30 FACTS IN 30 DAYS

PULMONARY FIBROSIS® awareness month SEPTEMBER

PRESENTED BY Pulmonary™ Fibrosis Foundation

The word “pulmonary” means lung and the word “fibrosis” means scar tissue— similar to scars that you may have on your skin from an old injury or surgery. So, in its simplest sense, “pulmonary fibrosis” means scarring in the lungs.

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The most common symptoms of pulmonary fibrosis are dry, persistent cough and shortness of breath.

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Interstitial lung diseases (ILD) are a broad category of over 200 lung diseases that affect the lung interstitium. Typically, ILDs cause inflammation, fibrosis (scarring), or an accumulation of cells in the lung not due to infection or cancer.

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ILDs are characterized by varied amounts of inflammation, scarring, or both, that damage the ability of the lung to absorb oxygen from the air.

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More than 250,000 Americans are living with PF and ILD.

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The prevalence of PF and ILD is on the rise with more than 50,000 new cases diagnosed annually.

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There are five main categories of pulmonary fibrosis that have identifiable causes :

- Drug-induced
- Radiation-induced
- Environmental
- Autoimmune
- Occupational

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In the United States, **Environmental** or **Exposure-Related**, and **Autoimmune** causes are the most common types of PF of known cause.

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Idiopathic pulmonary fibrosis (IPF) is the most common form of pulmonary fibrosis. Idiopathic means “of unknown cause."

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A survey conducted by the PFF in 2020 revealed that 86% of Americans do not know the symptoms of pulmonary fibrosis.

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Despite the overall lack of awareness of PF symptoms, 82% of Americans consider PF to be a serious disease.

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Because of advocacy efforts, public funding for PF research has steadily increased in recent years. Advocating with elected officials and other policy makers is an important way to improve the lives of people living with PF.

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For those living with PF, accessing accurate and current information about the disease can be a challenging and frustrating task. The PFF’s Help Center provides the most up-to-date medical information, communicates the availability of support services, and provides information about other essential resources.

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Every individual diagnosed with pulmonary fibrosis has a unique experience with the disease. There is no “standard” or expected clinical course.

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Whether you are a spouse, partner, child, or friend, caring for someone with a serious illness is a challenge.

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The PFF Support Group Network has more than 150 virtual support groups across the country led by passionate volunteer group leaders.

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People living with PF are at greater risk of severe illness from COVID-19 and should take steps to protect themselves, such as vaccination and mask wearing in public places.

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The PFF hosts four telephone-based support groups. Each group supports those who have a specific experience with pulmonary fibrosis.

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There are countless ways to support the PF community, ranging from legislative advocacy, to hosting a fundraiser, to sharing your story!

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The PFF Care Center Network (CCN) is a group of 68 medical centers in 33 states dedicated to improving the lives of those with pulmonary fibrosis. Care Centers have expertise in treating adult patients with fibrotic lung diseases and utilize a multidisciplinary approach to deliver comprehensive patient care, patient-oriented PF research, and additional programming.

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Physicians currently have no way to predict the course of any individual case of PF, but the PFF Registry is working to change that.

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Products that promise a natural cure for PF do not have scientific data to support their claims. Doctors have a number of ways to treat PF, including the use of medications, oxygen therapy, non-medical treatments, and even lung transplantation.

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Drug therapy for PF is often specific for the particular type of PF a patient has. In other words, the treatment for one type of PF may not be the right one for another. It is important to discuss drug therapy with your physician relative to your type of PF.

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A clinical data registry records, analyzes, and reports information about a patient’s health status and care received over time in order to improve health outcomes.

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The PFF Registry is an unparalleled research tool that 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.

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Currently, stem cell therapy is not a proven treatment for pulmonary fibrosis and may cause serious harm.

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PF is one of the diseases for which lung transplant is an option; others include chronic obstructive pulmonary disease (COPD), cystic fibrosis, pulmonary arterial hypertension, and sarcoidosis.

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A referral for a unilateral (single) or bilateral (double) lung transplant will come from your primary care physician or pulmonologist (lung doctor).

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To date, our Team PFF volunteers have raised over $2,499,471.92 for the PF community.

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Team PFF hosted over 40 fundraising events in 2020. From virtual concerts to happy hours, PFF volunteers raised over $71,587.32 for the community last year alone.