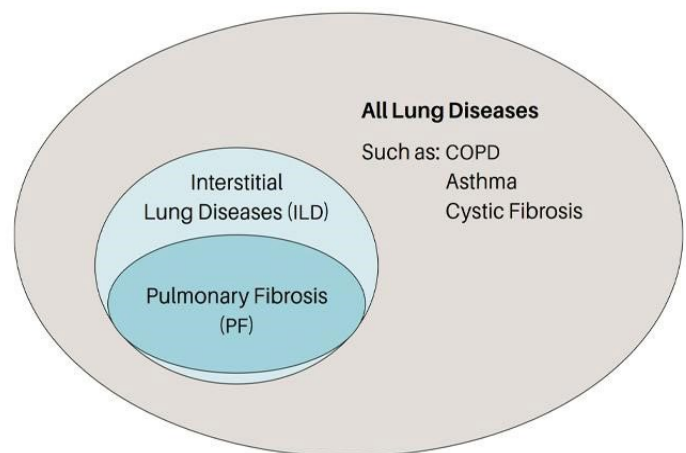


Rural Outreach in Pulmonary Fibrosis: Patient Statement

What is Pulmonary Fibrosis?

The word “pulmonary” means lung and the word “fibrosis” means scar tissue— similar to scars that form on the skin from an old injury or surgery. Pulmonary fibrosis (PF) is a process that causes lung scarring, in which fibrotic tissue blocks the movement of oxygen from inside the tiny air sacs in the lungs into the bloodstream. Low oxygen levels (and the stiff scar tissue itself) can cause people who have pulmonary fibrosis to feel short of breath, particularly when walking and exercising.

Pulmonary fibrosis isn’t just one disease. It is a family of more than **200 different lung diseases** that all look very much alike. The PF family of lung diseases is part of an even larger group of diseases called interstitial lung diseases (also known as ILD), which includes all of the diseases that have inflammation and/or lung scarring. In ILDs, it is the walls of the air sacs of the lung, and the tissue and space around these air sacs, where the injury and damage occur. Some interstitial lung diseases don’t include lung scarring. When an interstitial lung disease does include scar tissue in the lung, we call it pulmonary fibrosis.



The goal of this statement is to increase awareness of pulmonary fibrosis in rural communities and to describe the Rural Health Initiatives of the Pulmonary Fibrosis Foundation (PFF). Available resources for patients living with pulmonary fibrosis who reside in rural areas are described. We define rural areas as places with populations under 50,000 that are not close to a large, urban area. The resources included within this statement may benefit all individuals affected by PF, regardless of proximity to urban areas. Not all resources may be available in your area; consult with your healthcare provider to learn more.

Resources for Patients Living with Pulmonary Fibrosis in Rural Areas

Telemedicine

- Telemedicine definition: Telemedicine is the use of technology (smartphone, tablet, laptop, or desktop computer) that enables patients to communicate directly with members of their healthcare team. Benefits of telemedicine include access to specialists not located close to a patient's home. Televisits between patients and healthcare providers can be conducted by video or phone. Preparation by the patient is the most important prerequisite for a successful televisit. You can be more prepared by referring to the resources below.

Resources

Telemedicine Basics for the Pulmonary Fibrosis Patient Booklet (https://www.pulmonaryfibrosis.org/docs/default-source/programs/educational-materials/telemedicine-materials/pff_telemed_f.pdf?sfvrsn=4acebce_8)

Checklist for a Successful Telemedicine Visit (https://www.pulmonaryfibrosis.org/docs/default-source/programs/educational-materials/telemedicine-materials/pff_telemedcklist_digital.pdf?sfvrsn=4dfec308_6)

Telemedicine 101: Making the Most of Your Virtual Visits Video (<https://youtu.be/hQL6Fhbi4Qs>)

Support Groups

- Connecting with others facing similar experiences can improve emotional well-being and have a positive impact on the health of people who are living with pulmonary fibrosis. Support groups provide an opportunity for participants to share experiences, practical information, and resources. A support group can also be a valuable source of encouragement and inspiration for patients, caregivers, family members, and friends. Virtual support groups have more recently emerged and can provide access to those with electronic devices and by telephone.
- The PFF hosts monthly virtual support groups for anyone who is affected by pulmonary fibrosis using a program called Zoom. If you are not able to attend an in-person group, or simply want more opportunities for support between meetings, consider joining one of the PFF's monthly support group calls.
- To find a support group near you or to learn more about the PFF's monthly virtual support groups, more information can be found at pulmonaryfibrosis.org/supportgroups.

Medication

- Drug therapy for pulmonary fibrosis is often specific to each type of PF. Due to differences in the causes of PF, a medication prescribed to treat one form of the disease may not be right for another. It is important to discuss drug therapy with your healthcare provider to learn what medications may be appropriate to treat your form of pulmonary fibrosis. PF medications have differing side effects which may be unfamiliar to many clinicians outside of medical centers with expertise in caring for patients with PF. Shared decision-making is improved by a knowledge of anticipated side effects and is important in helping patients to make the right choice for them. Many times, staying on these medications requires some lifestyle/diet changes, dose changes or even taking over-the-counter or prescription medication to keep going.
- Monitoring side effects and lab studies is an essential component of the safe use of medications. There is also collaboration between the prescribing provider and the local healthcare provider regarding blood testing, tracking results, and sharing those results with the patient.

Resources

- Fact sheets on a variety of medications can be found at [pulmonaryfibrosis.org/medication](https://www.pulmonaryfibrosis.org/medication)
PFF YouTube playlist Treatment and Symptom Management (<https://www.youtube.com/playlist?list=PLpH8pAi91UL1yP-OUTQifQhfJQVeB-k2g>)

Information on the PFF Care Center Network can be found at <https://www.pulmonaryfibrosis.org/researchers-healthcare-providers/community-engagement/care-center-network>.

Pulmonary rehabilitation

- Pulmonary rehabilitation (PR) is a structured exercise program designed for people living with chronic lung diseases like pulmonary fibrosis (PF). Exercise can give you more energy and improve your focus, your mood, and your overall sense of wellbeing.
- Pulmonary rehabilitation includes:
 - Exercise training
 - Education on managing your disease
 - Learning how to develop behavior change strategies and stick with healthy behaviors
- In-person PR is at this time considered the most effective and safest model of PR in the US. However, some people aren't able to attend an in-person pulmonary rehabilitation (PR) program because of distance or cost. The PFF has developed a Pulmonary Rehabilitation Toolkit that provides some of the information and resources that you would receive through a pulmonary rehabilitation program, although these are not a substitute for in-person pulmonary rehabilitation (see resources below). Talk with your health care provider before starting any new exercise routine, including those found online, to make sure that it is safe and appropriate for you

Resources

To access the Pulmonary Rehabilitation Toolkit, including exercise videos, visit

[Pulmonaryfibrosis.org/prtoolkit](https://www.pulmonaryfibrosis.org/prtoolkit)

- Directory of pulmonary rehabilitation programs here: AACVPR Pulmonary Rehabilitation Program Directory

Oxygen Therapy

- People living with lung disease often have lower than normal levels of oxygen in their blood. When oxygen saturation levels drop to 88% or lower, a healthcare provider may order supplemental oxygen. Oxygen is not addictive and does not weaken your lungs. Use it as prescribed by your healthcare provider.
- The benefits of oxygen therapy may include:
 - Reducing breathlessness
 - Increasing your ability to maintain an active lifestyle
 - Helping to reduce stress on other organs
- Patients may experience difficulty accessing supplemental oxygen. This may be especially true in rural areas, when the durable medical equipment (DME) companies (these are companies that provide oxygen and equipment) may be located far from rural patients. If you have questions about your oxygen equipment, get in touch with the DME company that serves your community.

Resources for Oxygen Therapy

Oxygen Basics Booklet (<https://www.pulmonaryfibrosis.org/docs/default-source/programs/educational-materials/oxygen-basics/oxygen-basics-booklet.pdf>)

Palliative Care

- Palliative care is specialized care for people living with any serious illness that causes a high burden of symptoms such as pulmonary fibrosis. Palliative care focuses on providing relief from the symptoms and stress that pulmonary fibrosis can cause. The goal is to improve your and your caregiver's ability to enjoy life. A palliative care team usually consists of trained doctors, nurses, social workers, and other team members who work together with your existing care team to provide an extra layer of support.

Resources

- Palliative Care Position Statement
- Symptom Management for PF: How Palliative Care Can Improve Quality of Life
- [Getpalliativecare.org](https://www.getpalliativecare.org)

Lung transplantation

- Lung transplantation may be an option for some patients with pulmonary fibrosis. The Scientific Registry of Transplant Recipients (SRTR) lists 74 centers in the United States that perform lung transplantation, and these centers are predominantly located in urban areas. This means that patients living in rural areas likely have to travel greater distances to be evaluated at a lung transplantation center. Lung transplant criteria and evaluations varies by center and your healthcare provider can help you understand if this is an option you may need to consider.

Resources:

- Preparing for a Lung Transplant Booklet (https://www.pulmonaryfibrosis.org/docs/default-source/programs/educational-materials/preparing-for-a-lung-transplant/pre-transplant-booklet.pdf?sfvrsn=1762dcb4_9)
- Life After Lung Transplant Booklet (https://www.pulmonaryfibrosis.org/docs/default-source/programs/educational-materials/life-after-lung-transplant/post-transplant-booklet.pdf?sfvrsn=dcbb4a97_9)
- Lung Transplant Playlist on YouTube (<https://www.youtube.com/playlist?list=PLpH8pAi91UL39LPq-ZPQwYEd1puX3cpO->)

Clinical Trials

- Clinical trials for pulmonary fibrosis treatment are research studies that explore whether a medical strategy, treatment, or device is safe and effective for humans. These studies also may show which medical approaches work best for certain illnesses or groups of people. Clinical trials for pulmonary fibrosis treatment produce the best data available for health care decision making.
- The purpose of clinical trials is research, so the studies follow strict scientific and ethical standards. These standards protect patients and help produce reliable study results.
- Patients with pulmonary fibrosis 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 the participant 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.
- Clinical trials are more likely to be available at academic medical centers in urban areas. Patients living outside of urban areas may need to travel farther to participate in clinical trials. Trial sponsors may consider providing financial support for travel or other accommodations for patients living outside of urban areas. Some clinical trials are done primarily online and may also be an option.

Resources

- PFF Clinical Trials Education Center ([Pulmonaryfibrosis.org/clinicaltrials](https://www.pulmonaryfibrosis.org/clinicaltrials))
- Participating in Clinical Trials: A Guide for Patients with Pulmonary Fibrosis (https://www.pulmonaryfibrosis.org/docs/default-source/programs/educational-materials/clinical-trials-guide/clinical-trials-guide-_3-22-22.pdf?sfvrsn=cd622169_2)
- PFF Clinical Trial Finder tool (trials.pulmonaryfibrosis.org)
- <https://www.pfpatientengagement.org/>
- [Clinicaltrials.gov](https://clinicaltrials.gov)

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