

PULMONARY FIBROSIS FOUNDATION

# Breathe

BULLETIN

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## Our Mission

The Pulmonary Fibrosis Foundation mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live longer, healthier lives.

*Breathe Bulletin* is published biannually by the Pulmonary Fibrosis Foundation. Opinions expressed by the authors and interviewees are their own and do not necessarily reflect the policies of the Pulmonary Fibrosis Foundation.

### DISCLAIMER:

The material contained in this newsletter is for educational purposes only and should not be considered as medical advice. Consult your healthcare provider for treatment options.

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### Pulmonary Fibrosis Foundation

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[pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)

# Letter from our President & CEO

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## DEAR FRIENDS,

At the Pulmonary Fibrosis Foundation, our efforts to educate the public, patients, and healthcare providers about pulmonary fibrosis (PF) are complemented by our significant support of the important research that leads to improved drug therapies.

The PFF Patient Registry is a centerpiece of that research support. With the completion of phase I of patient enrollment, the Registry has reached an important developmental milestone—but our work is far from over.

A growing body of current research is based on the invaluable data generated by the Registry and its associated biorepository, but much more participation and data are needed, particularly for clinical trials. We need your continued support and involvement to ensure the Registry will keep expanding our understanding of this complex disease and moving us toward more and better therapies.

As we work toward improved treatment options for tomorrow, the Foundation is also focused on the quality of life for PF patients today. We know that many of you face challenges in using supplemental oxygen. With heightened legislative advocacy, a new booklet on oxygen basics, and our Oxygen Information Line, the PFF is increasing our efforts to improve patients' understanding of and access to oxygen.

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Your support makes this progress possible, and I invite you to make a gift to the PFF to continue our momentum.

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In this issue of the Breathe Bulletin, you'll learn more about these initiatives and find updates on the myriad other ways the Foundation is supporting, educating, and advocating for people living with PF. Your support makes this progress possible, and I invite you to make a gift to the PFF to continue our momentum. You're a valued member of the PF community—we're grateful to have you traveling alongside us on our journey to a cure.

Sincerely,



**William T. Schmidt**

PRESIDENT AND CHIEF EXECUTIVE OFFICER



# Starting a Support Group: Insight From Two Support Group Leaders

There are more than 150 pulmonary fibrosis support groups in communities nationwide to provide patients and caregivers with an outlet to share and help one another with their diagnoses. We asked two support group leaders, Tim Cox of Charlotte, North Carolina, and Madeline Wollmer of Phoenix, Arizona to talk with us about how their groups started and the impact they are making today.

## FINDING STRENGTH IN VULNERABILITY



Tim Cox was diagnosed with IPF in June of 2014 and, like most folks, knew nothing about the disease. He and his wife committed at that time to learn as much as they could and they began a discovery process about pulmonary fibrosis and lung transplantation.

Cox, a pastor, was introduced by a friend to Pastor David Russell from another church in the community. Russell had pulmonary fibrosis several years earlier and received a lung transplant. They met regularly and Russell mentored Cox about what his experience with a lung transplant would be like. Cox was interested in attending a support group but the closest was in Greensboro, which was two hours away. Two and a half years later, Cox received a double lung transplant at the Cleveland Clinic in Ohio and joined the Cleveland PF support group.

After returning to Charlotte in 2017, Cox joined Russell to start the Next Breath Support Group. It began with eight people and reached an attendance as high as 26. Cox said the support group helps members navigate practical matters like how to take a shower with supplemental oxygen or the emotional aspects of the life-threatening disease. “Talking about your weaknesses gives you strength,” Cox said. “The hardest thing is to be vulnerable, yet when you are, you are strengthened. The responses from others provide great encouragement.”

## SHARING COMPASSION AND EDUCATION



When Madeline Wollmer's husband was diagnosed with IPF in 2014 after experiencing respiratory problems, she was shocked. As a former critical care nurse, she had never heard of the disease.

Wollmer immediately tried to find a support group in the Phoenix area. The only one in Arizona at the time was in North Scottsdale, a nearby suburb. Wollmer contacted the group and learned that a nurse practitioner and a social worker in the Phoenix area were interested in starting a support group in Phoenix.

They held the first meeting in the fall of 2014 with four people. Now, the attendance ranges from 20-25 people at each meeting. Meetings include member-requested presentations on pulmonary rehab, oxygen use, and healthy eating. Members also enjoy meetings where patients and caregivers have separate breakout sessions and private discussions.

Wollmer became a support group leader because she wanted to educate herself and help others who were experiencing similar challenges. Her husband passed away in 2016 and she continues to lead the group to honor his legacy.

“I feel so committed to contributing to this group of people. The conversations at our meetings are loving, compassionate and joyful,” Wollmer said. “I can help people get adjusted to this diagnosis and that's my gift.”

The PFF offers resources on finding and starting support groups. For more information, visit [pulmonaryfibrosis.org /life-with-pf/support-groups](https://pulmonaryfibrosis.org/life-with-pf/support-groups).

**LEFT:** Tim Cox (left) and Jim Schimmel (right).  
**RIGHT:** Madeline Wollmer's support group.

# ¿Habla Español?

## New Spanish Materials Available

The Pulmonary Fibrosis Foundation is committed to providing quality disease education to the pulmonary fibrosis community. This year, the Foundation has expanded its resource library to include translations in Spanish.



### Current materials in Spanish include:

- Pulmonary Fibrosis Information Guide
- Quick Start Guide for Supplemental Oxygen
- Traveling with Supplemental Oxygen Brochure
- Physician Notepad
- Disease Awareness Poster
- And more to come

To order free materials for your support group, education event, or to share with family and friends, please contact the Patient Communication Center at **844.TalkPFF** or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

## You are invited! PFF Voices

PFF Voices is the Pulmonary Fibrosis Foundation's telephone-based support group for people living with pulmonary fibrosis, caregivers, family members, and anyone else affected by this disease. Each monthly meeting provides a chance to discuss different topics related to PF, share personal stories, ask questions and provide support to one another from the comfort of your own home.

Meetings are held on the third  
Thursday of each month

11:00 a.m. PT  
12:00 p.m. MT  
1:00 p.m. CT  
2:00 p.m. ET

Call-in information for  
PFF Voices

Phone Number: 1-571-317-3116  
Access Code: 124-558-453

For more information, visit  
[pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)  
or call **844.TalkPFF**.

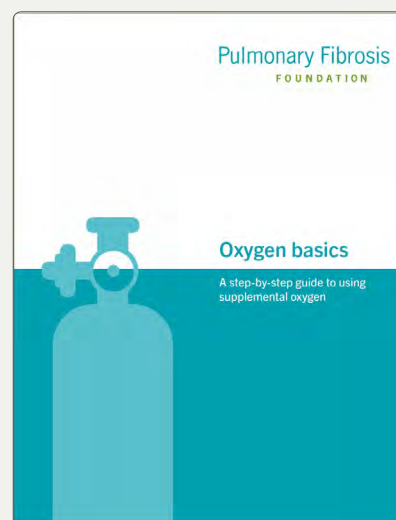
Thank you to our  
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## MORE OXYGEN RESOURCES

The PFF recently began distributing a comprehensive booklet on oxygen use, covering basics, equipment, safety tips, details on Medicare coverage, and guidelines for traveling with oxygen.

Staffed by trained professionals, the PFF Oxygen Information Line is available Monday to Friday between 9:00 a.m. and 5:00 p.m. CT at **844.825.5733**.





# PFF Continues Advocacy, Oxygen Initiatives



## PFF ADVOCACY KEEPS LEGISLATORS IN THE LOOP

Educating members of Congress about the prevalence and challenges of pulmonary fibrosis is a critical step toward funding additional research into the disease. As part of its continuing advocacy efforts, the Pulmonary Fibrosis Foundation presented “Lethal Lung Disease on the Rise: Investing in Pulmonary Fibrosis Research” on February 5 in Washington, D.C.

More than 20 staff members from congressional offices attended the Capitol Hill briefing at the invitation of Senator Christopher A. Coons (DE), a champion of PF research. The event was co-hosted by Senators Amy Klobuchar (MN) and Christopher Murphy (CT). Speakers included James P. Kiley, PhD, director of the Division of Lung Diseases at the National Heart, Lung, and Blood Institute; David Lederer, MD, MS, pulmonologist and associate professor at Columbia University Medical Center and PFF Senior Medical Advisor; and Sonye Danoff, MD, PhD, assistant professor in the Division of Pulmonary and Critical Care Medicine and codirector of the Johns Hopkins Interstitial Lung Disease Clinic. Doreen Walls, who lost her husband, Harry, to PF while the couple had four young children, gave a moving talk about the impact of PF on her family.

“Our speakers did a wonderful job of presenting and personalizing the issues,” says Kate Gates, PFF Director of Programs. “We had an engaged group of attendees, many of whom stayed to ask questions afterward. That interest reflects the broad bipartisan support medical research receives.”

**ABOVE:** From left to right: PFF President and CEO, William Schmidt; David Lederer, MD, MS; Sonye Danoff, MD, PhD; James P. Kiley, MD; Doreen Walls

## PATIENT SURVEY IDENTIFIES WIDE-SPREAD ISSUES WITH SUPPLEMENTAL OXYGEN USE

The Pulmonary Fibrosis Foundation is surveying patients currently using oxygen. The PFF plans to use this survey to monitor the potential impact of recent changes to the way that providers are paid for supplemental oxygen through Medicare.

The PFF first surveyed 583 patients in December 2018 to obtain a baseline for future comparison. Some preliminary results:

- 48% of respondents indicated they have experienced some type of problem related to supplemental oxygen
- 36% have received poor-quality service from their oxygen supplier
- 20% have experienced a high out-of-pocket cost for oxygen
- 26% have received oxygen systems that did not deliver sufficient oxygen flow rates
- 27% have received unreliable oxygen equipment
- 34% could not travel due to their oxygen delivery system

For example, patients reported being limited to 30 tanks per month, delivery frequency being reduced from every two weeks to monthly without notice, and delivery being suspended without notice.

“The PFF will continue to survey over the coming months to identify any trends or changes in patients’ access to oxygen,” says Kate Gates, PFF Director of Programs.

If you’re a PF patient who currently uses oxygen and hasn’t yet taken the survey, visit <http://bit.ly/oxygensurvey2> to participate.

# In Thanks To Daniel M. Rose, MD



## PFF Chair Emeritus laid the groundwork for the Foundation's current success

Every high-achieving organization is shaped by the combined vision of its leaders. The Pulmonary Fibrosis Foundation owes much of its success to the forward-looking focus of Daniel M. Rose, MD, former Chief Executive Officer and chair of the board of directors.

Rose, whose family founded the PFF after being personally touched by the disease, was instrumental in professionalizing the Foundation. “He studied what other successful organizations, particularly the Cystic Fibrosis Foundation, did and looked for ways to apply those models to the PFF,” says Scott Staszak, PFF Chief Operating Officer, who has worked with Rose since Staszak joined the staff in 2011.

The PFF Patient Registry, now a linchpin of the Foundation's research efforts (also see page 11), and the Care Center Network, which is creating uniformity and best practices in PF patient care (see page 8), were both part of Rose's vision. He also came up

with the idea for the PFF Summit, which started in 2011 with 350 attendees and will attract a projected 1,100 this fall.

“I strongly believe the first Summit was the turning point that showed the PF community the Foundation wasn't going to be a passive organization; that we were instead going to proactively engage in discussions about the importance of research and find ways to engage all our stakeholders in that conversation,” Staszak says.

### BOUNDLESS ENERGY AND PASSION

“Dan is the reason I got involved with the PFF,” says Michael Henderson, a PFF board member, former board chair, and PF patient. “When he stepped in as CEO in 2009, things started to really happen. It was all driven by Dan and his passion for finding treatments and a cure for PF. He lived and breathed that passion and had boundless energy to pursue it.”

From tirelessly marketing the Foundation to strengthening connections with patients to recruiting staff and board members with deep expertise in PF, Rose “was a very effective leader of the organization at that point in time,” Henderson says. “Very few people can get up and tell the story of PF and the Foundation like he can, and his status as a cardiac surgeon meant he was recognized and respected within the healthcare community.”

Henderson adds, Rose's direct involvement helped convince University of Washington Medical Center administrators to establish an interstitial lung disease center—“so I owe him a great personal debt of gratitude.” Henderson received a double lung transplant at UWMC in 2006.

Rose, who recently stepped off the PFF Board of Directors, is the first to hold the title of PFF Chair Emeritus. To honor his distinguished service to the organization, the PFF recently created a proclamation recapping Rose's many achievements.

“A lot of leaders, dedicated staff, donors, and volunteers have worked together to execute and build upon Dr. Rose's vision,” William Schmidt, President and CEO of the PFF says. “It took a lot of committed people to get us to this place, but without Dr. Rose, we wouldn't be here. His many contributions have significantly improved the lives of the PF community worldwide.”

# CCN Site Profile: The University of Kansas Health System



## From research to direct patient care to outreach, TUKHS is a regional leader

With approximately 1,200 patients traveling from a five-state region, The University of Kansas Health System (TUKHS) in Kansas City is a regional leader in treating pulmonary fibrosis and a dynamic and influential member of the Pulmonary Fibrosis Foundation's Care Center Network (CCN).

TUKHS PF program director Mark Hamblin, MD, FCCP, Assistant Professor of Pulmonary and Critical Care Medicine, has built an active pharmaceutical clinical trials program to assist with therapeutic development for patients living with PF.

Both Hamblin and his colleague Janell Reichuber, BSN, RN, are extremely active with the PFF. Along with Anne Turner, RN, Vanderbilt University Medical Center, Reichuber is chairing a PFF ILD Nurse and Allied Health Network committee that's creating a binder of comprehensive PF information to give to patients at CCN sites across the country.

Hamblin chairs the PFF communications committee, charged with improving dialogue and collaboration among CCN sites to standardize care and share best practices. The committee is exploring various platforms for adoption to share information, including Twitter. As the committee's work progresses, "We've realized we also need to expand outward and look at external communications to community providers," Hamblin says. "Many of these providers

report that they don't have ready access to thoracic radiologists. One physician in Wichita told us she'd only seen one case of PF and didn't feel she could accurately diagnose and manage the disease. So the communications committee started looking at ways to address some of these gaps and fill these needs."

One tool that's helping bridge the gap between CCNs and community providers is Extension for Community Healthcare Outcomes, or Project ECHO. This guided practice model uses multi-point videoconferencing to conduct virtual clinics with community providers, helping train primary care doctors, nurses, and other clinicians in providing specialty care to patients in their own communities. TUKHS launched a pulmonary fibrosis offering in its Project ECHO series in May 2017.

The TUKHS PF program recently debuted Cough 55, another initiative designed to help raise community providers' awareness of the disease. The project urged providers to send patients for imaging if they're over age 55 with a chronic cough that doesn't respond to treatment within three months. "The journey to a PF diagnosis starts in primary care or an emergency room," Hamblin says. "A lot of patients are misdiagnosed two or three times, causing a delay during which the disease potentially progresses."

Besides Hamblin, the TUKHS PF program has two other pulmonologists, one of whom is actively exploring the possibilities of artificial intelligence and CT scanning for earlier and more active PF diagnosis and a nurse practitioner, Kristy Delaney, APRN-NP. The program also has three clinical research coordinators and an unusual level of nursing support: three dedicated nurses, Sara Manning BSN, RN, Jamie Ludwig BSN, RN, and Janell Reichuber BSN, RN.

"Our dedicated nurses are an integral part of patients' experience and care. They do great work in educating patients, particularly those who are in the palliative stage or having trouble with oxygen," says Hamblin.

"As nurses, we take a holistic approach. When our patients leave here, we're the ones they'll be calling to talk about their journey," adds Reichuber. "Whether it's answering questions about the disease and medications, helping caregivers with their concerns, or being patient advocates with medical equipment companies, we provide all-around support."



# Meet Susan S. Jacobs, RN, MS: A Voice For Patients



## With research, education, & advocacy, Stanford's Susan S. Jacobs is raising the bar for PF patient care

Two decades ago, Susan S. Jacobs, RN, MS, was a research coordinator in Stanford Health Care's pulmonary and critical care division. She and her colleagues were just beginning fledgling studies into idiopathic pulmonary fibrosis. "More and more patients with interstitial lung disease started coming in, and we decided we should start a dedicated ILD clinic," she recalls.

Today, the Stanford ILD program—part of the Center for Advanced Lung Disease—is a Pulmonary Fibrosis Foundation Care Center Network (CCN) site, operating a busy clinic and hosting a support group for patients and caregivers. The interdisciplinary center collaborates with thoracic surgery, rheumatology, transplant, and other departments, and has a dedicated ILD nurse as well as a social worker.

Jacobs also helps coordinate an innovative event that brings together the PF expertise of several institutions. "Pulmonary Fibrosis: The Journey from Diagnosis to Treatment, a Seminar for Patients, Caregivers, and Families" is a biannual seminar sponsored by Stanford and two other PFF CCN sites: University of California San Francisco and University of California Davis. Attracting between 150-250 attendees, the educational event features leading experts

in interstitial lung disease and addresses various topics related to PF, as well as resources.

Jacobs is active in several roles with the PFF, serving as a member of the PFF ILD Nurse and Allied Health Network, member of the PFF Summit steering committee, and PFF Ambassador. Through the years, the PFF "has really inspired and supported me in caring for the ILD population," she continues. "As the CCN grew, it provided me with other advanced practice nurses who could collaborate with me on projects like seminars and workshops and manuals. And the nursing network has been invaluable, especially to nurses who are just beginning to work in ILD."

Years of experience in the Stanford ILD clinic showed Jacobs how many patients struggle with access to appropriate supplemental oxygen. "Patients were coming in not adequately oxygenated, and many were reporting problems with their oxygen companies and their equipment."

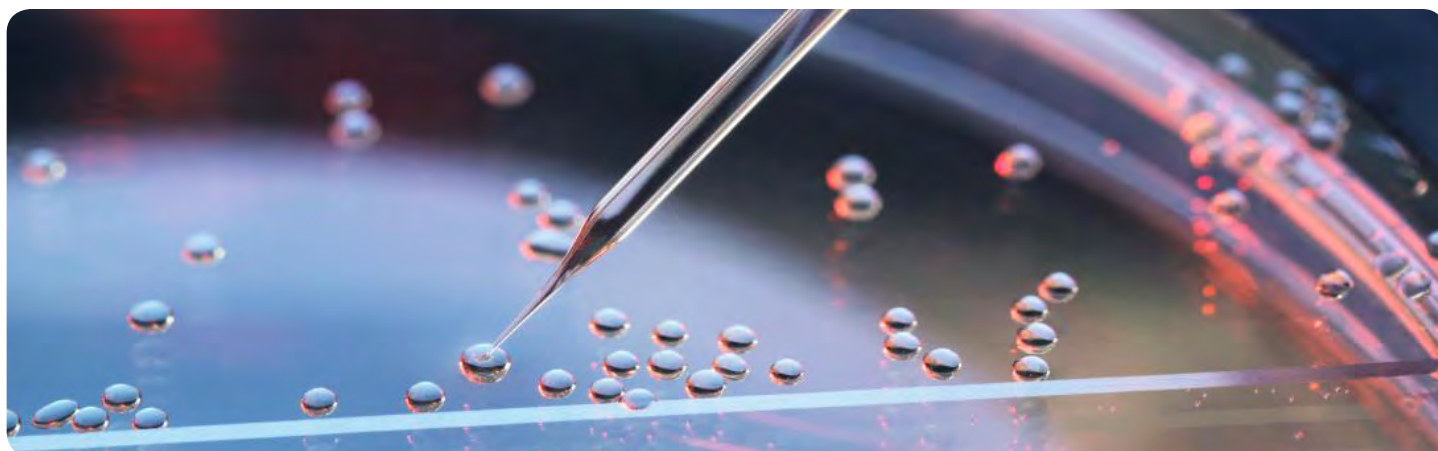
As a member of the American Thoracic Society (ATS) nursing assembly and nursing program planning committee, Jacobs heard the same complaints from nurses across the U.S. and the globe, "so we decided to create an oxygen working group that later became a standing committee," Jacobs says.

Realizing that little hard data was available in this area, the group conducted a survey and follow-up workshop that exposed widespread oxygen problems and gathered perspectives from patients, health care providers, and relevant governmental organizations. A resulting report identifying the range of issues and strategies for addressing them was published in the *Annals of the American Thoracic Society* in December 2018.

"Changing policy is difficult," Jacobs says. "Patients have felt the impact of very low Medicare and Medicaid reimbursement to suppliers, and access to liquid oxygen is one of the biggest losses," she says.

In the meantime, patient advocacy is critical to producing important change. "We want patients to understand that they need to contact their Congressional representatives, in person, by phone, or by letter, to help build awareness in Congress," she says.

# The PFF Urges Caution Against Stem Cell & Cell-Based Therapy



The medical advisory board of the Pulmonary Fibrosis Foundation issued an updated statement on the use of stem cell and cell-based therapies on March 5, 2019. The statement strongly cautions patients with pulmonary fibrosis against using stem cell treatments outside of an approved clinical trial.

“We understand that patients are eager to identify therapies that will prevent the devastating effects of their disease,” said Dr. Gregory Cosgrove, Chief Medical Officer for the PFF. “But experimental treatments provided by unregulated, commercial stem cell centers have the potential to cause great harm to individuals who are dealing with pulmonary fibrosis.”

Several cases of severe respiratory illness resulting from “stem cell” infusions from commercial centers have been identified and reported to federal regulatory agencies. The direct-to-consumer marketing of stem cell therapies currently exaggerate claims of the benefit of stem cells/cell-based therapy without an established record of safety.

“Desperate patients and their physicians continue to succumb to an onslaught of marketing and branding of as yet unproven stem cell treatments,” said Dr. Andrew Limper, Chair of the PFF Medical Advisory Board.

Limper and Cosgrove urge patients to learn about relevant and feasible clinical trials that may be available to them on the PFF website, [trials.pulmonaryfibrosis.org](https://trials.pulmonaryfibrosis.org). Specific clinical trials evaluating innovative therapies can be located using the PFF Clinical Trial Finder.

A clinical trial can be identified by the following characteristics:

- There are no costs or fees associated with participation; the cost of the clinical trial is paid for by drug developers or governmental agencies.
- Written informed consent is required.
- Decisions are based on a research protocol.
- It is designed and intended to benefit future patients.
- There are periodic and systematic assessment of patient data
- The study is protected by government agencies, institutional review adherence to professional and legal standards.

“The PF community should be heartened by the progress made in PF research and patient care, including the identification and drug agency approval of two therapies for patients with IPF,” said Cosgrove. “These advancements were made possible through the careful implementation of rigorous scientific efforts, including randomized clinical trials.”

To provide the best care for patients with pulmonary fibrosis, or any illness for that matter, a meticulous evaluation of any therapy in controlled clinical trials is the only way to assess the benefits and potential harm. This includes prudently evaluating stem cell and cell-based therapies.

The full statement along with a summary statement can be found at [pulmonaryfibrosis.org](https://pulmonaryfibrosis.org).



# Therapeutics Pipeline & PFF Patient Registry News

## NEW SEARCH OPTIONS HELP PAIR PATIENTS WITH RELEVANT STUDIES



One of the most difficult steps in the clinical trial process is finding people to participate. Many pulmonary fibrosis patients are eager to actively join research efforts to accelerate new PF treatment options, but finding appropriate trials can be challenging. To more easily and effectively bring together patients and researchers, the Pulmonary Fibrosis Foundation unveiled the Clinical Trial Finder in early 2018.

The Clinical Trial Finder is an easy-to-use tool that allows users to search by geography, demographics, and keywords to find the right clinical trials for them. The tool is continually undergoing revisions and improvements, says Rex Edwards, Vice President for the PFF Patient Registry.

Recently added search options include the following:

- Users can now enter a keyword to search for certain terms (for example, a sponsor or therapy name).
- Users can now look for trials involving a specific investigator.
- International users can now enter their location and learn the closest trials to them. Previously, the location search was based only on US ZIP codes.

“An upcoming new feature, the Trial Match, will allow users to store their search criteria and receive an email when a new trial meeting those criteria is posted,” Edwards says.

Since its debut, the Clinical Trials Finder has been a popular resource with PF patients, who find it far simpler to navigate than the government site ClinicalTrials.gov. Visit [trials.pulmonaryfibrosis.org](https://trials.pulmonaryfibrosis.org) to search for a trial. For more information, call the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or email [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

## SEVENTEEN STUDIES IN VARIOUS STAGES MAKE FULL USE OF REGISTRY DATA

What would it cost to replicate current research studies that are using data from the Pulmonary Fibrosis Foundation Patient Registry?

Thus far, 17 research projects, including four biomarker studies, have received approval from a PFF research review panel to use data generated by the Registry.

“We estimate that recreating these 17 studies without Registry data would cost tens of millions of dollars,” says Rex Edwards, VP for the PFF Patient Registry. “The Registry is an invaluable source of data, and we’re sharing it at no cost to promote research into PF and interstitial lung disease.”

The Registry reached its first enrollment goal of 2,000 patients with the generous funding of Genentech, Boehringer Ingelheim, InterMune, The Cowlin Family Fund at the Chicago Community Trust, the Rattner Family Foundation, the McQuaid Family Foundation, Hales Family Foundation Inc., Biogen, Goldhirsh-Yellin Foundation, Steffy Family Foundation Fund, and the Jenny H. Krauss and Otto F. Krauss Charitable Foundation Trust, in memory of Stephen N. Dirks.

To expand patient participation and follow already enrolled patients for longer periods of time—developments that are key to meeting the needs of more researchers and additional studies—the Foundation is currently seeking additional funding.

### PFF PATIENT REGISTRY BY THE NUMBERS

Patients enrolled	2,003
Consented to future research	89.0%
Consented to biorepository	88.4%
Research projects approved	17
Presented at international conferences	12
Manuscripts in progress	5

# Register Now for PFF Summit, November 7-9, 2019



Registration for PFF Summit 2019 is now open. The Summit is the largest healthcare conference on pulmonary fibrosis in the world. It is unlike any other PF conference, because the Foundation welcomes everyone who has been impacted by the disease, including patients, caregivers, transplant recipients, and those who have lost a loved one.

Register today at [pffsummit.org](http://pffsummit.org).

The Summit, to be held November 7-9 in San Antonio Texas, provides an opportunity to network with others who have shared experiences. Numerous group discussions, networking breaks, and the Friday dinner allow attendees to mingle and make meaningful connections. In addition, the Poster Presentation held during the welcome reception allows all attendees to interact with leading researchers in the PF field.

For healthcare professionals, the Summit will feature a continuing medical education (CME) and Maintenance of Certification (MOC) program in addition to a continuing education (CE) program for nurses, respiratory therapists, and pharmacists.

## KEYNOTE SPEAKERS

We are pleased to announce Bray Patrick-Lake, MFS, and Edith A. Perez, MD as our keynote speakers for the PFF Summit 2019.



Both women offer expertise relevant to our patient and professional audiences. As Director of Stakeholder Engagement and Research Together program lead, Bray Patrick-Lake supports efforts to facilitate partnerships between patients, health advocacy organizations, sponsors, and investigators in Duke Clinical Research Institute's portfolio of research activities, which includes a broad spectrum of industry sponsored trials and federally-funded research. In 2010, Ms. Patrick-Lake founded the Patent Foramen Ovale (PFO) Research Foundation in response to the lack of definitive scientific information regarding the condition of PFO after being a patient in an aborted device clinical trial. Coupled with her professional expertise and her patient perspective, Ms. Patrick-Lake will address the opportunities to engage patients as active participants in the clinical trial process, not only as study subjects but as key thought leaders in the development of clinical trials.



Dr. Edith Perez is an internationally recognized translational researcher and cancer specialist, Professor of Medicine at Mayo Clinic, and Director of the Mayo Clinic Breast Cancer Translational Genomics Program. Her career experiences include leadership in academic and biopharmaceutical environments, with an added focus on philanthropic endeavors. Dr. Perez will provide a unique perspective on the role of genetic and genomic biomarkers to accelerate personalized therapies in breast cancer and its relevance to the pulmonary fibrosis community.



“The dynamics of patients, physicians, caregivers and industry professionals all in one conference is incredibly unique and valuable.”  
– Healthcare professional

## PROGRAM

The program will include a wide variety of tailored sessions, although attendees are welcome to attend any session included in the program. Sessions this year include two plenary sessions, Clinical Trials: Empowering Patients to Participate (Bray Patrick-Lake, MFS) and Translational Genomics: The Future is Now (Edith Perez, MD). For healthcare providers, the program will feature sessions on senescence, domestic and international registries, IPF diagnostics, transcriptomics, nuances and similarities of autoimmune ILDs, Chronic Hypersensitivity Pneumonitis (CHP), and therapeutic challenges and controversies in ILD. The program will also include a variety of other options for the patient and caregiver, lost a loved one, and transplant recipient, covering topics such as a disease overview, caregiving, planning for the future, treatment options, advocacy, managing mental and physical wellness, and more.

## THE POSTER PRESENTATION



The Pulmonary Fibrosis Foundation invites academic and industry researchers to submit abstracts of their scientific research for poster presentation at the Summit. All applicants must be registered for the conference in order to be considered for presentation. Academic abstracts will be subject to peer-review.

All abstracts will require submission through the online portal, proposalCENTRAL. The Call for Abstracts will open on Monday, June 10 and close on Friday, August 16 at 5:00 p.m. ET. For more information about the Poster Presentation and for the guidelines, please visit [pulmonaryfibrosis.org/pff-summit-2019/posters](http://pulmonaryfibrosis.org/pff-summit-2019/posters).

## CONFERENCE VENUE AND HOTEL ACCOMMODATIONS

The PFF Summit is taking place at the JW Marriott San Antonio Hill Country Resort in San Antonio, Texas. To book your hotel room, please visit <https://book.passkey.com/go/PulmonaryFibrosisFoundation>. Guest room block rates are \$239 per room night (single and double), and the deadline for group rates is October 15, 2019. Hotel rates apply three days before and after Summit.

Onsite activities include a six acre water park, two 18-hole golf courses, tennis courts, a world class spa, six on-site dining options, as well as hiking and biking. The average temperature in November for San Antonio is a high of 72 and a low of 52 degrees fahrenheit.

## THANK YOU TO OUR PFF SUMMIT 2019 SPONSORS

Sponsorship opportunities are available. To learn more, please contact Jennifer Mefford at [jmefford@pulmonaryfibrosis.org](mailto:jmefford@pulmonaryfibrosis.org) or visit [pffsummit.org](http://pffsummit.org).

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## WHAT PFF SUMMIT 2019 ATTENDEES ARE SAYING

“I really appreciate the ability to go to research as well as patient/caregivers lectures. I think this helps with educating oneself with progress in research and better navigate the disease.” – PF Patient

“The PFF Summit is really the premier national meeting that brings together into one setting physicians, nurses, researchers, patients, and caregivers who have a shared mission of working together to foster advancing the care of patients with pulmonary fibrosis.”  
– Healthcare professional

# Exploring Racial Disparities in Pulmonary Fibrosis



## Researcher looks for genetic markers that contribute to varying outcomes

With more than 40 million people, African Americans are the largest U.S. minority race and have worse survival rates than non-minorities in numerous pulmonary diseases. Although recent studies conducted in non-African American patients suggest genetic factors contribute to the risk of developing pulmonary fibrosis, “the variation of these genetic markers and their association with PF in African Americans is unknown,” says Ayodeji Adegunsoye, MD, MS, a clinical instructor of medicine at the University of Chicago.

As part of a 2018 I.M. Rosenzweig Junior Investigator Award from the Pulmonary Fibrosis Foundation, Adegunsoye is using clinical and genetic data collected across diverse races to identify genetic markers associated with the most severe form of PF in African American

and non-African American patients. With this approach to precision medicine, he hopes to identify new genes and gene pathways that may serve as targets for treating PF across African American and non-African American populations.

Using data from the PFF Patient Registry, Adegunsoye looked for differences in outcomes based on racial ancestry. “In analyzing data from 1,700 patients with different forms of PF, we found that regardless of the original classification of PF, African Americans had a diagnosis an average of a decade earlier than other people,” he says.

“That’s striking because this data isn’t generated from a single geographic center; it’s spread across the nation. It’s reminiscent of other researchers’ discovery that African Americans may develop colorectal cancer earlier than patients of other races.”

These recent findings echo results of previous research Adegunsoye’s team conducted in the Chicago area and published in the *European Respiratory Journal* last year.

### CREATING PF PHENOTYPES

In related research, Adegunsoye’s laboratory has identified several distinct interstitial lung disease phenotypes: observable expressions of individuals’ genetic makeup and the environment, such as height, weight, and skin color. After an independent review of patients to assess for lung honeycombing, a development that confers higher mortality among patients with PF, Adegunsoye’s team is beginning genotyping—investigating small genetic differences—among the patients across all racial groups.

“My expectation is that this work will improve our understanding of the relationship between the underlying honeycombing and the genetic markers among racial groups,” Adegunsoye says.

At the American Thoracic Society annual conference in May, Adegunsoye will make two presentations related to this research: “Racial and Ethnic Survival Patterns in Pulmonary Fibrosis” and “Phenotypic Clusters Predict Outcomes in a National Pulmonary Fibrosis Cohort,” the latter of which he’s also currently preparing a manuscript.



“One of the Registry’s greatest beauties is the fact that it’s a huge cohort of patients across diverse locations, with data points accrued over a period of time. It’s a huge data repository with tremendous benefits.” -Ayodeji Adegunsoye, MD, MS

## IRREPLACEABLE DATA SOURCE

Adegunsoye, an active member of the PFF Research Review Committee, says the availability of national Registry data helps researchers guard against geographical tilt, and the longitudinal nature of the Registry is more predictive than data obtained at a single point in time.

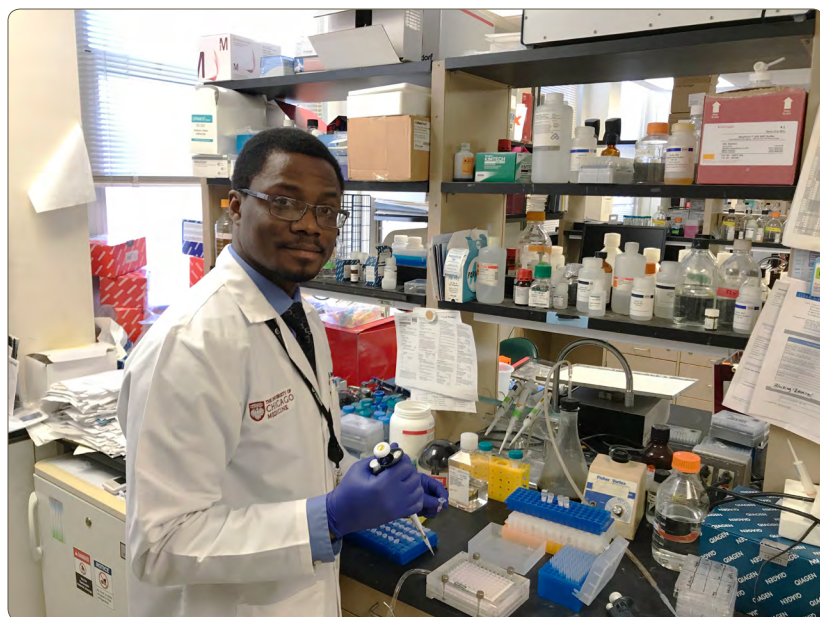
“One of the Registry’s greatest beauties is the fact that it’s a huge cohort of patients across diverse locations, with data points accrued over a period of time,” Adegunsoye says. “It’s a huge data repository with tremendous benefits.”

As a young physician, Adegunsoye saw many patients in his rural Nigerian home suffer from pulmonary diseases that went untreated due to lack of resources. He came to the U.S. in 2009 for a residency where the death of a patient with PF “left a deep impression on me,” he recalls.

Soon afterward, he heard a presentation on PF and its causes from the University of California San Francisco’s Talmadge E. King Jr., MD. It was a turning point for Adegunsoye.

“I told myself I’ve got to devote my career to helping improve the quality of life and life expectancy for patients with this condition,” he says.

This research award is funded by Boehringer Ingelheim Pharmaceuticals, Inc.



## REVAMPED RESEARCH PROGRAM NOW IN FIRST CYCLE

The new PFF Scholars Program, which replaces the Albert Rose Established Investigator Award and the I.M. Rosenzweig Junior Investigator Award, is now in its first application cycle.

The new program is designed to support early-stage researchers, develop participants’ professional networks, and provide career development opportunities to future leaders in the field of PF. An award of up to \$50,000, to be given over a two-year period, supports investigators—individuals within five years of completion of their formal training—as they seek “K” or “R”-level NIH funding. PFF Scholars are provided supplementary mentorship by a PFF advisor, participate in PFF Scholar activities throughout the year, at the PFF Summit, and annual Volunteer Meeting, and have the opportunity to invite a PFF visiting professor to their home institution.

The PFF Research Review Committee is currently reviewing full proposals and the PFF will notify all applicants of their proposal status by early June. The PFF will announce four new awardees in the late summer of this year.

# PFF Welcomes New Board Members



## SCIENTIST AND LEADER

The Mayo Clinic's Andrew Limper, MD, joined the Board of Directors in January. He also serves as chair of the newly created Medical and Scientific Advisory Committee (MSAC), which is responsible for advising the PFF Board on goals and overall direction of the scientific and clinical programs that the PFF funds.

"The Foundation is the only patient advocacy organization solely dedicated to working on patient advocacy, research, and education with the overall goal of improving the lives of people with PF," Limper says. "I've been involved in a lot of medical organizations, but the one I'm most excited to be part of is the PFF."

Limper has long been involved with the Foundation. He's the chair of the Medical Advisory Board and past-chair of the former Scientific Advisory Committee, which is now the Research Review Committee (RRC). He's also been actively involved in each of the PFF Summits and serves on the committee to peer review all academic abstracts for poster presentation and award selection.

At the Mayo Clinic, Limper studies lung defense and elimination of fungal infections, such as pneumocystis pneumonia, in patients with impaired defense systems. His additional research interests focus on interstitial lung diseases and pulmonary fibrosis. Limper's laboratory studies the causes and mechanisms of PF in an effort to identify new drug combinations that may be beneficial for patients with these diseases.

"We still suffer from PF not having the public awareness that diseases like lung cancer and chronic obstructive pulmonary disease have," Limper added. "But the tide is beginning to turn. There's a lot of work to do and it's an exciting time."



## PATIENT AND ACTIVIST

Barbara Murphy joined the Board in February. A longtime volunteer with the PFF, Murphy has been a support group leader, Team PFF leader, PFF Ambassador, and *Broadway Belts for PFF!* committee member.

Murphy was incorrectly diagnosed with IPF in 2003. Several years later, her diagnosis was revised to scleroderma-related, and she received a lung transplant from New York-Presbyterian/Columbia University Medical Center, a PFF Care Center, in 2012. "When I was first diagnosed, I didn't think I'd live to see my grandchildren—now I have four," she says. "I consider myself very lucky."

After her initial diagnosis, Murphy started the Garden State Pulmonary Fibrosis Support Group in 2004 when she discovered no New Jersey support group existed. "We're celebrating 15 years now," says Murphy, who still leads this active group.

In 2009, the group wanted to have a fundraiser and decided on a 5K. The annual 5K has now raised more than \$112,000 for PFF programs and initiatives.

After so much PFF involvement, joining the Board feels like a natural next step to Murphy. "I've wanted to be a part of the PFF's long-range strategic planning," says Murphy, a retired information technology professional. "The Foundation has grown so much since I've been involved with them—now, it's a large organization that does a lot of really good work." Murphy's interests span across the Foundation's many initiatives, but is grateful that education and awareness are continued high-priority focus areas. "Even now, 16 years after my diagnosis, people aren't as aware of PF as we'd like them to be".



# A Night to Remember: *Broadway Belts for PFF!*



**TOP LEFT:** Patti Murin (Broadway's *Frozen*) and Robert Creighton (Broadway's *Frozen*; *Cagney*) perform "Suddenly Seymour."



**BOTTOM LEFT:** Surprise guest Lilli Cooper (Broadway's *Tootsie*, *Spongebob Squarepants*) belts out a show-stopping performance of "Love You, I Do."



**RIGHT:** Inaugural Ralph Howard Legacy Award honorees Doug (left) and Gay (right) Lane with hostess Julie Halston.

The glitz and glamour of *Broadway Belts for PFF!* made its triumphant return to the Edison Ballroom for the ninth year on February 25th. Thanks to generous sponsors, attendees, and donors, more than \$400,000 was raised to support the PF community—a record-breaking achievement!

It was an especially moving evening as event hostess and co-creator, Julie Halston, introduced the Ralph Howard Legacy Award in memory of her husband, Ralph Howard, who passed away due to complications from the disease in August 2018.

"Ralph's endless curiosity about the world, and his direct and generous engagement with it, inspired us to create the Ralph Howard Legacy Award," Halston said. "I can't think of a better way to honor my beloved Ralph's legacy than by presenting this award at *Broadway Belts for PFF!* It means so much to remember my husband and celebrate our remarkable honorees, who have been a driving force in the success of the event from the very beginning."

The inaugural award was presented to Doug and Gay Lane for their generosity and unwavering support to the pulmonary fibrosis community, and to countless other causes.

Julie Halston and Ralph Howard helped create *Broadway Belts for PFF!* along with producers D. Michael Dvorchak, Sue Frost and Ed Windels, and Director Carl Andress in memory of Associated Press theatre critic, Michael Kuchwara, who succumbed to IPF in 2010.

To view a full list of this year's dazzling cast and for updates about the special 10th anniversary event in 2020, visit [BroadwayBeltsForPFF.org](https://BroadwayBeltsForPFF.org).

## THANK YOU TO OUR SPONSORS

Doug & Gay Lane

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## CHICAGO BEARS RUNNING BACK JORDAN HOWARD WINS FOR PULMONARY FIBROSIS

As the Chicago Bears added wins to their 2018 season scorecard, Jordan Howard issued a gift and fundraising challenge to support the PF community. Howard, who lost his father, Reginald B. "Doc" Howard, to pulmonary fibrosis, joined forces with the PFF in 2016.

Howard pledged to donate \$1,000 for every Chicago Bears win of the regular season. He invited the PF community to join him by making a \$1 donation for every win.

The Bears wrapped up the regular season and headed into the playoffs with 12 wins. Howard's gift of \$12,000 was increased by more than \$4,000 from fans in Chicago and beyond.

He also participated for the third consecutive year in the NFL's My Cause, My Cleats campaign during the Chicago Bears game against the New York Giants on December 2, 2018. The cleats raised \$2,910 with all proceeds benefitting the Foundation.

With an indomitable spirit, Howard urges the PF community to keep having hope and keep believing there will be a cure. Howard will play for the Philadelphia Eagles this fall and the PFF wishes him all the best with his new team.



# PFF Ambassador Heather Kagel Helps the Foundation ‘Go Big’ With Dallas Walk



PFF Ambassador and Dallas resident, Heather Kagel, turned 50 in 2017. As part of her mid-life reassessment, she made a commitment to give back to the PF community. Last September, Kagel and her husband Rick Tidwell created Ready. Set. Breathe, a community walk that raised \$65,000 for the Pulmonary Fibrosis Foundation.

“I wanted to do something for the incredible group of friends and fellow warriors who had given me so much comfort and support,” said Kagel. “Staying active is more difficult when you struggle for each breath. But keeping our lungs and bodies strong is the best thing we can do for ourselves.”

This year, Kagel’s Dallas walk will join the PFF Walk series in Chicago, New York, and Washington, D.C.

“It was a huge success and we were so grateful to our whole community,” Kagel said. “With the backing and support of the PFF, this year’s walk will be bigger and better.”

Before her diagnosis of idiopathic pulmonary fibrosis (IPF) in 2013, Kagel was an avid runner who enjoyed participating in 5Ks, 10Ks and half-marathons. After a case of bronchitis left a lingering cough, her pulmonologist ordered a CT scan of her chest. When Kagel saw the scarring on her lungs, the mother of two knew it meant IPF. Kagel recognized it because she had lost both her father and grandfather to the disease.

Kagel stays active and walks regularly. She finds hope and comfort in coming together with other members of the PF community through events like the PFF Walk, PFF Summit and monthly support group meetings in Dallas.

“These opportunities to be with other patients and clinicians to understand what’s happening in the PF world give me hope and remind me that we’ll get through this together,” said Kagel.

Learn more and register today at  
[pffwalk.org](http://pffwalk.org).

## UNITE, CELEBRATE, AND WALK

Join the Pulmonary Fibrosis Foundation for the third annual PFF Walk in four cities and virtually nationwide. The PFF Walk unites the community by sharing stories, celebrating loved ones, and walking together in the search for a cure.

Last year, the PFF Walk collectively raised over \$650,000 for research and initiatives that help patients and their families.

## JOIN THE PFF WALK!

SEPTEMBER 14, 2019 CHICAGO

[Diversey Harbor](#)

OCTOBER 12, 2019 WASHINGTON D.C.

[National Harbor](#)

OCTOBER 26, 2019 DALLAS

[Cypress Waters](#)

NEW YORK CITY, APRIL 2020

[TBA](#)

WALK IN YOUR COMMUNITY

[Virtual](#)



**ABOVE LEFT:**  
Heather Kagel and her husband Rick Tidwell.

# Team PFF Event Leader Honors Husband's Legacy with Golf Tournament



Doris Coode has had a long journey with pulmonary fibrosis. The pain of watching three family members battle the disease and the fear of it affecting her children motivated her to become a Team PFF Event Leader.

When Coode's mother-in-law was diagnosed with idiopathic pulmonary fibrosis, family and friends assumed it was because she was a smoker, and because no one had ever heard of the disease, they never considered a genetic link. When she passed away

in 1993, the family still didn't know much about this disease. It wasn't until 21 years later that pulmonary fibrosis made an abrupt reappearance.

"When my husband was diagnosed with IPF on January 2, 2014, my life changed forever," Coode said. Her husband, Peter, had retired just six months prior so they could travel and spend time together. But instead, their life was soon filled with doctor's appointments, respiratory rehabilitation, and oxygen concentrators. They tried to make the most of their new normal.

After battling the disease for nearly three years, Peter passed away in October 2016, but Coode's journey didn't end with her husband's death. In April 2018, Peter's younger brother David succumbed to IPF after having been diagnosed only 18 days prior.

"Now, there is definitely no denying the fact that it's genetic, and a doctor at Vanderbilt confirmed the gene mutation in my husband's family," Coode said. "There is a cloud that now hangs over my family as to who might get this disease in the future. We have to find a cure."

When her husband's golf instructor and family friends suggested hosting a memorial golf tournament, it seemed like the perfect opportunity for her to get involved with the Foundation and lead

the way toward a cure. "Since Peter loved golf, I thought it would be a great way to honor my husband," said Coode. "To me, the PFF was the obvious choice to receive the funds."

Last October, Coode and her friends and family hosted the Inaugural Peter Coode Memorial Golf Tournament in Raleigh, North Carolina, and raised over \$26,000.

"The golf tournament brought together many individuals who knew my husband but did not necessarily know the details of IPF," said Coode. "Through speeches and informational guides, we were able to give attendees a better understanding of the disease and the work of the Pulmonary Fibrosis Foundation."

Coode said that while creating an event can be a daunting task, with a good network and the guidance of the PFF, you can be successful. "My advice for someone starting their own event is to always remember to start with your primary contacts," said Coode. "A heartfelt email with a request for donations will often yield more results than you expect."

For Coode, hosting an event was the perfect way to bring her family and friends together to honor her husband's legacy while also paying it forward so that future generations of her family won't have to face the same battle.

**ABOVE LEFT:** The Peter Coode Memorial Golf Tournament Event Leaders (left to right) - Elyssa Nastalski, Dave Nastalski, and Doris Coode.

**BELOW, LEFT:** The Coode family (left to right) - Christine Coode, Brent Pace, Beth Coode, Zachary Coode, and Doris Coode.

**BELOW, RIGHT:** Christine Coode celebrating her winning shot during the tournament.



A community event is a great way to raise funds and build awareness. Get started today by contacting Jackie Williams at [312.224.4667](tel:312.224.4667) or [jwilliams@pulmonaryfibrosis.org](mailto:jwilliams@pulmonaryfibrosis.org).



# Planned Giving Allows Donor Legacies to Live on



In 2000, pulmonary fibrosis touched Albert Rose and his family and they felt the devastating consequences of the disease. Rose didn't want the disease to continue to impact other families, so he pledged \$1 million to form an organization that would fight this disease: the Pulmonary Fibrosis Foundation.

Nineteen years later, the PFF has continued the great work that Rose made possible. We are proud to honor Rose and his legacy by introducing The Albert Rose Legacy Society. We invite individuals to become members by making a gift to the Foundation through a will, trust, retirement plan, or insurance policy. Like Albert Rose, who pledged \$1 million to create the PFF, donors can make a tremendous impact on the PFF's efforts to both identify a cure for this deadly disease and expand our robust offering of patient-centric programs.

"Individuals who want to contribute to the Albert Rose Legacy Society are offered a myriad of giving options," said Seth Klein, Vice President of Development for the PFF. "Bequests are the most straight forward option for leaving a legacy. All gifts are special and can be made in any amount. We recommend that donors speak with their financial advisors or attorneys to discuss planned giving as part of their estate planning."

"Following a life-saving lung transplant, I wanted to help save the lives of others," said Laurie Chandler, Board of Directors member and treasurer of the PFF. "As a Pulmonary Fibrosis Foundation volunteer and board member, I know the value my dollars bring to fund research, patient education, and family support."

If you would like to discuss becoming part of the Albert Rose Legacy Society, please contact Seth Klein, Vice President, Development, at **312.224.2670** or [sklein@pulmonaryfibrosis.org](mailto:sklein@pulmonaryfibrosis.org).



**ALBERT ROSE**  
**LEGACY SOCIETY**

Pulmonary Fibrosis  
FOUNDATION

LEFT: Albert Rose

RIGHT: Laurie Chandler

# Let the World Know: New Initiatives and PF Awareness Month



## PFF LAUNCHES ITS FIRST AWARENESS CAMPAIGN, “NOT EVERYONE BREATHES EASY”

Last October, the PFF partnered with Chicago-based L.C. Williams & Associates (LCWA) to launch a new campaign, “Not Everyone Breathes Easy,” aimed at increasing awareness about pulmonary fibrosis and the PFF’s expertise and resources. The campaign is targeted to individuals who may

be at risk for the disease or are undiagnosed, and encourages them to speak with a physician about PF.

To kick off the awareness campaign, LCWA and the PFF created a microsite, [AboutPF.org](http://AboutPF.org), for visitors to learn about specific symptoms and risk factors. The site includes a Pulmonary Fibrosis Risk List worksheet that individuals can download and bring with them to their next doctor’s visit, as well as patient stories of those living with the disease. The microsite also directs individuals to [pulmonaryfibrosis.org](http://pulmonaryfibrosis.org) for resources to help them with next steps.

Visit the campaign microsite at [AboutPF.org](http://AboutPF.org) and join the conversation on social media with the hashtag, [#NotEveryoneBreathesEasy](https://twitter.com/NotEveryoneBreathesEasy).

## 30 REASONS TO GIVE: JOIN US FOR PULMONARY FIBROSIS AWARENESS MONTH

Mark your calendars! September is Pulmonary Fibrosis Awareness Month. This momentous occasion puts pulmonary fibrosis in the spotlight by sharing facts, stories, photos, videos, and much more on social media at [@pfforg](https://twitter.com/pfforg).

Starting on September 1, be sure to follow the PFF on Facebook, Twitter, and Instagram. This year, join us as we celebrate September with the “30 Reasons to Give” campaign. At the conclusion of PF Awareness Month on September 30, the Foundation welcomes everyone who has been touched by the stories, facts, and more to make a gift to help people everywhere who are living with pulmonary fibrosis.

Your participation is crucial in Pulmonary Fibrosis Awareness Month’s mission to let the world know. Learn more and start planning today by visiting our website at

<https://www.pulmonaryfibrosis.org/get-involved/pf-awareness>.



Pulmonary fibrosis patients, their loved ones, and care team can now connect through a platform jointly launched by the PFF and Responsum Health. Responsum for PF enables patients to easily access trusted, comprehensive, and understandable content at [responsum.com/responsum-for-pf](http://responsum.com/responsum-for-pf).

The free platform features a uniquely personalized newsfeed and a searchable database of over 500 article summaries, curated for the pulmonary fibrosis community. Patients can contact their healthcare providers directly from Responsum for PF to ask questions regarding articles or news featured on the platform.

“While the Internet offers the promise of unfettered access to massive amounts of information, patients can easily find themselves overwhelmed,” said Andrew M. Rosenberg, Founder and CEO of Responsum Health. “We all agree that a better informed patient makes for better outcomes, and that is our number one goal.”

The platform also provides useful health data tools including a shareable Patient One-Sheet and links to additional resources like Patient Services, Inc.’s financial assistance program. Responsum for PF was built by a team of patient engagement experts and based on over four years of patient interviews and input.



# Ways to Get Involved



Together we can make a difference. You can help the PF community and lead the way toward a world without pulmonary fibrosis by getting involved with the Foundation. Below are just some of the ways that you can make an impact. To learn more, visit [pulmonaryfibrosis.org/get-involved](https://pulmonaryfibrosis.org/get-involved) or call us at **844.TalkPFF** (844.825.5733).

## ADVOCACY

With leadership and guidance from the Pulmonary Fibrosis Foundation, pulmonary fibrosis patients and supporters from across the country are playing a major role in driving federal policy outcomes. Together, we are on the path to finding a cure, and your support and advocacy is bringing us ever closer.

## ATTEND AN EVENT

Attending or supporting an event is a great way to participate and learn more about the Foundation's programs and services, to educate yourself and others about PF, and to connect with other PF advocates. Use our event calendar—which is updated weekly—to locate an event in your area or find inspiration for creating an event of your own.

## FUNDRAISE FOR TEAM PFF

Join Team PFF and be a part of a committed group of volunteers across the country. Turn your passions and interests into a unique fundraising event to advance vital research and support patient programs that help patients and their families live longer, healthier lives.

## PFF WALK

Join us for the annual PFF Walk in Chicago (September 14), Washington, D.C. (October 12), Dallas (October 26), virtually, and New York City (April 2020)! The PFF Walk offers an inclusive opportunity for those who have been touched by pulmonary fibrosis to unite in the search for a cure while sharing stories, celebrating loved ones, and walking together with the community of patients, caregivers, healthcare professionals, and friends.

## PULMONARY FIBROSIS AWARENESS MONTH

Each September, come together with all who have been impacted by pulmonary fibrosis worldwide and unite for Pulmonary Fibrosis Awareness Month. Follow the PFF on social media at [@pfforg](https://twitter.com/pfforg) as we share facts, stories, videos, and much more to spread the word far and let the world know.

## SHARE YOUR STORY

Everyone who has been impacted by pulmonary fibrosis has a story to tell. Through the Portraits of PF series on Facebook, the Foundation features stories of the PF journey from people just like you. By sharing your story, you can help raise awareness and connect with others.

## SHOP PFF

Shop PFF merchandise is an excellent conversation starter, perfect for handing out at awareness and fundraising events. From bracelets to t-shirts to mugs and more, Shop PFF has something for everyone. Visit [www.Shop-PFF.com](https://www.Shop-PFF.com) today.





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The Pulmonary Fibrosis Foundation rates among top charities in the U.S. The PFF has a three-star rating from Charity Navigator and is a Better Business Bureau accredited charity.



# Pulmonary Fibrosis

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