In 1996, the CHEST Foundation was founded as CHEST’s charitable foundation to serve CHEST members, their patients, and the public by supporting clinical research, patient education, and community service. From our early focus on tobacco prevention in young girls and women, to our new disease awareness campaigns that reach millions, we’ve had a significant impact in the last 20 years. More than 95 cents of every dollar raised goes toward advancing our mission-based programming. Since our inception, we’ve provided more than $10 million in funding for clinical research and community service, with a reach that spans more than 60 countries. It is with sincere appreciation that we acknowledge our tireless volunteers and the committed donors who have worked with us over the years to champion lung health.

The CHEST Foundation recognizes the support of the Feldman Family Foundation and their commitment to the pulmonary fibrosis community. This patient education material was partially funded by the Feldman Family - Mitch Feldman, Laury Feldman and Mara Fox. Through our continued partnership, The CHEST Foundation and Feldman Family Foundation will impact and improve the quality of life for patients and caregivers battling pulmonary fibrosis.

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IPF is more common in men than in women, although the number of cases of IPF in women is on the rise.

Lung transplantation may be an option for patients who meet criteria with severe IP.
Learn About Pulmonary Fibrosis

Pulmonary fibrosis (PF) is a rare but serious lung disease that occurs when lung tissue becomes scarred and stiffens. Pulmonary means related to the lungs, and fibrosis means scarring. It usually gets worse over time. It typically leads to shortness of breath and eventually the need for supplemental oxygen.

PF complicates many of the more than 200 lung conditions that make up a category of lung disorders called interstitial lung disease (ILD). ILDs cause inflammation and scarring around the tiny air sacs in the lungs. It may be hard to determine the actual cause of lung scarring, which makes diagnosing a particular form of PF very difficult.

Patients can develop PF when they have an autoimmune disease (like rheumatoid arthritis), from exposure at the workplace (such as hazardous chemicals), or from environmental substances (such as asbestos). It can also happen when patients have unusual or damaging reactions to certain medicines (including some cancer treatments). About 60% to 70% of patients with PF are current or former smokers.

Idiopathic pulmonary fibrosis (IPF) is a severe type of ILD. Idiopathic means that the cause is unknown. There is no cure for IPF, but there are treatments that can slow the progression and help reduce symptoms.
Normal oxygen (O2) exchange; Elastic interstitial space
Idiopathic Pulmonary Fibrosis

Damaged bronchioles and alveoli

Fibrosis between alveoli

Alveoli distorted

Capillary

Fibroblasts

Excess fibrin: scar tissue

oxygen (O2) exchange due to fibrosis; tissue filling interstitial space
There are different ways in which the lungs can get scarred – some known, some unknown. But scarring causes lung tissue to thicken and stiffen. As a result:

- It is more difficult for lungs to expand (get larger) and take in air when breathing.
- It is difficult for oxygen to get from the lungs into the bloodstream and circulate to tissues and organs in the body.

As the lungs become more scarred, patients experience more shortness of breath, especially with activity.
To understand how PF affects the body, you first need to understand the way lungs contribute to the normal flow of blood and oxygen. The heart is divided into two sides: the left and the right. Each side has an atrium (a receiving chamber) and a ventricle (a pumping chamber). Each side is responsible for pumping blood, but for different reasons. The left side of the heart pumps blood through arteries to supply oxygen and vital nutrients to cells and tissues throughout the body. All the cells and tissues of the body need oxygen to function. Once the oxygen is delivered, the cells produce carbon dioxide, which enters the bloodstream through veins and returns back to the right side of the heart where it is pumped back to the lungs. In the lungs, carbon dioxide is breathed out of the body and oxygen is breathed in and crosses into the bloodstream to be pumped by the left side of the heart to the body.

For patients with PF, as the scarring increases and the lung tissue becomes stiffer, it gets harder for oxygen to move from the lungs into the bloodstream. Oxygen levels in the blood can become very low. The lack of oxygen causes stress on the heart and brain. Some patients develop high blood pressure in the arteries in their lungs (known as pulmonary hypertension). In some cases, without wearing oxygen, it can become difficult to deliver the needed amount of oxygen to the other organs like the heart, brain, and kidneys, which can result in damage to these organs.
How Serious Is Pulmonary Fibrosis?

PF is a condition that typically gets worse over time. The scarring that happens cannot be reversed or repaired. Because the cause is unknown in IPF, it cannot be prevented either. In other forms of PF when a cause can be identified, removal of certain exposures or treatment of autoimmune disease may result in improvement. Unfortunately, there is no known way to reverse PF.

Unlike other chronic diseases, such as diabetes or high blood pressure, PF is relatively rare, especially in younger patients. IPF affects about 132,000 people in the United States. Almost 50,000 new cases are diagnosed every year. The symptoms of PF are similar to those of other more common lung diseases, including pneumonia, asthma and chronic obstructive pulmonary disease (COPD). Because of that, patients have a delay in the correct diagnosis up to 50% of the time.

If the main symptom is shortness of breath, heart disease may be suspected first rather than a lung disorder. The earlier a correct diagnosis is made, the better a treatment plan can be put in place, including possible prescriptions for medications that may help slow down the disease.

Some patients with IPF may not have much worsening of their symptoms over time or may never need to use supplemental oxygen. However, most patients will gradually lose lung function over time and will likely suffer from flare-ups (also called exacerbations). Acute exacerbations may cause rapid worsening of the disease and require hospitalization. Sadly, some patients experience rapid loss of lung function, which may lead to respiratory failure and death. Their only option is a lung transplant, if they are eligible.

Patients with PF that is not due to IPF may respond to certain medications. Their lung disease may stabilize or even improve with the right treatments.
What Are the Symptoms of Pulmonary Fibrosis?

The most common symptom of PF is shortness of breath, especially during exertion. Other symptoms include:

- A dry, hacking cough
- Fast, shallow breathing
- Fatigue
- Shortness of breath, especially walking upstairs or inclines
- Weight loss
- Clubbing (a widening or rounding of the tips of fingers and toes)

The severity of symptoms varies from person to person. Some patients may have mild shortness of breath for years before being diagnosed. Shortness of breath is typically greater with activity and can progress to being present at rest or with minimal activity. It may even become difficult to breathe when taking a shower or talking on the phone.
What Causes Pulmonary Fibrosis?

Finding a cause can be challenging. In some cases, lung scarring is secondary to another disease (such as rheumatoid arthritis) or is the result of exposure to a damaging substance in the environment or workplace. In most cases, no clear cause is identified, making it idiopathic — cause unknown.

Effective treatments are available for some forms of PF. That’s why it’s important to search for an underlying cause to get a specific diagnosis.
Known causes for pulmonary fibrosis include:

**Autoimmune diseases**, like rheumatoid arthritis, as well as connective tissue diseases, collagen vascular diseases, or rheumatologic diseases that affect the immune system. In these cases the body's own immune system may attack the lungs, causing inflammation and scarring. These include:

- Rheumatoid arthritis
- Systemic Scleroderma
- Systemic lupus erythematosus
- Polymyositis/dermatomyositis

**Workplace exposures**, typically inhaled into the lungs over time, including, but not limited to:

- Asbestos
- Silica
- Coal dust
- Beryllium
- Grain dust
- Hard metal dusts

**Environmental exposures**, including, but not limited to, extended exposure to birds, molds, and hot tubs.

**Medications** - these include:

- Chemotherapy drugs (methotrexate or bleomycin)
- Heart medications (amiodarone or propranolol)
- Antibiotics (nitrofurantoin and sulfasalazine)
- Antiseizure drugs

**Systemic diseases**, such as sarcoidosis.

**Radiation treatments**, often related to cancer treatment.

**Genetics** - In about 10% to 15% of cases of idiopathic pulmonary fibrosis, more than one family member becomes afflicted with the disease. This is called familial pulmonary fibrosis (FPF) or familial interstitial pneumonia (FIP). New research indicates that this may be caused by genetic abnormalities, but genetic testing is not typically performed for IPF. If more than one person in your family had been diagnosed with some form of PF, ask your pulmonologist (lung doctor) about genetic counseling and evaluation.
What Are the Risk Factors for Pulmonary Fibrosis?

Risk factors for PF include:

**Age:** PF is more likely in patients over age 50 compared with younger patients.

**Smoking:** More smokers or former smokers develop PF than nonsmokers.

**Occupation:** Certain occupations, like mining, farming, dentistry, or construction increases the likelihood for PF in which people may be exposed to harmful chemicals or dust particles over time.

**Cancer treatment:** Radiation treatments and certain chemotherapy drugs increase the risk for pulmonary fibrosis.

**Genetic factors:** Some families have genes that do not function normally and lead to scarring of lung tissue.
How Is Pulmonary Fibrosis Diagnosed?

Your pulmonologist (lung doctor) will take a thorough medical, social, family, and work history. This is to try to identify a cause for the disease, if there is one. Your doctor will do a physical examination and listen to your lungs with a stethoscope for abnormal breath sounds. Additional testing may include:

### Lung Function Tests

- **Pulmonary function testing:** This test involves breathing through a tube that is connected to a machine. It measures the volume of air in the lungs. It also measures how much and how rapidly air can move in and out of the lungs. If PF is diagnosed, this test is often repeated a few times a year to see if there is any change or worsening.

- **Pulse oximetry:** This test uses a small device that is typically placed on the tip of a finger. It measures the amount of oxygen (oxygen saturation) in the blood. You may be asked to walk while oxygen saturation is continuously measured. This will show if you need supplemental oxygen when exerting yourself if the level drops below 89%. Many living with PF will order a pulse oximeter for home use to monitor oxygen saturation.

- **6-minute walk test:** This test measures how far you can walk in 6 minutes. It may be repeated throughout the year with pulmonary function tests if pulmonary fibrosis is diagnosed.

- **Arterial blood gas test:** This test measures the levels of oxygen and carbon dioxide in your bloodstream. It involves blood sampling from an artery in the wrist.

- **Overnight oximetry:** This test measures your oxygen saturation by monitoring your blood oxygen levels overnight while you are sleeping. The test shows if you need supplemental oxygen during sleep. For this test, you wear a monitor on your finger that records the amount of oxygen in your bloodstream while you sleep.

### Imaging Tests

- **Chest X-ray:** Chest x-rays can show the scarring of the lungs. This test is usually the first diagnostic test to examine the lungs when there is the suspicion that a patient may have PF. It is also used on subsequent visits to tell if disease is stable or getting worse.

- **Computerized tomography (CT) scan:** CT scanners take many x-rays from different angles to show cross-sectional, highly detailed images of the lung. A high-resolution CT scan (HRCT) is often used to diagnose PF because the images are more precise. This helps determine the extent of lung damage or scarring caused by PF and shows changes to the lungs in much greater detail. In many cases, a HRCT is clear enough for your doctor to make a diagnosis (in combination with history and blood tests) so that a lung biopsy may not be needed.

- **Echocardiogram:** This is an ultrasound test that uses sound waves to get pictures of the heart. It allows doctors to measure pressures in the heart chambers and helps determine if the pressure in your lungs is abnormal as a result of the scarring of the lungs.
Tissue Sample Tests

IPF can often be diagnosed with a HRCT scan alone, but if fibrosis is caused by other types of ILD (or when IPF is present but the HRCT alone doesn’t give enough information to make a diagnosis of IPF), a tissue sample may be needed to ensure the correct diagnosis. In these cases, a small amount of lung tissue is needed to accurately diagnose PF, which is collected via a tissue biopsy. There are different methods for obtaining lung tissue biopsies, including:

- **Bronchoscopy:** During a bronchoscopy, a thin flexible tube is placed through the nose or mouth to collect cells, fluid, or tissue samples from your lungs.
- **Bronchoalveolar lavage:** This procedure is done in conjunction with a bronchoscopy. A small amount of saline (salt water) is placed into the lungs and then retrieved to obtain cells and secretions from the air sacs in the lungs. This by itself does not provide any pieces of lung tissue.
- **Endoscopic Lung Biopsy:** This procedure is performed by passing small probes through a channel in the bronchoscopy that can obtain small pieces of tissue. Transbronchial Biopsy is one type of procedure that uses a small forceps to obtain tissue, and a newer procedure called **Cryoscopic Lung Biopsy** is being used by many centers and involves freezing lung tissue with a small probe and then pulling the tissue out through the bronchoscopy.
- **Video-assisted thoracoscopic surgery (VATS):** In this minimally invasive procedure, a small tube with a tiny camera on the end is inserted through the ribs and chest into the lungs to obtain slightly larger tissue samples to look for scarring. This is done in the operating room and sometimes requires an overnight stay in the hospital.
- **Thoracotomy:** During this procedure, a surgeon makes an incision in the chest wall to directly access and remove a sample from the lung. This is done in the operating room and requires an overnight stay in the hospital. This procedure has the highest complication rate of all the methods that can be used to obtain a biopsy of the lung.

Your doctor will decide if a biopsy is necessary and which procedure offers the best way to obtain the tissue samples needed to diagnose your condition.

Other Tests

- **Tuberculosis (TB) test:** TB has many of the same symptoms as PF. Your doctor may want to do a skin or blood test to rule TB out.
- **Esophagram:** Sometimes disorders of the esophagus, particularly gastroesophageal reflux disease (GERD), occur at the same time as PF. A number of tests can be used to see if the esophagus is functioning properly, and it can be important for your doctor to determine if you have such an underlying medical condition.
- **Blood tests:** Blood testing to assess liver and kidney function can help your doctor understand if there are any other certain underlying medical conditions present. Other blood tests that screen for autoimmune conditions (such as joint disorders like rheumatoid arthritis or scleroderma) are often performed when physicians are trying to make a specific PF diagnosis.
Knowing the cause of a patient’s PF is very important for developing an effective treatment plan. There are medicines that may be effective or at least partially effective treatments for IPF or other disorders that scar the lungs. Generally, treatments do one of two things: they either reduce the symptoms or they slow down progression of the disease.

Treatments are not yet available that can reverse or even stop scarring of the lungs in patients with IPF. Much research is being done to find new medications that are effective for lung conditions, such as IPF or other types of PF in which scarring can’t be stopped with currently available therapies.
Medications for PF include:

**Corticosteroids (Prednisone):** This drug suppresses the immune system and decreases inflammation. Corticosteroids may prevent lung scarring for some lung conditions. However, they are not effective for treating IPF. They may cause unwanted and possibly serious side effects if used as a chronic therapy for IPF.

**Cyclophosphamide (Cytoxan):** This is a chemotherapy drug (usually used to treat certain types of cancer) that can also suppress inflammation. Used with a corticosteroid, it may allow for a reduction of the corticosteroid dose so that fewer side effects occur.

**Mycophenolate mofetil (CellCept®):** This medicine suppresses the immune system. It can decrease inflammation and help control the disease while allowing corticosteroid doses to be reduced (and possibly discontinued).

**Azathioprine (Imuran®):** This is an anti-inflammatory drug used in treating autoimmune diseases, such as rheumatoid arthritis or other autoimmune conditions that can involve the lungs and may cause lung scarring. Azathioprine may be used in place of corticosteroids or allow corticosteroid doses to be reduced.

**Nintedanib (Ofev®):** Nintedanib, a relatively new, FDA-approved antifibrotic drug, can slow down lung scarring in patients with IPF. Although clinical testing showed that it can slow down the decline in lung function, it is not a cure for IPF and has not been approved for the treatment of other types of PF.

**Pirfenidone (Esbriet®, Pirfenex®, Pirespa®):** Pirfenidone is another relatively new, FDA-approved antifibrotic medicine. Clinical trials have shown that it slows down the progression of lung scarring and loss of lung function in patients with IPF. It is not a cure for IPF and is not approved for the treatment of other types of PF.

Your medical team may also suggest the following treatments for PF:

**Supplemental oxygen therapy:** Supplemental oxygen is often prescribed for PF patients to prevent shortness of breath, keep oxygen saturation levels at the correct ratios, and provide some relief when the oxygen in the bloodstream is too low. Oxygen may help prevent shortness of breath, improve quality of life, maintain activity, and prevent pulmonary hypertension (when the pressure needed to pump oxygen through the lungs is too high). Oxygen is not addictive, meaning increased use won’t make you need it more. Oxygen therapy may also help improve sleep, mood, and mental alertness; better allow the body to conduct its everyday functions; and help prevent heart failure.

There are three types of oxygen:

- **Compressed gas oxygen,** which comes in steel or aluminum containers in different sizes for home use and traveling.
- **Liquid oxygen,** which changes liquid into a breathable gas.
- **Oxygen concentrators,** electrical devices that remove nitrogen from the air, thus concentrating the oxygen.

If your pulmonologist prescribes oxygen, be sure to ask about:

- The oxygen flow rate or setting, so you receive the right amount of oxygen per minute of use
- When you should wear your oxygen, such as during activity, while sleeping, or continuously.
- Which type of oxygen equipment best suits your lifestyle needs.
Pulmonary rehabilitation: Pulmonary rehabilitation is a formal exercise program specifically designed for people with lung conditions. This outpatient activity is paid for by Medicare and most other insurances and is designed to help you control or reduce breathlessness and recondition the body to feel less short of breath. Exercise can also keep muscles throughout the body in better shape so that patients can better tolerate exercise.

This comprehensive program offers:

- Structured and monitored exercise training
- Nutrition advice
- Techniques for reducing and controlling breathing problems
- Education about maintaining and improving body function
- Help to quit smoking
- Emotional and psychological support
- Improved muscle function that decreases shortness of breath

Your doctor must prescribe pulmonary rehabilitation and will need to specify the activity level you can tolerate.

Lung transplantation: PF is the leading cause for lung transplants in the United States today. A lung transplant can improve both a patient’s survival and quality of life. However, serious complications sometimes occur.

Lung transplantation involves replacing one, or sometimes both, of your diseased lungs with a donor lung. To be considered, a candidate generally must:

- Be oxygen-dependent
- Have a severe lung disease that no longer responds to medical treatment and may be fatal in 2 years
- Be physically able to undergo surgery and the treatment that follows
- Usually be under the age of 65-70, although the most recent guideline states that patients can be up to age 75 years if they are otherwise very healthy.

Lung transplantation has many risks and donor lungs are not easily available. Waiting for a donor lung can sometimes take up to 2 or more years. Also, after surgery, you will need to take many different medications for the rest of your life to prevent rejection of the transplanted lung(s) and to prevent infection and additional medicines will be needed to treat episodes of rejection as well as infections should these complications occur.

Choosing to undergo lung transplantation is a big decision and is not the right course for everyone with PF. Be sure to discuss these options thoroughly, both with your pulmonologist and other clinicians who are expert at these procedures.
Living With Pulmonary Fibrosis

Your pulmonologist and medical team will help you manage your disease and symptoms as they change over time. Living with PF means you and your caregivers:

- Must speak for yourself—you play the most vital role in your health care and know your body best. Don’t be shy. Ask questions and speak up about your experiences and preferences for care.
- Be prepared for doctor visits by keeping careful notes on your treatments, medications, and symptoms.
- Allow friends and family to help. PF changes your life and you need all the support you can get.
- Consider joining a local support group(s) (such as one listed on the Pulmonary Fibrosis Foundation website) to understand your diagnosis and find out how others cope with the disease.

What To Expect

PF is a progressive disease that tends to get worse over time. As more scarring occurs in the lungs, it becomes harder to breathe. However, each patient with PF has a unique experience of the disease, with different symptoms and courses of progression. Some patients may have long periods where their disease remains stable with no change in symptoms. Others may have improved prognosis and improvement in symptoms if they have a type of PF that responds to treatments. Some patients experience a sudden worsening of the disease, which is known as an exacerbation or flare-up. This tends to happen when a triggering event causes a sudden increase in scarring and may require hospitalization. Unfortunately, the damage done during an exacerbation is usually permanent. That’s why it is so important for PF patients to maintain daily activity, exercise, manage their diet and weight, pay attention to other health issues, and avoid tobacco smoke.
Managing the different aspects of PF can be challenging. It is important to keep your pulmonologist and health-care team up to date with your symptoms, medications, and treatment progress. Be sure to organize and keep copies of all medical records.

The best way to manage PF is by maintaining a healthy lifestyle. This includes:

- Quitting the use of tobacco products
- Avoiding exposure to second-hand smoke
- Engaging in regular exercise (including pulmonary rehabilitation)
- Following a healthy diet
- Taking all medications as prescribed
- Using supplemental oxygen therapy as directed

Finding Support

It is important to seek help from local and web-based support groups. This can help to find solutions to problems and understand how others cope with and manage their disease and symptoms. The Pulmonary Fibrosis Foundation has a detailed website. It can be a valuable resource for information and for finding local support groups and meetings.

Here are a few other good sources of information about PF and finding a local support group to join:

Pulmonary Fibrosis Foundation
pulmonaryfibrosis.org/life-with-pf/support-groups

Introduction to Pulmonary Fibrosis
American Lung Association
lung.org

Idiopathic Pulmonary Fibrosis
National Heart, Lung and Blood Institute
www.nhlbi.nih.gov/health-topics/idiopathic-pulmonary-fibrosis
Questions to Ask Your Doctor About Pulmonary Fibrosis

Your pulmonologist (lung doctor) and medical team is very important in the management of your disease and your symptoms. Providers are there to help you.

Here are some questions to ask your doctor:

- What kind of tests should I expect each time I come to the doctor?
- What are the results of each test? What do they mean about my PF?
- What kind of PF do I have?
- What are the best treatment options for this form of PF?
- Do you know what may have caused my PF or is it idiopathic (unknown cause)?
- Do you recommend pulmonary rehabilitation? If so, where do you recommend I go to get it?
- Do you recommend oxygen therapy? What kind? How often do I need to use it?
- What are the symptoms I should watch for to catch an exacerbation or flare-up early?
- Who should I contact if I am having worsening symptoms, new symptoms, or other health problems?
- How often will I need follow up testing to monitor the progress of the disease? Which tests do you want me to have?
- Am I a candidate for medical therapies (medications)? Which one(s)?
- Are there clinical trials I can participate in?
- Should I be referred to a center with expertise in diagnosis and treating PF?
- What kind of support groups are there locally?
- What kind of palliative care is available to me, and how will it help me as the disease progresses?
- When do we need to discuss end-of-life issues, including hospice care?
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Navigating Pulmonary Fibrosis

PATIENT EDUCATION GUIDE

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