trial is cancelled. Your participation in clinical trials is essential to bring new treatments and a cure to the market. Many trials are currently recruiting and need your help! Consider joining a clinical trial to help get new treatments on the market. To get started, visit **trials.pulmonaryfibrosis.org.**

# 30 Facts
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A Google search and various websites online can contain misleading and outdated information about pulmonary fibrosis. The Pulmonary Fibrosis Foundation's website, **pulmonaryfibrosis.org**, is your source for accurate, trusted information that you can rely on. The Foundation works with teams of medical experts who thoroughly review all content. If you prefer to speak with someone one-on-one for information, call the PFF Help Center at **844.TalkPFF** or email **help@pulmonaryfibrosis.org.**

# 30 Facts
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No one has to live with pulmonary fibrosis alone — you can connect with others who know exactly what you're going through. The PFF has a network of more than 150 support groups across the United States that you can join today. Joining a support group can boost your mental health and help you learn about living with this disease. Visit **pulmonaryfibrosis.org/supportgroups**

# 30 Facts
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Continue to learn about pulmonary fibrosis. The more you know, the better you will be able to manage your disease and recognize when you need to access health services. To help you stay current with all the latest information, you can attend the PFF's monthly webinar series. Each month, we host a live, one-hour webinar presentation about a different topic. All the webinars are recorded and then posted on our YouTube channel. There are hundreds of videos about a large variety of topics.