

PULMONARY FIBROSIS FOUNDATION

Breathe

BULLETIN

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Table of Contents



GENERAL INTEREST

Letter From our President and CEO	03
PFF Voices: A Support Group You Can Join From Anywhere	04
Life With Pulmonary Fibrosis: Our All-New PFF Video Series	05
Nutrition Tips for People Living with PF	06

RESEARCH NEWS

PFF Care Center Network and PFF Patient Registry Continue to Expand	08
PFF Patient Registry Data is Supporting a Variety of Research.....	10
New Tool Makes it Easy to Find the Right Clinical Trial For You	11
Why Volunteer for a Research Study?	12
Translating the Terminology of Clinical Research.....	13
Manage Your Care While Moving Research Forward with the new PF Health App	14

PUTTING YOUR DOLLARS TO WORK

Research: A Priority Across PFF Programs and Initiatives	15
PFF Research Dollars: A Powerful Return on Investment	16
Research Report: “Thyroid Hormone as a Novel Therapeutic Agent in Lung Fibrosis”	17
PFF Intensity Survey Results Reach Wider Audience	18

FOUNDATION NEWS

PFF Increases Advocacy Efforts	19
Bringing the PF Community Together: <i>PFF Summit 2017</i>	20
Let the World Know: Pulmonary Fibrosis Awareness Month	21
The PFF Walk is Back Bigger and Better than Ever	22
Meet Jane Nelson and Join Team PFF	24
Sold Out ‘Broadway Belts for PFF!’ Breaks Records	26
Dancing Toward a Cure: You Did it!	27
Meet New Board Members Wendi Mason and Jeff Harris	28
Calendar of Events	30
Meet the Staff	31

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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Letter from our President & CEO

DEAR FRIENDS,

Through the combined efforts, energy, and enthusiasm of the pulmonary fibrosis (PF) community, the Pulmonary Fibrosis Foundation (PFF) has achieved outstanding momentum over the past few years. Now, the seeds we've planted are yielding remarkable growth in programs and initiatives that will make a tangible difference to people living with pulmonary fibrosis.

Last fall, the Foundation launched PF Health. This innovative app for smartphones and tablets allows patients to track symptoms and measurements, organize their medical records, and easily share this information with their physicians. If they choose, users can also help move PF research forward by sharing their anonymized data with the PFF Patient Registry.

We're also thrilled to announce the new PFF Clinical Trial Finder for patients who'd like to participate in a trial. This easy-to-use tool makes it simple to search by geography, demographics, and keywords—so you can find the right clinical trial for you and actively join research efforts to accelerate new PF treatment options.

PF Health and the Clinical Trial Finder are only two milestones in our ever-expanding support for research. Investigators are using the growing base of data from the PFF Registry in a variety of studies, the Foundation continues to sponsor research awards that frequently lead to larger government grants, and the PFF Therapeutics Network will facilitate the faster development of drugs to treat PF. Earlier this year, *BioMed Central Pulmonary Medicine Journal* published the results of the PFF INTENSITY survey exploring ways that delayed diagnosis affects the lives of PF patients.

Now, the seeds we've planted are yielding remarkable growth in programs and initiatives that will make a tangible difference to people living with pulmonary fibrosis.

Recognizing the importance of legislators' support in the fight against PF, the PFF has also stepped up our government relations initiatives. Last fall, we announced a new partnership between the PFF and Pulmonary Fibrosis Advocates (PFA), a group that has worked for years to educate members of Congress about PF. The PFA has been responsible for a sharp increase in federal funding for PF research, and we're delighted to combine our efforts in this area.

As summer arrives, please consider sponsoring or joining a *Team PFF* activity supporting the Foundation's mission—a fun way to connect with others touched by PF while working for a cure. You'll find an event calendar, as well as tips and support for organizing an event, at pulmonaryfibrosis.org. Thank you for your tireless support in our shared battle against PF. We are stronger—and accomplishing great things—together.

Sincerely,



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER



PFF Voices: A Support Group You Can Join from Anywhere

Support groups are invaluable sources of information, encouragement, problem solving, and camaraderie for pulmonary fibrosis patients and their caregivers. But some patients live far from established support groups, and others aren't physically able to travel to meetings. PFF Voices is a new support group that meets entirely by phone—so connecting with others is just a conference call away.

Launched in October 2017 in response to community requests, PFF Voices meets on the third Thursday of each month from 1:00-2:00 p.m. central time. To join, call [1.571.317.3116](tel:15713173116) and use access code 124-448-453. No RSVP is required, and participants can attend as many or as few meetings as they wish.

Meetings are led by either a Pulmonary Fibrosis Foundation staff member or PFF support group leader. Following a presentation on topics ranging from PF symptom management and supplemental oxygen to pulmonary rehabilitation and PFF resources, attendees are invited to ask questions and share their thoughts.

“Feedback from attendees has been very positive so far,” says Laura Devitt, PFF Manager of Volunteer Programs. “We have a mix of people who can't attend a physical meeting and individuals who go to other meetings and are looking for an additional source of support,” she says. “People are telling us PFF Voices is a great resource. Some have even told us it's the first time they've been able to connect with someone else with PF.”

Wendy Kaiser, who founded the Peoria Pulmonary Fibrosis Support Group in Illinois, has also participated in PFF Voices. When people are first diagnosed, they can feel overwhelmed, but through support groups, the upbeat Kaiser says she tries to help others discover how a positive outlook helps make the most of a modified lifestyle. “I've found it helpful to hear from others going through the same things,” she says.

For more information about PFF Voices, contact Laura Devitt at [312.224.8619](tel:3122248619) or ldevitt@pulmonaryfibrosis.org.



“People are telling us PFF Voices is a great resource. Some have even told us it's the first time they've been able to connect with someone else with PF.”

Life With Pulmonary Fibrosis: Our All-New PFF Video Series

Have you wondered how to use supplemental oxygen or sought information about what pulmonary fibrosis treatment options you should consider? Have you thought about what it would be like to start a support group or have you contemplated donating your data to the PFF Patient Registry?

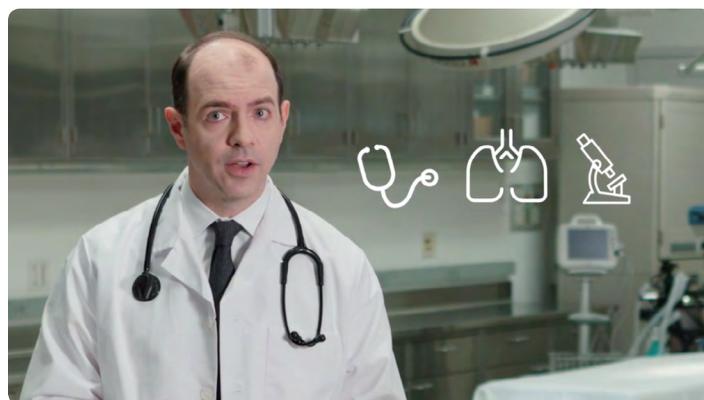
These topics and more are featured in the Foundation's new video series, *Life With Pulmonary Fibrosis*, produced for the PF community. The videos include individual patient profiles (Portraits of PF), explanations of pulmonary rehab and PF disease progression, a description of palliative care, and much more.

"Our intent with this video series is to offer patients, their caregivers, and loved ones an easy resource to provide a deeper understanding of living with pulmonary fibrosis," said Kate Gates, Director of Programs. "The videos are a tool for patients to learn and share important information and personal stories connected to the disease."

The documentary-style patient profiles feature people living with PF helping others as they continue with their own journeys. Patients share their stories about coping with the disease and seeking support from family members, friends, and others. They recount their personal ups and downs with PF and share specific strategies that have helped them along the way.

In the PF education videos, Dr. David Lederer, the PFF's Senior Medical Advisor for Education and Awareness, describes PF, the progression of the disease, and explains that each person's experience is unique.

The video series is available on the PFF's website and YouTube channel. Be sure to subscribe to our monthly newsletter and to our YouTube channel so you can be the first to know when new videos are published!



Nutrition Tips for People Living with PF

Achieving a healthy weight is an important part of everyone's health. Many people with PF struggle with either loss of appetite or an inability to shed excess pounds.

If you are facing a lung transplant, body weight is an even more important issue, since some transplant centers have strict criteria regarding body weight and transplant eligibility. For these reasons, requests for nutrition information are among the most common queries received by health providers and the PFF Patient Communication Center.

"Nutrition and ILD," a popular webinar in the PFF Disease Education Webinar Series, provides easy-to-understand suggestions for healthy eating with pulmonary fibrosis and other ILDs. Presented by Michelle MacDonald, MS, RDN, CDE, Clinical Dietitian and Certified Diabetes Educator and Gregory P. Cosgrove, MD, PFF Chief Medical Officer, the full webinar is available for viewing on the PFF's YouTube channel.

NUTRITION NEWS YOU CAN USE

SOME OF THE WEBINAR'S GENERAL NUTRITION SUGGESTIONS FOR PEOPLE LIVING WITH PF INCLUDE:

- Keep a regular eating pattern of three meals and one or two snacks daily.
- Choose lean protein sources like beans, chicken, eggs, fish, low-fat dairy, meat, seafood, tofu, and turkey.
- Aim for a plant-based, well-balanced diet.
- Design your diet depending on your needs: acid reflux, underweight/normal weight/overweight, medical side effects, or other special needs.

IF YOU HAVE ACID REFLUX:

- Backflow of food from the back of your throat or stomach may contribute to cough and might increase your risk for aspiration and infection.
- Choose drinks including caffeine-free coffee substitutes, herbal teas, low-fat milk, non-citrus juices, and water.
- Eat lean proteins, grains, non-citrus fruits, and vegetables.
- Avoid chocolate, fatty meats, full-fat dairy, fried foods, tomatoes, hot peppers, and spicy foods and condiments.



Watch the Webinar!

The full "Nutrition and ILD" webinar has many more tips for eating well with PF. Watch on YouTube or at: pulmonaryfibrosis.org/life-with-pf/pff-educational-resources/webinars/nutrition-and-ild.

“Requests for nutrition information are among the most common queries received by health providers and the PFF Patient Communication Center.”

IF YOU HAVE APPETITE LOSS:

- Recognize it as a warning sign of sickness and weight loss. Don't accept it; manage it.
- Talk to your doctor to find out if your appetite loss is related to medications you are taking or medical problems you may be experiencing.
- Treat food like medicine, taken by the clock and on schedule.
- Choose favorite foods any time of day—breakfast foods for lunch, for example.
- Focus on easy-to-prepare foods.
- Avoid difficult-to-digest, gas-producing, or diet foods.

IF YOU'VE LOST SIGNIFICANT WEIGHT AND WANT TO GAIN POUNDS, TALK TO YOUR DOCTOR ABOUT:

- Adding and concentrating calories in your daily diet.
- Avoiding non-calorie beverages; instead choosing milk, juice, homemade smoothies, and nutrition supplements.
- Choosing big portions of protein foods at meals.
- Adding fat and oils to foods.

IF YOU'VE BEEN ADVISED TO LOSE WEIGHT TO QUALIFY FOR A LUNG TRANSPLANT:

- Choose non-caloric drinks.
- Reduce “fast” (refined and processed) carbs like bread, pasta, potatoes, and sweets.
- Build a “healthy plate”: large portions of vegetables, moderate portions of lean proteins, three or fewer small fruits a day, and limited portions of starches and whole grains.

IF YOU HAVE MEDICATION SIDE EFFECTS:

- Manage appetite and weight gain if you take oral corticosteroids such as prednisone: develop an eating plan, fill up on veggies and lean proteins, and choose foods that take work to eat.
- Talk to your doctor about following the BRAT (bananas, rice, applesauce, and toast) diet if you have diarrhea caused by medications.



WATCH FREE WEBINARS ABOUT PULMONARY FIBROSIS!

The PFF Disease Education Webinar Series provides a free, convenient way to learn from and connect with pulmonary fibrosis specialists on a variety of topics. These broadcasts provide essential information for those affected by PF.

SOME PAST TOPICS INCLUDE:

- Clinical PF Research
- Oxygen Equipment Overview
- Ask a Doc
- Caregiving and PF

Join our live webinars on your computer or mobile device or watch the archived webinars on the PFF website (pulmonaryfibrosis.org) or the Foundation's YouTube channel. It's education from the comfort of your home—or on the go!

Visit the PFF website at pulmonaryfibrosis.org to find out about upcoming webinars or to browse the webinar archive. Call 844.TalkPFF or email pcc@pulmonaryfibrosis.org for more information.



PFF Care Center Network and PFF Patient Registry Continue to Expand

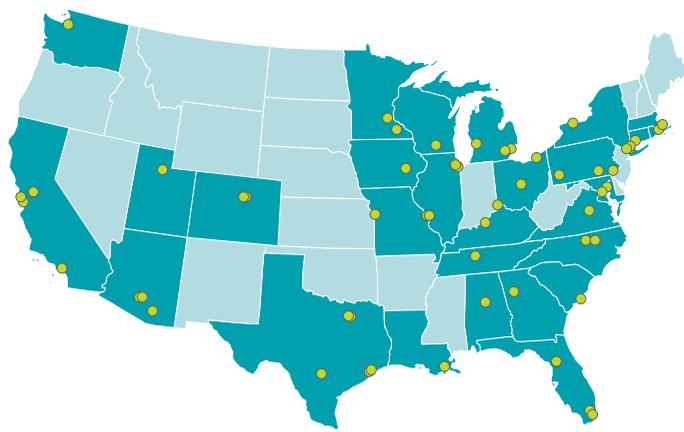
As part of the Pulmonary Fibrosis Foundation's commitment to promoting earlier diagnosis of pulmonary fibrosis and ensuring patients receive the highest standard of care, the PFF continues to work with the PF medical community to expand the PFF Care Center Network (CCN).

At this group of medical centers—now 60 sites—with expertise in accurately diagnosing and treating people living with PF, patients and their families can find experienced medical professionals who understand their disease and provide support services to improve the quality of their lives. PFF Care Centers embrace a multidisciplinary approach to care to improve accuracy of diagnosis and provide the most comprehensive patient care. Experts in pulmonary medicine, rheumatology, radiology, pathology, nursing, and others specializing in interstitial lung disease make up the care team at each PFF Care Center.

In addition to providing quality medical care, the Care Center Network forms an infrastructure that facilitates research on PF, an important step toward a cure. The PFF Patient Registry, one of the most important PF research initiatives to date, allows PF patients to voluntarily share their medical data and HRCT images (without information that could identify the participant). The result is a continually growing base of data that can be used in a variety of research studies. Registry participants may also choose to provide blood samples for a research-supporting biorepository.

NEW CCN SITES SELECTED

Although the CCN has established a solid framework across the country in its first several years, the PFF is partnering with new sites to substantially increase the number of patients served by PFF Care Centers. "We're striving to reach the point at which we have a PFF Care Center within a two-hour drive of 90% of the country's population," says Rex Edwards, PFF Vice President for the Patient Registry.



This spring, the PFF reviewed nearly 30 applications from medical centers seeking to become sites in the network.

New PFF Care Center Network Sites

1. Banner University Medical Center (Phoenix, Arizona)
2. UC Davis Interstitial Lung Disease Program (Sacramento, California)
3. University of Colorado Anschutz Medical Campus (Aurora, Colorado)
4. Cleveland Clinic Florida (Weston, Florida)
5. University of Florida (Gainesville, Florida)
6. Loyola University Medical Center (Maywood, Illinois)
7. University of Iowa (Iowa City, Iowa)
8. Henry Ford Health System (Detroit, Michigan)
9. Spectrum Health System (Grand Rapids, Michigan)
10. St. Luke's Hospital (Chesterfield, Missouri)
11. LeBauer Health Care at Cone Health (Greensboro, North Carolina)
12. Cleveland Clinic (Cleveland, Ohio)
13. Baylor University Medical Center (Dallas, Texas)
14. Houston Methodist Hospital (Houston, Texas)
15. University of Wisconsin (Madison, Wisconsin)

THERAPEUTICS NETWORK BRINGS PF COMMUNITY TOGETHER FOR DRUG DEVELOPMENT

Observing the impact similar initiatives have had on other diseases, such as cystic fibrosis and multiple myeloma, the PFF is creating a Therapeutics Network (TN), an ambitious initiative to facilitate development of drugs to treat pulmonary fibrosis.

“People living with PF and their families can find experienced medical professionals who understand their disease”

By advising on clinical trial protocols, supporting ambitious patient recruitment, and collaborating with manufacturers to conduct novel and efficient clinical trials, the TN will establish an environment to sustain continued and enhanced investment in idiopathic pulmonary fibrosis treatments and develop an evidence base to support therapy for other types of PF. Partners including pharmaceutical companies, PFF Care Centers, and PFF Registry sites are highly supportive of this initiative.

A number of potential PF therapies are in the research and drug approval pipeline, requiring a sharply increased number of trial participants—and a much longer timeline—if current trial design is utilized. “We’re looking at how we can improve clinical trial design and evaluation of multiple potential candidates to reduce the time involved,” says Gregory Cosgrove, M.D., PFF Chief Medical Officer. (Also see page 11 and 14 for details on the new PF Health app and Clinical Trial Finder.)

“The TN is the next step toward identifying a cure; it really integrates the essential components of research and clinical care,” Cosgrove adds, noting the value new board member Wendi Mason (see page 28) brings to this initiative. “For us to be successful, all our efforts have to be integrated, with the entire community—PFF, the pharmaceutical industry, the National Institutes of Health, all our partners—coming together.”



PAULINE BIANCHI, R.N., B.S.N., TO LEAD PFF CARE CENTER NETWORK AS NEW VP OF RESEARCH AND DEVELOPMENT

Expanding the Pulmonary Fibrosis Foundation’s research footprint is central to the PFF’s mission and strategic goals. Pauline Bianchi, R.N., B.S.N., veteran nurse and pharmaceutical industry expert, will help lead this effort in her new role as PFF Vice President of Research and Development.

Bianchi’s responsibilities include leading the PFF Care Center Network and PFF Therapeutics Network, both key elements of the organization’s strategic plan to bring high-quality care to patients and accelerate the development of clinical trials.

“Pauline’s experience as both a nurse and executive in the pulmonary fibrosis area will allow us to enhance training and communications with our Care Center Network partners and with nurses across the country,” said William T. Schmidt, PFF President and CEO. “Pauline’s deep understanding of the patient, healthcare provider, and industry perspectives make her a unique and valuable asset to our team.”

In her most recent position as Senior Director of Medical Affairs at Veracyte, a leading genomics diagnostic company, Bianchi collaborated with the PFF on a patient survey about the barriers to timely diagnosis. Results were presented at the biennial *PFF Summit* and published in the January 17 *BMC Pulmonary Journal* (also see page 20).

She also worked closely on the Envisia Genomic Classifier, a diagnostic tool for idiopathic pulmonary fibrosis (IPF) that may improve the ability to differentiate IPF from other interstitial lung diseases and is less invasive than a surgical lung biopsy. While at InterMune (now Genentech), Bianchi was involved in clinical trials for pirfenidone, one of only two FDA-approved drug therapies for IPF.

“I have worked with the PFF for several years and it is a highly effective and dedicated organization that provides patients with important resources that are realistic and provide hope,” Bianchi says. “There is a tremendous increase in the research of pulmonary fibrosis, and I am eager to help facilitate improved therapies and diagnostic tools.”

Among other initiatives, Bianchi will launch an interstitial lung disease (ILD) nursing network designed to provide training and share knowledge of best practices in ILD with the nursing community across the country.

PFF Patient Registry Data is Supporting a Variety of Research Studies

The PFF Patient Registry combines medical data from thousands of volunteers to give researchers a large database of information to use for improving our understanding of pulmonary fibrosis.

Unlike a clinical trial, in which therapies are tested in specific types of patients with scheduled visits and tests, the Registry includes patients with many different types of PF and collects information from their regular clinical care, without altering how they interact with their doctors.

Because this kind of data isn't as structured as that gathered during a clinical trial, there are some questions the Registry isn't designed to answer: for example, "Is treatment X better than treatment Y?" But there are lots of important questions that it can help address—through ancillary studies and through research proposals submitted to the PFF for evaluation by a review committee of PF researchers and statisticians.

Ancillary studies approved by the PFF have access to Registry data, blood samples in the associated biorepository, and HRCT images to answer their proposed research questions.

Some of the questions that have been proposed or studied so far are:

- "What are the characteristics of IPF patients using anti-fibrotic treatments?"
- "What patient characteristics drive the confidence of their IPF diagnosis?"
- "What is the role of high-density lipoproteins in interstitial lung disease?"
- "How does use of a multidisciplinary diagnosis review affect patient outcomes?"
- "What are the genetic factors of chronic hypersensitivity pneumonitis?"
- "How does where patients live affect their outcomes?"
- "What are the differences in how HRCT images are being used in the diagnosis of IPF patients?"
- "What is the prevalence and impact of chronic cough in patients with ILD?"

The PFF accepts and reviews ancillary research proposals three times a year. "As we add more data to the Registry, there are more questions we'll be able to answer more accurately," says Rex Edwards, PFF Vice President for the Patient Registry. "We look forward to continuing to assist the research community in answering key questions about this disease as we march toward a cure."



New Tool Makes It Easy to Find the Right Clinical Trial for You



Clinical trials are a critical step to determining if an experimental treatment is safe and effective for treating a specific medical condition. But clinical trials aren't possible without you, the patient.

The PFF Clinical Trial Finder, which debuted in January, is intended to help raise awareness of and increase participation in clinical trials, accelerating the development of new treatment options for patients with pulmonary fibrosis.

Until now, finding an appropriate PF clinical trial has been daunting for patients. Information on every current and upcoming U.S. trial is listed on the government website ClinicalTrials.gov, but the site offers little ability to tailor a search. Users have found it difficult to pinpoint trials that meet their specific needs and demographics.

The PFF Clinical Trial Finder allows searchers to filter information from ClinicalTrials.gov by zip code, how far they're willing to travel, age, gender, disease status, and type of trial. There's even a keyword option to further narrow results.

"Clinical trial awareness and participation are a great way for individuals to get involved in research to speed the development of new therapies," says Mike Wenger of Clinical Trial Connect, the company that created the PFF Clinical Trial Finder. "The PFF Clinical Trial Finder makes that process easy."

Clinical Trial Connect has built similar tools for approximately 10 other disease advocacy organizations. Wenger says user feedback from these groups has been positive, especially since his company continually refines its product based on user feedback. "We closely monitor how many results each community is getting to make sure searches are effective and not overwhelming, and we're constantly looking to add more features and functionality," he says.

One feature currently in development is the ability to receive notifications as new trials become available. "That's not available on ClinicalTrials.gov, so users have to keep going back and searching again," Wenger says.

Visit pulmonaryfibrosis-org.clinicaltrialconnect.com to search for a clinical trial that's right for you. For more information, call the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or email pcc@pulmonaryfibrosis.org.

Why Volunteer for a Research Study?

Clinical research studies involve human volunteers to answer specific health questions. They're one of the main ways researchers find out if treatments work. Unfortunately, many research studies are delayed or canceled because not enough volunteers can be found. Joining a study is a meaningful, personal way to further the fight against pulmonary fibrosis.

Clinical research studies take many different forms. Some test a specific therapy, while others gather information to learn more about a disease. Each study looks for a specific type of volunteer, and each requires different amounts of effort from its patients.

You may not qualify for certain studies, but there are lots of options. With approximately 20,000 research studies seeking volunteers in the U.S. at any given time—hundreds of them in pulmonary fibrosis—chances are good that you can find a study that fits you. The PFF's new Clinical Trial Finder can help you discover opportunities that may be right for you (see page 11).

Some things to think about when considering volunteering for clinical research:

- What is the purpose of the study?
- What will you be required to do and how might it affect your day-to-day life?
- How far away are the visits?
- How long will the study last?
- Will it cost you anything to participate?
- What costs will the study cover?

The research study team can answer these questions for you, and you should ask any other questions you may have before you agree to join a study. Researchers are concerned first and foremost with your safety, so their studies are designed with patient safety in mind. Be sure to consult your personal healthcare provider before deciding to join a study.

To learn more, call the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or email pcc@pulmonaryfibrosis.org.



Translating the Terminology of Clinical Research

Interested in participating in a clinical research study, but unfamiliar with some of the terminology you're seeing? Here's some information designed to demystify some common research jargon.

WHAT IS AN INSTITUTIONAL REVIEW BOARD?

The rights and well-being of people who volunteer for clinical research studies are the top priority of researchers. To ensure research is conducted in a safe and ethical way, institutional review boards (IRBs) oversee all clinical research studies. IRBs are panels of research experts—scientists, ethicists, and, often, patients—who review and approve research studies in advance. They have the power to reject studies or make changes they deem necessary to ensure the welfare of research subjects.

IRBs review the study protocol, the informed consent form for potential subjects, and any materials you might receive during the study, including questionnaires to be filled out, advertising about the study, and rules for any financial compensation provided. All of this ensures that no one is coerced into a study, that risks are minimized, and that benefits are worth any risks.

Research studies are also reviewed at least once a year. The IRB can halt a study at any time if it feels subjects' rights are not being well protected.

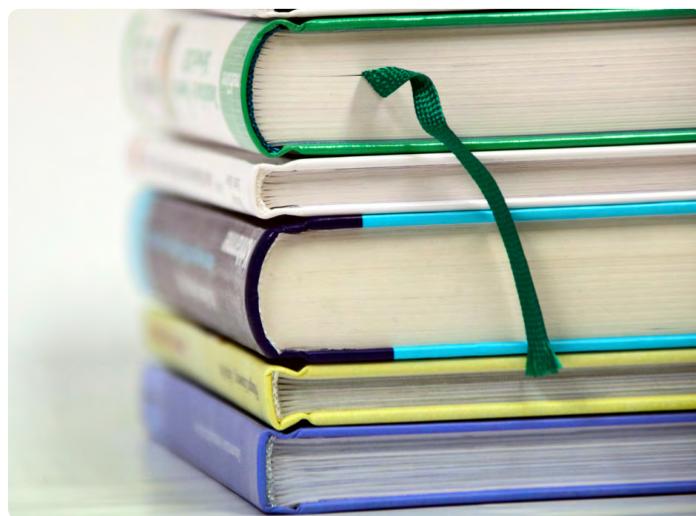
Along with sponsors, investigators, and research staff, IRB members are part of the system working to ensure that participating in research is as safe and valuable as possible.

WHAT IS INFORMED CONSENT?

Informed consent is one of the core principles of clinical research. It means that anyone volunteering to participate in research must agree to do so only after fully understanding their role in the study, including possible risks and benefits.

If you participate in clinical research, you'll need to read and sign an informed consent form describing key aspects of the research, such as:

- Why is the research being done?
- How many people are going to participate in the study?
- What specific tests or procedures will you undergo?
- How long will the study last?
- What are the risks and benefits for you and what other options do you have?



The form should be written in a clear and understandable way, but it can also be very detailed and may sometimes seem overwhelming. In addition to reading the form itself, talk with the research team and ask any questions you have before signing. You can also review the form with your local physicians, friends and family to see what they think about the study.

You should never feel pressure to participate—research is always voluntary. If you change your mind and wish to stop your participation, you can do so at any time. The informed consent process is there to make sure there are no surprises for you during the study.

WHAT DOES “PLACEBO CONTROLLED” MEAN?

Researchers use clinical trials to test the safety and effectiveness of a new treatment. Sometimes this “other” treatment is a proven therapy, but in many cases, the other treatment is an inactive substance called a placebo. A placebo is typically used when there are no known effective therapies for comparison.

A placebo (often called a “sugar pill”) is made to look exactly like the new treatment, but it doesn't affect the human body. Because the treatments appear the same, no one involved in the study knows which one they're receiving. This “blinding” allows researchers to be confident that the effect of the new treatment is not influenced by the knowledge of which treatment you're getting.

When you join a study, you're randomly assigned to the new treatment or to the placebo. Usually, this will be a 50-50 chance, but sometimes a study will be designed to have more than half the people receive the new treatment. You may see a term like “2:1 randomization,” which means two of every three participants will receive the new treatment and one of three will get the placebo.

Manage Your Care While Moving Research Forward with the new PF Health App

Keep track of your symptoms for better disease management, access the latest Pulmonary Fibrosis Foundation news and information, and help move pulmonary fibrosis research forward faster. All with one easy-to-use app.

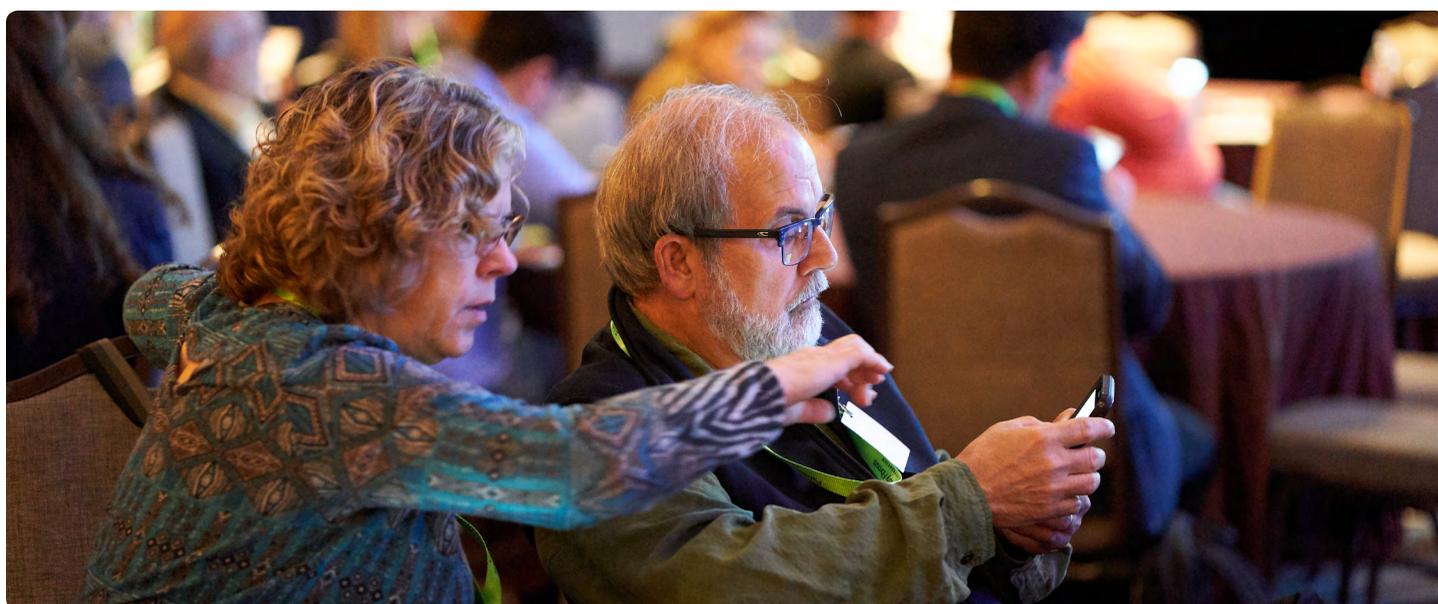
Launched in November 2017, the PF Health app will accelerate clinical trials and research by making it simple for patients with PF to share their de-identified health data with researchers anytime, anywhere. PF Health is in beta (test) version and currently available for iOS only; download the app for your iPhone or iPad from the iTunes App Store. An Android version will be released soon.

PF Health was developed by the PFF in partnership with monARC Bionetworks, whose digital research platform modernizes the clinical trial model by empowering patients to easily share their data and participate in clinical trials. “PF Health users who choose to share their information with the PFF Registry (also see page 10) will supplement the data we have in the registry, creating a much broader pool of information that will help the entire PF community,”

says Rex Edwards, PFF Vice President for the Patient Registry. “Users can also elect to be notified of clinical trials in which they may wish to participate.”

The app also has multiple day-to-day benefits for patients. “Users can track their symptoms, capture measurements like oxygen saturation levels on a regular basis—rather than only during doctor visits—and share that information with their healthcare providers to improve their care package,” says Edwards. PF Health also allows patients to digitize their medical records, making information sharing among a patient’s physicians easier.

Visit pulmonaryfibrosis.org/life-with-pf/pf-health-app to learn more about the app, or to add your name to a list to be notified when the Android version becomes available.



Research: A Priority Across PFF Programs and Initiatives



Research is the key to shortening the time to diagnosis, identifying new treatments, and improving the lives of people living with pulmonary fibrosis. The Pulmonary Fibrosis Foundation funds research through its annual grants to both junior and established PF investigators. The PFF is also interested in partnering with other professional organizations and foundations to offer shared grants that might help to increase the scope and size of awards available for PF.

In addition to direct grants, the thread of research runs through many more PFF programs and initiatives. The biennial *PFF Summit* contains important research elements, from poster presentations to sessions for scientists that delve into current PF research. Even more significantly, the PFF Care Center Network and PFF Patient Registry (also see page 8) together represent a major milestone in the effort to collect detailed patient data and biological samples that will lead to new research discoveries...and, hopefully, an eventual cure.



PFF Research Dollars: A Powerful Return on Investment

Pulmonary Fibrosis Foundation research grants frequently form the seeds of projects that go on to garner more significant research awards sponsored by government and corporations—bringing us ever closer to improved treatments and a potential cure for pulmonary fibrosis.

“PFF research awards help get important studies started and pave the way for larger grants,” says Zoe Bubany, PFF Vice President for Board and External Relations. “We know that almost \$100 million in National Institutes of Health grants are a direct result of PFF awards—and that doesn’t include VA grants, privately sponsored research, and other sources of funding.”

Among recent examples, Jung-whan (Jay) Kim, D.V.M., Ph.D., of the University of Texas at Dallas, is a 2014 recipient of the PFF’s I.M. Rosenzweig Junior Investigator Award who later received an NIH grant totaling more than \$350,000. Data from these studies appear in “Targeting hypoxia-inducible factor-1 α /pyruvate dehydrogenase kinase 1 axis by dichloroacetate suppresses bleomycin-induced pulmonary fibrosis” in the *American Journal of Respiratory Cell and Molecular Biology* in February 2018.

Based on preliminary data from his 2012 PFF Albert Rose Established Investigator Award, the University of California at San Diego’s James S. Hagood, M.D., secured over \$1.8 million in NIH funding for his study. “Thy-1 dependent uptake of mesenchymal stem cell-derived extracellular vesicles blocks myofibroblastic differentiation” appeared in *Scientific Reports* in December 22, 2017.

Jerry Yu, M.D., Ph.D., of the University of Louisville Research Foundation, Kentucky, is a 2016 Albert Rose Established Investigator Award recipient. He received a U.S. Veterans Affairs (VA) Merit Review Award of more than \$1 million to continue his study, data from which appear in “Neuro-immune interaction during development of pulmonary fibrosis” in *Pulmonary and Critical Care Medicine*, 2017.



“I really appreciate the PFF’s support because if I hadn’t had the PFF grant, I would not have been able to secure my current VA Merit Review Award to further examine the neuro-immune mechanisms in the development of pulmonary fibrosis,” Dr. Yu says.

“With the PFF grant support, I was able to address concerns raised by VA grant review panels through the supported experiments. The PFF grant also helped me gain additional publications and presentations, and significantly improved my score on the Merit Review Award. Although the monetary amount was not large, PFF’s support to my research was crucial.”

NEXT RESEARCH GRANT CYCLE UNDERWAY

No matter the time of year, the Pulmonary Fibrosis Foundation is actively supporting important research into pulmonary fibrosis and interstitial lung disease.

The Foundation sponsors two categories of annual research awards: the I.M. Rosenzweig Junior Investigator Award and the Albert Rose Established Investigator Award. The 2018 grant cycle is currently underway. Proposals have been submitted and are being peer reviewed by the Scientific Advisory Committee, which includes a wide-ranging group of international experts.

Normally, the Foundation awards two grants each year in the junior category and two in the established category. Recipients will be announced in the fall 2018 issue of the *Breathe Bulletin*.

Research Report: “Thyroid Hormone as a Novel Therapeutic Agent in Lung Fibrosis”



Created to allow established investigators to explore novel, innovative areas of research, the Pulmonary Fibrosis Foundation’s Albert Rose Established Investigator Award provides critical support to the development of new projects, and enables the investigator to pursue additional funding through the National Institutes of Health

or other agencies. Two \$50,000 grants are awarded per annual cycle, disbursed over a two-year period.

Yale University’s Guoying Yu, Ph.D., a 2016 recipient of an established investigator award, recently shared a 12-month progress report on his research grant.

Though chronic lung diseases are the third leading cause of mortality in the U.S., current therapy mainly relies on short-term drug therapy and lung transplantation with limited sustained clinical benefit. Dr. Yu’s work focuses on a novel approach that might foster healing of the lung. He is able to stimulate healthy growth of cells that line air sacs (alveoli) of the lung. These cells, called alveolar epithelial cells (AECs), could increase the lung’s capacity to undergo self-repair.

However, AEC growth in a diseased lung is frequently handicapped by the abnormal lung tissue in pulmonary fibrosis. Consequently, impaired lung repair often creates excessive scar formation and fibrosis that might inhibit normal cell growth, Dr. Yu says.

“We studied the effect of thyroid hormone administration on the physiology of AECs when these lung cells were exposed to bleomycin—a medication used to treat cancer which has pulmonary toxicity. We showed that thyroid hormone can promote healthy mitochondria (the part of the cells that create energy) and improve healing of injured cells,” he says.

Results of this study were shared in Dr. Yu’s paper “Thyroid hormone inhibits lung fibrosis in mice by improving epithelial mitochondrial function,” published online by Nature Medicine

in December 2017. In the paper, Dr. Yu and his coauthors state, “We conclude that the antifibrotic properties of thyroid hormone are associated with protection of alveolar epithelial cells and restoration of mitochondrial function and that thyroid hormone may thus represent a potential therapy for pulmonary fibrosis.”

Naftali Kaminski, M.D., the Boehringer Ingelheim Endowed Professor of Medicine and Chief of Pulmonary, Critical Care, and Sleep Medicine at Yale School of Medicine, is a coauthor of the paper. A member of the PFF Medical Advisory Board and PFF Scientific Advisory Committee, Dr. Kaminski was the founding director of the Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease at the University of Pittsburgh Medical Center, which he led to national prominence and where Dr. Yu joined his research group in 2006.

A POTENTIALLY VALUABLE THERAPY

Currently, there two drugs, pirfenidone and nintedanib, approved to treat idiopathic pulmonary fibrosis. “Although these two drugs are used widely, neither drug leads to healing of the lung,” Dr. Yu says. Of his team’s recent research efforts, he adds, “One could argue that protection of AECs and increased anti-oxidant activity in the lung through improved mitochondrial function may help stop the vicious cycle that sustains pulmonary fibrosis. The well recognized safety profile of thyroid hormone as well as the possibility of using thyroid hormone as an inhaled therapy make this an appealing approach for future clinical trials in IPF.”

Dr. Yu earned his B.S., M.S., and Ph.D. degrees in the Henan Normal University, Yunnan University, and The Chinese Academy of Sciences in the Peoples’ Republic of China, respectively. After completing his pulmonary research fellow training as part of Dr. Kaminski’s group at the University of Pittsburgh, Dr. Yu moved to Yale in 2013.

He has undertaken basic and translational investigations into idiopathic pulmonary fibrosis. To gain insight into the pathogenesis of IPF, based on gene expression profiling of IPF lungs compared to normal lung, he focuses on the genes that exhibited altered expression in IPF under the rationale that genes likely contribute to the development of pulmonary fibrosis.

“One could argue that protection of AECs and reduction of oxidative stress through improved mitochondrial function may be a key intervention to stop the vicious cycle that sustains pulmonary fibrosis.”

PFF Intensity Survey Results Reach Wider Audience

With support from molecular diagnostics company Veracyte, Inc., the Pulmonary Fibrosis Foundation commissioned the Interstitial Lung Disease (ILD) Patient Diagnostic Journey (INTENSITY) survey in 2015. The survey sought to better understand the steps required for people with these potentially fatal lung diseases to receive a diagnosis, the road blocks that delay diagnosis, and the impact of these diagnostic journeys on patients, their doctors, and the healthcare system.

A pre-specified total of 600 adult U.S. residents with a diagnosis of ILD were recruited to participate in this 40-question online survey. Key findings included:

- Survey participants saw an average of three physicians before receiving a diagnosis; more than a quarter (26%) saw five or more doctors.
- 64% said they agreed or mostly agree that it was “very stressful not to know what was wrong with me.”
- Nearly half of survey participants (45%) underwent surgical lung biopsy—an invasive, expensive, and sometimes painful procedure—as part of their diagnosis.
- Survey respondents reported that the PFF (60%) and their personal physicians (52%) were the two most valuable sources of information about ILD during their diagnostic journey.

Now, detailed findings from the survey have been published in a scholarly paper that will bring the information to a wider audience of health care providers and researchers, leading to improved patient care. “Barriers to timely diagnosis of interstitial lung disease in the real world: the INTENSITY survey,” coauthored by Gregory Cosgrove, M.D., PFF Chief Medical Officer; Pauline Bianchi, R.N., B.S.N., PFF Vice President for Research and Development; Sherry Danese, Vice President, Outcomes Insights; and David Lederer, M.D., PFF Senior Medical Advisor, appeared in *BioMed Central (BMC) Pulmonary Medicine Journal* on January 17 of this year.

“The diagnosis of IPF is challenging for even the most experienced clinicians,” the coauthors write in the introduction to the paper. “Accurate diagnosis requires careful exclusion of alternative etiologies and skillful integration of findings from clinical, radiologic, and pathologic exams. Current diagnostic guidelines define characteristic radiologic and histopathologic features that suggest a diagnosis of IPF; however, high-resolution computed tomography scans and lung biopsies frequently exhibit mixed or

discordant patterns, and findings in patients with IPF and other ILDs are often marked by subtle differences.

“Studies evaluating diagnostic agreement among pulmonologists, radiologists, and pathologists have reported only modest inter-observer agreement, even among expert observers,” the coauthors continue. “Additionally, early diagnosis is further complicated by the insidious onset and nonspecific nature of the initial symptoms, which patients often initially attribute to age or deconditioning, leading to a delay in seeking medical attention.”

The paper includes detailed information on respondent characteristics, their initial presentation of symptoms, common misdiagnoses, timeframe to correct diagnosis, and procedures employed to reach the correct diagnosis. The paper also explores the effects a delayed diagnosis has on patients’ emotional, physical, and financial health, as well as on their personal and professional lives.

“While a minority of patients with ILD will experience an appropriate and expedient diagnosis, the more typical diagnostic experience for individuals with ILD is characterized by considerable delays, frequent misdiagnosis, exposure to costly and invasive diagnostic procedures, and substantial use of healthcare resources,” the coauthors conclude. “These findings suggest a need for physician education, development of clinical practice recommendations, and improved diagnostic tools aimed at improving diagnostic accuracy in patients with ILD.” The PFF Care Center network and Patient Registry was established to provide a foundation to address these important and complex issues affecting each patient and family member affected by PF.



PFF Increases Advocacy Efforts

PFF EXPANDS COMMITMENT TO GOVERNMENT AFFAIRS

The Pulmonary Fibrosis Foundation is taking a stand to spread awareness of pulmonary fibrosis to lawmakers. In November during *PFF Summit 2017*, PFF President & CEO Bill Schmidt announced a new partnership between the PFF and Pulmonary Fibrosis Advocates (PFA).

Since 2010, PF patient Paul Fogelberg and former Congressman Brian Baird have worked through PFA to forge relationships in Washington and educate members of Congress about pulmonary fibrosis. In its eight years of operation, PFA influenced a sharp increase in federal funding for PF research.

“Paul Fogelberg and Congressman Baird have worked tirelessly on behalf of the PF community,” said Schmidt. “We owe them a huge debt of gratitude for their efforts.”

The collaboration between the PFF and PFA reflects the Foundation's increased focus on government relations. Schmidt and Kate Gates, PFF Director of Programs, will spearhead the Foundation's expanded government relations efforts.

Want to join us in our advocacy efforts? Visit pulmonaryfibrosis.org/get-involved/contact-your-legislator to get involved and sign up for advocacy alerts.

RAISING AWARENESS OF RARE DISEASES AND THEIR IMPACT

One in 10 people will live with a rare disease at some point—but no cure is available for the majority of rare diseases, and many go undiagnosed. To raise awareness among the public and key decision-makers about the impact of rare diseases on patients' lives, the Pulmonary Fibrosis Foundation once again participated in Rare Disease Day, held annually on the last day of February, and Rare Disease Week, observed the last week in February.

PFF's Rare Disease Day efforts included a pulmonary fibrosis awareness campaign centered on social media. “We recapped what we've accomplished in our PFF programs over the past few years, encouraging patients, caregivers, and others in the PF community to get involved in the Foundation's initiatives,” says Kate Gates, PFF Director of Programs.

PFF representatives traveled to Washington, D.C., during Rare Disease Week for a three-day program of advocacy for expanded research. After a day of training hosted by the Rare Disease Legislative Advocates and attended by representatives of many patient advocacy organizations, participants spent a lobby day on Capitol Hill meeting individually or in small groups with members of Congress or their aides. On the final day, Brian Baird, a former

U.S. representative and pulmonary fibrosis advocate, moderated a briefing for the Rare Disease Congressional Caucus, hosted by Caucus Co-chair Leonard Lance (R-NJ).

For more information on advocating with the Pulmonary Fibrosis Foundation, please contact Kate Gates at **312.224.9820** or kgates@pulmonaryfibrosis.org.



ABOVE: PFF President and CEO, Bill Schmidt, announced the Foundation's merger with Pulmonary Fibrosis Advocates (PFA) at *PFF Summit 2017*. Pictured: Brian Baird (left), Paul Fogelberg (center), and Bill Schmidt (right).

PFF advocate Doug Jones with Senator Claire McCaskill (MO) and Desiree Mowery, legislative director, for Senator Roy Blunt (MO)

Bringing the PF community together: *PFF Summit 2017*

A record-breaking 895 attendees from 46 states and 12 countries gathered in Nashville for the biennial *PFF Summit*. Patients, caregivers, transplant recipients, those who have lost a loved one, healthcare professionals, researchers, and industry experts all came together to share the latest research, as well as to exchange stories and ideas.

THE PFF SUMMIT 2019 IS GOING TO SAN ANTONIO, TEXAS

We are excited to announce that *PFF Summit 2019* is heading to San Antonio, Texas! The conference will be held at the JW Marriott San Antonio Hill Country Resort from November 7 through 9, 2019. We look forward to bringing the PF community together, surrounded by rolling oak-covered hills and stunning views. Stay tuned for further details at pffsummit.org.

RECORDED SESSIONS NOW AVAILABLE ON YOUTUBE

For those who were unable to join us in Nashville, tune in to our YouTube channel to view more than 70 recorded sessions from *PFF Summit 2017*. Watch the full sessions online for free at youtube.com/c/pulmonaryfibrosisfoundation.

“CAN’T TAKE OUR BREATH AWAY”

With help from Grammy-award winning Kidbilly Music, 50 patients and caregivers at the *PFF Summit* joined together to write a heartwarming song about living with pulmonary fibrosis, which the PF community titled “*Can’t Take Our Breath Away*.” On Friday night during the Networking Dinner, the song debuted live on stage to all conference attendees! To listen to the song and read the lyrics, please visit our YouTube channel.

THANK YOU TO OUR KEYNOTE SPEAKERS

We were honored to have an incredible array of speakers and presentations at the *PFF Summit*, including our keynote speakers:

James Kiley, PhD, National Heart, Lung, and Blood Institute (NHLBI)
“NHLBI Support for Personalized Therapy in IPF”

Gordon Bernard, MD, Vanderbilt University
“Re-thinking Clinical Trials in IPF”

WHAT PFF SUMMIT ATTENDEES ARE SAYING

“From the PFF staff, to the patients, to the doctors, everyone was so upbeat and excited. I liked viewing the abstracts and listening to the doctors explain them.”

“As a patient, I left feeling encouraged about all the efforts made to attack this disease.”

“I really appreciated the ability to go to research [sessions] as well as patient/caregiver lectures. I think this helps with educating oneself with progress in research and to better navigate the disease.”

THANK YOU TO OUR EVEREST SPONSORS



Are you interested in becoming a sponsor for the *PFF Summit 2019*? Contact Jennifer Mefford at jmefford@pulmonaryfibrosis.org or **312.46.4105**.



TOP LEFT:
During the Poster Presentation, researchers explained their latest findings and answered questions.

TOP RIGHT:
At the *PFF Summit*, all attendees were invited to attend any session of interest.

BOTTOM:
You can listen to the studio-recorded version of ‘*Can’t Take Our Breath Away*’ and read the lyrics on our YouTube channel.

Let the World Know: Pulmonary Fibrosis Awareness Month

This September, join the pulmonary fibrosis community to raise awareness across the world for Pulmonary Fibrosis Awareness Month.

As the Pulmonary Fibrosis Foundation prepares for Pulmonary Fibrosis Awareness Month, we encourage you to reach out to family, friends, healthcare professionals, community leaders, and elected officials to help ignite your efforts! For more information about these activities, visit pulmonaryfibrosis.org.

JOIN THE PFF WALK

Our PFF Walk has expanded to include Chicago, New York City, and Washington D.C! The Virtual Walk is also an option for those who want to participate close to their own homes. Read more about the PFF Walk on page 22.

HOST AN EVENT

If you are interested in organizing a walk, golf tournament, bake sale, or any event that showcases your interests, we have the tools to help you get started! To learn how you can start a fundraiser of your very own, download our planning guide at pulmonaryfibrosis.org, or contact Jackie Williams, Development Manager at jwilliams@pulmonaryfibrosis.org or [312.224.4667](tel:312.224.4667).

PORTRAITS OF PF: SHARE YOUR STORY

Many people still do not know the true impact of pulmonary fibrosis. To engage the public, every weekday of September we share a story and photo through our Portraits of PF series on Facebook. The stories provide a positive outlet for patients, caregivers, and loved ones to receive messages of support and connect with others. Send us your story and photo today at socialmedia@pulmonaryfibrosis.org.

#BLUEUP4PF

Our #BlueUp4PF social media campaign has grown phenomenally over the past few years, and participating is fun and easy! All you have to do is wear as much blue as possible (you can even dye your hair or wear a blue wig), snap a photo, and share it with us on social media. Want to take your message further? Download and print our selfie sign!

Many organizations have joined the cause by changing the lights of their locations to shine blue. In 2017, 14 sites ranging from the Willis Tower in Chicago, to City Hall in San Francisco, to Niagara Falls in New York, have joined the cause. Is there a building or landmark that you would like to see “go blue?” With enough advance notice, many buildings will reserve a date in September to #BlueUp4PF. Reach out today!

PROCLAMATIONS

Spread awareness to your community by reaching out to your local officials and ask them to declare September as Pulmonary Fibrosis Awareness Month. Let them know we need funding to improve treatment and find a cure. Last September, we received 17 proclamations from all over the world thanks to the efforts of advocates just like you.



TOP: Kathy Mason Fisher, a PF patient, participated in Portraits of PF by sharing a photo of a new scooter that her family bought for her. Her photo helped spread significant awareness of PF via social media, and she received many positive messages of support.

MIDDLE: Amanda Holzer of New York asked Niagara Falls to go blue (and green!) for PF Awareness Month. Her request was in memory of her grandfather, who passed away from IPF in 2005.

BOTTOM: Phoolio Jen from Honolulu, Hawaii, dyed her hair blue in September in memory of her mother.

The PFF Walk is Back Bigger and Better than Ever!

Mark your calendars for the
PFF Walk 2018!

New York City

Saturday, June 23rd
Central Park

Chicago

Saturday, September 15th
Diversey Harbor

Washington, D.C.

Sunday, October 14th
National Harbor



Register today at PFFWalk.org!

The PFF Walk will kick off in New York City's Central Park on Saturday, June 23. Additional walks will take place in Chicago on Saturday, September 15 and in Washington D.C. on Sunday, October 14. You can also participate virtually and complete your miles at a nearby park or route close to home. There are many ways to join the fun and lead the way toward a cure for PF.

Last year, the inaugural PFF Walk in Chicago raised more than \$230,000 to fund crucial research, increase awareness, and sustain vital programs that help support people with PF and their families. The expansion of the PFF Walk offers an unprecedented opportunity to unite more patients, caregivers, and medical professionals in communities around the country, and provide them with a platform to share their stories with others who have been affected by pulmonary fibrosis.

Meet three families who will participate in the *PFF Walk 2018*.

TERENCE STARTED A WALK FOR PF IN NEW YORK'S CENTRAL PARK THAT WILL KICK-OFF THE FIRST PFF WALK 2018!

Where are you walking?

I am walking in New York City's Central Park. Over the past 10 years, we have grown from a grassroots effort with 20 core supporters to over 350 people strong and raising over \$650,000 to date for this important cause. I look forward to walking with my family, friends, colleagues and supporters from the NYC metropolitan area. Our event has gained national and global exposure via social media over the years. There is strength in numbers and together we can really make a difference!

Why are you walking?

I am walking to help increase awareness of pulmonary fibrosis and to raise much needed funding for research, patient services and support. The walk is a way for those affected by PF to take action against a devastating diagnosis.

How does the PFF Walk inspire you as a member of the PF community?

The PFF Walk is an opportunity for our community to come together to support each other, share stories and experiences.



Would you like to participate in the PFF Walk and/or become a sponsor? For more information or questions, please contact Amy Kozyra by e-mail at akozyra@pulmonaryfibrosis.org or 312.878.2351. Visit us online at PFFWalk.org.

“Build a team, raise funds, and lead the way toward a world without pulmonary fibrosis!”

NITA'S LEADERSHIP WILL HELP THE PFF WALK LAUNCH IN THE WASHINGTON D.C. MARKET.

Where are you walking?

I will walk at the National Harbor in Washington D.C. with Team MollyK family and friends.

Why are you walking?

I will walk to honor the memory of my mom Mradula “Molly” Kalathia (MollyK) who passed away from idiopathic pulmonary fibrosis.

How does the PFF Walk inspire you as a member of the PF community?

The PFF Walk allows those affected by the disease to come together, share our stories, and lend support to one another. We are proud to join the PFF Walk with Team MollyK so that we can expand the reach nationally and continue to support the PF community, build awareness to the general public, and raise funds to help sustain vital programs and research efforts.



SHONA WILL PARTICIPATE IN THE VIRTUAL PFF WALK.

Where are you walking?

We are walking in Wakefield, Mass., just outside of Boston. I am joined by family and friends for my dad Joseph “JP” O’Brien, who died in April 2017. We also have an overseas contingent, a group of family and friends who walk on the same day and time in Tralee, County Kerry in Ireland. It’s been dubbed “Boston & Tralee Walk for JP!”

Why are you walking?

Our family is walking because our Dad was taken from us too soon by this dreadful disease, and raising awareness has become a passion in our family.

How does the PFF Walk inspire you as a member of the PF community?

The PF community is very special to us. We found this organization after we lost our Dad. Though we wish we had the knowledge of this amazing foundation sooner, we have found comfort in connecting with those with a similar story to ours. We also live in fear about who in our family could be next. Being involved in this walk and physically *walking toward a cure* gives us hope.



Meet Jane Nelson and join *Team PFF!*

In the February issue of *Good Housekeeping*, Team PFF Leader Jane Nelson recounted her PF journey from initial symptoms to diagnosis to waiting for and receiving a lung transplant. Diagnosed at age 26, Jane received a life-saving double lung transplant at 29. Below is an excerpt of her story in *Good Housekeeping* (copyright by *Good Housekeeping* February 2018).

"It started with the kind of cough that sounds like you're clearing your throat. "Just cough up whatever's in there," my family would say, annoyed by the noise, that spring of 2011. But it was a dry cough and, according to my doctor, nothing more than allergies or seasonal asthma. Then the cough got worse, and one morning a year later, I woke up with intense pain in my chest. The urgent-care doctor said it was probably pneumonia and if I wanted to be extra careful, I should get an X-ray. I said yes.

Minutes later he rushed back into the room. "The good news is, you don't have pneumonia," he said. "The bad news is, your left lung is 95% collapsed and is balled up like a fist inside your chest." I was rushed to the hospital. Sometimes a person's lung can collapse for no obvious reason, and they didn't see a reason in my case. I had to have surgery to reinflate it.

Then, months later, my right lung collapsed. This time I had a biopsy along with the surgery. When I woke up, one of the doctors told me I had a form of interstitial lung disease, and it turned out to be pulmonary fibrosis, a progressive scarring that leaves people increasingly out of breath and usually kills them within just a few years. "The last time I saw lungs like this, it ended up in a transplant," the doctor told me.

I barely heard his words. I just kept thinking, *No. No. No.*

By then, I was 26 and living in San Francisco. I had moved there to go to culinary school and be close to my boyfriend, whom I'd been dating on and off for six years. But now I was too sick to stay, and in the summer of 2013, I moved back to New York City to be near my family. By October 2014, I was on the waiting list for new lungs. I had read about organ donation, of course, but whoever thinks it will affect him or her personally? I never had."

Read Jane's complete story, "When Both of My Lungs Collapsed, I Relied on a Stranger to Save My Life" in the February 2018 issue of *Good Housekeeping*.

Today, Jane is healthy, living her life to the fullest, and participates in Team PFF. As a Team PFF Leader, Jane gives back to the PF community by hosting an annual fundraising event, "Take a Bite out of Pulmonary Fibrosis" in New York City every spring. The event includes an evening of Southern fare, cocktails, a silent auction, and keynote remarks by a leader in the PF community.

BECOME A TEAM PFF EVENT LEADER LIKE JANE!

Hosting your own fundraising campaign is a great way to get involved and make a difference in the pulmonary fibrosis community. Team PFF Leaders play a crucial role to help us reach our vision of a world without pulmonary fibrosis. We can help you combine your interests and skills to create an event that is unique to you! Events range from dinners like Jane's, to walks, to jeans days, and everything in between.

The Team PFF program is new and improved for 2018! We have expanded our resources to make planning your event easy and successful! Visit our website to read our upgraded **Team PFF Event Leader Guide** and to learn more about how you can lead the way toward a world without pulmonary fibrosis through Team PFF.

For more information and to get started as a Team PFF Event Leader, contact Jackie Williams, Development Manager, at [312.224.4667](tel:312.224.4667) or jwilliams@pulmonaryfibrosis.org

CLOCKWISE, LEFT TO RIGHT:

Attendees at the annual Comedy for a Cause event at Big Tommie's Comedy Club in Novi, Michigan.

Tom Rutledge Memorial Ready, Set, Breathe 5K in Benton, Louisiana.

Jane Nelson was diagnosed with PF at age 26.

“Learn how you can join Team PFF by downloading our new and improved Team PFF Event Leader Guide!”



Sold-Out 'Broadway Belts for PFF!' Breaks Records

The PFF's annual *Broadway Belts for PFF!* raised a record-breaking \$370,000, bringing its eight-year fundraising total to nearly \$1.2 million.

The sold-out event on March 12 featured a star-studded "Sweet 16" revival of the Tony Award-winning musical *Hairspray*. Original cast members came together to honor Margo Lion, a producer and a longtime supporter of *Broadway Belts for PFF!*

The reunion, helmed by its Tony Award-winning composers Marc Shaiman and Scott Wittman, and featuring stunning performances by Andrew Rannells, Harvey Fierstein, Jackie Hoffman, Chester Gregory, Marissa Jaret Winokur and many original *Hairspray* cast members, drew standing ovations from the crowd. Bryan Terrell Clark (*Hamilton*, *Motown: The Musical*), Robert Creighton (*Broadway's Frozen*, *CAGNEY*), Stephanie Gibson (*Charlie and the Chocolate Factory*), Alex Getlin (*Anything Can Happen in the Theater*), and Olivier Award Winner Lesli Margherita (*Broadway's Matilda*, *Dames at Sea*) were among the Broadway greats that graced the stage. New York Yankees legend and Latin Grammy-nominee, Bernie Williams, performed in memory of his father who succumbed to idiopathic pulmonary fibrosis (IPF) in 2001.

The exclusive fundraiser at New York City's Edison Ballroom was hosted by Broadway star and comedienne Julie Halston. As leading advocates for the PFF, Halston and her husband Ralph Howard co-created the event after their friend, Associated Press theater critic Michael Kuchwara, passed away from IPF. Coincidentally, Howard was subsequently diagnosed with IPF and has received a lung transplant.

"Broadway Belts for PFF! has been a labor of love from the start," said Julie Halston. "And through the enormous generosity of the Broadway community we have grown bigger every year to provide resources for pulmonary fibrosis patients and their families."

The benefit was produced for the eighth straight year by D. Michael Dvorchak, Sue Frost (*Memphis*, *Come From Away*), Julie Halston, and Ed Windels. *Broadway Belts for PFF!* was directed by Carl Andress (*The Divine Sister*) with Christopher McGovern (*Cagney*) as Musical Director and Ed Windels as Music Coordinator.

"*Broadway Belts for PFF!* is an extraordinary opportunity for us to raise awareness and funds for pulmonary fibrosis programs and research," said Bill Schmidt, PFF President and CEO. "On behalf of the pulmonary fibrosis community, I am pleased to thank and congratulate Julie Halston and the entire Broadway Belts team for a truly outstanding and memorable event."

A SPECIAL THANK YOU TO OUR SPONSORS WHO MADE THIS EVENT POSSIBLE:

• **Genentech**
A Member of the Roche Group

- Margo Lion
- Gay and Doug Lane Charitable Foundation
- Steffy Family Foundation
- The Ettinger Foundation, Incorporated
-  **Boehringer Ingelheim**
- Goldhirsh-Yellin Family Foundation
- Debby & Rocco Landesman
- David Rockwell
- Daryl & Steven Roth Foundation
- Broadway Cares
- Hales Family Foundation
- Judith Z Friedman
- Jerry & Sis Levin
- Dr. Dan Rose
- Rosenthal Family Foundation
- Icahn School of Medicine at Mount Sinai ILD/Advanced Lung Disease Program Division of Pulmonary, Critical Care, and Sleep Medicine Mount Sinai – National Jewish Health Respiratory Institute
- Kathy Tullis Memorial
- Weill Cornell Division of Pulmonary and Critical Care Medicine
- The Yale Center for Interstitial Lung Diseases, Section of Pulmonary, Critical Care and Sleep Medicine at Yale School of Medicine (a PFF Care Center Network site)



The original cast of Broadway's "Hairspray" reunited for the eighth annual event.

Dancing Toward a Cure: You Did It!

Last fall, we launched our year-end campaign, **Dancing Toward A Cure**, with an ambitious fund-raising goal of \$125,000. We are thrilled to report that **you** blew us away and nearly tripled our goal, raising over **\$300,000!**

We extend a special thank you to everyone that posted social media videos of themselves, friends, and family members **Dancing Toward A Cure**. The variety of dances and dancers provided a great impetus for liking and sharing on our social platforms. We are confident your efforts in this campaign helped raise awareness of the urgency of our battle.

Thank you to the Hales Family Foundation, who generously donated a \$75,000 gift and matched—or tripled—each donation from **you**. Whether you danced, donated, or shared the campaign, your actions resulted in our most successful year-end campaign ever.

We'd like to offer a special note of thanks to Valeria Hatcher, PFF Ambassador and 2017 Fall Appeal spokesperson.

Because of your generosity, we are already putting your donations toward critical research and crucial programs in fighting this devastating disease. We imagine a world without pulmonary fibrosis and we are grateful for your help and for dancing with us toward a cure!

Want to check out some of the PFF Dance Challenge videos? Head on over to our Facebook page to watch the PF community in action. Please keep an eye out for our Spring Appeal!

THANK YOU TO OUR NATIONAL SPONSORS

The PFF Corporate Sponsorship and Foundation Programs are unique opportunities to collaborate with the Foundation to meet corporations' and foundations' goals, objectives, and philanthropic endeavors. The funds donated through this program will assist the Foundation in imagining a world without pulmonary fibrosis.

- AllianceRx Walgreens Prime
- Attwell Family Foundation
- Biogen
- Boehringer Ingelheim
- Genentech, a Member of the Roche Group
- Goldhirsh-Yellin Family Foundation
- Hales Family Foundation
- The Chuck and Monica McQuaid Family Foundation
- monARC Bionetworks
- Steffy Family Foundation

If you would like to learn more about becoming a National Sponsor, contact Jennifer Mefford at jmefford@pulmonaryfibrosis.org.



Nurse-Researcher Wendi Mason, M.S.N., Joins the PFF Board of Directors

Wendi Mason has joined the Pulmonary Fibrosis Foundation Board of Directors. As the Interstitial Lung Disease Program Director at Vanderbilt University, Nashville, Tennessee, Mason brings a combined patient care and research background to the board.

“I’ve been impressed with the way the Foundation’s mission has expanded,” says Mason. “Where it was once a bench research, scientist-based program, it’s now exploded and is the leading advocacy group for pulmonary fibrosis. I’m thrilled to be a part of an organization that’s doing so much for patients.”

Working with James Loyd, M.D., and Lisa Lancaster, M.D., Mason helped build Vanderbilt’s nationally recognized program of excellence marrying the post-diagnosis management needs of IPF patients to a variety of pharmaceutical and government sponsored research programs.

The program serves the seven-state region surrounding Tennessee, actively provides the outpatient healthcare needs of about 400 IPF patients, follows the health of family members of over 550 families with IPF, has nearly 1,000 unique individuals in its pulmonary fibrosis registry, and has participated in more than 50 placebo-controlled or open-label clinical trials.

Besides directing Vanderbilt’s IPF Program, Mason holds a faculty appointment as an Assistant in Medicine through Vanderbilt’s Department of Medicine. Initially employed by Vanderbilt Medical Center in 1994 as a nurse’s assistant, Mason attended Tennessee State University to earn a Bachelor of Science degree in nursing.

She began her work with IPF patients in 2001 as research nurse coordinator for Vanderbilt’s placebo-controlled interferon gamma trial. Mason earned a Master of Science in nursing degree from Vanderbilt and certification as an acute care nurse practitioner in 2003. In addition to her responsibilities in the outpatient setting, she oversees the management responsibilities of the IPF program and research staff.

Mason succeeds Kathleen O. Lindell, PhD, RN, Research Assistant Professor at the University of Pittsburgh School Of Medicine, on the PFF board. She sees her role as bringing a similar perspective based on her direct patient care.

“One of my goals is to be a voice for the patient, and I’m honored to fill Kathy’s shoes,” Mason says.

“Seeing how the Foundation’s work has grown over the last several years, especially with the PFF Care Center Network (CCN) and PFF Patient Registry, I’m excited to be part of this next wave,” she adds. “Research is essential to helping patients with lung disease, improving treatments, and ultimately finding cures. The CCN and Patient Registry will help us into this next phase of pharmaceutical treatment and government funding.”

“The next few years are going to be incredible—if the PFF can stay on the same incline we’ve been on the last several years, there’s no telling what the Foundation will look like then.”

BOTTOM:
Wendi Mason provides a lecture for patients and caregivers, “Diagnosis and Treatment of Comorbidities: Gastroesophageal Reflux Disease (GERD)” at PFF Summit 2017.



PFF Board of Directors Welcomes Longtime Pulmonary Fibrosis Activist Jeff Harris

Jeff Harris, an officer and shareholder of the Chicago law firm of Figliulo & Silverman, P.C., is now a member of the Pulmonary Fibrosis Foundation Board of Directors.

A longtime leader in PF advocacy, Harris is the former chair of the board of the Coalition for Pulmonary Fibrosis, which merged with the PFF in late 2015. His wife Mary D. Harris was one of several members of her family to be diagnosed with PF and passed away in 1997.

“I started a foundation in Mary’s memory, not quite knowing where that would go, but wanting to be involved in doing something about PF,” Harris says. Since his wife had been waiting for a lung transplant, his interest extended to organ donation, so he joined the board of directors of Gift of Hope Organ and Tissue Donor Network at about the same time he helped found the Coalition for Pulmonary Fibrosis. In 2005, he received the Coalition’s Frank Cabral Humanitarian Award in recognition of his contributions to furthering education, patient support, and research regarding the disease.

After the Coalition ceased operations, Harris spent some time thinking about where to center his energies in PF advocacy—and accepted an invitation to join the PFF board. He’s glad to be joining the Foundation at a time of powerful momentum, he says.



“It’s very gratifying to me to have seen the incredible progress made over the last 20 years in the fight against PF,” Harris explains. “Whether you’re talking about public and patient awareness, patient advocacy, physician education, legislative progress, research, or approval of new drug therapies, I know how far everybody has come.”

“We’re light years from where we were. There’s still a long way to go, but looking back at what we did in 20 years, what can we accomplish in the next five?”

Harris’s business litigation practice of nearly 40 years includes matters relating to construction, commercial real estate, corporate and partnership disputes, professional liability, and fiduciary duties. He is also president of the Mary D. Harris Memorial Foundation, current member and former chair of the board of Gift of Hope, and vice president of LAH Oil, Inc.

The PFF Patient Registry provides a potential solution to a problem the PFF and Coalition both identified from the beginning: lack of sufficient, shared data with which to conduct studies, says Harris. “This truly

could be a breakthrough development,” he notes.

“The idea of helping to shape that and everything else the PFF is doing to advance the ball is exciting to me. The level of progress is exhilarating, and as things happen more quickly, it creates the potential for more positive developments to unfold. I’m pleased to be part of getting this organization to the next stage.”

Harris received his undergraduate degree from Miami University in Oxford, Ohio, and his J.D. degree from Washington and Lee University in Lexington, Virginia.

ABOVE: Jeff Harris and his wife Jennifer attended a networking dinner with PF Advocate and NFL Running Back, Jordan Howard.



Calendar

Attending or supporting an event is a great way to get involved and learn more about the Pulmonary Fibrosis Foundation's programs and services, to educate yourself and others about pulmonary fibrosis, and to connect with other PF advocates.

The PFF's event calendar is updated regularly. To view the most current event listing, please visit our website at pulmonaryfibrosis.org/get-involved/attend-an-event.

JUNE 21

PFF Voices

Call-in number: 1-571-317-3116

Access code: 124-558-453

JUNE 23

PFF Walk - NYC

Central Park, New York City

JUNE 28

Just Breathe for Pulmonary Fibrosis

Miami, Florida

AUGUST 10

3rd Annual Tee It Up with Twisters Golf Outing

Bath, Michigan

AUGUST 16

PFF Voices

Call-in number: 1-571-317-3116

Access code: 124-558-453

JULY 28

Roger Kirk Memorial Car Show and Shine

Royston, Georgia

SEPTEMBER

Pulmonary Fibrosis Awareness Month

Nationwide

SEPTEMBER 15

PFF Walk - Chicago

Diversey Harbor, Chicago

SEPTEMBER 25

Inova Fairfax PF Education Day

Fairfax, Virginia

OCTOBER 14

PFF Walk - Washington, D.C.

National Harbor, Washington D.C.

OCTOBER 20

Cosmic Bowling in Memory of Greg Yamanaka

Aiea, Hawaii



Attendees of the Second Annual Violet Rippy Memorial Lecture, Pulmonary Fibrosis: Past, Present, and Future on February 12 at UPMC. David Lederer, MD, MS, was the presenter.

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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.



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