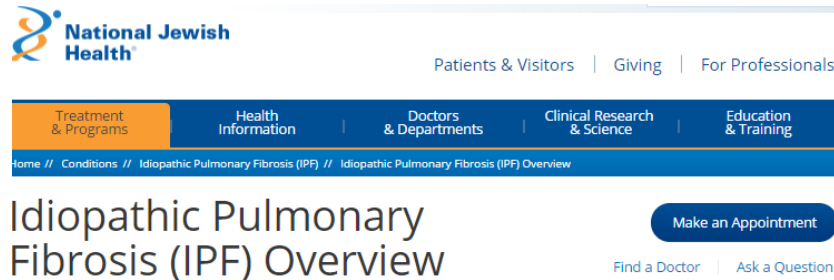


***Optimizing Management of Idiopathic
Pulmonary Fibrosis through Effective
Healthcare Provider-Patient
Communication:***

*A Sustainable, Interdisciplinary Performance
Improvement & Quality Improvement Initiative*

Genentech Request #G-45021




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Idiopathic Pulmonary Fibrosis (IPF) Overview

[Make an Appointment](#)

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Reviewed by Jeffrey James Swigris, DO, MS (September 01, 2017)

What is Idiopathic Pulmonary Fibrosis or IPF?

Interstitial lung disease (ILD) is a broad category of lung diseases that includes more than 200 disorders that can be characterized by fibrosis (scar) and/or inflammation of the lungs.

Despite an exhaustive evaluation, in many people the cause of ILD remains unknown. In these cases, the ILD is considered "idiopathic" (meaning of unknown cause).



What is Idiopathic Pulmonary Fibrosis (IPF)

What is IPF?

- Idiopathic Pulmonary Fibrosis (IPF) Overview**
- IPF: Symptoms
 - IPF: Diagnosis
 - IPF: Management
 - IPF: Stages
 - IPF: Information for Caregivers
 - IPF: Questions to Ask your Doctor
 - IPF: Lifestyle Management
 - IPF: Patient and Provider Resources
 - Search Conditions A-Z

Prior to this project, there was not a specific webpage for IPF, there was only an ILD page. All IPF-related web content resulted from focus groups and surveys conducted from this QI project.

Living with Idiopathic Pulmonary Fibrosis (IPF)

Idiopathic Pulmonary Fibrosis (IPF) Overview

- IPF: Symptoms
- IPF: Diagnosis
- ▶ IPF: Management
- ▶ IPF: Stages
- ▶ IPF: Information for Caregivers
- ▶ IPF: Questions to Ask your Doctor
- ▼ IPF: Lifestyle Management

Living with Idiopathic Pulmonary Fibrosis (IPF)

▶ Living with Chronic Lung Disease

Living with chronic lung disease changes a person's life and requires adjusting to a new way of being in the world. You may have been physically active your entire life, and now that you have Idiopathic Pulmonary Fibrosis (IPF), you may find that you can't do things you once enjoyed. You may feel slowed down and less spontaneous. You may feel self-conscious about not being able to keep up, being on oxygen or having a chronic cough. You may be reluctant to go out in public.

These are common emotions for people with IPF. It is normal to feel angry, afraid, sad, depressed, guilty, stressed and frustrated with all of the changes. You will be better off if you allow yourself to feel all of these things, even when it is uncomfortable. Using the support of others will help you feel stronger and less alone in dealing with the challenges of IPF. Adjusting to an illness is a process and will not happen overnight. Be patient with yourself. Learn more about your disease and how to make lifestyle adjustments that can help maintain your quality of life.



Featured Stories



How Palliative Care Services Can Help Individuals with Chronic Conditions

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Advance Directive: Tools for Communicating Your Health Care Wishes

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Traveling with Oxygen

[Read more](#)

Healthcare Provider Resources

Were developed according to findings of focus groups and surveys.

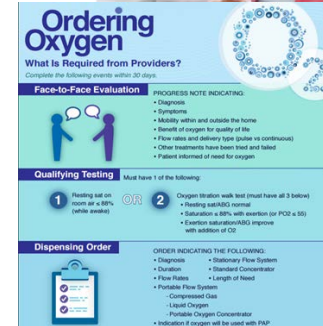
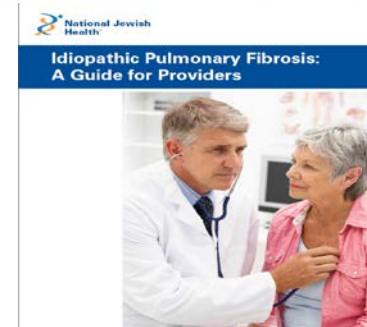
IPF Provider Resources

To order a comprehensive toolkit of all IPF educational resources listed below, please [email us](#).

• [Idiopathic Pulmonary Fibrosis: A Guide for Providers](#) (PDF brochure)

• [Ordering Oxygen](#) (PDF Infographic)

• [IPF Health Checklist](#) (PDF brochure)



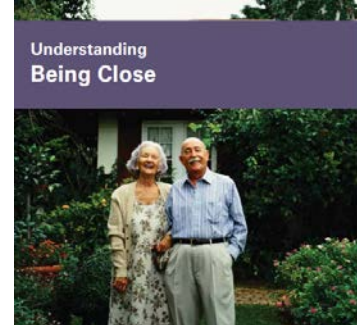
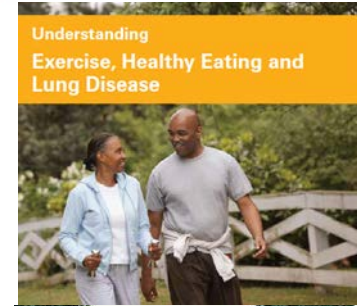
Patient Resources

Were developed according to findings of focus groups and surveys.

Med Facts Stages of IPF:

- [Stage 1 IPF](#): Recently Diagnosed (PDF brochure)
- [Stage 2 IPF](#): Needing oxygen with activity, but not at rest (PDF brochure)
- [Stage 3 IPF](#): Needing oxygen 24 hours a day, with activity, at rest and during sleep (PDF brochure)
- [Stage 4 IPF](#): Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a patient's needs) (PDF brochure)

- [Advance Directive](#) (PDF brochure)
- [Palliative Care](#) (PDF brochure)
- [On the Go with Oxygen](#) (PDF brochure)
- [Transtracheal Oxygen](#) (PDF brochure)




Understanding IDIOPATHIC PULMONARY FIBROSIS (IPF)

Understanding Being Close

MEDfacts
An Educational Health Series from National Jewish Health®

Ask an expert or to make an appointment call 1.877.CALLNJM (1.877.225.5056)

Stage 2: Needing oxygen with activity, but not at rest with IPF

There is no formal staging system for IPF. However, thinking of IPF in four stages can help people with IPF and their caregivers prioritize their needs and keep them from feeling overwhelmed. Although education regarding a variety of topics can occur at any time, the stages may help patients and their caregiver focus on what is needed and what to expect as time goes by.

The Four Stages of IPF

- Stage 1: Recently diagnosed
- Stage 2: Needing oxygen with activity, but not at rest and during sleep
- Stage 3: Needing oxygen 24 hours a day, with activity, at rest and during sleep
- Stage 4: Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a patient's needs)

Stage 2: Needing oxygen with activity, but not at rest

What should I focus on when needing oxygen with activity, but not at rest?

- Work with your health care provider. The health care provider will write a prescription for oxygen based on your oxygen saturations with rest and activity. A durable medical equipment (DME) company will provide the oxygen.
- Learn about the medical equipment. This includes the stationary/in-home and portable oxygen systems that are available.
- Use a pulse oximeter to check your oxygen saturations when you are active or exercising to make sure you are getting the right flow of oxygen to maintain your saturation equal to or greater than 90 percent.
- Ask about the medications that may be used for IPF. Learn the dose and time the medicine is taken, how it may be helpful and what side effects to watch for.
- Breathing retraining may be helpful with the shortness of breath.

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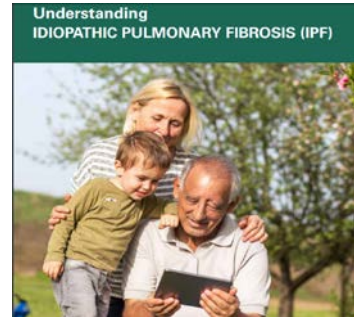
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Caregiver Resources

Materials for caregivers weren't initially planned as part of this initiative, but results from surveys and focus groups demonstrated a great need.

- Understanding Booklets
 - [Understanding IPF](#) (PDF)
 - [Understanding Exercise, Healthy Eating and Lung Disease](#) (PDF)
 - [Understanding Being Close](#) (PDF)
 - [The Caregiver Journey: A Guide for IPF](#)



MEDICATION TRACKER

Use this tool to keep track of your medications and discuss with your healthcare provider at each visit. Put a check mark (✓) in the last column to communicate with your healthcare provider about how your medications are working.

Name:	Date of Birth:
Pharmacy Name:	Pharmacy Number:
Allergies:	

Medication	Amount	Time Taken	Purpose	Date Started	Date Stopped	Side Effects	Response to Medications
		<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Bedtime					
		<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Bedtime					
		<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Bedtime					
		<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Bedtime					
		<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Bedtime					

- [IPF Medication Tracker Tool](#) (PDF)
- [IPF Questions to Ask your Doctor](#) (PDF)
- [Four HO₂PES](#) (PDF)

Four HO₂PES

Being prescribed supplemental oxygen can be life-changing. However, maybe not all of the changes is for the better. While there are some benefits to using supplemental oxygen, some patients find that supplemental oxygen allows them to do more, to be more active, to have greater dignity, to spend holidays they've left behind. What do you hope using supplemental oxygen will do for you?

Hope #1: _____

 Hope #2: _____

 Hope #3: _____

 Hope #4: _____

“Dealing with supplemental oxygen 24/7- tubes, tanks, machines – do I have enough? Will I have enough? Can I carry it?” – Patient Respondent

A strong theme found in the qualitative data from the patient survey was a need for educational resources related to supplemental oxygen. In response to concerns voiced in the patient/caregiver focus groups, the following infographics and videos were created.

Busting Myths about Oxygen Therapy

If oxygen therapy is recommended for you, ignore the myths and get the facts.

<p>Myth #1 Oxygen means I can't be active. You will have less shortness of breath and can be more active on oxygen.</p>	<p>Myth #2 Oxygen is addictive. Oxygen is not addictive.</p>	<p>Myth #3 Oxygen means this is the end. No, oxygen therapy helps you to live longer, feel better and be more active.</p>
<p>Myth #4 Portable oxygen concentrators meet all oxygen needs. Portable oxygen concentrators are not good for continuous flow or higher liter flow needs.</p>	<p>Myth #5 Petroleum jelly is best for nose dryness. Water-based moisturizers are best for nose dryness.</p>	
<p>Myth #6 I can't travel with oxygen. You CAN travel with oxygen; it just takes some planning.</p>	<p>Myth #7 I can use a portable oxygen concentrator during sleeping. Portable oxygen concentrators don't provide enough oxygen for sleeping.</p>	
<p>Myth #8 Oxygen will cause a fire. Oxygen is not flammable; it supports a flame, but does not cause fires.</p>	<p>Myth #9 Everyone will see the oxygen tubing on my face. Maybe, but there are many options for oxygen delivery, even glasses.</p>	

On The Go with Oxygen

If your oxygen level is 88 percent or below, oxygen therapy is often recommended to ensure your blood has enough for your body's needs.

<p>HOW OXYGEN LEVEL IS MEASURED</p> <p>Pulse oximetry Arterial blood gas</p> <p>Your oxygen level can be measured from a device on your finger or through a blood test.</p>	<p>OXYGEN PRESCRIPTION INCLUDES</p> <ul style="list-style-type: none"> How much oxygen to use in liters When to use the oxygen, (rest, activity, sleep, altitude) Which oxygen system is recommended
<p>Your doctor prescribes the oxygen. A durable medical equipment company provides the oxygen.</p>	
<p>TYPES OF OXYGEN SYSTEMS</p> <ul style="list-style-type: none"> Concentrators Portable concentrators Compressed gas Liquid 	<p>ON DEMAND OR PULSE FLOW vs CONTINUOUS FLOW</p> <p>Provides oxygen when you breathe in by triggering oxygen release (not recommended for sleep or everyone)</p> <p>Provides a set liter flow of oxygen</p>



An informational booklet designed **directly from feedback received** in the patient and caregiver focus groups and surveys. The booklet emphasized what to expect after diagnosis and a Four Stage disease trajectory was created with correlating questions to ask your provider at each stage.

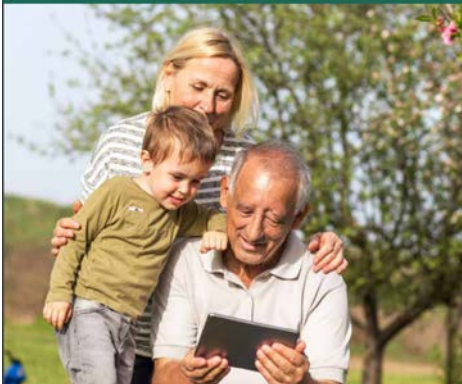
Understanding IDIOPATHIC PULMONARY FIBROSIS (IPF)

An educational health series from National Jewish Health®

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Understanding IDIOPATHIC PULMONARY FIBROSIS (IPF)



On both the focus groups and surveys, patients and caregivers indicated that their top educational need related to what to expect after diagnosis. In order to facilitate understanding of disease progression, four stages corresponding to increasing oxygen needs was created with questions to ask your provider at each stage.

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An Educational Health Series From National Jewish Health[®]



Stage 1: Recently diagnosed with Idiopathic Pulmonary Fibrosis (IPF)

There is no formal staging system for IPF. However, thinking of IPF in four stages can help people with IPF and their caregivers prioritize their needs and keep them from feeling overwhelmed. Although education regarding a variety of topics can occur at any time, the stages may help patients and their caregiver focus on what is needed and what to expect as time goes by.

The Four Stages of IPF

- Stage 1: Recently diagnosed
- Stage 2: Needing oxygen with activity, but not at rest
- Stage 3: Needing oxygen 24 hours a day, with activity, at rest and during sleep
- Stage 4: Advanced oxygen needs (needing high-flow oxygen or when a lightweight, portable delivery system is unable to meet a patient's needs).

Stage 1: Recently diagnosed

What should I focus on when I am recently diagnosed?

When you are diagnosed with IPF you may want to:

- Partner with your pulmonologist to develop and individualize your action plan.
- Learn about IPF, including the symptoms, treatment and prognosis.
- Live a full life with IPF through:
 - Regular exercise. Stay active. Physical exercise is the most important thing you can do for yourself.
 - Healthy eating
 - Rest
 - Support from others
- Consider joining a support group in your area.
- If you smoke, work with your doctor on quitting smoking.
- Think about what you can do to avoid infections.
- Begin thinking and talking about advance directives.

IDIOPATHIC PULMONARY FIBROSIS

Resources for managing your health

1. Upon Diagnosis

- a. What treatment is available to me and how will it impact my quality of life?
- b. What should my caregiver and I expect as my disease progresses?
- c. Are there any support groups available for me to connect with fellow IPF patients?
- d. Are there good websites that provide helpful, reliable information?

2. When oxygen is needed with activity

- a. Does staying active actually extend my life or does it just improve my quality of life?
- b. What resources are available to help me be active with oxygen? Can I travel with oxygen?
- c. Do I have the freedom to adjust flow rates based on how I am feeling or am I bound to the "prescribed" flow rate?
- d. Do I need to be extra careful when exercising when using oxygen or is it based on what I can tolerate?
- e. Do you recommend formal pulmonary rehab or self-initiated physical activity or both?

3. When oxygen is also needed at rest

- a. At what point should I consider the trans-tracheal procedure for my oxygen needs?
- b. Do I need to be careful about physical activity?
- c. Am I a candidate for a lung transplant? If so, what do I do?

4. When advanced oxygen is needed

- a. What is the normal life expectancy at this point?
- b. What palliative care resources are available?
- c. At what point is it time to say goodbye? How much input should I accept from my loved ones?

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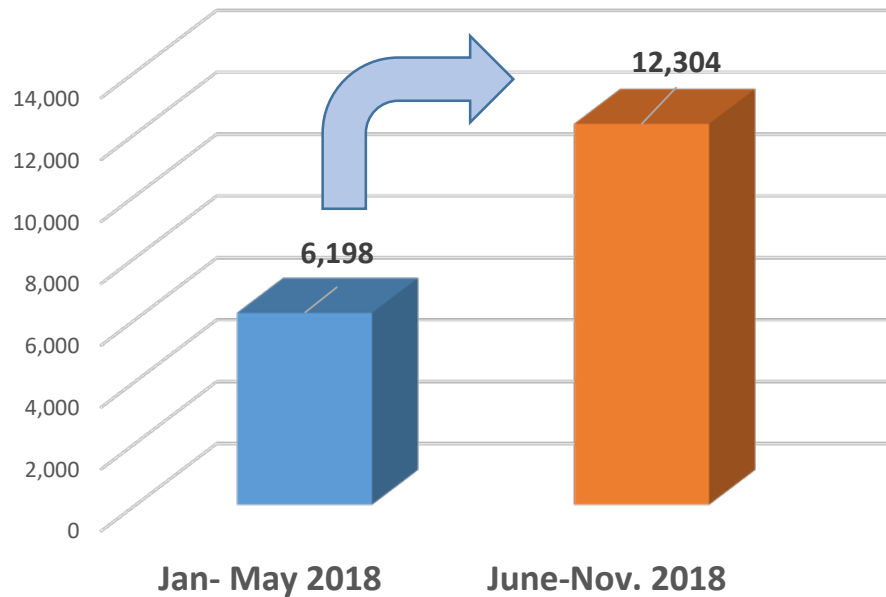


youtube.com/NationalJewish



twitter.com/njhealth

Overall Page Views



The newly created IPF website was launched in November, 2017 and saw a tremendous increase in page views from January 2018 through November 2018. In particular, the IPF Stages page received a notable 42% increase in page views during this timeframe highlighting its value to patients and caregivers.

Webpage views by section

	Jan- May 2018	June-Nov. 2018
IPF Program	1,257	1,379
IPF Overview	725	535
IPF Stages	693	1647
IPF Symptoms	223	196
Questions to ask doctor	182	246

In order to share the findings of the mixed-methods research and the solutions developed at NJH, an accredited, on-demand enduring activity was developed and disseminated to IPF treaters throughout the U.S. In this activity, Dr. Swigris highlights areas of care variation that were identified throughout the initiative.

CME/MOC/CNE Information >

 Listening to IPF Patients, Caregivers, and Providers: What Are Their Unmet Needs? >

Jeffrey James Swigris, DO, MS
National Jewish Health
Denver, Colorado

 Practical Strategies for Meeting the Challenges of IPF Diagnosis and Care >

Jeffrey James Swigris, DO, MS

0.5 CME/MOC / 1.0 CNE
Post-Test and Certificate >

 Download IPF Educational Tools and Practice Aids, Slides, Monograph, and Audio Podcast >

Optimizing Management of Idiopathic Pulmonary Fibrosis Through Effective Healthcare Provider–Patient Communication: Insights From an Interdisciplinary Quality Improvement Initiative at NJH



Jeffrey James Swigris, DO, MS

Associate Professor
Director, Interstitial Lung Disease Program
Division of Pulmonary, Critical Care and Sleep Medicine
Department of Medicine
National Jewish Health
Denver, Colorado

This activity is supported by an educational grant from Ge

IMPACT – ENGAGEMENT

2,241  Engaged Learners

>15,600
patient visits per month



1,236
Additional Activity Interactions*
 iTunes

*Podcast, Slide Set, Practice Aid, Print Transcript downloads and SlideShare views