

30 Facts In 30 Days



PULMONARY FIBROSIS[®]
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SEPTEMBER

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The word “pulmonary” means lung and “fibrosis” means scar tissue. So in its 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.**

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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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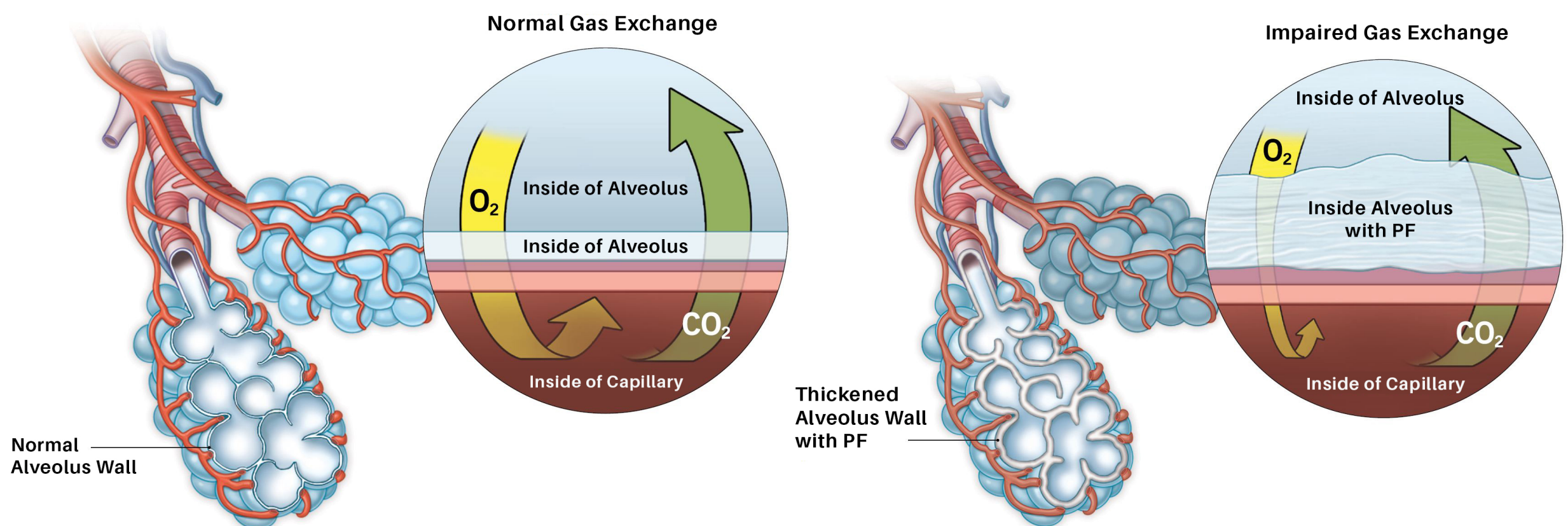


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Your lung is made up of millions of tiny air sacs called “alveoli.” The wall of each air sac is 10x thinner than a strand of hair, allowing oxygen to move throughout the body. With pulmonary fibrosis, thickened scar tissue and inflammation builds on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



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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. Current treatment options include supplemental oxygen, pulmonary rehabilitation, palliative care, and medications. In serious cases of PF, lung transplantation may also be an option.

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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

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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.

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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.

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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.

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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. Ask your doctor how to get started.

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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. Supplemental oxygen, cough treatments, and pulmonary rehab are all considered palliative care. Palliative care has been proven to enhance the quality of life in people living with a serious disease.

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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.

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It's easy to feel confused by all the terms and abbreviations used to describe pulmonary fibrosis. To help, the PFF offers an online glossary to help you identify new words or abbreviations you might come across. You can read it at pulmonaryfibrosis.org/glossary

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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. Research about this type of PF is underway. Thanks to a generous donor, this year the PFF will award a \$245,000 grant for researchers to further study FPF.

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A lung transplant is a complex procedure and a potential treatment option for serious cases of PF. To qualify, applicants must meet very strict criteria. The evaluation process can take months. If you're considering a transplant, begin the process as early as you can.

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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

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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.

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Every year, officials in Washington D.C. make decisions that impact the lives of people living with pulmonary fibrosis. Our program, PFF Advocates, is a volunteer opportunity that alerts you about issues and provides instructions on how you can take action. Join us and become an advocate at pulmonaryfibrosis.org/advocacy

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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 Registry is the Foundation's largest investment in research. This powerful research tool enables researchers to explore what therapies work best for patients and to find new ways to prevent, diagnose, treat, and potentially cure pulmonary fibrosis. Currently, 40 studies have emerged from the PFF Registry, worth over \$32 million in research costs. You can enroll in the PFF Community Registry today and help researchers at pffregistry.org.

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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. Visit pulmonaryfibrosis.org/zoom

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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 74 centers nationwide. To see if there's a PFF Care Center near you, visit pulmonaryfibrosis.org/medicalcare

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It is not uncommon for people living with PF to struggle with anxiety and depression. Your emotions are valid, and the connection between physical and mental health is worth exploring while living with PF. 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.

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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.

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In order for a drug to be available on the market, it must be tested on humans through an FDA-approved 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.

Find a PF clinical trial at
trials.pulmonaryfibrosis.org

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The internet can contain misleading 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**.

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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

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During the 2021 calendar year,
Team PFF fundraisers raised
\$194,131.56 with contributions
to over 49 different events.

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A survey conducted in 2020 revealed that 86% of Americans do not know the symptoms of pulmonary fibrosis. Despite the overall lack of awareness, 82% of people consider it to be a serious disease.