

Beyond the Guidelines

# **Promising Practices to Improve the Care of Patients With Pulmonary Fibrosis**

A supplement to CHEST Physician<sup>®</sup>



Beyond the Guidelines

# Promising Practices to Improve the Care of Patients With Pulmonary Fibrosis

A supplement to CHEST Physician®

This continuing education supplement was developed from interviews with interstitial lung disease (ILD) centers, both in the Pulmonary Fibrosis Foundation Care Center Network and those outside of it. It is part of a three-phase curriculum, *IPF Education for ILD Centers and Their Communities: Applying Behavior Change Theory to Facilitate and Measure Adoption of Current Standards of Practice Across Individuals and Systems in IPF*. The supplement content brings together data from a patient survey and a previous CME/CE activity in this curriculum, "Practice Self-Assessment for Diagnosis and Management of Idiopathic Pulmonary Fibrosis (IPF)," found at: <https://tinyurl.com/IPFAssess17>, both of which were used to develop the interview questions for the interstitial lung disease centers.

This supplement was written by a team at Global Academy for Medical Education, LLC, Pro-Change Behavior Systems, and Stephanie Breslan, MS, medical writer.

Neither the editors of CHEST Physician nor the Editorial Advisory Board nor the reporting staff contributed to its content. The ideas and opinions expressed are those of the faculty and do not necessarily reflect the views of the supporters, Global Academy for Medical Education, LLC, Postgraduate Institute for Medicine, or the Publisher.

Copyright © 2017 by Global Academy for Medical Education, LLC, Frontline Medical Communications Inc., and its Licensors. All rights reserved. No part of this publication may be reproduced or transmitted in any form, by any means, without prior written permission of the Publisher. Global Academy for Medical Education, LLC, will not assume responsibility for damages, loss, or claims of any kind arising from or related to the information contained in this publication, including any claims related to the products, drugs, or services mentioned herein.

## Table of Contents

<b>Introduction</b> .....	<b>4</b>
<b>Rationale and Methodology</b> .....	<b>4</b>
<b>The "Bright Spots": Identifying and Promoting Successful Practices</b> .....	<b>5</b>
<b>Standardization of Care</b> .....	<b>5</b>
<b>Efficiency</b> .....	<b>6</b>
<b>Unparalleled Commitment to Compassionate Patient Care</b> .....	<b>7</b>
<b>Deep Specialized Multidisciplinary Expertise</b> .....	<b>8</b>
<b>Coordination of Research and Clinical Care</b> .....	<b>8</b>
<b>Mentorship and Training</b> .....	<b>9</b>
<b>Nonpharmacological Treatments</b> .....	<b>10</b>
<b>Collaboration and Communication</b> .....	<b>10</b>
<b>Promotion of Shared Decision-Making</b> .....	<b>11</b>
<b>Appropriate Framing and Early Introduction of Palliative Care</b> .....	<b>12</b>
<b>Focus on Continuous Quality Improvement</b> .....	<b>12</b>
<b>A Look to the Future</b> .....	<b>13</b>
<b>Posttest and Evaluation Form</b> .....	<b>15</b>

Jointly provided by



Global Academy for  
Medical Education



Postgraduate Institute  
for Medicine

In collaboration with

Pulmonary Fibrosis  
FOUNDATION

Supported by  
educational grants from

**Genentech** and  
**Boehringer Ingelheim**

Original Release Date: **December 31, 2017**  
Expiration Date: **December 31, 2018**  
Estimated Time to Complete Activity: **1.0 hour**

## Method of Participation

Participants should read the activity information, review the activity in its entirety, and complete the online posttest and evaluation. Upon completing this activity as designed and achieving a passing score on the posttest, you will be directed to a web page that will allow you to receive your certificate of credit via email or you may print it out at that time.

The online posttest and evaluation can be accessed at: <https://tinyurl.com/IPFBrtSp17>. Inquiries may be directed to Global Academy for Medical Education at [info@globalacademycme.com](mailto:info@globalacademycme.com) or (973) 290-8225 or the Postgraduate Institute for Medicine at (720) 895-5357.

## Accreditation Statements

**Physicians:** This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint provider-ship of the Postgraduate Institute for Medicine and Global Academy for Medical Education. The Postgraduate Institute for Medicine is accredited by the ACCME to provide continuing medical education for physicians.

The Postgraduate Institute for Medicine designates this enduring material for a maximum of 1.0 *AMA PRA Category 1 Credit(s)*<sup>™</sup>. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

**Nurses:** The Postgraduate Institute for Medicine is accredited with distinction as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

This educational activity for 1.0 contact hour is provided by the Postgraduate Institute for Medicine.

## Target Audience

This activity has been designed to meet the educational needs of healthcare providers in interstitial lung disease centers, both in the Pulmonary Fibrosis Foundation Care Center Network and outside the Network, including physicians, registered and advanced practice nurses, physician assistants, and nurse practitioners. Interstitial lung disease centers' consultative personnel, including

cardiologists, gastroenterologists, geneticists/counselors, infectious disease specialists, psychiatrists/psychologists, sleep medicine specialists, pathologists (pulmonary), radiologists (thoracic), rheumatologists, surgeons (general/thoracic), and community pulmonologists may also be interested in the activity.

## Program Overview

Idiopathic pulmonary fibrosis is a progressive interstitial lung disease with poor prognosis and no cure. Despite the availability of evidence-based guidelines, significant gaps in care remain, including delayed or inaccurate diagnosis, delayed referral to specialty care, limited use of recommended multidisciplinary (interprofessional) care, variable approaches to management, and poor patient-provider communication. The Pulmonary Fibrosis Foundation Care Center Network has the potential to improve patient outcomes by sharing local expertise and clinical excellence in idiopathic pulmonary fibrosis diagnosis and disease management with other care center network sites and community clinicians. Thus, one of its goals is to bring together the collective resources of centers and facilitate intercenter communication to establish current standards of practice. This monograph reflects interviews with personnel at five Pulmonary Fibrosis Foundation Care Center Network sites who provided self-reflection on what they do well in the care of their patients with pulmonary fibrosis.

## Learning Objectives

- Identify strategies to standardize the clinical management of patients with idiopathic pulmonary fibrosis
- Describe strategies to increase patient education within the existing workflow of idiopathic pulmonary fibrosis patient management
- Describe strategies to improve inter-professional collaboration related to the management of idiopathic pulmonary fibrosis

## Disclosure of Conflicts of Interest

The Postgraduate Institute for Medicine (PIM) requires instructors, planners, managers, and other individuals who are in a position to control the content of this activity to disclose any real or apparent conflict of interest (COI) they may have as related to the content of this activity. All identified COIs are thoroughly vetted and resolved according to PIM policy. PIM is committed to providing its learners with high-quality CME/CE activities and related materials that promote

improvements or quality in healthcare and not a specific proprietary business interest of a commercial interest.

The planning staff and content managers hereby state that they or their spouse/life partner do not have any financial relationships or relationships to products or devices with any commercial interest related to the content of this activity of any amount during the past 12 months.

## Global Academy for Medical Education

**Staff:** **Sylvia H. Reitman, MBA, DipEd;** **Mike LoPresti;** **Shirley V. Jones, MBA;** **Ron Schaumburg;** and **Stephanie Breslan, MS;** hereby state that they or their spouse/life partner do not have any financial relationships or relationships to products or devices with any commercial interest related to the content of this activity of any amount during the past 12 months.

## Postgraduate Institute for Medicine:

The following planners and managers, **Trace Hutchison, PharmD;** **Samantha Mattiucci, PharmD, CHCP;** **Judi Smelker-Mitchek, MBA, MSN, RN;** and **Jan Schultz, MSN, RN, CHCP;** have nothing to disclose.

## Disclosure of Unlabeled Use

This educational activity may contain discussion of published and/or investigational uses of agents that are not indicated by the FDA. The planners of this activity do not recommend the use of any agent outside of the labeled indications.

The opinions expressed in this educational activity are those of the faculty and do not necessarily represent the views of the planners. Please refer to the official prescribing information for each product for discussion of approved indications, contraindications, and warnings.

## Disclaimer

Participants have an implied responsibility to use the newly acquired information to enhance patient outcomes and their own professional development. The information presented in this activity is not meant to serve as a guideline for patient management. Any procedures, medications, or other courses of diagnosis or treatment discussed or suggested in this activity should not be used by clinicians without evaluation of their patients' conditions and possible contraindications and/or dangers in use, review of any applicable manufacturer's product information, and comparison with recommendations of other authorities.

---

**This activity is not an official program of the American College of Chest Physicians (CHEST) and accordingly is not accredited by CHEST<sup>®</sup>.**

# Introduction

Idiopathic pulmonary fibrosis (IPF) is the most common and lethal of the idiopathic interstitial pneumonias. Although rare enough to be considered an orphan disease, the annual incidence of IPF is 94 cases per 100,000 person-years.<sup>1</sup> IPF accounts for 15,000 to 40,000 deaths per year in the United States—and the incidence and mortality of IPF are increasing.<sup>1-3</sup> The disease is characterized by an insidious onset and progressive decline in lung function because of fibrosis of the lung parenchyma. Despite the recent approvals of two new drugs, each shown to slow the decline in lung function, there is no therapeutic cure for IPF.<sup>4</sup> The only treatment shown to improve survival is lung transplantation.<sup>5</sup> Indeed, the prognosis of IPF is poor, with median survival estimates of 3.8 years or less.<sup>1</sup>

An international coalition of societies, including the American Thoracic Society, published comprehensive guidelines for the diagnosis and management of pulmonary fibrosis in 2011 and subsequently revised eight treatment recommendations in 2015.<sup>4,5</sup> Despite the availability of these evidence-based guidelines, significant gaps in the care of patients with IPF remain. These gaps include delayed or inaccurate diagnosis, delayed referral to specialty care, limited use of recommended multidisciplinary (interprofessional) care, variable approaches to management, and poor patient-provider communication.<sup>6</sup>

The Pulmonary Fibrosis Foundation (PFF), founded in 2000, established the Care Center Network (CCN) as its central effort to improve and standardize medical care in pulmonary fibrosis. As of December 2017, the PFF CCN includes 45 centers in 27 states. The PFF CCN has the potential to improve patient outcomes by sharing local expertise and clinical excellence in IPF diagnosis and disease management with other CCN sites and community clinicians. In practice, the CCN sites face diverse challenges, and recent discussion of these issues by stakeholders demonstrated the clear need for a consistent “top-down” strategy that incorporates current standards of practice and can be extended to all centers.<sup>7</sup> Thus, one of the PFF’s CCN goals is to bring together the collective resources of centers and facilitate intercenter communication to establish current standards of practice in the management of interstitial lung disease (ILD).<sup>7</sup>

# Rationale and Methodology

In their 2010 book, *Switch: How to Change Things When Change Is Hard*, authors Dan Heath and Chip Heath shed new light on how to effect transformative change.<sup>8</sup> Rather than identifying problems and trying to solve them, their approach involves identifying “bright spots”—places where success is being achieved—and replicating those behaviors that lead to success.

Toward that end, Pro-Change Behavior Systems conducted interviews and site visits with a convenience sample of CCN sites between August and October 2017 to gain insight into

implementation of promising practices in the treatment of IPF. Telephone interviews were conducted with the directors of three PFF CCN sites: National Jewish Health (Denver), Johns Hopkins University (Baltimore), and the University of Maryland (College Park). In-person site visits were conducted at two CCN sites, the University of Chicago Medicine and Piedmont Healthcare (Atlanta). It is important to note that the sites included in the interview process were part of a segmented exercise; their inclusion in this analysis does not imply superiority over other CCN sites.

# The "Bright Spots": Identifying and Promoting Successful Practices

Familiarity with and adherence to the clinical practice guidelines for diagnosis and management of IPF is the cornerstone for quality care. Beyond guideline-recommended care, several consistent themes regarding clinical practices emerged among the sites. This list of themes should not be considered evidence-based clinical recommendations, nor is it an exhaustive list of best practices. Instead, these items represent the centers' self-reflection on what they do well in the care of their patients with pulmonary fibrosis and reflect key commonalities in their approach. The key themes identified are:

- Standardization of care
- Efficiency
- Unparalleled commitment to compassionate patient care
- Deep specialized multidisciplinary expertise
- Coordination of research and clinical care
- Mentorship and training
- Nonpharmacological treatments
- Collaboration and communication
- Promotion of shared decision-making
- Appropriate framing and early introduction of palliative care
- Focus on continuous quality improvement

## Standardization of Care

A care network "harnesses the collective intelligence of patients, clinicians, and researchers" and standardizes processes to advance care.<sup>9</sup> The PFF CCN, specifically, works to develop and promote a standardized approach to the clinical management of people with pulmonary fibrosis.<sup>10</sup> And indeed, standardization emerged as a common theme at each ILD center in the CCN, particularly around standard order sets for the diagnosis and evaluation of patients with ILD. The degree of standardization varied. Several sites incorporate "smart phrases" in the Epic

electronic medical record (EMR; also called the electronic health record) to generate very specific order sets, such as high-resolution computed tomography (HRCT) (eg, expiration series), autoimmune serology panels, and comprehensive pulmonary function tests. Other sites use comprehensive standard notes that include extensive and careful history and exposure questions as well as treatment options. Prompts related to common comorbid conditions (eg, obstructive sleep apnea and gastroesophageal reflux disease [GERD]) are also often included. Most centers reported that the smart phrases and note templates were developed internally and programmed in Epic by in-house personnel.

A standardized and comprehensive note facilitates the capture of a detailed and comprehensive patient history despite the barriers (eg, the fact that the time needed to take a thorough history is not reimbursable). Nevins Todd, MD, from the University of Maryland, underscored

***"We actually designed [a standard note template] with some of the research points in mind because when the research coordinators are going through the note after clinic and extracting information that goes into the database, it gives them a format they know... and we are not missing fields of information."***

—Cathy Bonham, MD, University of Chicago Medicine

***"We don't have a checklist about diagnosis or treatment on paper. It is somewhat built in[to] the EMR, not an official document. We have an after-visit summary in the EMR in some detail, especially for the first visit. The after-visit summary is empty until you fill it in. There's a template that automatically populates and edits (eg, deletes rehab if [the patient] had it already). The summary includes templates for each disease [for the patient] (eg, template for how to set up pulmonary rehab and how it benefits [the patient])."***

—Leann Silhan, MD, Johns Hopkins University

the importance of delving deeply into the patient's history to identify the etiology of ILD. He remarked that Gregory Cosgrove, MD, from National Jewish Health, gives grand rounds talks where he explains that 85% of ILD is in the history. Because he thinks this best practice is "massively underappreciated," Dr Todd created a standard history form, reviewed it with his fellows, and distributed it to his multidisciplinary care team as a template in Epic. He finds that the template facilitates engaging in a dialogue with the patient to obtain the history and consequently allows him to focus on listening to patient responses, allowing him to determine where he needs to ask follow-up questions. The template provides useful defaults; for example, each element of the detailed environmental exposure and history is phrased negatively so that the clinician has to change only those that are relevant to that particular patient (eg, no mold, no smoking).

The University of Chicago Medicine makes its standard note template for patients with ILD widely available. If fellows are seeing a patient in the general pulmonary clinic outside of the ILD clinic, the template is available to them. The template includes items found in a typical note, including the referring physician and additional healthcare providers, as well as a regular review of systems and physical exam findings, but it also includes information specific to ILD, such as:

- Review of systems based on rheumatologic, autoimmune, and gastrointestinal symptoms
- Ulcers on fingertips?
- Connective tissue disease?
- Environmental review
- Hypoxia present?
- Plan for oxygen use
- GERD?
- Other ILD abnormalities on CT?
- Chronic obstructive pulmonary disease? Emphysema?
- Immunosuppression? Prescribed by?
- Vaccinations?

Dr Cosgrove described a checklist at National Jewish Health that the nurse goes through and that forces clinicians to address all of the pertinent issues in a templated fashion. For example, it touches on every aspect of rehabilitation therapy, oxygen therapy, vaccinations, necessary follow-up, and future monitoring. Each clinician is able to modify and individualize the template so that each item is either addressed or removed if unnecessary.

Beyond capturing critical details on medical history and symptoms, a standard note or after-visit summary template can prompt the discussion of recommended nonpharmacological treatments, facilitate research, and provide an informative note to referring physicians in the community and/or to others who may be involved in the ongoing management of the patient.

#### **Dr Cosgrove summarized three points of contact with out-of-state patients:**

- Conduct a preview call with coordinator and patient
- Send the patient an information packet
- Make a follow-up call to ensure the patient has everything needed before their visit

## **Efficiency**

Several ILD centers reported that they implement a variety of other steps (eg, checklists, prescreening visits) to increase the effectiveness and efficiency of the initial patient visit. Betsy Rambo, RN, the nurse coordinator from Piedmont Healthcare, believes that getting new patient records is instrumental to a successful patient visit. Obtaining CT and lung biopsy reports and pulmonology and primary care records is important to developing a plan for the patient visit. The University of Chicago Medicine relies heavily on its clinic coordinator to accomplish these tasks. The clinic coordinator prescreens incoming patients prior to and during the first hour of the appointment to inform them about the ILD center, obtain a thorough history, and ensure that the latest records and test results are uploaded into the EMR. This process is instrumental to ensuring that tests are not unnecessarily repeated and that the team has the information they need to rule out differential diagnoses.

Dr Cosgrove explained that a similar procedure is in place at National Jewish Health, where they first utilize an intake form to ensure patients are being referred to the appropriate pulmonologist. They also utilize a previsit checklist to determine what diagnostic procedures have already been completed and to ensure the results are available, particularly because patients are often traveling a considerable distance for the appointment. Previsit planning for patients with complex, chronic conditions is recommended by the National Committee for Quality Assurance.<sup>11</sup> What's more, studies of previsit planning indicate that the majority of patients not only complete, but prefer, preordered tests, which result in improved efficiency and beneficial face-to-face discussion of results.<sup>12,13</sup>

Another important step in increasing the efficiency of the visit is to embed language in the order set to adequately explain the purpose of the specified diagnostic test to ensure it will not be denied by insurers. One pulmonologist explained that clinicians at his center utilized their experience with insurance denials to create a preformatted order describing the purpose of the study as "ILD" and the reason as "a need to evaluate effective therapy and treatments for progressive symptoms and preexisting ILD." He described

that overcoming this relatively simple operational issue facilitates efficient completion of the appropriate studies with the least amount of involvement of the doctors so they can focus on the patient and not on the insurance company. Indeed, according to a study of more than 1300 primary care physicians, specialists, and surgeons across disciplines, interactions with health insurance plans are associated with significant time—an estimated three hours weekly for physicians and even more for nurses and administration staff—and cost—approximately \$23 billion to \$31 billion each year.<sup>14</sup>

A number of participating clinicians described various modifications that could be programmed into the EMR to maximize efficiency. At Piedmont Healthcare, for example, Amy Case, MD, is advocating that IPF medications automatically populate with dosing schedules and appropriate follow-up lab orders for ongoing monitoring. Dr Cosgrove recognizes that there are areas in the diagnostic process where differences should be systematically identified and addressed. He suggested, for example, that an order for a scan related to ILD should, by default, change to an HRCT scan. He stated, "CT scans are expensive, so we should probably make sure the right one is done. It might save [community doctors] from calling the radiologist to [ask] what [test] should be ordered."

Finally, several of the participating centers reported that they have made a concerted effort to ensure that the diagnostic and treatment services that patients need are located in as close proximity as possible. Piedmont Healthcare, for example, has on-site pulmonary rehabilitation at each of its clinic sites because travel in Atlanta can be very inconvenient. Similarly, the University of Chicago Medicine often has ILD and rheumatology in the same clinic so patients can more readily see both specialties in one visit.

Dr Cosgrove described the facilities at National Jewish Health:

*"Because we're relatively small, a patient only has to go a total of four floors to get every study. The first floor is the clinic, rehab is on the second floor, CT imaging is on the third floor, the lab is on the first floor, and cardiology is in the basement.*

At other institutions, because they're so massive with huge infrastructure, [patients] might have to go to three or four or five different buildings. And if [patients are] breathless, going for 20-minute walks just to get a study done—and there [may be] four or five studies—that can really tire patients out and makes it less efficient.”

Dr Cosgrove referenced a group at Penn Medicine as a good model for a large institution. They redesigned their pulmonary center and kept radiologists, CT surgeons, and pulmonologists spatially close to one another. They also redesigned how they ran their clinic so the patients could benefit from an efficient approach.

## Unparalleled Commitment to Compassionate Patient Care

Patients with IPF have reported a lack of support as they attempt to understand their diagnosis and disease process. They also note a lack of information and educational resources regarding IPF and its management at the time of diagnosis.<sup>15-17</sup> The impact of this lack of communication may be exacerbated by the fact that 40% of patients with IPF consult multiple physicians and receive conflicting information before they eventually receive an accurate diagnosis.<sup>18</sup> Patients visiting CCN sites have a very different experience because CCN sites that demonstrate an unparalleled commitment to compassionate patient care focus on spending adequate time with patients and providing substantial educational resources. Such steps are critical for these patients, who likely have experienced a long and frustrating journey before receiving care at an ILD center.

Everyone interviewed for this report discussed the importance of spending adequate time with patients. The need for extended patient visits—especially the initial visit—was a common theme. Mary Strek, MD, of the University of Chicago Medicine, explained that new patients see their clinic coordinator for one hour prior to seeing the doctor for another hour. She also said that often the 30-minute follow-up visits do not allow sufficient time, despite the fact that theoretically such visits should only be 20 minutes long. She said that the concept of IPF is unknown to many patients, requiring considerable patient

***“Patients have a dedicated line/phone number they can call that gets them directly to the nurse for the advanced lung disease program or gets them directly to the medical assistant. Over and over, patients have told us how grateful they are that they have that so they don’t have to go through the trials and tribulations of ‘Press 1 to speak with....’ They know someone is there. Patients feel confident calling.”***

—Betsy Rambo, RN  
Piedmont Healthcare

education. Team members at Piedmont Healthcare also reported lengthy initial visits that involve additional on-site evaluation. The commitment to patient education creates an environment where patients better understand their disease, recognize progressive symptoms and adverse events, and ultimately can play a more meaningful role in their own care, thus creating not only improved patient satisfaction but also improved health outcomes.<sup>19-21</sup>

The importance of a dedicated and familiar patient resource emerged as a critical component of patient care. When asked about the specific practices that contributed to the ability to implement best practices in IPF care at Piedmont Healthcare, one of the initial answers provided by Betsy Rambo, RN, was availability. As those calls come in, Ms Rambo assists patients in “working the maze of their disease,” dealing with all the issues that come up for them on a daily basis, whether it is side effects of medications, difficulty getting portable oxygen, or the family’s lack of understanding of the disease. Often, the support is as much about listening as it is about providing guidance. As Ms Rambo said, “Literally just listening, not so much even saying anything. Offering some direction and trying to help them live through this awful disease.”

Other members of the multidisciplinary team at Piedmont Healthcare also reported that patients readily contact them. The respiratory therapist reported that patients call them with questions about oxygen. Similarly, the research coordinators reported that the relationship they have with patients

results in a high degree of trust, so patients often contact them first when something happens.

The sentiment was almost identical at the University of Chicago Medicine, where several members of the multidisciplinary team identified Cathy Brown, RN, their nurse coordinator, as the “face of the program.” Her relationship with the patients begins during the preclinic screening visit, and she is often the first person patients turn to when they have questions or concerns. Patients have access to her direct line and are able to leave messages if she is not available. In addition, patients have their physicians’ email addresses in the event that they have questions. Another benefit of the availability of a trusted patient resource is that exacerbations can be detected early and acted on. For example, Ms Rambo described patients calling with complaints of shortness of breath despite increased oxygen, which she communicates to Dr Case, so they can manage the patients and admit them as necessary.

Offering ongoing and multisource patient education also emerged as a continuous process in which there are multiple participants at each ILD center. This education includes the different forms of ILD, what IPF entails, and why so much diagnostic testing is needed to ensure that the right diagnosis is reached. Patients are often bewildered by IPF, and the PFF website was often cited as a helpful resource.

At the University of Chicago Medicine, Ms Brown conducts a great deal of patient education. She observes as the doctors are educating in plain language about the diagnosis. But she also remains in the room after the doctor has left to ensure that the patient understood what was explained. She also provides information regarding registry studies, pharmacological treatment options and side effects, nonpharmacological treatment options, comorbidities, and ongoing lab tests that are needed to monitor disease progression. She provides specific practical guidance; for example, she notes, many patients are unaware that they can wear their oxygen equipment in the shower. The fellows also play a role in patient education, as do the research coordinators, because there is often patient education through the clinical trials.

***“The natural history database allows us to write papers, do research, and improve care.”***

—Spring Maleckar  
University of Chicago Medicine

Dr Case described a parallel process at Piedmont. The physician assistant or nurse follows up to reinforce the information provided by the doctor and is often aware of things patients may not have told the doctor. As Ms Rambo pointed out, “Dr Case obviously does patient education when she is working with a patient, and I am doing it daily when they call.” She went on to say that almost all of their patients with IPF are on therapy, so they have labs done regularly. When she receives lab results, she follows up with patients and asks how they are doing. Doing so leads to more discussion and creates an ongoing education process. Ms Rambo also mentioned the role of the education support teams within pharmaceutical manufacturers, where patients can have one-on-one meetings with their nurse educator through a 24-7 hotline from the beginning of their therapy. She concludes, “There is education available all the time either through me, Dr Case, or through the companies themselves.”

Support groups also play a role in patient education. At Piedmont Healthcare, a support group initially started by the daughter of a patient who died of IPF is now supported by a respiratory therapist who helps arrange speakers. It is held at one site, but patients can teleconference in from the other site. Leann Silhan, MD, from Johns Hopkins University, also noted that support groups, sometimes led by former caregivers of patients with IPF, are good resources; they are also beneficial for caregivers because they can get their questions answered.

***“We all have different strengths ... Dr Noth is very pure IPF focused, whereas Mary is more [focused on] autoimmune and connective tissue disease patients. Dr Vij [focuses on] a lot of those things too but has a special interest in RA. I see a lot of sarcoidosis. Dr Adegunsoye sees lots of hypersensitivity pneumonitis. So, we all have our own niches, but it is nice for us to talk because of how much we see in terms of overlap. [It is] great to get feedback, especially for patients with atypical features, and useful clinically for how you design a treatment strategy for them—for example, what medications you might use [and] how you might follow up with them.”***

—Cathy Bonham, MD, University of Chicago Medicine

## **Deep Specialized Multidisciplinary Expertise**

Consistent with the PFF requirements of a “multispecialty team approach” within CCN sites, the accumulated multidisciplinary expertise of the sites visited was notable. For example, Dr Strek began the first multidisciplinary conference at the University of Chicago Medicine approximately 10 years ago, well in advance of its becoming part of standard care. The conference has evolved and grown significantly over time but has continued to fulfill its purpose of increasing “awareness and understanding of the complexities of diagnosis and difficulties with treatment.” As a result, even first-year fellows have a highly sophisticated understanding of ILD. As Dr Strek said, “It is such a part of what we do here.” That deep expertise in ILD has attracted best-in-class chest radiologists, a nationally renowned pathologist, research faculty, and trainees who continue to advance the mission. Many of the current faculty trained as fellows at the University of Chicago Medicine, contributing to their team’s accumulated institutional knowledge. When asked to describe their culture in one word, interview participants separately stated, “multidisciplinary,” “expert,” and “diverse.”

The specialization within the advanced lung disease (ALD) clinic was also clear at Piedmont Healthcare. Ms Rambo explained that each physician on the ALD team has a specialty, and the goal is to refer all patients with IPF (both external and internal referrals) to Dr Case.

This deep, specialized expertise in IPF underscores the importance of early referral from community pulmonologists and referral even from within the broader pulmonology clinic or service.

## **Coordination of Research and Clinical Care**

Many of the sites expressed the importance of the integration of research efforts and clinical care as part of a collective commitment and passion to advance the field and improve treatment. These sites are conducting research despite the perceived and real challenges of coordinating research and clinical care workflow (eg, scheduling, resource utilization, recruitment, and obtaining informed consent).<sup>22</sup> These sites also embrace the Institute of Medicine “learning healthcare system,” described as a “culture of shared responsibility for evidence generation and information exchange, in which stakeholders (researchers, providers, and patients) embrace the concept of a healthcare system that learns and works together.”<sup>23</sup> In fact, the research coordinators at Piedmont Healthcare explained that their employment contract includes a pledge to be an advocate for patients and to fulfill the Piedmont Promise to make a positive difference in every life. Clinicians there state that their work is more than just a job; they are keenly aware of how they impact patient and family lives by being oriented to the goal of making a difference and providing hope.

Gokhan Mutlu, MD, from the University of Chicago Medicine, described his view of clinical care and research, saying, “We have to be willing to work together and collaborate; research and clinical care work together to find better therapies for this disease.” Dr Strek further explained that their complete multidisciplinary team meets weekly, alternating between a true multidisciplinary case conference—in which they are reviewing cases and reaching a consensus diagnosis—and a research-focused meeting. She emphasized that this combination ensures that “we are absolutely up to date with what is going on” and able to “get to the next level.” Dr Bonham explained that the University of Chicago Medicine organizes clinical and research operations around pulmonary fibrosis, such that many of their fellows in pulmonology and critical care become interested in research. She herself came up through this program and now does a lot of bench science researching immune drivers of pulmonary fibrosis. The care of patients is systematically

organized to allow clinicians and team members to “collect patient data to enable the pairing of longitudinal clinical data with what is going on from a biological basis (in their blood draws).” One advantage of this approach is that team members can examine how patients change over time.

The fellows at the University of Chicago Medicine pointed out that many patients may come to Chicago for the clinical trials, recognizing that it is an academic institution. They want to see new developments in the field and are very supportive of the research. Furthermore, the pathologists, transplant physicians, and radiologists are also leading related and/or collaborative research efforts. In total, investigators at the University of Chicago Medicine spend one to four days a week on their research efforts and often present at national meetings and/or publish the findings. Multisite research studies also enable collaborations with other ILD centers.

In turn, the research at each of the sites informs their clinical approach. Ayodeji Adegunsoye, MD, from the University of Chicago Medicine, explained that their research foundation's case-control experiments and randomized controlled trials provide the underpinning for their treatment approach.

There is also a strong focus on maximizing registry and clinical trial recruitment. The research coordinators emphasized their role in enrolling participants into registry studies and clinical trials. Dr Todd explained that patients have been 100% receptive to the registry, which was true at Piedmont Healthcare and the University of Chicago Medicine as well, in part because patients understand that, while the research may not help them directly, it may help others. Minimizing the need for additional patient visits has been instrumental in removing a key barrier to patient participation. To avoid overwhelming patients with multiple simultaneous registry requests, the University of Chicago Medicine invites patients in a stepwise fashion across multiple appointments. It is part of the nurse coordinator's standard process to invite patients to be part of the ongoing natural history registry at the initial visit. EMR data are also reviewed to identify patients who may be eligible for ongoing clinical trials.

***“We can’t keep all fellows—we have four a year. Sending them out in the world is good for everyone. Legacy of mentorship is something we take pride in—[we] can collaborate with them [in other institutions].”***

—Mary Strek, MD  
University of Chicago Medicine

## Mentorship and Training

Mentorship and training were evident in various ways across different centers. At the University of Chicago Medicine, there is a constant pipeline of members of the ILD team beginning with third-year medical students who rotate through specialty clinics. Residents and fellows are comprehensively involved in specialty clinics and research, often completing an ILD rotation and one year of research on some aspect of ILD as a fellow. Many of the current faculty in pulmonology are former fellows who have worked there for many years. Dr Todd's team at the University of Maryland also heavily involves fellows in patient care. Educating tomorrow's pulmonologists is a way to build capacity outside of the ILD center. For example, more than 50 fellows have graduated from the University of Maryland over the past 10 years. Dr Todd's hope is that they go into communities with the principles established, having ongoing informal and formal interactions with their training site.

The transition of the pulmonologists trained at one of the PFF CCN sites offers the advantage of ongoing collaboration once they are practicing in the community. Often, those fellows are invited to continue to participate virtually in the multidisciplinary team reviews if their schedule permits. Dr Cosgrove added that the community pulmonology physicians who were trained as fellows at National Jewish Health do not hesitate to call. While there are various strategies to provide information, such as EMR, the most important aspects are maintaining a personal relationship and talking to people on the phone.

Each ILD center is also making efforts to enhance the capacity of community pulmonologists. Some of the pulmonologists do outreach to community pulmonologists, for example, via PFF program education,

***“Our program, like others around the country, is seeing fewer referrals for IPF since FDA-approved therapies became available in 2014. This hampers enrollment in research studies and leaves me concerned that though they may be given an antifibrotic drug, the patients are missing out on education, support groups, pulmonary rehab, and other elements of comprehensive care.”***

—IPF Healthcare Provider

and have performed virtual consults with community pulmonologists. Dr Cosgrove explained how one of the National Jewish Health team members goes out in the community, locally and nationally, to do education for pulmonologists via grant programs, thus creating a network of engaged healthcare teams who may be able to identify and refer patients earlier.

Part of the education of community pulmonologists is also accomplished via communication back to them subsequent to their patient's visit. Dr Strek explained that their standard ILD note at the University of Chicago Medicine conveys significant and helpful information to the referring physician, including, where appropriate, documentation of the multidisciplinary review and consensus diagnosis. She includes her phone number if she thinks a conversation would facilitate ongoing management of the patient. Other pulmonologists expressed similar philosophies. In fact, both Drs Todd and Strek communicated willingness to share their standard note templates, although they acknowledge that each ILD center or community pulmonologist would have to implement the template in their own EMR.

Finally, a number of efforts to educate other healthcare providers were described. Piedmont Healthcare, the University of Maryland, and Johns Hopkins University host an annual pulmonary fibrosis symposium for healthcare providers, patients, and caregivers. In addition, Dr Case often speaks to primary care physicians to educate them on the available pharmacological therapies, and Dr Silhan indicates she also speaks to small local community hospitals.

## Nonpharmacological Treatments

### Pulmonary Rehabilitation

Pulmonary rehabilitation is almost universally recommended for patients with IPF. The availability of in-house rehabilitation depended on the site. The University of Maryland, for instance, does not have an in-house rehabilitation facility. The University of Chicago Medicine has one but, like Maryland, it relies heavily on programs in the community close to patients' homes to reduce barriers to participation. The nurse coordinator at the University of Chicago Medicine provides a prescription for patients to attend a 12-week program in their own community, advising them that each facility prefers the prescription in a different format and that the patient can have the facility fax her the form they require. Though patients with IPF are automatically eligible for pulmonary rehabilitation from an insurance perspective, barriers can include costs related to co-pays or deductibles, transportation issues, and distance. Co-location with the clinic or established relationships with pulmonary rehabilitation programs in nearby communities can address this barrier for some and offers the advantage of easy communication between the pulmonary rehabilitation therapist and others on the team.

### Respiratory Therapy

Regular assessment of lung function and oxygen therapy as needed were also key components of treatment for IPF across centers. The charting of lung function provides crucial information to the treatment team about the progression of the disease.

### Referral for Consideration of Lung Transplant

There appeared to be a consensus that the timing of referral for consideration of transplantation was complex, but that it was preferable to refer too early to initiate the potentially time-consuming workup, especially given the unpredictable trajectory of disease progression. Remzi Bag, MD, from the University of Chicago Medicine, expressed dismay about the low proportion of patients with IPF who are referred for consideration, which in his estimation was about 5%, as well as about the timing of the majority of transplantation patients, which, as he

said, was too late. Dr Case indicated she refers people who are candidates for lung transplant earlier than they need. She also tries to prepare people who are not likely to be candidates, though she doesn't object to their evaluation. On the other hand, she indicated that some patients put off evaluation longer than they should and others are trying to reduce their weight first.

### Active Monitoring

In addition to utilizing nonpharmacological options, many physicians also prescribe pharmacotherapy. Doing so has implications for ongoing monitoring and management. Dr Silhan from Johns Hopkins University, for example, involves specialty pharmacists who speak to the patient via email and phone and provide advice on adherence and overcoming barriers (eg, paying for the medication). Dr Cosgrove explained that the nurses at National Jewish Health proactively call patients and say, for example, "You started your medication, and our recommendation is to get blood work every four to six weeks to make sure you're not having adverse effects." Similarly, the nurses will create reminders to call patients to communicate that it is time to schedule blood work. In case they lose track of patients, they only supply enough medication for three months as a safeguard to ensure the patient is receiving appropriate monitoring. They also use the opportunity to ask patients how they are doing, if they are having any problems, and if anything has changed. Dr Cosgrove describes it as getting an update on their clinical course so that medications are not being given blindly.

### Collaboration and Communication

As revealed through the interviews, several factors that affect the interprofessional collaboration and communication and day-to-day team interactions were identified as contributing to a team's successful approach to IPF. One example is the in-basket and other features in the EMR that enable asynchronous communication within the team and with other specialties within the hospital or other setting. Dr Cosgrove utilizes a tasking system in the EMR so that he and others, after reviewing information (eg, a nodule identified on CT scan that requires follow-up), can assign a task to say, "This needs to be addressed in

***"We learn from each other, back each other up, and learn best practices from each other. [We] bounce things off each other. [We have a] culture all about excellent patient care and patient safety. That carries over into research protocols."***

–Liz Wilkins, Piedmont Healthcare

three months," or "I'm really concerned this might represent a cancer." These EMR-based methods work well within a system. For clinicians outside the system, pulmonologists tended to rely on copies of assessment and clinic notes and personal calls to outside clinicians.

Co-location was also leveraged to facilitate easy communication (eg, experts from rheumatology and pulmonology on the same floor with offices next to one another). Rekha Vij, MD, from the University of Chicago Medicine, explained that EMR is a way to communicate when not in the office or clinic at the same time, but that co-location with other specialties is good. Dr Cosgrove added that all of the ILD physicians at National Jewish Health are located in eight stations, and that five ILD nurses are across the hall, allowing for ad hoc advice. He noted that rheumatology is in the next room, so he can walk across the hall to share concerns or request a patient be seen. He states, "We don't rely on just reading the chart and figuring it out; it's more of a two-minute update or two-minute question that really drives home the important interaction and messaging. That's a luxury we have being spatially close to one another."

Dr Adegunsoto identified open communication channels as critical to the success of the team at the University of Chicago Medicine, underscoring that they collaborate in and out of the clinic through multiple means. Ongoing multidisciplinary team case review meetings are just one example of this continuous communication. Scheduling rheumatology and pulmonology clinics on the same day in the same space is done for patient convenience but also to facilitate discussions of disease progression with the experts collaborating on care. The fellows reported that they feel very comfortable going directly to or emailing the radiologist to help reach consensus on a diagnosis. The enduring communication

facilitates both clinical work and research. The research coordinators at Piedmont, for instance, meet once weekly with Dr Case and communicate through Epic and phone in the interim, and the director of research works very closely with all of the ALD physicians.

Each team also holds a multidisciplinary team meeting, although the frequency varies from weekly to once every two or three weeks. The composition of the meeting also varies. In some instances, pathologists are present at each team meeting, and in other cases, they may only attend once monthly. At National Jewish Health, it is common for the radiologist, the pulmonologist, the rheumatologist, fellows, residents, and coordinators all to be present. At the University of Maryland, a research coordinator, transplant team members, radiology, pathology, pulmonary faculty, and fellows often attend. Other sites use different forms of multidisciplinary review meetings. Dr Case at Piedmont Healthcare described a weekly ALD management conference that, when possible, includes five ALD physicians, the nurse coordinator, and physician assistants, when available. The purpose of that meeting is to discuss and resolve diagnostic and treatment dilemmas for high-risk or hospitalized patients. Independent of that meeting, Dr Case has a more traditional monthly multidisciplinary diagnostic conference with a rotating radiologist and a pathologist to reach a consensus diagnosis. Patients with critical biopsies and those being referred for lung transplants are discussed.

One of the intended benefits of these meetings is, of course, to include multiple perspectives on complicated patients, so as to ensure that the right diagnosis is reached and the correct treatment plan is established. Several of the clinicians interviewed also provided examples of how the meetings have improved each other's work. Dr Case, for example, remarked that, as a result of participating in the multidisciplinary review meetings, the radiologists now create much more detailed and descriptive reports. Dr Strek shared that collaborating so closely in a shared clinic with rheumatology has made her much more sensitive to and knowledgeable about rheumatology and immunosuppression and has made the rheumatologists much more knowledgeable about ILD.

These meetings are often supplemented with didactic lectures. Dr Todd, for example, explained that “[The team] has many didactic lectures where ILD cases get talked about. We have four educational conferences weekly in pulmonary and critical care.”

As might be expected, there is some variability in the extent to which ILD centers communicate with each other. Drs Silhan and Todd both agreed that communication with external providers is simplified immensely if the clinician is within the same health system because they can rely on the shared EMR or face-to-face communication. Dr Cosgrove shared that National Jewish Health has a monthly remote ILD conference with a group in New York City, through which they have four institutions linked on their end of the video conference to present and discuss cases. Dr Silhan explained that pulmonologists from Johns Hopkins University are able to join University of Maryland multidisciplinary team meetings once or twice a month. Dr Cosgrove explained that his external communications sometimes occur informally. He described a time when he and the referring physician were concerned about a patient, so he reached out to six colleagues around the country to share the case and ask if they had ever seen a similar patient—a practice that, as he pointed out, is common.

Dr Todd reported that the University of Maryland routinely attends the biennial PFF Summit and the administrative meeting in the spring to learn from the experiences of other centers. His center also is trying to interact with other centers on support groups for patients associated with PFF. Dr Vij pointed out that cross-institution research also provides a mechanism for collaboration. Weekly phone calls are often part of the multicenter trials, and investigators see one another at national meetings. The research coordinators at Piedmont, for example, have a quarterly call with all participating sites to talk about barriers to enrollment in the registry and to share successes. This call involves the coordinators and the site principal investigators.

## Promotion of Shared Decision-Making

Assessing patients' desire to participate in decision-making and engaging them in discussion of treatment options lead to more realistic expectations of treatment results, improved acceptance, greater satisfaction, and better treatment outcomes.<sup>20,24-27</sup> Accordingly, the 2015 international guidelines for the diagnosis and management of IPF encourage healthcare professionals to educate patients so that they may participate in shared decision-making.<sup>4</sup> It is not surprising, then, that there was universal agreement about how critical it is to engage patients in shared decision-making about treatment options and end-of-life care planning, particularly given the ambiguity that often surrounds these decisions.

At times, shared decision-making is accomplished with some type of decision aid, but more often, shared decision-making involves a conversation, or rather multiple conversations, with one or more members of the care team. Dr Todd indicates that shared decision-making is valued because “hard and fast rules are few and far between in ILD.” He describes that, at his institution, shared decision-making happens with the patient, not with a tool. He explains, “We are trying to elicit patient preferences in their treatment. We don't have formal decision aids ... We try to refer patients to the PFF website. There is back and forth with the patient.”

Many clinicians commented on the need to allow adequate time and to individually tailor conversations so as to ascertain goals of care and facilitate shared decision-making. Dr Bonham points out that longer clinic visits are needed for complex decision-making (eg, transplant, planning for end of life),

***“I make sure the patient makes the decision themselves with our guidance. We frown on a paternalistic approach. I present patients with available evidence on treatment options (eg, side effects, expected trajectory, benefits of the therapy, and other treatment options).”***

—Ayodeji Adegunsoye, MD  
University of Chicago Medicine

***“We see [patients] more often as the disease progresses. They comment on fatigue. We talk about their plans. Their body is worn out. We see their numbers getting worse. Some mention what their plans are for hospice, but some families are in denial. The patient is tired, their body is worn out. But the daughter or spouse wants them to do more. The patient knows they can’t.”***

—Respiratory Therapist  
Piedmont Healthcare

and depending on the severity of the patient, she does not always introduce these topics on the first visit. Dr Cosgrove believes each clinician has a unique approach and that there is no single protocol. In his practice, he asks patients, “Why are you here? What are your goals?” He suggests that conversations regarding transplant, therapy with maximum “curative intent,” and stabilization often reveal their true goals. Dr Case points out that she cannot make decisions for her patients:

*“I do try not to tell people what to do, but give facts and help them decide. I feel [it is] important to inform and educate and let them make decisions. I can’t tell their values. [For example], one patient has terrible side effects but she won’t reduce dosage [because] she’s afraid she will ‘fall off a cliff,’ but her quality of life is suffering. I cannot decide for her as my values are not her values.”*

Family members often play a role in the decision-making process. Dr Silhan engages caregivers in the clinic visits. She explains that patients with IPF are generally older and often have children who are integral in making decisions and carry the burden of those decisions. She adds that patients often feel overwhelmed by symptoms and they are focused on how to feel better, while the caregiver might be better able to see the big picture and be more objective about therapy and rehabilitation. Dr Silhan believes that caregivers can positively influence patients. On the other hand, family members’ preferences and values do not always align with those of the patient. Dr Silhan pointed out that the ability to communicate their values and preferences varies from patient to patient, and that willingness to discuss

***“A lot are not ready or their family is not ready. I tell them that palliative care can help with durable medical equipment ... that gets them into system, support service, without making them think about hospice, but then the delivery truck says palliative and hospice care and sometimes gets sent away.”***

—Cathy Brown, RN  
University of Chicago Medicine

end-of-life care planning varies based on whether patients have spoken to their family about it. Some patients want to protect their family from having to think about the topic but may be more willing to talk with their doctor.

When discussing end-of-life care, Dr Case tries to plan ahead of time and bring the patient back for a 30-minute visit. She frames the visit to the patient as thinking ahead to goals of care and talking to family about end of life. She admits that sometimes disease progression blindsides everyone and states that when death is imminent, it needs to be talked about that day. Dr Silhan starts by assessing the patient’s perception of optimal end of life and whether the patient has formal documents in place. From there, she lets the patient lead the discussion and she advocates for home hospice. She points out that some patients do not want to discuss hospice because doing so can make them feel hopeless and feel like giving up.

### **Appropriate Framing and Early Introduction of Palliative Care**

The key messages of the 2017 consensus statement on palliative care in ILD were that “Palliation should be discussed and initiated early in the disease course depending on the individual patients’ needs, preferences, culture, and religion.” In addition, “Patients and caregivers should be realistically educated on all aspects of the disease from the moment of diagnosis depending on the individual patients’ needs and preferences.”<sup>28</sup> While none of the centers interviewed provide outpatient palliative care, they do have varying degrees of inpatient palliative care and strong referral networks. Although data show improvement in symptoms and mortality

with initiation of palliative care,<sup>29,30</sup> many clinicians noted that a delicate balance must be struck when raising the topic of palliative care. Many patients have misperceptions about it or lack an understanding of how beneficial it can be. The labels matter. As Dr Bonham commented, “Palliative care needs significant rebranding because it’s the current perception in the community that you go to palliative care when there are no options left.” Care team members have to present palliation as care focused on providing relief from the symptoms and stress of IPF. Dr Bonham describes it to patients as something that should be considered in conjunction with treatment, but she admits, “Some patients and families, no matter how you talk about it, think ‘Oh no, this doc thinks I am really bad off that they are talking about palliative care already.’ It is an ongoing conversation.” She concedes that patients often come to the decision later than they should.

Physicians try to time the conversation about palliation based on disease progression, but even then they have to be mindful to frame the discussion appropriately to increase the patient’s and family’s receptivity to it. Dr Strek underscores the distinction between hospice and palliative care. Dr Cosgrove avoids using the term “palliative care” and prefers to focus on the concept of supportive care. He first gets a sense of the patient’s goals and then drives the conversation from there. Some clinicians interviewed noted that PFF has good resources online about palliation and that support groups can also be helpful in that regard.

### **Focus on Continuous Quality Improvement**

Several of the clinicians expressed a true dedication to continuous quality improvement within their ILD center or to address a specific aspect of patient care. Dr Case, for example, highlighted the procedure that she and her ALD colleagues at Piedmont Healthcare periodically use for identifying strategic objectives for improving the team’s processes. Dr Silhan provided an example of a quality improvement project dedicated to increasing flu and pneumonia vaccinations at Johns Hopkins University. Dr Adegunsoye described how the University of Chicago Medicine team’s standard collection of data points began with guidelines that

have been updated several times since. Many clinicians said these continuous improvement efforts were heavily influenced and informed by ongoing research. Dr Bonham believes that continuous improvement is mainly driven by research outcomes at the University of Chicago Medicine. They discuss outcomes at their biweekly research meeting and make changes accordingly. As she explains:

*"[Our clinic coordinator] orders a certain number of tests when she does preclinic. She usually meets with each new patient before they actually come in to see the MD, and that is great because she will order all the blood work, imaging, and whatever else needs to be done ahead of time so they are neatly packaged when they come to their physician. We can review everything all at once, because otherwise we see people and they don't have labs or they are incomplete. If they haven't had a workup yet, we can't really give them a good opinion because we're still gathering information. So, one way that we do on the fly quality improvement [is to] say to the clinic coordinator, for*

***"Having all these heads in the same room at the same time, reviewing cases during meetings, leads to, 'How can we do this better or differently?' [New ideas] get added to the agenda of the research meeting the next week."***

–Rekha Vij, MD  
University of Chicago Medicine

*example, maybe we don't need to order 'X' test for everyone, just those who are suspected to have 'Y'."*

Other improvements arise out of an ongoing desire to improve processes. The fellows at the University of Chicago Medicine explained that some changes to the standard note arose out of a need to better quantify data students needed to inform ongoing research studies. Their goal was to make data collection more standardized and meaningful without compromising clinical care in any way; in fact, the change has to further patient care.

Dr Case explained that the ALD group at Piedmont Healthcare is planning to more

broadly initiate a new patient flow that is modeled after the way she currently structures her initial visits. Recognizing that these patients are coming in for second or third opinions, there are many prior imaging studies, cardiac workups, and other information but patients are often unable to articulate the results. The nurse coordinator for the group obtains and summarizes new patient records, giving Dr Case an opportunity to review them prior to seeing the patient. In addition to ensuring that the visit is more efficient and effective, this approach also enables Dr Case to know which patients may be appropriate for ongoing registry studies or clinical trials.

### Action Steps

- Consider a self-reflective examination of best practices and needed improvements
- Collaborate with another CCN site regarding best practices
- Choose a bright spot to emulate and seek out additional information if needed

## A Look to the Future

When asked about improvements most needed in their clinical care of patients with IPF, the CCN sites provided the following suggestions:

- Provide better education to help patients understand their disease
  - Recognize that patients develop inflammation by way of different processes, and that it would be helpful for patients to understand those processes
  - Create a standard detailed educational packet for all patients
- Systematically review risk factors (eg, autoimmunity, hypersensitivity pneumonia, environmental exposures, short telomeres syndrome) for disease progression with each patient
- Include education on lifestyle modifications to prevent more rapid disease progression (eg, quit smoking, quit a job if there are work-related inhalations, avoid certain plants and bird feeders, raise the bed or do not eat before bed if reflux is present)
- Focus on comorbidities
  - Utilize Epic to automate
  - Co-manage with primary care
- Provide better psychosocial support
- Include palliative care doctors on the multidisciplinary team so we can learn from them
- Raise awareness about IPF in the population and among physicians to create a better mechanism for thorough evaluation and referral based on CT results
- Provide earlier referral for transplant
- Improve standardization of templates among doctors in a practice/health system
- Reorganize and streamline the visit process with a standard visit protocol
- Reach more of the patients in our health system who have IPF
- Increase support staff
- Obtain more clinic space

While all of the CCN sites interviewed described many strategies they effectively employed to improve the care of patients with IPF, they also self-reported areas in which they desired to do better. What became clearly evident is that the strategies that some centers perform well were identified by others as areas where improvement was needed. This serves to illustrate that even the best ILD centers across the country have much to share and learn from others, and that, because of their unwavering commitment to the best and most compassionate care of patients with IPF, they will continue to evolve and improve over time.

***"Everyone should do this. It was a great, insightful exercise to self-reflect on our processes."***

–CCN Site

## REFERENCES

- Raghu G, Chen S-Y, Yeh W-S, et al. Idiopathic pulmonary fibrosis in US Medicare beneficiaries aged 65 years and older: Incidence, prevalence, and survival, 2001-11. *Lancet Respir Med*. 2014;2(7):566-572. doi:10.1016/S2213-2600(14)70101-8.
- Hutchinson JP, McKeever TM, Fogarty AW, Navaratnam V, Hubbard RB. Increasing global mortality from idiopathic pulmonary fibrosis in the twenty-first century. *Ann Am Thorac Soc*. 2014;11(8):1176-1185. doi:10.1513/AnnalsATS.201404-145OC.
- Nalysnyk L, Cid-Ruzafa J, Rotella P, Esser D. Incidence and prevalence of idiopathic pulmonary fibrosis: Review of the literature. *Eur Respir Rev*. 2012;21(126):355-361. doi:10.1183/09059180.00002512.
- Raghu G, Rochwerg B, Zhang Y, et al. An Official ATS/ERS/JRS/ALAT Clinical practice guideline: Treatment of idiopathic pulmonary fibrosis. an update of the 2011 clinical practice guideline. *Am J Respir Crit Care Med*. 2015;192(2):e3-e19. doi:10.1164/rccm.201506-1063ST.
- Raghu G, Collard HR, Egan JJ, et al. An official ATS/ERS/JRS/ALAT statement: Idiopathic pulmonary fibrosis: Evidence-based guidelines for diagnosis and management. *Am J Respir Crit Care Med*. 2011;183(6):788-824. doi:10.1164/rccm.2009-040GL.
- Spagnolo P, Tonelli R, Cocconcelli E, Stefani A, Richeldi L. Idiopathic pulmonary fibrosis: Diagnostic pitfalls and therapeutic challenges. *Multidiscip Respir Med*. 2012;7(1):42. doi:10.1186/2049-6958-7-42.
- Cottin V, Roman J, Eu J, Furlong P, Sherry D, Morthanos J. Leveraging the PFF Care Center Network. In: *PFF Summit, from Bench to Bedside 2015*. Washington, DC; 2015. <http://www.pffsummit.org/professionals.html>.
- Heath C, Heath D. *Switch: How to Change Things When Change Is Hard*. New York, NY: Penguin Random House; 2010.
- Margolis PA, Peterson LE, Seid M. Collaborative Chronic Care Networks (C3Ns) to transform chronic illness care. *Pediatrics*. 2013;131(Supplement 4):S219-23. doi:10.1542/peds.2012-3786J.
- Pulmonary Fibrosis Foundation. The Facts: PFF Care Center Network and PFF Patient Registry. [http://www.pulmonaryfibrosis.org/docs/default-source/news-documents/pulmonaryfibrosisfoundation\\_pffregistryfactsheet.pdf?sfvrsn=0](http://www.pulmonaryfibrosis.org/docs/default-source/news-documents/pulmonaryfibrosisfoundation_pffregistryfactsheet.pdf?sfvrsn=0). Accessed October 20, 2017.
- National Committee for Quality Assurance. *NCQA's Patient-Centered Medical Home (PCMH) 2011*. [https://www.ncqa.org/Portals/0/Programs/Recognition/PCMH\\_2011\\_Overview\\_5.2.pdf](https://www.ncqa.org/Portals/0/Programs/Recognition/PCMH_2011_Overview_5.2.pdf).
- Hunt VL, Chaudhry R, Stroebel RJ, North F. Does pre-ordering tests enhance the value of the periodic examination? Study design-process implementation with retrospective chart review. *BMC Health Serv Res*. 2011;11:216. doi:10.1186/1472-6963-11-216.
- Rivo J, Page TF, Arrieta A, et al. The impact of comprehensive pre-visit preparation on patient engagement and quality of care in a population of underserved patients with diabetes: Evidence from the care management medical home center model. *Popul Health Manag*. 2016;19(3):171-177. doi:10.1089/pop.2015.0063.
- Casalino LP, Nicholson S, Gans DN, et al. What does it cost physician practices to interact with health insurance plans? *Health Aff (Millwood)*. 2009;28(4):w533-43. doi:10.1377/hlthaff.28.4.w533.
- Russell A-M, Ripamonti E, Vancheri C. Qualitative European survey of patients with idiopathic pulmonary fibrosis: Patients' perspectives of the disease and treatment. *BMC Pulm Med*. 2016;16:10. doi:10.1186/s12890-016-0171-y.
- Collard HR, Tino G, Noble PW, et al. Patient experiences with pulmonary fibrosis. *Respir Med*. 2007;101(6):1350-1354. doi:10.1016/j.rmed.2006.10.002.
- Schoenheit G, Becattelli I, Cohen AH. Living with idiopathic pulmonary fibrosis. *Chron Respir Dis*. 2011;8(4):225-231. doi:10.1177/1479972311416382.
- Wuyts WA, Peccatori FA, Russell A-M. Patient-centred management in idiopathic pulmonary fibrosis: Similar themes in three communication models. *Eur Respir Rev*. 2014;23(132):231-238. doi:10.1183/09059180.00001614.
- Smith CW. The patient, the provider, and participatory medicine—are we a house divided? *J Particip Med*. 2014;6:e3. <http://www.jopm.org/opinion/editorials/2014/02/06/the-patient-the-provider-and-participatory-medicine-are-we-a-house-divided/>. Accessed December 4, 2017.
- Institute of Medicine. Partnering with patients to drive shared decisions, better value, and care improvement. In: *Roundtable on Value and Science-Driven Health Care*. Washington, DC: National Academies Press (US); 2014.
- Bonvicini KA, Perlin MJ, Bylund CL, Carroll G, Rouse RA, Goldstein MG. Impact of communication training on physician expression of empathy in patient encounters. *Patient Educ Couns*. 2009;75(1):3-10. doi:10.1016/j.pec.2008.09.007.
- Weng C, Li Y, Berhe S, et al. An Integrated Model for Patient Care and Clinical Trials (IMPACT) to support clinical research visit scheduling workflow for future learning health systems. *J Biomed Inform*. 2013;46(4):642-652. doi:10.1016/j.jbi.2013.05.001.
- Institute of Medicine. *The Learning Healthcare System: Workshop Summary*. Washington, DC: The National Academies Press; 2007. doi:10.17226/11903.
- Laursen DH, Christensen KB, Christensen U, Frølich A. Assessment of short and long-term outcomes of diabetes patient education using the health education impact questionnaire (HeiQ). *BMC Res Notes*. 2017;10(1):213. doi:10.1186/s13104-017-2536-6.
- Politi MC, Dizon DS, Frosch DL, Kuzemchak MD, Stigebout AM. Importance of clarifying patients' desired role in shared decision making. *BMJ*. 2013;347:7066. <http://www.bmj.com/bmj/section-pdf/750201?path=/bmj/347/7936/Analysis.full.pdf>. Accessed December 4, 2017.
- Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361-1367. doi:10.1007/s11606-012-2077-6.
- Haskard KB, Williams SL, DiMatteo MR, Rosenthal R, White MK, Goldstein MG. Physician and patient communication training in primary care: Effects on participation and satisfaction. *Heal Psychol*. 2008;27(5):513-522. doi:10.1037/0278-6133.27.5.513.
- Kreuter M, Bendstrup E, Russell A-M, et al. Palliative care in interstitial lung disease: Living well. *Lancet Respir Med*. 2017;5(12):968-980. doi:10.1016/S2213-2600(17)30383-1.
- Bajwah S, Ross JR, Wells AU, et al. Palliative care for patients with advanced fibrotic lung disease: A randomised controlled phase II and feasibility trial of a community case conference intervention. *Thorax*. 2015;70(9):830-839. doi:10.1136/thoraxjnl-2014-206583.
- Higginson IJ, Bausewein C, Reilly CC, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomised controlled trial. *Lancet Respir Med*. 2014;2(12):979-987. doi:10.1016/S2213-2600(14)70226-7.

# Beyond the Guidelines: Promising Practices to Improve the Care of Patients with Pulmonary Fibrosis Posttest

FOR REVIEW PURPOSES ONLY.  
MUST BE COMPLETED ONLINE.

Original Release Date: **December 31, 2017** • Expiration Date: **December 31, 2018**

Estimated Time to Complete Activity: **1.0 hour**

To get instant CME/CE credit online, go to <https://tinyurl.com/IPFBrtSp17>. Upon successful completion of the online test and evaluation form, you will be directed to a web page that will allow you to receive your certificate of credit via email.

If you have any questions or difficulties, please contact:  
Global Academy for Medical Education at [info@globalacademycme.com](mailto:info@globalacademycme.com) or (973) 290-8225.

---

## POSTTEST CME/CE QUESTIONS

- 1. Which of the following were bright spots identified among the sites in the Pulmonary Fibrosis Foundation Care Center Network?**
  - A. Standardization of care, diagnosis, multidisciplinary expertise, and monitoring for progressive disease
  - B. Efficiency, coordination of research and clinical care, mentorship and training, and shared decision-making
  - C. Coordination of research and clinical care, monitoring for progressive disease, shared decision-making, and focus on quality improvement
  - D. Staging, nonpharmacological treatments, collaboration and communication, and appropriate framing and early introduction of palliative care
- 2. Which of the following is true related to previsit planning?**
  - A. The majority of patients complete preordered tests
  - B. It improves the efficiency and benefit of the patient visit
  - C. It is recommended by the National Committee for Quality Assurance
  - D. All of the above
- 3. The average yearly cost for physicians, nurses, and administration staff to interact with insurance companies in the United States is which of the following?**
  - A. \$64 to \$70 million
  - B. \$2 to \$8 billion
  - C. \$23 to \$31 billion
  - D. \$57 to \$62 billion
- 4. What percentage of patients see multiple physicians before receiving an accurate diagnosis of idiopathic pulmonary fibrosis?**
  - A. 10%
  - B. 20%
  - C. 40%
  - D. 50%
- 5. How much time do you now plan to invest in standardizing the clinical management of patients with idiopathic pulmonary fibrosis?**
  - A. None
  - B. Not very much
  - C. Some
  - D. A moderate amount
  - E. A significant amount
- 6. To what degree will interprofessional collaboration now be a priority in the clinical management of patients with idiopathic pulmonary fibrosis in your practice setting?**
  - A. Not a priority
  - B. Low priority
  - C. Somewhat a priority
  - D. High priority
  - E. Essential priority

# Beyond the Guidelines: Promising Practices to Improve the Care of Patients with Pulmonary Fibrosis Evaluation Form

FOR REVIEW PURPOSES ONLY.  
MUST BE COMPLETED ONLINE.

Original Release Date: **December 31, 2017** • Expiration Date: **December 31, 2018** • Estimated Time to Complete Activity: **1.0 hour**

To assist us in evaluating the effectiveness of this activity and to make recommendations for future educational offerings, please take a few minutes to complete this evaluation form. Your response will help ensure that future programs are informative and meet the educational needs of all participants. CME/CE credit letters and long-term credit retention information will only be issued upon completion of the posttest and evaluation online at: <https://tinyurl.com/IPFBrtSp17>.

**Please indicate your profession/background:**

- MD/DO   
  MSN/BSN/RN   
  PA   
  APN/NP   
  PharmD/RPh   
  Resident/Fellow Researcher   
  Administrator   
  Student  
 Other; specify \_\_\_\_\_

<b>LEARNING OBJECTIVES:</b> <i>Having completed this activity, you are better able to:</i>	Strongly Agree	Agree	Somewhat Agree	Disagree	Strongly Disagree
Identify strategies to standardize the clinical management of patients with idiopathic pulmonary fibrosis.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Describe strategies to increase patient education within the existing workflow of idiopathic pulmonary fibrosis patient management.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Describe strategies to improve interprofessional collaboration related to the management of idiopathic pulmonary fibrosis.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

**If you do not feel confident that you can achieve the above objectives to some extent, please describe why not.**

\_\_\_\_\_

**If you anticipate changing one or more aspects of your practice/professional responsibilities as a result of your participation in this activity, please briefly describe how you plan to do so.**

\_\_\_\_\_

**Based on the content of this activity, what will you do differently in the care of your patients/regarding your professional responsibilities? (check one)**

- Implement a change in my practice/workplace.  
 Seek additional information on this topic.  
 Do nothing differently. Current practice/job responsibilities reflect activity recommendations.  
 Do nothing differently as the content was not convincing.  
 Do nothing differently. System barriers prevent me from changing my practice/workplace.

**If you plan to change your practice/workplace, may we contact you in two months to see how you are progressing?**

- Yes. Email address: \_\_\_\_\_  
 No.     I don't plan to make a change.

**If you are not able to effectively implement what you learned in this activity, please tell us what the system barriers are (eg, institutional systems, lack of resources, etc).**

\_\_\_\_\_

<b>OVERALL EVALUATION</b>	Strongly Agree	Agree	Somewhat Agree	Disagree	Strongly Disagree
The information presented increased my awareness/understanding of the subject.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
The information presented will influence how I practice/do my job.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
The information presented will help me improve patient care/my job performance.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
The program was educationally sound and scientifically balanced.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Overall, the program met my expectations.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
I would recommend this program to my colleagues.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

**What topics do you want to hear more about, and what issue(s) regarding your practice/professional responsibilities will they address?**

\_\_\_\_\_

\_\_\_\_\_

**Please provide additional comments pertaining to this activity and any suggestions for improvement.**

\_\_\_\_\_

\_\_\_\_\_

Jointly provided by



Postgraduate Institute for Medicine

In collaboration with



Supported by educational grants from



The Postgraduate Institute for Medicine thanks you for your participation in this CME/CE activity. All information provided improves the scope and purpose of our programs and your patient care.