

PULMONARY FIBROSIS FOUNDATION

breathe

WINTER 2023



PFFWALK

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OUR MISSION

The mission of the Pulmonary Fibrosis Foundation is to accelerate the development of new treatments and ultimately a cure for pulmonary fibrosis. Until this goal is achieved, the PFF is committed to advancing improved care of patients with PF and providing unequalled support and education resources for patients, caregivers, family members, and health care providers.

The Pulmonary Fibrosis Foundation rates among top charities in the U.S. The PFF has a three-star rating from Charity Navigator and is an accredited charity by the Better Business Bureau (BBB) Wise Giving Alliance. The Foundation has met all of the requirements of the National Health Council Standards of Excellence Certification Program®, and has earned the Candid Platinum Seal of Transparency.



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Pulmonary Fibrosis Foundation

230 East Ohio Street, Suite 500
Chicago, Illinois 60611
844.TalkPFF (844.825.5733)

pulmonaryfibrosis.org

Letter from Our President and CEO

DEAR FRIENDS,

As we all adapt to life in the “new normal” nearly three years into the COVID-19 pandemic, the Pulmonary Fibrosis Foundation (PFF) has much good news to report.

First, the PFF Community Registry is now open and enrolling participants. The new Registry’s primary goal is to address various issues in pulmonary fibrosis (PF) and interstitial lung disease (ILD) to improve diagnosis, care, and outcomes in the patients, caregivers, and family members who are affected by it. For the first time, caregivers and family members of living or deceased patients, and lung transplant recipients who have had PF or ILD, can join along with people currently living with this illness.

Additionally, our recent advocacy efforts have paid off as Congress once again adopted our recommendations for language about the importance of PF research in the report accompanying the Fiscal Year 2023 funding bill for the National Institutes of Health. The fact that they include our language shows that Congress recognizes the importance of PF-related research.

One of the most welcome aspects of 2022 was the return to a fully in-person season of six PFF Walks and a virtual National Walk Day. From spring through fall, the Walks supported the PFF’s mission while raising funds and providing an opportunity to connect with others in the PF community.

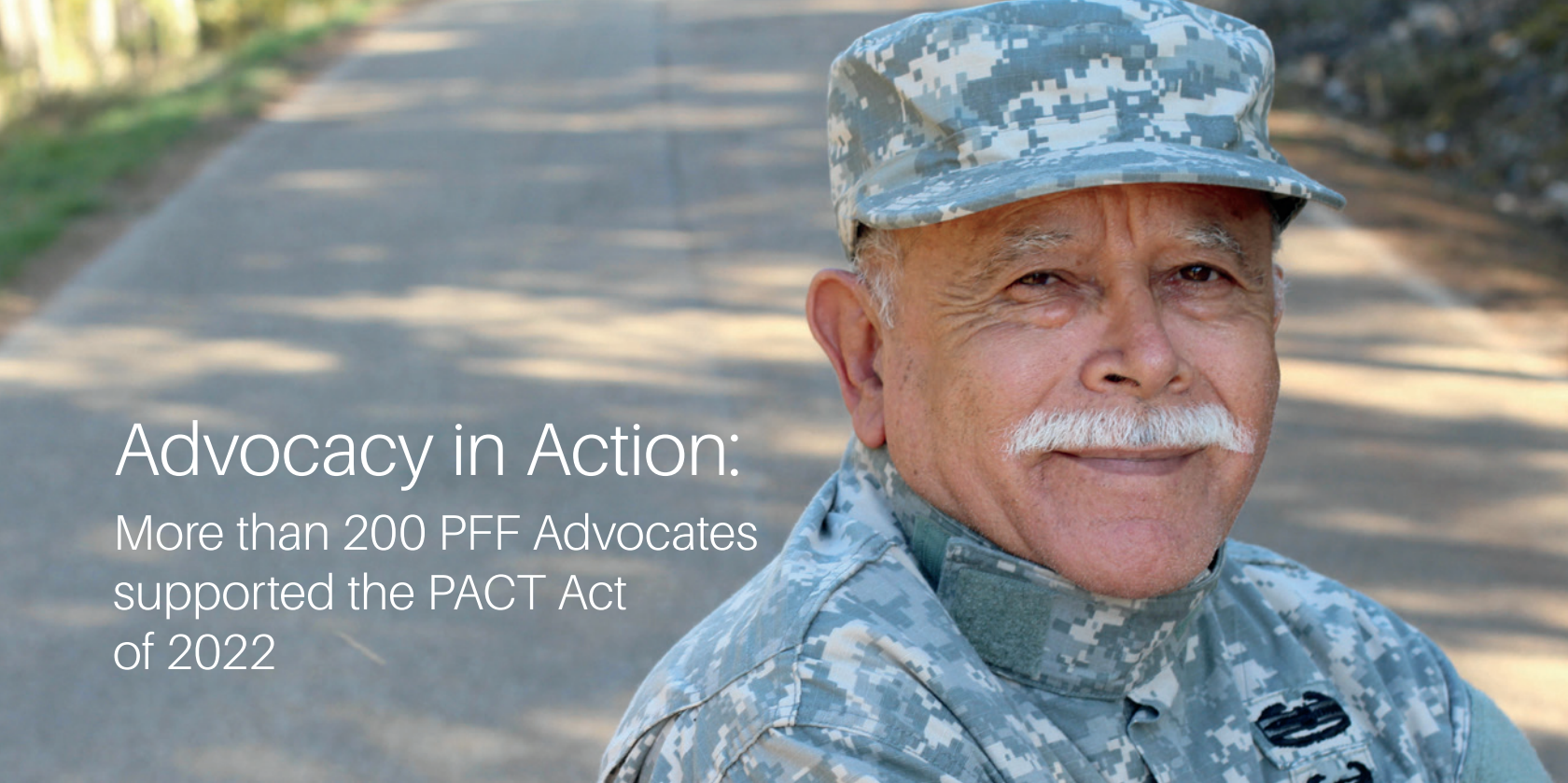
And as usual, Pulmonary Fibrosis Awareness Month (PFAM) in September was a highlight of our year.

None of this progress would have been possible without the unwavering loyalty of the PF community. If you’re able, please support the PFF with a financial gift. And remember: Now people from throughout the PF and ILD community can share their experiences with researchers via the new PFF Community Registry. **Participation is easy, and I encourage all eligible community members to enroll at pffregistry.org.**



William T. Schmidt
PRESIDENT AND CHIEF EXECUTIVE OFFICER





Advocacy in Action:

More than 200 PFF Advocates supported the PACT Act of 2022

Last August, President Joe Biden signed the Promise to Address Comprehensive Toxics Act (PACT Act) into law.

This is especially significant because some service members who were exposed to burn pits during their service may develop PF or ILD. Previously, it was the veteran's responsibility to prove their illness was connected to their military exposure and Veterans Affairs (VA) denied a majority of claims, citing a lack of evidence.

The PACT Act of 2022, which has been called the most significant expansion of benefits and services for toxic-exposed veterans in 30 years, will remove this burden. Veterans will now be allowed to simply provide information

on their deployment. They will also need to document their qualifying health condition, including PF and ILD. This change will expand the eligibility to health care benefits and disability benefits for service members with PF and ILD who have been exposed to burn pits or had other toxic exposures.

More than 200 PFF Advocates reached out to their members of Congress to ask them to support this bill. "The outreach made by our advocates helped bring the needed attention to this legislation," says Jamie Hillner, PFF Manager, Volunteer Programs and Advocacy. "This new law will provide service members with PF and ILD the health care benefits and access to disability support that they have had to previously work so diligently to qualify for."

PFF Advocates Increase Awareness of Need for PF Research

During PFF Hill Day in March, PFF Advocates successfully requested that Congress include language about the need for PF research in their annual funding report. This helps ensure that PF research is prioritized at the National Heart, Lung, and Blood Institute (NHLBI) — the nation's largest funder of PF research.

"Pulmonary Fibrosis (PF) — Many PF patients wait more than a year for diagnosis after symptom onset, and patients with some types of PF have a life expectancy of only 3-5 years. The Committee urges NHLBI to support

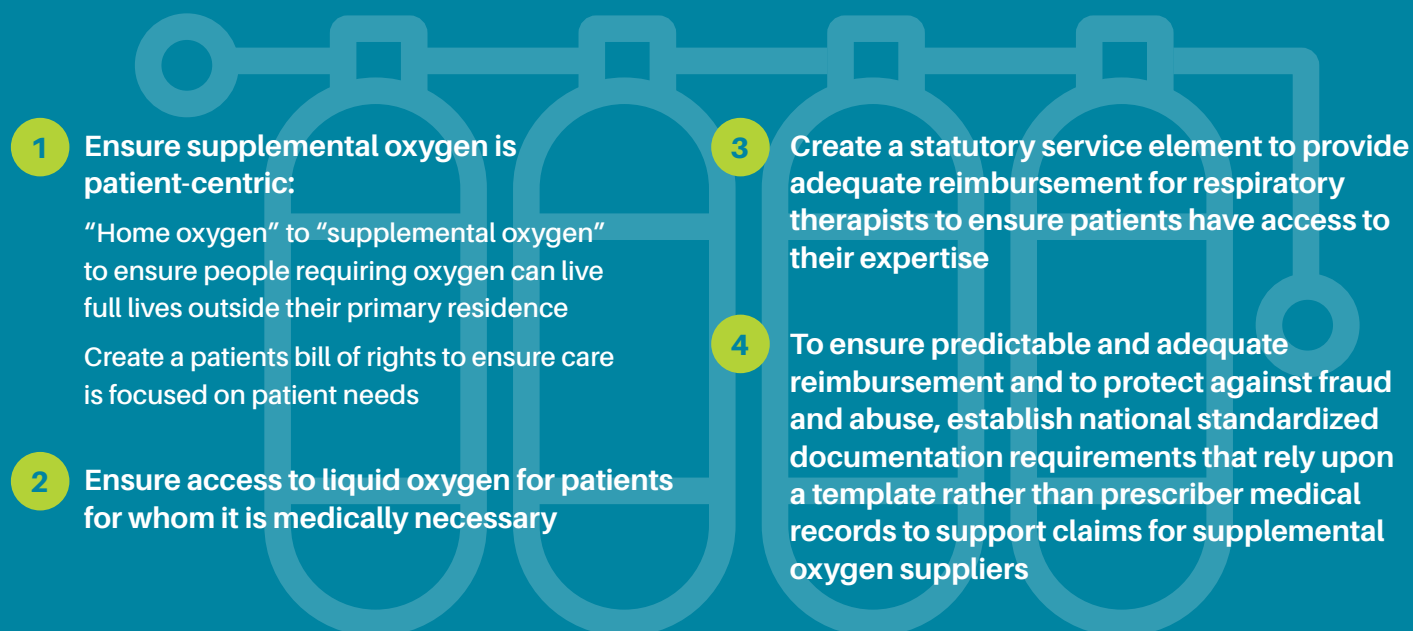
research into biomarkers that can aid in earlier, safer diagnosis of pulmonary fibrosis, as well as tools that can help predict which patients will experience disease progression. The Committee also encourages NHLBI to support the development of novel outcome measures for clinical trials in pulmonary fibrosis, such as imaging, and to continue to fund research involving early phase clinical assessment of novel drugs and personalized approaches to therapies. The Committee requests an update on PF research in the fiscal year 2024 Congressional Justification."

Oxygen Advocacy Builds Momentum

Four Pillars for Oxygen Reform

At the PFF, we believe that the Centers for Medicare and Medicaid Services (CMS) should ensure anyone who requires supplemental oxygen can access the most appropriate type of oxygen for their needs. That's why we have joined with the American Lung Association, the American Thoracic Society, the American Association for Respiratory Care, and many other organizations to urge Congress and CMS to update their oxygen policies.

Together, we have created the Four Pillars for Oxygen Reform. These are consensus principles that will form the basis of our legislative reform efforts:



"There is a lot of work to be done to improve patients' access to necessary oxygen equipment and supplies," explains Kate Gates, PFF Vice President, Advocacy and Programs. "Half of patients with PF report that they have problems with their oxygen, such as receiving incorrect equipment. These Pillars are an important step toward a community-wide effort to implement new policies that will allow patients to receive the oxygen they need."

How You Can Help

Sign the petition in support of the Four Pillars for Oxygen Reform at pulmonaryfibrosis.org/advocacy.

Note: This petition is only for individuals who use supplemental oxygen or used supplemental oxygen before a lung transplant, their caregivers, and their loved ones who live in the United States.

Learn About PF Directly From the Experts In Our Webinar Series



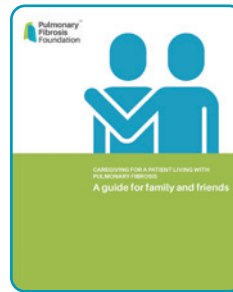
Want to learn about ILD directly from the experts? Tune in to the Disease Education Webinar Series! This series provides a free, convenient way for patients, caregivers, and families to

learn from PF specialists on a variety of important topics. The 60-minute presentations can be viewed from the comfort of your home.

The PFF hosts at least six webinar broadcasts per year featuring presentations by a combination of pulmonologists and other health professionals like nurses, respiratory therapists, and rheumatologists. In 2022, webinars covered topics including *What is Pulmonary Fibrosis? An Overview*; *Financial Assistance for PF Medications*; *Demystifying the Role of Palliative Care in Pulmonary Fibrosis*; and more.

After each webinar, attendees can provide their feedback on the webinar and share ideas for future topics in a post-webinar survey. Each presentation is recorded and posted on both the PFF website and YouTube page so that the community can watch them on their own time or share them with a relative or friend. For announcements about upcoming webinars, join our email list at pulmonaryfibrosis.org/newsletter, or follow us on social media on Facebook, Instagram, and Twitter at [@pfforg](https://twitter.com/pfforg).

New! Caregiving: A Guide for Family and Friends



The Pulmonary Fibrosis Foundation recently unveiled a new education resource dedicated to caregivers of patients with pulmonary fibrosis to help educate and empower them on their caregiving journey. Caregiving for a patient with pulmonary fibrosis can be a substantial responsibility, and caregivers often find themselves thrust into this new role with little

notice or training. Caregivers take on many different roles and are responsible for myriad tasks, ranging from household responsibilities to hands-on care.

Caregiving for a Patient Living with Pulmonary Fibrosis: A Guide for Family and Friends discusses caregiving basics, organization tips, safety reminders, and more. Several experienced pulmonary fibrosis caregivers are featured throughout the piece in vignettes, sharing bits and pieces of their unique caregiving experiences. This resource also provides additional tools and resources for caregiver support. To order a hard copy of this material, call the PFF Help Center at **844.TalkPFF** or email help@pulmonaryfibrosis.org.

Thank you to our generous sponsors, Boehringer Ingelheim and Genentech, A Member of the Roche Group, for their support of the Pulmonary Fibrosis Foundation's educational materials and resources.



Clinical Trial Finder Launches New Improvements to Help Patients Navigate with Ease

The Foundation has launched two brand new features for the PFF Clinical Trial Finder: account creation and Clinical Trial Navigators.

Available now, users can create an account and request assistance from Clinical Trial Navigators. Creating an account allows you to save your questionnaire responses to come back and review your matched studies later or update your responses. Additionally, you receive the option to sign up for emails about new matches and other relevant research updates.

Once you create an account, you can request assistance from Clinical Trial Navigators. Navigators are available 9:00 a.m. - 5:00 p.m. ET to help you search for clinical studies, complete your Match Questionnaire, or connect you directly to a trial site location.

The information displayed within our Finder is sourced directly from ClinicalTrials.gov and is presented in an easy-to-understand format. Both interventional studies and observational studies are included. Interventional studies are when a treatment is being studied, such as a drug, device, or procedure. Observational studies are those where participants are assessed and followed, such as the PFF Community Registry.

The Finder includes studies for a variety of conditions, such as idiopathic pulmonary fibrosis, connective tissue disease related interstitial lung disease, lung transplant complications, and conditions commonly related to ILD, such as chronic cough and pulmonary hypertension.

To get started and find clinical trials that might be relevant for you, visit trials.pulmonaryfibrosis.org. For questions, email partnerships@pulmonaryfibrosis.org.

The Class of 2022 PFF Ambassadors Leans into Hope and Helping Others



The PFF's new class of Ambassadors come from different parts of the U.S. and have a range of experiences with the disease, but when faced with PF, one thing remains clear — utilizing the PFF's resources transformed their approach to the diagnosis and helped them learn to live with PF.

PFF Ambassadors are trained volunteers who help the Foundation raise awareness of the disease by sharing their personal stories with groups across the country. They are compelled to support others by directing them to the PFF's resources and explaining the many ways community members can get involved in advocacy, events, research, and more. This year's class of 19 PFF Ambassadors includes nine patients, five lung transplant recipients, one caregiver, and four individuals who have lost a loved one.

"Never give in and never give up" are among the recurring themes from the class of 2022. They encourage newly diagnosed patients and their loved ones to learn as much as possible about PF and use this knowledge to empower themselves. While a diagnosis of PF is devastating, they urge patients to be present and live their lives to the fullest. The journey is different for everyone and having support is crucial.

PFF staff are seeking opportunities to introduce these dynamic volunteers to patients, healthcare providers, and others interested in learning about living with PF. For more information on the PFF Ambassador program or to request a PFF Ambassador for your next event, contact the PFF Help Center at **844.TalkPFF** (844.825.5733) or email help@pulmonaryfibrosis.org.

The PFF is grateful to all of our 2022 PFF Ambassadors and their efforts to raise awareness and support others on this difficult journey. Keep your eye out for stories about members of the Class of 2022 PFF Ambassadors throughout the year.

The Inaugural PFF Education Symposium Brings the Community Together



The inaugural PFF Education Symposium, held November 3 and 4, 2022, allowed patients, caregivers, and families around the country to connect with each other and learn from healthcare providers.

We listened to feedback from our PF community, whose participation at our biennial Summit has increased steadily over the years. This year's Education Symposium was open to the public, and we were delighted to have more than 400 registrants. The program included two Clinical Trials Innovation Series sessions, and attendees were able to meet representatives of presenting companies in the exhibit hall that accompanied the virtual conference platform. Patient and caregiver focused sessions were moderated and led by our PFF staff and medical team. Sessions included Pulmonary Fibrosis 101, separate roundtables for patients and caregivers, and an all community networking event.

Thank you to our Sponsors and Exhibitors



Accredo
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PFF Registry
PFF Care Center Network
University of Colorado -
APPLE

THE CLINICAL TRIALS INNOVATION SERIES: A Unique Look At Potential New Treatments In Development

The goal of the Clinical Trials Innovation (CTI) Series is to provide an overview and update on the research and development of innovative therapies to improve the lives of those living with pulmonary fibrosis and related conditions. The CTI Series took place at noon on Thursday, November 3rd and Friday, November 4th. Attendees heard presentations from sponsors Boehringer Ingelheim, CSL, Genentech, Horizon Therapeutics, and PureTech Health regarding their various Phase 2 and Phase 3 clinical studies in interstitial lung diseases.

In addition, attendees enjoyed presentations on the following academic and organization-led clinical studies: Advancing Prevention of Pulmonary Fibrosis (APPLE) by Dr. David Schwartz; the PFF Community Registry by Junelle Speller; and Prospective Treatment Efficacy in IPF Using Genotype for Nac Selection (PRECISIONS) by Dr. Imre Noth. The presentations are available now on the PFF's YouTube channel. Hurry, the sessions are only available for a limited time!





PFF SCHOLAR PUBLISHES NEW STUDY ON AGENT ORANGE AND IPF

Current PFF Scholar **Bhavika Kaul, MD, MAS**, has published a new study on whether presumed exposure to the wartime toxin Agent Orange is associated with

an increased risk of idiopathic pulmonary fibrosis (IPF) among a national cohort of U.S. veterans who served in the Vietnam War. In May, "Agent Orange Exposure and Risk of Idiopathic Pulmonary Fibrosis Among U.S. Veterans" appeared in the peer-reviewed American Journal of Respiratory and Critical Care Medicine.

Dr. Kaul examined the records from nearly 3.6 million veterans who served in Vietnam and received healthcare at a Veterans Administration (VA) facility between 2010 and 2019. She found that 950,000 veterans may have been exposed to the chemical defoliant Agent Orange during their service.

Dr. Kaul and her coauthors found that veterans who had been exposed to Agent Orange may have a slightly greater risk of developing IPF than those who were not exposed. Exposure to Agent Orange was associated with an 8% higher risk of IPF after Dr. Kaul adjusted for age, race, ethnicity, smoking history, and rural residence.

"This study is the first to identify a possible epidemiological association between Agent Orange and an increased risk of IPF in exposed veterans," says Dr. Kaul, an Assistant Professor at Baylor College of Medicine in Houston. "This study reinforces the need for future research to examine the role of exposures in the development of fibrotic lung diseases."

NIH FUNDS TWO NEW ILD-RELATED STUDIES

The National Heart, Lung, and Blood Institute at the National Institutes of Health (NIH) recently awarded funding to two promising studies that focus on interstitial lung disease.



David A. Schwartz, MD, Distinguished Professor of Medicine at the University of Colorado, is leading a study on familial pulmonary fibrosis. "We are actively recruiting first-degree relatives in families with two or more cases of PF who are not known to have the disease. In this study, participants

will be screened using imaging, surveys, and collection of biosamples such as blood," says co-investigator Joyce Lee, MD, MAS, a PFF Senior Medical Advisor. "We are trying to understand their risk for disease by studying the genetic and environmental interactions that lead to disease."



Additionally, **Augustine M.K. Choi, MD**, the Dean of Weill Cornell Medical College, is heading a study that will examine the biological pathways associated with PF and emphysema. The goal is to understand the similarities and differences between these diseases.

One reason the NIH funded this study is the planned use of biosamples from the PFF Patient Registry, which highlights the many positive collaborations between the PFF, the NIH, and leading investigators.



PFF SUMMIT 2023: WE'RE GOING TO ORLANDO!

Mark your calendars for the PFF Summit 2023 to be held at the lovely JW Marriott Grande Lakes Resort in Orlando November 9-11, 2023. Those who attended our last in-person Summit will appreciate this sister property to the JW Marriott Hill Country Resort in San Antonio. Located on a lush, 500 acre property with spacious facilities both indoors and outdoors, we are planning another stellar opportunity to bring the PF community together to learn, grow, and share together.

PFF Research Advances with PFF Scholars

Early-career researchers are assisted by the PFF Scholars program with highly competitive two-year research grants. The intention is to provide investigators with the necessary skills to eventually secure funding from the National Institutes of Health (NIH) and other esteemed independent sources. Applicants may include the use of PFF Registry data in their proposals and all awardees are provided with professional mentorship separate from their primary mentor at their home institutions.



LUIS RODRIGUEZ, PHD
University of Pennsylvania

TITLE: "Metabolic Dysfunction and Epigenetic Reprogramming in Distal Alveolar Epithelial Progenitor Cell Function and IPF"

Funded by Boehringer Ingelheim Pharmaceuticals, Inc.

The lung has an incredible ability to regenerate after injury. When the lining of the lung, made of alveolar type one cells (AT1s), gets damaged, alveolar type two cells (AT2s) act as progenitors, replicating and differentiating into flat AT1s that are essential for breathing. In pulmonary fibrosis, the emerging consensus is that dysfunction begins in the alveolar epithelium and spreads through the lung initiating remodeling and fibrosis. For his PFF-funded research, Rodriguez will study how dysfunctional metabolism results in impaired differentiation of the AT2 into the AT1. Using a novel genetic mouse model, Rodriguez will explore how metabolic disruption of AT2-AT1 transition results in accumulation of an intermediate cell that further exacerbates the fibrotic process. His preliminary data suggests that if you can correct the metabolic defect, you can revert the AT2 back to its normal biology. "There are drugs and therapeutics already on the market that target metabolism, but they haven't been applied to pulmonary fibrosis," Rodriguez says. "There is a lot of potential here."



CATHRYN LEE, MD, MS
University of Chicago

TITLE: "Identifying the Impact of Workplace Exposures on Quality of Life, Lung Function, and Survival Across Interstitial Lung Disease"

Funded by Boehringer Ingelheim Pharmaceuticals, Inc.

As there is no known cure for pulmonary fibrosis or interstitial lung disease, the importance of research into preventing specific causes cannot be overstated. Lee's PFF-funded research revolves around occupational exposures related to PF and ILD. In her study, she will use implementation science strategies to better understand the circumstances surrounding occupational exposures in ILD patients and whether these exposures are related to quality of life. Additionally, she will employ advanced machine learning techniques to cluster co-exposures together into groups to find which occupations are associated with worse lung function and survival. Her early data has shown how prevalent environmental exposures are in ILD patients and that two-thirds of the population have some sort of occupational or domestic exposure that could potentially contribute to the underlying disease process. "It's hard to know what occurs at the workplace without being present ourselves," says Lee. "But comprehensive surveys are the first step towards elucidating these relationships. We aren't going to know about these connections unless we start asking about them - both on the research level and patient level."



GENTA ISHIKAWA, MD, MPH
Yale University

TITLE: "Neuro-innate Interactions in Pulmonary Fibrosis"

Funded by Chuck and Monica McQuaid Family Foundation, and the Jenny H. Krauss and Otto F. Krauss Charitable Foundation Trust, in memory of Stephen N. Dirks

Although there are therapies and drugs to slow the progression of idiopathic pulmonary fibrosis (IPF), there is still research and work to be done to improve treatment and medicine options. Ishikawa's PFF-funded research will look to find an innovative route to block the fibrotic pathway by examining the interactions between nerves in the lungs and fibrosis. His group found that sympathetic nerves seem to grow into fibrotic lung regions where they participate in scar formation by releasing a neurotransmitter called noradrenaline. He will test his hypothesis that noradrenaline interacts with lung immune cells called macrophages, altering them to pro-fibrotic subtypes which facilitate fibrotic response. "If we can explain the interaction between nerve-derived noradrenaline and macrophages leading to lung fibrosis, we can repurpose medications the FDA has already approved for treatment of other conditions," says Ishikawa. "The hope for the research is for it to progress and become a better treatment option or possibly cure IPF."



ALISON DEDENT, MD
University of California San Francisco

TITLE: "Development of a Telehealth Intervention Targeting Barriers to Early Guideline-Concordant Idiopathic Pulmonary Fibrosis Care for Rural Populations"

Funded by Nelda Hagaman

For individuals living with pulmonary fibrosis, having access to quality health care is vital for early identification and treatment of the disease. DeDent's PFF-funded research focuses on identifying, understanding, and addressing health disparities within the pulmonary fibrosis community. The primary focus of the study is exploring geographic disparities for rural populations affected by pulmonary fibrosis, with one portion of the study being an expansion of prior research around geographic disparities and the other portion centered around understanding how to expand access to care earlier in the disease course. DeDent will conduct interviews with patients in rural areas to explore the barriers that prevent them from receiving care and develop a strategy using telehealth to target those barriers based on her research and patient input. She will then test her strategies to find if they are effective. "This research is important because pulmonary fibrosis is a rare disease, and specialty care can be limited in rural areas. This proposal will focus on exploring mechanisms to deliver equitable PF care directly into rural communities."

THE PFF SCHOLARS PROGRAM GROWS STRONGER THIS YEAR

The 2023 class of PFF Scholars will each receive a \$100,000 research grant over a two-year period, an increase of \$25,000 per scholar. Our PFF Scholars will be tomorrow's leaders in the field of pulmonary fibrosis research. We are pleased to increase our support of their vital research that will shed light on some of the most pressing questions we have about PF. Expansion of the program has been made possible by private donations to the PFF.

RESEARCH REVIEW COMMITTEE

The PFF is pleased to announce that Beth Moore, PhD from the University of Michigan has been appointed Chair of the PFF Research Review Committee (RRC). Mitchell Olman, MD from the Cleveland Clinic has been appointed Vice Chair. Both will serve two year terms that began in October 2022. We want to thank Drs. Moore and Olman for their service, and to Michael F. Beers, MD from the University of Pennsylvania for his service as Chair of the RRC for the last two years.

The PFF Community Registry is Here!

The PFF's overarching priorities remain as ambitious as ever: faster and more accurate diagnoses, better treatments, and a cure for pulmonary fibrosis and other interstitial lung diseases. We believe that more research will help us reach these goals. The PFF Registry is the most efficient tool we have for providing researchers the data they need.



The PFF Registry includes the PFF Patient Registry and the new PFF Community Registry. The primary difference between the two registries is the source of the data. The PFF Patient Registry has collected physician-reported data for 2,000 patients at participating PFF Care Centers across the U.S. since 2016. Although the PFF Patient Registry is closed for enrollment, researchers have been able to use the data to produce new findings about the disease.

Launched in July, the PFF Community Registry is open for your participation! This registry relies on ongoing data reported by participants through online surveys. There is no limit to the number of participants who can join the PFF Community Registry.

The new PFF Community Registry is now enrolling participants, and we need your help.

Many people believe that only patients can sign up and take part in registries. At the PFF, we know that serious illnesses like PF and ILD affect caregivers and family members, too. That's why we're spreading the word: Patients diagnosed with PF or ILD, caregivers and family members of patients, including those who have passed away, and lung transplant recipients who have had PF or ILD, are invited to sign up for the PFF Community Registry. You can make a difference by participating in PF research.




Here's How to Participate

Once enrolled, PFF Community Registry participants will receive one survey every six months. Each survey takes about an hour to complete and doesn't need to be completed in a single sitting. Just save your answers, then return later to finish!



Be Part of Something Special!

You can join the PFF Community Registry if you fall into one or more of these categories:

-  **Patient diagnosed with PF or ILD**
-  **Lung transplant recipient who has had PF or ILD**
-  **Caregiver and/or biological family member (parent, child, full/half sibling) of patient with PF or ILD, including those who have passed away**

Participants must be 18 or older and live in the U.S.

Caregivers and family members who have lost a loved one are invited to participate. Your valuable insights will help medical research. **Sign up today at pffregistry.org!**

Here's what you need to know:

- Visit pffregistry.org to join and later access the PFF Community Registry online portal.
- Share only the information you're comfortable sharing. How much information you provide is up to you.
- Relax knowing the PFF Community Registry database is highly secure, using the same technology trusted by doctor's offices, hospitals, and clinical trials worldwide.

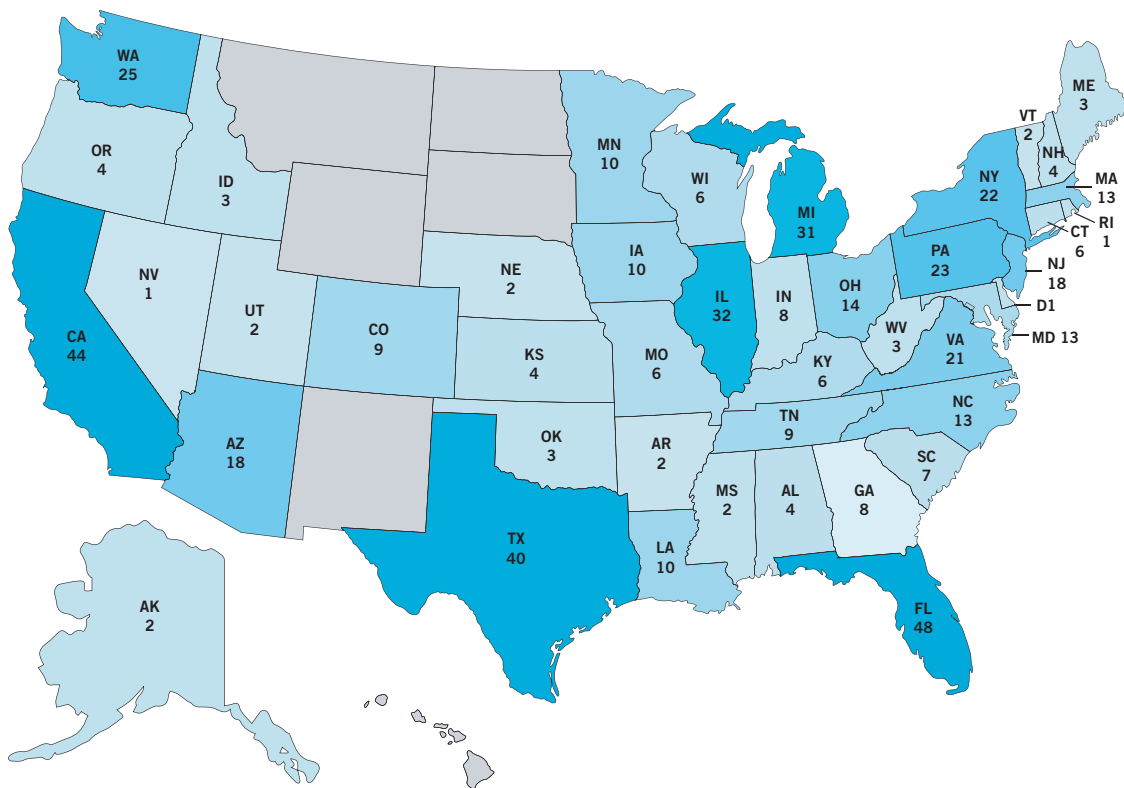
With your participation, we can fast-forward medical research and improve the lives of patients with PF and ILD and their families, for today's and future generations.

Help Us Turn the Map PFF Blue!

In just one month, we enrolled 455 individuals in 40+ states! The sky is the limit: the PFF Community Registry has room for everyone affected by PF and ILD, so enroll today.



NUMBER OF PATIENTS IN THE COMMUNITY REGISTRY BY STATE



PFF Scholars: Dr. Gillian Goobie Publishes Air Pollution Study



Shortly after Gillian Goobie, MD, completed her two-year term award period as a PFF Scholar, she achieved a longtime goal: publication of her research analyzing how exposure to airborne pollutants over time affects clinical outcomes in patients with fibrotic ILDs. The article was published in JAMA

Internal Medicine online in October 2022.

Dr. Goobie, while at the University of Pittsburgh, cross-referenced satellite-based pollution data with medical data from 6,500 patients with ILD, including 1,800 in the PFF Patient Registry. In addition to receiving financial support and mentorship separate from their primary mentor, applicants may include the use of PFF Registry data in their proposals. . "The PFF Patient Registry played a huge part in making this research successful," she says.

What Are Your Local Air Pollutants?

Dr. Goobie tracked how patients with ILD did in terms of lung function decline, exacerbations, and mortality. Then, she put that information in the context of annualized levels near patient homes of a type of air

pollution known as particulate matter 2.5 (PM 2.5), which means particles smaller than 2.5 microns.

Some PM 2.5s occur naturally, while others come from human sources of pollution, including steel and coal production, agriculture, and traffic fumes. Dr. Goobie developed an exposure-matching technique that can break PM 2.5 data down into seven components. "The three that really jumped out at us were sulfate, nitrate, and ammonium, all of which are derived from human activities," she says. "We found that patients who lived in high-exposure areas to these specific components had much higher mortality rates than patients in lower-exposure areas."

Looking Ahead: Better Air Quality?

Dr. Goobie's work continues, and she has a related paper currently going through the peer-review process. She hopes her work can be used to advocate for air-quality improvements. "Everyone should be able to live, work, and play in a healthy environment," she says. "What we need is more stringent public health and environmental policy to prevent these exposures for future generations, which will impact everyone, not only patients with ILD."

This project was funded by The Peter L. O'Neill Memorial Fund.

New Study Pushes Boundaries



conversation of the role of air pollution in causing ILDs.

For a researcher, any scientific publication is a source of pride. Dr. Gillian Goobie believes that her recent JAMA Internal Medicine article has the potential to broaden the scientific

Dr. Goobie's study, which used data from the PFF Patient Registry, is:

- The largest and most geographically diverse of its type
- The first study to look at the composition of PM 2.5 molecules
- One of only a few pollution-related studies to examine patients with many different forms of ILD

PFF Care Center Network Expansion Increases Access to Top-Quality Care

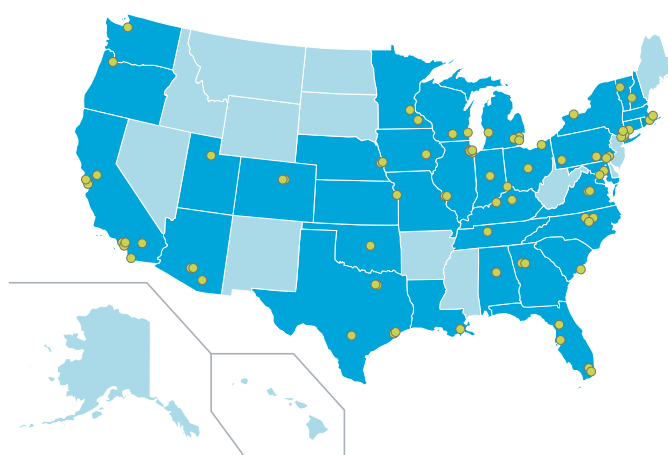
The PFF recently announced that 13 new sites have joined the PFF Care Center Network (CCN) this year, increasing the number of sites to 81 in total. This designation indicates that they provide specialized, multidisciplinary ILD care, conduct ILD research, and offer educational events for the community to help patients and their loved ones.

The newest medical centers to receive the PFF Care Center Network designation are:

- Corewell Health East (Royal Oak, MI)
- University of California San Diego (San Diego, CA)
- Cedars-Sinai (Los Angeles, CA)
- Dartmouth Hitchcock Medical Center (Lebanon, NH)
- Froedtert & the Medical College of Wisconsin Froedtert Hospital (Milwaukee, WI)
- Center for Advanced Lung Disease at Keck Medicine of University of Southern California (Los Angeles, CA)
- Loma Linda University Health (Loma Linda, CA)
- University of Nebraska Medical Center (Omaha, NE)
- The University of North Carolina at Chapel Hill (Chapel Hill, NC)
- OU Health (Oklahoma City, OK)
- Rush University Medical Center (Chicago, IL)
- University of South Florida-Tampa General Hospital (Tampa, FL)
- VCU Health (Richmond, VA)

Jessica Shore, PhD, RN, PFF Vice President, Clinical Affairs and Quality, points out that people with ILD who live in Oklahoma and New Hampshire will have ready access to a PFF Care Center in their state for the first time. The other newly designated PFF Care Centers all expand specialty ILD care options for patients in their respective states.

"I'm most excited about the energy that was expressed in the Care Center applications and the dedication these new centers have shown to improving the lives of patients living with PF," Shore says. "They'll all be providing access to support groups, serving on CCN committees and work groups and participating in the continued expansion of the Nurse and Allied Health Network."



NEW RESEARCH EXAMINES BEST PRACTICES ACROSS THE CARE CENTER NETWORK



Every PFF Care Center provides patients living with PF and ILD with high-quality, multidisciplinary care that is tailored to their specific diagnosis. But does each Care Center achieve the same patient outcomes?

Joyce S. Lee, MD, MS, PFF Senior Medical Advisor, Research and Health

Care Quality, is using data from the PFF Patient Registry to answer this question. "To be able to join the Care Center Network, a center must already be the best of the best, but there may be room for fine-tuning," Dr. Lee says. "My role is to help identify best practices, which we can then institute across the entire Care Center Network."

Dr. Lee, who also directs the ILD Program at the University of Colorado, and her co-authors studied key long-term patient outcomes across Care Centers, including:

- Time to first hospitalization
- Time to lung transplant
- Time to death

"We've learned that, at least from a statistical standpoint, there are different outcomes by center," Dr. Lee says. "This study doesn't tell us why, just that some important differences exist."

After presentation in a poster at the 2022 American Thoracic Society Annual Meeting, this study was then accepted in the *American Journal of Respiratory and Critical Care Medicine* (AJRCCM), also known as the "Blue Journal."

Next up, Dr. Lee and Dr. Jessica Shore will perform a study to identify specific practice patterns that could explain some centers' better outcomes.

"As pulmonologists, we're all deeply invested in making patients' lives better, but we can also learn from each other," Dr. Lee says. "This research should show us some very tangible ways to further benefit our patients."

Dr. Kevin Flaherty: Leading the Charge for the PFF Registry

When Kevin R. Flaherty, MD, MS, Chair of the PFF Registry Steering Committee, began working on the PFF Registry way back in 2013, many eminent pulmonologists contributed to the PFF's vision of what its registry should be.

"Kevin is the one who brought everyone together to shape many competing ideas and make the Registry a reality," says Scott Staszak, PFF Chief Operating Officer. "We couldn't have done it without him."

With an advanced degree in biostatistics and experience serving on the University of Michigan's institutional review board for clinical research, Dr. Flaherty brought hands-on expertise to the role, as well as a reputation as an impeccable clinician.

"'Putting the patient first' has become a buzzword, but that really is how Kevin operates," Staszak says. "When we were designing the Patient Registry, Kevin had strong feelings from years of patient care about what might be a burden to patients and what we could reasonably ask them to do."



Dr. Flaherty also recognized the limitations of following only 2,000 patients via the PFF Care Centers and wanted to reach out into the broader community to learn how these diseases affect patients, caregivers, and family members.

From working to help secure the Registry's initial seed funding to persuading colleagues at other PFF Care Centers to commit to Registry participation, Dr. Flaherty's immense standing in the PF/ILD professional community opened many doors for the PFF. "People see that genuine character and caring," Staszak says. "Everyone likes Kevin."

PRECISIONS Study Update



The PRECISIONS trial, which received an unprecedented \$22 million in funding from the National Institutes of Health and Three Lakes Foundation, is the first ever to apply precision medicine principles to diagnosing and treating IPF. Among its aims, PRECISIONS studies whether the

over-the-counter supplement N-acetylcysteine (NAC) can treat people with IPF who have a specific gene variant.

Co-principal investigator Fernando Martinez, MD, MS, of Weill Cornell Medicine, reports that PRECISIONS is currently recruiting patients, many of whom are part of the PFF Patient Registry.

"The PF community has been so actively engaged in advancing PF research that PRECISIONS is already starting to have an impact on how patients with fibrotic lung disease will be evaluated and—hopefully—treated in the future," Dr. Martinez says. "We use precision medicine, in which we take into account very specific characteristics of a patient when designing the therapeutic approach, which is standard in oncology, but quite radical in IPF research." PRECISIONS is due to be completed in 2025.

Find out more at bit.ly/3Y1Um2N

A Swimming Success: 'The New England Gills for PFF' Build Comradery and Raise Crucial Funds

The New England Gills for PFF may be one of the newest additions to the growing National Walk Day program, but its leaders, Laurie Chandler and John Massaua, are no strangers to the pulmonary fibrosis community.

Chandler received a lung transplant in 2014 due to PF and currently serves as the PFF's Vice-Chair and Treasurer on the dynamic Board of Directors. Massaua has been living with PF since 2017 and serves on the PFF Finance Committee.

The "Gills" have undoubtedly proven that they're swimming in the big pond — all together, the team raised an astounding \$56,000 for the PF community! Their achievement represents more than 127% of their original goal.

The team's walk was held on September 24 along the byways of the majestic Great Island Common, comprised of 32 acres of seaside green space and beach in New Castle, NH.



The team was formed as way to not only participate in National Walk Day, but to bring the New England area together to build comradery and raise awareness among the local pulmonary fibrosis community. To learn more about The New England Gills for PFF or to join their team, please visit bit.ly/NEGills4PFF.

Mana Ka Ha: Power in Your Breath



Imagine heading to your favorite vacation destination and instead landing in the intensive care unit at a hospital with early stages of organ failure. That's what

happened to Sean Craig, a lung transplant recipient and PF support group leader. Craig, a Hawaii native, was on his way to Disneyland when he had an acute exacerbation.

Diagnosed with idiopathic pulmonary fibrosis three years earlier, Craig adopted a positive mindset and did his best to lead a healthy lifestyle. He discovered the PFF's useful information and resources, and felt empowered to advocate for himself. He was able to continue working while taking medication and using supplemental oxygen to manage the disease.

On the day of his exacerbation, Craig woke up struggling to breathe and felt enormous pressure on his chest. By the time he arrived at the hospital, his lungs were on the

verge of collapse. He was shocked to learn that not only did he need new lungs, but he also needed a kidney. Craig received what he refers to as a "miracle" at UCLA Medical Center, a Pulmonary Fibrosis Foundation Care Center Network site. He went into surgery and woke up with three new organs.

He credits the PFF with helping him through the worst experience of his life by empowering him with the knowledge he needed during his experience. "My greatest resource is the PFF," Craig said. "Now, I dedicate myself to helping others with the disease."

"I know there is power in my breath," he continued. "I can use my power to help someone else."

Craig is grateful for his new organs. He knows that his journey is not over, but he has a new lens on life. He started a support group near his home in Kilua and tries to help others living with PF.

Craig finally made it to Disneyland in September with his family. He is grateful for the support of family, friends, and the PFF. He often wonders if the outcome would have been different without the PFF.

If you would like to help support people like Sean Craig, please make a gift today at bit.ly/fallpff2022.

PFF Walk 2022: Together Toward a Cure

In a powerful demonstration of the strength and support for the PF community nationwide, the PFF Walk 2022 set a new yearly fundraising record of more than **\$1 million**. After two years of virtual walks due to the pandemic, people living with PF, their families, friends, and loved ones took a tremendous, united step forward by making the PFF Walk 2022 the most successful yet.

“We are thrilled with the response to this year’s Walk program,” said Seth Klein, Chief Development Officer for the PFF. “Our 2022 participants doubled down on their fundraising goals and helped us come back stronger than ever.”

PITTSBURGH

Kicking off the 2022 PFF Walk season on July 23 at North Shore Riverfront Park, the Pittsburgh Walk set the tone for those to follow. Smiling faces and sunny weather created a joyful reunion of families, friends, and supporters. PFF volunteer Tami Rippy, who lost her mother Violet to IPF, shared her devotion to raising awareness and funds for PF, calling it her life’s mission.

TOTAL RAISED:

\$119,000



NEW YORK CITY

Liberty State Park in Jersey City provided a beautiful backdrop for the PFF Walk - New York City. Attendees enjoyed walking along the water against the skyline of Manhattan, followed by lunch, community engagement, and much more. PFF volunteer Adam Faatz joined the event and spoke about how finding the PFF empowered him to set his sights on new goals while living with the disease. PFF Board member Terence Hales was there to thank participants for their outstanding fundraising achievements.

TOTAL RAISED:

\$141,000

NATIONAL WALK DAY

Walkers from coast to coast participated in the 2022 National Walk Day! Individuals and teams headed out to beaches, trails, and parks in their communities as they expanded the footprint of the PFF Walk across the country.

TOTAL RAISED:

\$165,000



BAY AREA

Although it was set to launch in 2020, the Bay Area Walk in San Francisco was delayed because of COVID-19. With two years of built-up anticipation, walk attendees were delighted to finally meet one another and enjoy the celebration. With the Golden Gate Bridge in the background, participants took a scenic walk along the beaches and open spaces. PFF Ambassador and support group leader Forrest Reed traveled from Sacramento to join the community. He expressed his gratitude for the PFF's information and resources that have given him hope and motivation to stay active.



TOTAL RAISED:
\$149,000



CHICAGO

Hundreds of people gathered along Chicago's lakefront at Diversey Harbor for the PFF Walk - Chicago. Voice actor, Tim Dadabo, whose father passed away from IPF, kicked off the event as the emcee. PFF President and CEO, Bill Schmidt and Board member and volunteer Martin Attwell, welcomed attendees and thanked them for their continued support of the PF community. After completing the course, families shared stories of who they walked for and how PF has impacted their lives.

TOTAL RAISED:
\$226,000

WASHINGTON, D.C.

National Harbor was the perfect setting for the PFF Walk - Washington, D.C. as participants brought their passion for our cause. A sea of walkers wearing PFF blue t-shirts enjoyed connecting with one another before, during, and after the walk. PFF Ambassador Lukas Sehlke remembered his beloved grandmother as he shared his story and desire to help other families along their disease journey.

TOTAL RAISED:
\$155,000



DALLAS

Walk season culminated with a glorious day at the PFF Walk - Dallas. PFF Ambassador Stephanie Golden shared memories of her mother, Olga, and her role as caregiver to someone with a rare and unfamiliar diagnosis. Dr. Joseph Lasky, Chief Medical Officer for the PFF, spoke about the new PFF Community Registry, which is currently enrolling patients, caregivers, family members, and lung transplant recipients.

TOTAL RAISED:
\$88,000

An Empowering Way to Drive Research



When **Shomala Tambyraja** contacted the PFF to make a donation in her husband Sam's memory, she wasn't thinking about research. Tambyraja's goal was simply to give to the Foundation so it could continue to help others.

Tambyraja was connected to Seth Klein, the PFF's Chief Development Officer. They spoke about Tambyraja's experience losing her husband to familial PF, and Klein suggested she fund a PFF Scholar. The idea of funding research immediately appealed to her, as her husband Sam was a child psychiatrist for 40 years and was passionate about learning.



The PFF Scholars program is designed to support and enable promising researchers to obtain independent funding and continue their cutting-edge research. Tambyraja is sponsoring PFF Scholar, **Dr. Andrea Oh**, a radiologist at UCLA Health in Los Angeles. Dr. Oh is working to develop a statistical model using patient-

related factors including demographics, pulmonary function tests, blood work results, and CT scan results (with both an expert radiologist's interpretation and AI-generated fibrosis scores) to try and identify those patients with PF-ILD as early as possible.

Tambyraja hopes this kind of research will help other families facing a diagnosis of all types of PF. "I want to help wipe out this disease and I know research can lead to a cure," Tambyraja said. "It's been done for other diseases and we need to keep going."

Klein said the PF community agrees, and, as a result, the PFF Scholars program is growing. "Pulmonary fibrosis research is a priority for the PFF. Our goal is for PFF Scholars to receive independent funding to continue their research. This program allows us get closer to finding answers to key questions about PF."

Tambyraja applauds the PFF's focus on accelerating research. She often thinks about the health of her children and grandchildren. "We need to help the next generation and I'm grateful for the opportunity to do so."



The PF Community In Action: A Successful 2022 Pulmonary Fibrosis Awareness Month and ILD Day

Held each September, Pulmonary Fibrosis Awareness Month (PFAM) was a resounding success last year. Thanks to your likes, comments, and shares, you helped the PFF reach more than 241,000 people on social media! This means that stories, facts, and photos from the PF community showed up on newsfeeds far beyond our followers. Further, more than 130 buildings participated in the #BlueUp4PF campaign. A new record! The second annual ILD Day was on September 14 in conjunction with PFAM. Led by leading ILD expert Dr. Anna Podolanczuk, a free webinar titled "Progressive Pulmonary Fibrosis: What Patients Need to Know" debuted for the community. The webinar was recorded and is available on our YouTube channel.



Want Daily News and Updates? Follow Us on Social Media!

The pulmonary fibrosis community is buzzing on social media, and we want you to join in on the conversations! Every day, the Foundation shares useful information about PF, whether it's the newest research findings, free educational materials, patient stories, videos from the community, upcoming events, and so much more. You can follow us on your favorite platforms, including Facebook, Instagram, Twitter, LinkedIn, and YouTube.

With more than 70,000 followers across all five channels, the PFF invites you to leave comments and interact with others in the community. Leaving comments is a great way to connect with others, share ideas and experiences, and to get your questions about PF answered.

We would love to hear from you. The Foundation's social media is an opportunity for you to share your photos and stories with the larger community. If you have photos from a recent event or if you participated in any unique PF-related activities, we'd love to share them with the entire PF community. You can send your photos and stories to the PFF at socialmedia@pulmonaryfibrosis.org.

We can't wait to hear from you — "see" you on social media!

Get PFF News Delivered to Your Inbox



Want exclusive information and all the latest news happening here at the PFF?

Join our email list today! We at the Pulmonary Fibrosis Foundation are the trusted resource for all things PF. Our emails are your opportunity

to have that information delivered straight to you.

We send monthly newsletters that feature a compilation of all you need to know, providing you with access to PFF updates and opportunities right off the press. When you join our email list, we work to deliver tailored communications that fit your interests. We have emails just for patients, caregivers, Support Group Leaders, Team PFF members, healthcare providers, and more.

Don't miss out on news, research updates, events, information on support groups, surveys, education materials, clinical trials information, free webinars, and more. Join our community of more than 50,000 readers and don't miss a beat.

Get Social With Us!

Facebook, Instagram, Twitter, and YouTube: [@pfforg](https://www.instagram.com/pfforg)
LinkedIn: [pulmonaryfibrosisfoundation](https://www.linkedin.com/company/pulmonaryfibrosisfoundation)



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 or call us at **844.TalkPFF** (844.825.5733).



ADVOCACY

With leadership and guidance from the Pulmonary Fibrosis Foundation, 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.

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 campaign to advance vital research and support patient programs that help patients and their families live longer, healthier lives. For questions, contact Katie Crowley at kcrowley@pulmonaryfibrosis.org or **312.224.4667**.

MAKE A RECURRING OR WORKPLACE GIFT

By setting up a monthly donation, you can provide continuous support on which the Foundation can rely. We support automatic monthly, quarterly, semi-annual, or annual donations. Additionally, you may be able to support the mission of the PFF through an automatic deduction from your paycheck. Check with your human resources department to see if your company offers a workplace giving or a matching gift program. Visit pulmonaryfibrosis.org/DonationFAQs to learn more about these programs.

ATTEND A VIRTUAL EVENT

Attending or supporting a virtual 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 online event calendar—which is updated weekly—to locate an online event or find inspiration for creating an event of your own. To find an event, visit bit.ly/pffevents.

ENGAGE WITH US ON SOCIAL MEDIA

Follow us on Facebook, Instagram, Twitter, and LinkedIn to learn about the latest news, resources, and information about the disease, upcoming events, and so much more. Our social media channels are updated daily, and you can help the PFF's messages gain momentum throughout the web each time you like, comment on, and share the posts. Find us today on Facebook, Twitter, Instagram, and YouTube at [@pfforg](https://www.facebook.com/pfforg), and on LinkedIn and YouTube at [/pulmonaryfibrosisfoundation](https://www.linkedin.com/company/pulmonaryfibrosisfoundation).

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 [Shop-PFF.com](https://shop-pff.com) today.

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THE MAGIC RETURNS!

The Pulmonary Fibrosis Foundation's signature gala returns this spring on Monday, March 6! Tickets are on sale now. To secure your seat and learn more, visit BroadwayBeltsForPFF.org.

