

PULMONARY FIBROSIS FOUNDATION

breathe

WINTER 2021



**Congratulations
to Julie Halston,**
recipient of the 2020
Isabelle Stevenson Tony
Award in recognition
of her fundraising efforts
on behalf of the PFF.



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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 four-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 Guidestar Gold Seal of Transparency.



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Letter from Our President and CEO

DEAR FRIENDS,

The tribulations of the past two years have highlighted the power and persistence of the pulmonary fibrosis (PF) community. Healthcare providers have faced down the challenges of COVID-19 to continue providing quality care for patients with PF. And our devoted Pulmonary Fibrosis Foundation (PFF) staff has shown adaptability and creativity in the way it does its work. Not even a global pandemic has slowed our dedication to raising awareness of PF, supporting patients and caregivers, and pushing the parameters of research and treatment for this deadly disease.

From this “new normal” place, we have good news to celebrate and new offerings to announce. The PFF recently welcomed Joseph Lasky, MD, Professor and Pulmonary/Critical Care Section Chief at Tulane University Medical School, as our new Chief Medical Officer. Dr. Lasky is a highly respected researcher with more than 100 publications to his credit. We’re very fortunate to have his 30-year record of commitment to PF patients and PF research brought to this important position.

This fall, our great friend, dynamic TV and Broadway actress and comedienne Julie Halston, received the 2020 Isabelle Stevenson Tony Award for her more than 10 years of charitable work for the PFF. Julie, who serves on our Board of Directors, has raised more than \$2 million for the Foundation through the annual *Broadway Belts for PFF!* gala, her brainchild and our biggest fundraiser. It’s wonderful to see Julie being fully recognized by the theatrical community for these achievements—and it’s a tribute to the Tony organization that it values this work so much.

In another autumn accomplishment, the PFF participated in the first-ever Interstitial Lung Disease (ILD) Day on September 15. Because PF can be seen in many types of ILD, we were proud to join other organizations including the Arthritis Foundation, Foundation for Sarcoidosis Research, The Myositis Association, PF Warriors, Scleroderma Foundation, Scleroderma Research

Foundation, Sjögren’s Foundation, and the Wescoe Foundation for Pulmonary Fibrosis in driving awareness of ILD, including participating in an informational webinar.

Clinical trial recruitment continues to be a challenge in all fields. For the past several years, the Foundation has worked to improve PF patients’ ability to find clinical trials in which they may participate. In partnership with Carebox, an organization that connects patients and doctors with clinical trials, the PFF Clinical Trials Finder at **trials.pulmonaryfibrosis.org** is moving to a new level of search customization. The new and improved tool will help potential participants identify appropriate trials even more effectively.

The unwavering loyalty of the PF community has fueled all of this progress—and is key to our ongoing impact. If you’re able, please support the PFF with a gift. The obstacles we’ve overcome make me confident that, with your continued help, we can make our greatest strides forward yet.



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER



PFF Spotlight: Meet Darlene Cochran



To Darlene Cochran, family is “her core and her heart.” She married her husband, Jerry, in 1957 at age 18. They began building a beautiful life together and had three children — two sons and one daughter. Darlene’s family split their time between their home in California and a vacation home under the big sky of Montana.

Everything came to an abrupt halt in June 2003. Darlene and Jerry were at their home in Montana when their lives changed forever. Jerry tried to mow the lawn and became unable to breathe. He was rushed to the hospital and, dozens of tests later, ultimately given the diagnosis of idiopathic pulmonary fibrosis. Darlene and her husband had never heard of this disease and Jerry’s pulmonologist back home in California had only seen three cases throughout his career. Just 12 weeks later, before they could even begin to fully process this news and start to understand this disease, Jerry passed away.

Darlene and her family tried to rebuild and get past their brief time with idiopathic pulmonary fibrosis. To manage her grief, Darlene focused on staying busy and even left retirement to go back to work. Eventually, she found herself able to move forward.

In 2018, Darlene and her family experienced another blow to the family’s foundation. A nagging cough sent Darlene looking for answers. She had initially been diagnosed with pneumonia but further tests revealed that it was, in fact, pulmonary fibrosis. Again. Darlene was in utter shock and denial. How could this be? How would she tell her children? She kept the news to herself for a while but finally told them. They all had to digest this news and deal with history repeating itself.



While the diagnosis was the same, much had changed in the PF disease space since 2003. There are now two FDA approved treatments on the market. Clinical research trials are available to pulmonary fibrosis patients. Darlene also connected to the Pulmonary Fibrosis Foundation, which has expanded its reach and efforts during the years between her and her husband’s diagnoses.



Darlene credits staying busy as her ultimate coping mechanism and favorite disease treatment. She loves to read, is an active member of a book club, volunteers at her local rectory once a week, and even cooks for her neighbors on a regular basis. When she wants to find solace, she

enjoys packing up lunch for herself and her dog, Cookie, and hitting the open road in her Tahoe. Ultimately, her favorite hobby is chatting with family and catching up on all their adventures.

Darlene is also passionate about her volunteer role as a PFF Ambassador. Her wish is to help others receive an earlier diagnosis, push for additional treatments and ultimately find a cure for the disease that has shaken her family to its core. Darlene is also very active on the PFF Facebook page and loves to interact with other patients, often sending them encouraging words and well wishes.

Darlene’s family has continued to grow and she is now the proud grandmother to ten grandchildren and five great-grandchildren. The Montana home is still in the family.

MEET YOUR PF CARE TEAM:

New Blog Series Highlights Healthcare Roles

Care teams at Pulmonary Fibrosis Foundation Care Center Network (CCN) sites are made up of multidisciplinary healthcare professional teams, each with an important role to play in running the center and caring for patients with PF. Multidisciplinary team members organize and coordinate healthcare services to meet complex needs, and the team brings together the expertise and skills of different professionals to assess, plan, and jointly manage care.

However, with multiple people involved, it can be confusing to patients with PF. In response, the Pulmonary Fibrosis Foundation has created a "Meet Your PF Care Team" blog series to help highlight and further explain each role.



Amy Hajari Case, MD

The first blog post featured Dr. Amy Hajari Case, Senior Medical Advisor for Education and Awareness at the PFF and Medical Director for Pulmonary and Critical Care Research at Piedmont Health in Atlanta, Georgia. In her spotlight, she spoke about how she spends the majority of her time preparing

to see patients and conducting new patient or follow-up visits in clinic. Her job also entails reviewing records such as scans or biopsy results, answering questions from nurses

and other care team members, meeting with patients and family members, and then finally summarizing all of this by charting in the hospital's computer record system.



Max Whitehead-Zimmer

The second post featured Max Whitehead-Zimmers, a Human Research Technologist at the Penn State College of Medicine in the Division of Pulmonary, Allergy and Critical Care located at the Penn State Health Milton S. Hershey Medical Center in Hershey, Pennsylvania. Max currently

manages two different clinical trials and sees two-to-three patients per week for study visits. Max works under Dr. Rebecca Bascom, Care Center Director for the PFF Registry (see page 11), on several investigator-initiated studies, and also manages support group logistics and activities.

These are just two examples of individuals from a pulmonary fibrosis patient's care team. PFF Insights will continue to feature different multidisciplinary roles including that of a research nurse, respiratory therapist, and more. The blog posts mentioned here and upcoming features can be found at pulmonaryfibrosis.org/blog.

Working Together to Raise Awareness of Interstitial Lung Disease



The first-ever ILD Day took place on Wednesday, September 15, 2021, to drive awareness of interstitial lung disease. There

are more than 200 types of interstitial lung disease, and more than 250,000 Americans are living with pulmonary fibrosis and ILD. Pulmonary fibrosis can be seen in many of the more than 200 types of ILD. Idiopathic pulmonary fibrosis is one of the most common forms of ILD and has no known cause.

The PFF is proud to have partnered with eight organizations to present ILD Day, including the Arthritis Foundation, Foundation for Sarcoidosis Research, The Myositis Association, PF Warriors, Scleroderma Foundation, Scleroderma Research Foundation, Sjögren's Foundation and Wescoe Foundation for Pulmonary Fibrosis. ILD Day was supported by funding from Boehringer Ingelheim.

Interstitial lung disease, or ILD, is the umbrella term used for a large group of diseases characterized by inflammation and/or scarring in the lungs. The inflammation and scarring can injure the lungs, making it difficult to breathe and get oxygen to the bloodstream. The damage to the lungs can be irreversible and may worsen over time. ILD is difficult to diagnose, may be debilitating, and in some cases, incurable.

There are more than 50,000 new cases of ILD diagnosed in the U.S. annually. Any age group is subject to get an ILD. Patients with some inflammatory and connective tissue diseases are at a higher risk for ILD. In addition to IPF, people with diseases such as rheumatoid arthritis, scleroderma, Sjögren's syndrome, sarcoidosis, and myositis – including dermatomyositis and polymyositis (DM and PM), are at higher risk.

For more information, visit [ILDDay.org](https://ildday.org).

PFF Care Center Network Moves Research and Patient Care Forward

Care Center sites collaborate to expand understanding of PF, share best practices

Only a few years ago, “the idea that you could have a network of dozens of healthcare systems with a deep commitment to the care of interstitial lung disease patients was almost unbelievable,” says Sonye Danoff, MD, PhD, Senior Medical Advisor for the Pulmonary Fibrosis Foundation Care Center Network (CCN). “The CCN has proven that there are many different groups interested in moving forward in ILD research and patient care—and that the PFF can be an effective catalyst in helping people work together.”



PFF Care Center Network™

Care. Education. Innovation.

The Foundation offers the designation “PFF Care Center” to ILD programs that provide high-quality care, engage in ILD research, and work to educate the community about pulmonary fibrosis. To earn the designation, a program must have a full range of facilities and a multidisciplinary team that works collaboratively to diagnose and manage the care of people living with PF. From a handful of centers at its founding, the CCN has grown to include 68 individual care centers across the country. Find a complete list at pulmonaryfibrosis.org/medicalcare.

“The CCN gives voice to the immediate needs of our patient community, telling us what’s important and relevant to patients right now,” says Danoff, noting that the network’s steering committee includes patients and caregivers as well as healthcare providers. “That’s been evident in two recent areas of our focus: palliative care [see page 8] and COVID’s impact on patients with ILD. These are very busy care centers, yet we had 100% participation in both of these efforts.”

COLLABORATION IS KEY



Sonye Danoff, MD, PhD

Danoff, an Associate Professor of Medicine and Co-Director of the Interstitial Lung Disease/Pulmonary Fibrosis Program at Johns Hopkins Medicine, brings deep knowledge and a gift for inspiring cooperation to her leadership role at the CCN. “Dr. Danoff has expertise as a physician at the bedside, research experience, and a dedication to mentoring new investigators and new physicians,” says Jessica Shore, PhD, RN, PFF Vice President of Research and Programs. “Her goal is to improve patient satisfaction and outcomes so they can live longer, healthier lives, and she’s really bringing together the network to have that impact.”

“The network is building bridges between sites that are already working hard to move care forward,” Danoff says of her focus on collaboration. “Sometimes those connections already exist, but other sites may not have had a chance to participate. Now we’re going to invite everyone to come to the table.” As the network expands, it grows closer to its goal of having almost all Americans within a two-hour drive of a PFF Care Center. In sparsely populated areas, that objective is out of reach—and that’s one of the reasons the CCN is taking what Danoff calls a “hub-and-spoke approach,” forging connections and sharing expertise between CCN sites and local community providers in areas with limited specialty care for PF.

Shore says the network’s Rural Health Outreach Committee is currently developing a detailed plan to help patients and providers in rural communities engage with the network and what it can offer them. “There’s an assumption that lack of resources is the biggest challenge to PF care in rural communities,” she says, “but there may be other factors, like lack of high-speed internet and limited access to specialty physicians and clinical research.” The committee is building its understanding of the gaps “so we can develop resources to build out the future of how care is delivered to rural communities.”

To learn more about the CCN, visit pulmonaryfibrosis.org/medicalcare.

PFF CARE CENTER NETWORK GOALS

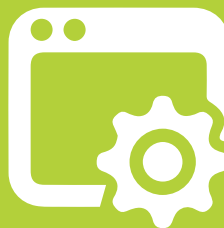
PFF Care Center sites collaborate with the community to identify patients with PF earlier, provide access to specialized care and cutting-edge research, and enhance awareness and understanding of PF. CCN goals include:

Diagnosis: Reduce time to accurate diagnosis of PF.

Quality of care: Ensure patients have access to high-quality care within two hours of their homes through the expansion of the CCN and their partners within the community.

Research: Facilitate research within the CCN and the PFF Registry to enhance our understanding of PF and expedite efficient clinical trials to identify effective therapies.

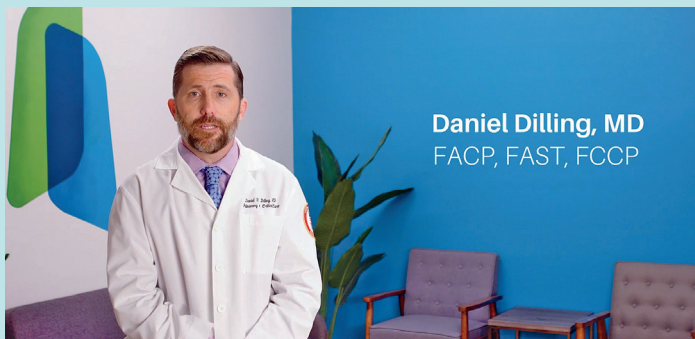
CCN TO RESUME ACCEPTING APPLICATIONS



Following a pause to re-evaluate the application and acceptance process to better serve the PF community, the PFF will resume the application cycle in 2022 from institutions seeking designation as a PFF Care Center.

Contact ccn@pulmonaryfibrosis.org to learn more.

New Videos Address Interstitial Lung Disease and Expand Spanish Language Content



Daniel Dilling, MD
FACP, FAST, FCCP

The PFF has expanded its video library with the addition of new disease education and Spanish language videos. Individuals with PF and their loved ones can increase their knowledge of the disease by watching the Life with PF collection, which highlights medically accurate information about PF as well as stories from patients and caregivers.

The recently released disease education videos focus on specific types of interstitial lung disease (ILD) including – pneumoconiosis (occupational ILD), familial pulmonary fibrosis, autoimmune ILD, hypersensitivity pneumonitis (environmental ILD), and idiopathic pulmonary fibrosis (IPF). Narrated by pulmonologists Dr. Ayodeji Adegunsoye from the University of Chicago and Dr. Daniel Dilling from Loyola University Medical Center, the videos provide viewers with a clear overview of these conditions. Each video runs about five to seven minutes in length.



Ayodeji Adegunsoye, MD, MS
FACP, FCCP

The popular Myths and Misconceptions series, which debunks common PF misunderstandings, is now available in Spanish. In addition, vignettes highlighting the story of patient and support group leader, Jose Vazquez, offer brief glimpses into life with the disease.

“We know that our community is eager to learn as much as possible about pulmonary fibrosis and interstitial lung disease,” said Kate Gates, Vice President of Advocacy and Programs. “Our videos provide trusted information and patient stories presented in a compelling visual format.”

The new videos complement the Words of Wisdom, Portraits of PF, COVID-19 support, and other guidance videos. You can view our full video library and find playlists on the PFF’s YouTube channel at youtube.com/pulmonaryfibrosisfoundation. Make sure to like the videos and subscribe so you never miss a new upload.

New PFF Position Statements Focus On Palliative Care

Palliative care delivered early in a patient’s treatment journey can significantly improve health and quality of life for both the patient and their caregivers as they deal with a life-changing diagnosis.

The Pulmonary Fibrosis Foundation recently expanded its collection of position statements to include two statements on palliative care: one aimed at patients and caregivers, and the other targeting healthcare providers who treat patients with pulmonary fibrosis and interstitial lung disease.

Patients with PF and their caregivers experience many symptoms and stresses throughout the disease course. Yet studies have shown that only a minority of patients with PF receive palliative care services, and most of these services are delivered in the last month of life. The PFF’s new position statements answer common questions from patients and providers about the purpose and benefits of palliative care—and point readers to sources of further information.

CREATED WITH PATIENT AND PROVIDER INPUT

The new position statements were created with substantial input from both patients and providers. Co-chaired by Sonye Danoff, MD, PhD, of Johns Hopkins Medicine and Kathleen O. Lindell, PhD, RN, ATSF, FAAN, of the Medical University of South Carolina, the PFF Palliative Care Working Group conducted a full review of available literature on the topic.

“The team created a detailed survey for members of the PFF Care Center Network to learn how palliative care is delivered within the network,” said Jessica Shore, PhD, RN, PFF Vice President of Research and Programs.

“We had input from numerous physicians, nurses, and other faculty and staff from the CCN,” Shore said. “We also spent a lot of time talking to patients and caregivers to understand their experiences. That was really important; we know that patients want to be told about palliative care and we want them to be empowered with a basic knowledge of palliative care and the tools and resources available to them.”

SHARING FINDINGS FOR WIDER REACH

To expand the reach of its work, the working group submitted an abstract to the American Thoracic Society and is creating a series of articles for submission to academic journals. “These will provide background on our process, help disseminate the results of the survey, and share current recommendations for palliative care for patients with PF,” Shore says.

Since patients and providers often have separate but overlapping questions, the PFF will continue creating two versions of position statements when appropriate, Shore says. A pair of statements on rural health is already in development, and “we’re assessing what will be the next priorities based on the many topics of interest across the CCN,” she says.

To download a copy of the PFF palliative care position statements, visit pulmonaryfibrosis.org/positionstatements. To receive a printed version in the mail, call the PFF Help Center at **844.TalkPFF**.

TOPICS COVERED IN PFF POSITION STATEMENTS ON PALLIATIVE CARE

FOR PATIENTS

- What is palliative care?
- What are the differences between palliative care and hospice?
- Why might a patient with PF need palliative care?
- How are caregivers’ needs addressed with palliative care?
- What palliative care resources are available for PF patients?

FOR PROVIDERS

- How do I introduce the topic of palliative care to my patients with PF?
- When should I refer a patient to palliative care?
- What does palliative care offer to PF patients who are early in the disease? Later in the disease?
- What are the differences between palliative care and hospice?
- What resources are available regarding symptom management?



PFF SUMMIT 2021: A VIRTUAL EXPERIENCE

PFF Summit 2021

DEVELOPED WITH BOTH PROVIDERS AND PATIENTS IN MIND

The all-virtual PFF Summit 2021 from November 8 – 13 this year featured over 30 sessions designed for patients, caregivers, lung transplant recipients, those who have lost a loved one, healthcare professionals, and industry representatives. The virtual conference welcomed more than 1,150 attendees — the most in the Summit's history! If you haven't registered yet, it's not too late! Register today at PFFSummit.org to view all Summit sessions on demand through February 20, 2022 exclusively on the MedScapeLIVE platform.

The PFF held two plenary sessions geared toward all of our constituents. On Tuesday, November 9, the session focused on therapies to improve quality of life. The keynote speaker was Dr. Kathleen O. Lindell, Mary Swain Endowed Chair in Palliative Care Health at the Medical University of South Carolina, who presented "Palliative Care: Spotlight on the Caregiver." On Friday, November 12, the plenary session was dedicated to topics about the critical importance of PF research and moving PF care forward. This session featured keynote speaker Dr. Gary Gibbons, Director of the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health, who addressed "The Importance of PF-Related Research at the NHLBI."

Tuesday evening featured a Fireside Chat, kicked off by PFF President and CEO, William T. Schmidt who unveiled an overview of the PFF's new strategic plan (page 14), and was followed by a live conversation with our esteemed medical team. The chat concluded with PFF CMO Dr. Joseph Lasky welcoming long-time IPF advocate, Yankee legend, and Latin Grammy nominated artist Bernie Williams to share an instrumental song written in honor of his father.

New to this year was the PFF Summit Social, held Thursday evening. The virtual event line-up featured interactive activities and entertainment, including music, yoga, improvisation, cooking, cocktails, and a live sky show studying constellations.

The popular Clinical Trials Innovation (CTI) Series included presentations on the latest developments in potential PF treatments from nine companies: Boehringer Ingelheim, Chiesi, FibroGen, Galecto, Genentech, Horizon

Therapeutics, Pliant Therapeutics, United Therapeutics, and Three Lakes Foundation. The CTI Series is available exclusively via the MedScapeLIVE platform through February 20, 2022.

The community pulmonologists and ILD fellows program featured robust content in two half-day sessions, as did two half-day sessions designed for nurses and allied healthcare professionals.

Academic posters were reviewed by a panel from the PFF's Research Review Committee, who selected the top five posters, each earning a cash award. The poster awardees were recognized at the awards ceremony on Monday evening, and all five presented a summary of their research during a scientific session on Thursday afternoon.

1st Place – Jason Gokey, PhD: Vanderbilt University Medical Center.

2nd Place – Luis Rodriguez, PhD: Perelman School of Medicine at The University of Pennsylvania.

3rd Place – Yi Yao, PhD: Henry Ford Health System

Honorable Mention – Margaret Thomas Freeberg, PhD: Virginia Commonwealth University

Honorable Mention – Bhavika Kaul, MD: University of California, San Francisco

Diamond Sponsor



Gold Sponsors



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An Inside Look at How SABER Supports the PFF Registry



The Statistical Analysis of Biomedical and Educational Research (SABER) group at the University of Michigan houses the PFF Registry's clinical databases. SABER also stores the Registry's biosamples and provides statistical support for various Registry

research studies. Cathie Spino, Sc.D, Director of SABER, sheds some light on what this means to the PFF.

How does SABER support researchers who are using PFF Care Center Registry data?

We have provided data sets to researchers who used our data in their own methods or joined them to other data sets. Companies also have used PFF Registry data to serve as a control data set in developing new PF treatments. They can compare the control data to their experimental treatment's data. This early comparison can help move the new treatment forward to clinical trial.

We also have provided data sets and biorepository samples from the PFF Registry to researchers to look for potential biomarkers. This could aid in more definitive

ILD diagnoses, more accurate prognoses, and better indications of various treatments' effectiveness in different patients. One project led directly to a clinical trial to see if patients with a particular genotype responded better to a potential antifibrotic treatment.

How helpful has it been to researchers to have access to SABER resources such as biostatistical support?

Researchers are familiar with using data collected to support specific research objectives like a clinical trial. However, PFF Registry data come from medical records that were not originally collected for research purposes. SABER statisticians can help guide researchers in managing the Registry data that they can use to answer many scientific questions. SABER statisticians will work with the investigators to understand the data. They also can collaborate with investigators to design and perform the analysis. SABER also assists researchers with the interpretation of research results from presentation to manuscript to publication.

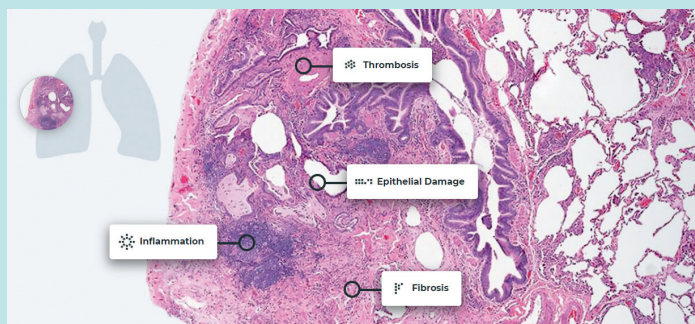
PROLIFIC Consortium: The Quest for PF Biomarkers

The PFF and Bristol Myers Squibb launched the Prognostic Lung Fibrosis Consortium, (PROLIFIC for short) to simplify drug development by promoting cooperation among pharmaceutical competitors. The goal is to create a shared test for use during drug development. Once this test has been developed, researchers from each member company will screen biosamples from the PFF Care Center Registry to identify and validate biomarkers for PF.

PROLIFIC members have agreed to focus their research on 12 biomarkers in four key categories:

- Epithelial damage – CYFRA 21-1, SP-D, CA-19-9, and KL-6
- Fibrosis – MMP-7, tenascin-C, and periostin
- Inflammation – CCL18, CXCL13, sICAM 1
- Thrombosis – PAI-1

Visit pulmonaryfibrosis.org/PROLIFIC to learn more about the roles epithelial damage, fibrosis, inflammation,



and thrombosis may play in PF. You'll also find links to published research and active clinical trials for each of the 12 biomarkers.

PROLIFIC members include the Pulmonary Fibrosis Foundation, Bristol Myers Squibb, Chiesi USA, Galapagos NV, Galecto, Genentech, Gilead Sciences, Lung Therapeutics, Novartis Institutes for BioMedical Research, OptiKira, Pliant Therapeutics, Three Lakes Foundation, and Tvardi Therapeutics.

The PFF Community Registry Nears Launch



After several years of planning and development, the PFF Community Registry will be open for enrollment in the new year! The PFF Community Registry welcomes everyone who has been touched by PF. This includes patients living with PF from any part of the U.S., family members, caregivers, and lung transplant recipients who have had PF. Sign up at **PFFRegistry.org** to get an email notification when the PFF Registry officially opens.

PFF Community Registry participants will report their own data remotely via regular questionnaires uploaded in an easy-to-use online portal. "Surveys will average about 45 minutes to complete, and we will tell you at the start how much time each will take," says Junelle Speller, MBA, Vice President, PFF Registry. "You should be able to answer most survey questions without consulting

PFF COMMUNITY REGISTRY FAST FACTS

This vital new research opportunity can help speed the progress toward a cure for PF.

The PFF Community Registry is:

- ✓ **Safe and secure**
- ✓ **Free and easy to use**
- ✓ **Open to everyone touched by PF, anywhere in the U.S.***

**Patients living with PF, caregivers, family members, and lung transplant recipients who have had PF can participate.*

your medical provider or records, and you can stop participating at any time."

The PFF Community Registry database is safe and highly secure. It uses the same technology trusted by doctor's offices, hospitals, and clinical trials worldwide. As a part of the PFF Community Registry, you will receive ongoing monthly emails and quarterly newsletters so that you can see how your information is helping to shape the future of PF research.

Once enrollment begins in the new year, you will be invited to enroll and complete the baseline questionnaire. You will receive follow-up surveys every six months and may receive additional questionnaires periodically.

THE PFF CARE CENTER REGISTRY CELEBRATES FIVE YEARS

The PFF Care Center Registry is an observational database that follows the care of patients with interstitial lung diseases including IPF, hypersensitivity pneumonitis, and other diagnoses. It records, analyzes, and reports information about participants' health status and medical care over time. Since 2016, the PFF Care Center Registry has collected medical data from 2,000 patients with PF who receive care at one of the PFF Care Center Network hospitals throughout the U.S. Unlike a clinical trial where subjects follow a specific treatment protocol, the Care Center Registry captures data from patients' real-world healthcare experience. The PFF Care Center Registry is one of the first nationwide research studies and biorepositories that lets researchers explore and find new ways to diagnose, treat, and potentially cure PF.

By collecting and studying participants' data, blood samples, and high-resolution computed tomography (HRCT) scans, we are increasing our understanding of what a typical disease course might be in PF. Researchers also use the PFF Care Center Registry to study diagnostic and predictive biomarkers, proteins that indicate that a person has PF or may develop it. "During the past five years, the PFF Care Center Registry has made huge amounts of data available to researchers and a clearer picture of PF is now emerging," says Kevin Flaherty, MD, MS, PFF Registry Steering Committee Chair. "Looking forward, the Registry is poised to make even greater contributions to PF research."

New PFF Scholars Announced

Increased award amount expands support of early-career investigators

The PFF Scholars program engages emerging researchers in the field of pulmonary fibrosis. With the goal of advancing research that could translate into successful therapies for PF, the PFF Scholars program offers bridge awards that enable promising researchers to continue their cutting-edge research—and eventually obtain independent funding from sources such as the National Institutes of Health. PFF Scholars are supported by generous donations from Boehringer Ingelheim Pharmaceuticals, Inc., private donors, and family foundations.



**MARGARET THOMAS
FREEBERG, PHD**
Postdoctoral Research
Fellow, Department of
Internal Medicine
Virginia Commonwealth
University
Project Title: *Targeting multiple
disease pathways*
Funded by Boehringer
Ingelheim Pharmaceuticals, Inc.

Idiopathic pulmonary fibrosis is driven by multiple overlapping disease-causing processes. Most current research focuses on treating single pathways, resulting in challenges and failure when translated from the lab to clinical trials. Freeberg will investigate a recently identified overlap of two previously presumed independent processes that promote fibrosis: tissue stiffness and energy metabolism by lung cells. “I’ve identified a probable cell receptor involved with these processes that has potential to be developed into a therapy that targets these multiple disease pathways at the same time,” she says. “The long-term goal is to identify a co-targeting treatment option that will more effectively block the progression of fibrosis compared to current single therapies.”



PETER JACKSON, MD
Assistant Professor of
Pulmonary and Critical Care
Virginia Commonwealth
University
Project Title: *Targeting
multiple disease pathways;
Investigating post-TB lung
impairment*
Funded by Boehringer
Ingelheim Pharmaceuticals, Inc.

Up to half of acute tuberculosis (TB) survivors will develop post-TB lung impairment (PTLI). With over 90 percent of TB cases occurring in low- to middle-income countries, PTLI often results in food insecurity, worse socioeconomic status, and increased mortality from secondary causes. Building on a postulated link between the bacteria that cause TB and the patient’s immune system, Jackson’s study will be the first not only to determine clinical risk factors for PTLI development, but also to evaluate over time the immunologic pathways that cause this disorder. He will analyze inflammatory cytokines (molecules secreted from immune cells that promote inflammation) and regulatory lipids (compounds that regulate certain biological processes) in the blood and lung “to identify the cause of PTLI and discover targets for therapies that can prevent this devastating disease,” Jackson says.

**BHAVIKA KAUL, MD**

**Assistant Professor of
Pulmonary and
Critical Care Medicine
University of California
San Francisco**

Project Title: *Targeting
multiple disease pathways;
Understanding gaps in access
to care*

Funded by the Chuck and

Monica McQuaid Family Foundation

Kaul's scholarship focuses on improving outcomes for patients with idiopathic pulmonary fibrosis (IPF). In her prior work, she has identified a national cohort of 139,000 U.S. veterans diagnosed with IPF between 2010-19 and found that less than 5 percent were prescribed antifibrotics. "Utilization was disproportionately low among female, Black, and rural patients with variability in practice patterns across Veterans Health Administration facilities," she says. During her tenure as a PFF Scholar, Kaul will explore the reasons for these disparities, identify access barriers, and suggest ways to address them. "My long-term goal is to develop new care delivery strategies to bridge access gaps and improve outcomes for patients with IPF," she says.

**ANDREA OH, MD**

**Assistant Professor
of Radiology
National Jewish Health**

Project Title: *Targeting
multiple disease pathways
Speeding the diagnosis
of PF-ILD*

Funded by Shomala
Tambyraja in memory of
Dr. Samuel Tambyraja

New antifibrotic drugs slow disease progression in progressive fibrosing interstitial lung disease (PF-ILD). However, PF-ILD currently requires documentation of disease progression by imaging or pulmonary function tests, which may delay treatment. "There is an urgent, unmet need to identify patients with PF-ILD as early as possible to improve long term outcomes," Oh says. Advanced computer techniques using artificial intelligence (AI) show promise as a better method than radiologist readings to assess fibrosis on computed tomography (CT). One AI technique, called data-driven textural analysis, can automatically detect and calculate the amount of fibrosis on CT. Oh will 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) from the PFF Registry to try and identify those patients with PF-ILD as early as possible," she says.

Generosity of Donors Leads to PFF Scholars Program Expansion

Thanks to the generosity of several donors, PFF Scholars, a grant program designed to support projects that are likely to improve the understanding of PF, has expanded from supporting four researchers per year at \$50,000 to at least four researchers per year at \$75,000. Since the PFF began funding research in 2000, the program has provided almost \$5.5 million in funding and recipients have gone on to receive over \$100 million in support from the National Institutes of Health.

PFF Scholars are selected from a group of promising early-career applicants nationwide. These physician-researchers study innovative projects that address key questions about PF. Areas of research include basic science, translational research, clinical research, epidemiological research, and health services research. To date, study topics have ranged from examining the impact of disease on caregivers of patients with interstitial

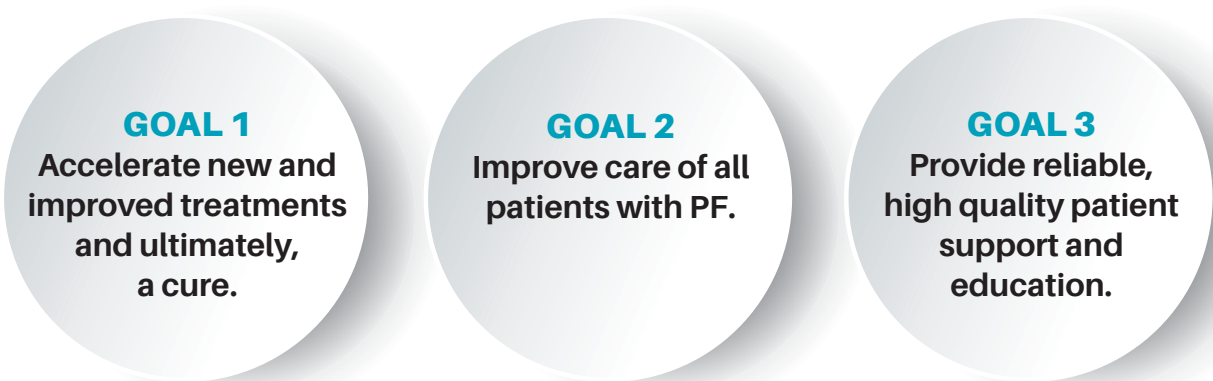
lung disease to analyzing the immune system in IPF using single-cell RNA sequencing.

With the support of donors, PFF scholars are positioned to compete for much larger federally funded research grants, so they can continue their critical research. Just last year, Dr. Jeremy Katzen at the University of Pennsylvania, a PFF Care Center Network site, received a National Institutes of Health mentored clinical scientist research career development (K08) award. Dr. Katzen's research focuses on the fundamental mechanisms of lung fibrosis.

For more information and to learn more about how you can support a PFF Scholar, please contact Seth Klein at sklein@pulmonaryfibrosis.org. For questions and information about becoming a PFF Scholar, please contact Zoë Bubany at zbubany@pulmonaryfibrosis.org.

New Strategic Plan Hopes to Accelerate Pace of Progress

The Pulmonary Fibrosis Foundation proudly announces the launch of *Accelerating the Pace of Progress: Pulmonary Fibrosis Foundation 2024 Strategic Plan*. “To achieve our overarching vision of a world without PF, the PFF identified three key strategic pillars or goals with corresponding initiatives to achieve each one,” says PFF President and CEO William T. Schmidt.



“Based on key input from the community and what we have learned over the past five years, we believe these three goals are the highest priorities for patients with PF and their families. In our view, these are also attainable goals,” Schmidt says. “By pursuing these goals aggressively and collaboratively, we believe we can shorten the timeline for a cure, and in the meantime, dramatically improve the lives of patients with PF.”

The PFF 2024 Strategic Plan was developed based on extensive feedback from an internal staff task force, the PFF Board of Directors, and the Medical and Scientific Advisory Committee of the Board. Significantly, four stakeholder groups participated, including patients with PF and caregivers, health care professionals, researchers, and industry partners. Professional facilitators led two discussions with each of these stakeholder groups.”

The input of these stakeholders informed every aspect of this plan, including the mission, values, and key goals and initiatives,” Schmidt says. “And we established metrics for each initiative over the next three years so that the community can track our progress.”

The PFF 2024 Strategic Plan also includes a new mission statement:

“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 NEW STRATEGIC PLAN ALSO LISTS CORE VALUES THAT ARE CENTRAL TO THE PFF’S MISSION:

• Patient-centered	• Inclusiveness
• Urgency	• Evidence-based
• Innovation	• Trusted information
• Collaboration	• Compassion

“These values sum up who we are and everything we strive to bring to the PF community,” PFF President and CEO William T. Schmidt says.

Dr. Joseph Lasky Joins the PFF as Chief Medical Officer

In August, the PFF announced the appointment of Dr. Joseph A. Lasky to the position of Chief Medical Officer. Dr. Lasky has served in numerous volunteer positions with the PFF over the years, including as Co-Chair of PFF Summit 2019 in San Antonio.



He serves as the Site Principal Investigator for numerous ongoing clinical trials in pulmonary fibrosis. Dr. Lasky has authored over 100 PF publications spanning basic molecular science to clinical trials. He is a Fellow of the American College of Chest Physicians and a member of

the of the American Thoracic Society. Dr. Lasky earned his medical degree at the University of Minnesota in Minneapolis and completed his internship and residency in internal medicine at the Mayo Clinic. He attended Duke University for his fellowship in pulmonary and clinical care.

"The PFF is pleased to welcome Dr. Lasky, a valuable member of the PF community, to our organization" says William T. Schmidt, President and CEO of the PFF. "With over 30 years of experience caring for patients with pulmonary fibrosis, he brings the expertise and compassion needed to improve outcomes for patients and provide support for their loved ones. Dr. Lasky's extensive prior work and leadership in clinical research in interstitial lung disease will strengthen the PFF's efforts to accelerate research and advance the development of therapies for this life-threatening condition."

Dr. Lasky is a professor and Pulmonary/Critical Care Section Chief at Tulane University Medical School.

"I am honored to join the PFF in its mission to improve upon ways healthcare providers diagnose and care for patients with PF," says Dr. Lasky. "I have dedicated my life's work to understanding PF and I am eager to help develop and lead initiatives that will speed advancements toward our goal to find a cure for PF. With exciting PF research underway and many new therapies in the pipeline, I am confident that, together with the community, we will achieve our goal."

Match and Connect to Clinical Trials



The Pulmonary Fibrosis Foundation is pleased to announce a new Clinical Trial Finder on the PFF website hosted by Carebox. The PFF Clinical Trial Finder is a comprehensive list of studies

for pulmonary fibrosis related conditions. Upgraded tools and functionality have been added to increase the ease of use for patients, caregivers, and families. Simply fill out a short questionnaire, and the Finder will automatically identify trials in North America with eligibility criteria that are a preliminary match!

Participation in clinical trials is important for patients, as research allows care providers to expand their knowledge on pulmonary fibrosis. This leads to improvements in medications and treatments of the disease. Additionally, clinical trials can show which medical approaches work best for specific types of illnesses or groups of people. Studies follow strict scientific standards which protect patients and help produce reliable study results.

Visit **trials.pulmonaryfibrosis.org** to begin searching today!

Funding PF Solutions — The Time is Now



Pulmonary fibrosis takes many forms and presents tremendous challenges for those living with the disease, their caregivers, and loved ones.

This unacceptable reality is the reason the PFF is doing everything possible to support patients, fund research, and raise awareness of the disease. And thanks to your support, we are pushing forward with enhanced educational resources, expanded patient programs, new advocacy initiatives, and larger research investments.

Your donations make a difference!

CLINICAL TRIAL FINDER

The PFF Clinical Trial Finder helps patients find clinical trials that are currently underway. This important tool on the PFF's website makes searching for trials easier, which can result in increased participation and, eventually, more available therapies.

With our recently upgraded PFF Clinical Trial Finder, patients have the ability to identify relevant clinical trials that are a preliminary match to their questionnaire responses.



\$36

funds the display of actively recruiting clinical trials on the PFF website for one Care Center Network location



SUPPORT GROUPS

The PFF coordinates 157 support groups across the U.S. These groups create a crucial bond among those living with PF and their caregivers. Since the onset of the COVID-19 pandemic, the PFF has trained support group leaders to host virtual meetings. PFF Support Group leaders have a PFF Zoom account so they can continue to meet and keep members connected.

\$20

funds a support group's Zoom account for one month



LEGISLATIVE ADVOCACY

The PFF advocates for our community on issues such as access to supplemental oxygen, the need for federally funded PF research, and inclusion of PF as a topic in the Peer Reviewed Medical Research Program at the Department of Defense. Each year, the Foundation organizes PFF Hill Day with volunteers to meet with lawmakers, inform them of the impact of the disease, and ask them for support.

\$100 funds training and virtual participation for one Hill Day volunteer

PFF HELP CENTER

The PFF Help Center offers everyone the most up-to-date medical information, support services, and other essential resources. Staffed by PFF staff members, the Help Center responds to inquiries from throughout the U.S. and overseas. Each year, we serve more than 4,000 individuals who call and email us for assistance. All materials are distributed free of charge.



\$40 provides an in-depth information packet to a newly diagnosed patient



EDUCATIONAL MATERIALS

As an organization committed to diversity, equity, and inclusion, we know that PF can impact anyone. The PFF provides educational materials for patients in multiple languages.

\$500 funds the cost of adding a translated one-page fact sheet to our library

PFF SCHOLARS

The PFF supports early-stage researchers with grants of \$75,000, enabling them to conduct cutting-edge PF studies that could translate into successful therapies. With funding from the PFF, these researchers can then compete for larger federal grants to improve the understanding of pulmonary fibrosis.



\$750 funds a PFF Scholar's attendance at the PFF Summit

A Legacy to Find a Cure



For more than 20 years, the Pulmonary Fibrosis Foundation has led the search for a cure to pulmonary fibrosis. When you support the PFF, you are not just funding research and advocacy — you are creating a brighter, healthier future for everyone living with this disease.

As we look to the next 20 years, there's a simple but powerful way you can create a brighter future for your loved ones and support the next generation of our important work: planned giving.

Planned giving is an impactful way to make the PFF's research, education, and advocacy initiatives a lasting part of your personal legacy. These gifts, most commonly made through a bequest in a legal will or trust, are made at no immediate cost, but provide sustained support to ensure

everyone living with pulmonary fibrosis has the information and resources they need.

More than that, your legacy gift can make the difference in our search for a cure. The dream of curing PF is possible, and we'd be honored to have you stand alongside us.

Planned giving can often feel like a lot to tackle, but it's easier to get started than you may think! Courtesy of our trusted partnership with FreeWill, the PF community can now write a legal will for free and easily include the necessary language to create a legacy gift in their plans. It takes 20 minutes or less, can be used with an attorney, and most importantly, is 100% free.

By including a legacy gift to the PFF in your plans, you'll join your fellow supporters in our Albert Rose Legacy Society. To get started, please visit **FreeWill.com/PFF**.

For questions, contact Seth Klein at **sklein@pulmonaryfibrosis.org**.

AND THE AWARD GOES TO...



The national spotlight shone on the Pulmonary Fibrosis Foundation on September 26 when actress and comedienne, Julie Halston, received the 2020 Isabelle Stevenson Tony Award in recognition of her charitable work and fundraising efforts on behalf of the PFF. Halston, a dynamic advocate for people living with pulmonary fibrosis, has raised more than \$2 million and brought international awareness to the cause through the annual *Broadway Belts For PFF!* gala.

"Julie Halston is a treasure – she is a creative force and an extraordinarily generous advocate for those with this life-threatening and under-recognized disease," said William T. Schmidt, President and CEO of the PFF. "Her brainchild, *Broadway Belts for PFF!*, has become the PFF's single largest fundraising event. We are so thrilled Julie was recognized with the Isabelle Stevenson Tony Award and we are truly grateful for all that she has done for our community."

The 2020 Isabelle Stevenson Tony Award is presented annually to a member of the theatre community who has made a substantial contribution of volunteered time and effort on behalf of one or more humanitarian, social service, or charitable organizations. Halston received this

award from the Tony Awards Administration Committee for the 2019-2020 season.

"PF is a terrible disease and there is no known cure yet, but there is hope," said Halston. "I am overwhelmed with gratitude for this award, and I want to thank all of the Broadway celebrities who have shared their gifts to benefit this vital cause."

Save the date for the return of *Broadway Belts for PFF!* on March 7, 2022. For more information, visit broadwaybeltsforpff.org.

New Study: Antifibrotic Medications May Improve Post-Hospitalization Survival

Ever since nintedanib and pirfenidone received FDA approval in 2014 to treat idiopathic pulmonary fibrosis (IPF), questions have persisted about whether these therapies extend the lives of people with IPF, and if so, under what circumstances.

A new study in the peer-reviewed journal *BMC Pulmonary Medicine* explores the effects of antifibrotic medications on survival following an acute exacerbation (AE). According to senior author Andrew Limper, MD, of the Mayo Clinic, a member of the Care Center Network, antifibrotics' effects on acutely ill and hospitalized patients have not been systematically studied since antifibrotic therapy became available. "We used a large U.S. medical-claims database to compare the outcomes of treated and untreated IPF patients hospitalized for acute respiratory-related causes," he says. "We hypothesized that antifibrotic therapy prior to hospitalization with an acute respiratory illness may offer a survival advantage compared to untreated patients."

Dr. Limper and colleagues identified approximately 2,900 patients with IPF in the database who had an AE requiring hospitalization during a three-year period. Of these patients, 402 had not filled a prescription for an antifibrotic medication during the 45 days before they were hospitalized. The researchers matched these patients with 402 similar patients who had taken antifibrotics before



Andrew Limper, MD

hospitalization, then compared their results. They looked at whether patients survived at 30 days after hospitalization and, if so, through up to two years of follow-up.

"To our knowledge, this is the first use of real-world data to evaluate the effects of antifibrotics on hospitalization outcomes in patients with

IPF," says Dr. Limper, who also chairs the PFF Medical and Scientific Advisory Committee and serves on the PFF Board of Directors. "Our findings are unique as previously published data regarding IPF respiratory hospitalizations have not accounted for the impact of antifibrotic therapy."

They concluded that treatment with antifibrotic medications does not appear to directly improve 30-day survival during or after respiratory-related hospitalizations. "Similar rates of ICU utilization across the cohort suggested treatment with antifibrotics prior to hospitalization did not reduce the acuity of hospitalizations," Dr. Limper says. "However, if patients survived hospitalization, those with ongoing antifibrotic treatment had improved survival compared to their untreated counterparts up to two years later."

Ultimately, patients who are on antifibrotic medications may have better longer-term outcomes after being in the hospital for a respiratory illness than those patients who are not on antifibrotic medications.

Pinpoint PF Campaign Raises Awareness of PF

Pinpoint PF

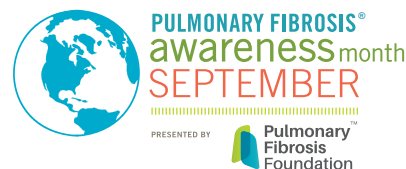
The PFF's awareness campaign, Pinpoint PF, continues to reach

at-risk audiences, healthcare providers, and the public with messaging about the disease, its symptoms, and risk factors. With a combination of earned and paid media aimed at target audiences, Pinpoint PF is driving traffic to the Foundation's website and PFF Help Center where individuals can receive additional information.

This year, designated observances such as Clean Air Month, Men's Health Month, and Clinical Trials Day provided opportunities to distribute newsworthy content to health media. Industry news on topics such as COVID-19 and PFF Scholars kept PFF experts top-of-mind with trade media. Ambassador stories highlighted advocacy and fundraising efforts in local communities nationwide. Digital ads promoted the PFF as a resource on Facebook and LinkedIn. Spanish Facebook ads shared key symptoms of PF and provided links to online resources.

Pulmonary Fibrosis Awareness Month 2021:

We are stronger because of YOU!



The Bell Works water tower shined blue September 27-30 in Holmdel, New Jersey; Alicia Williams colored her hair blue in memory of her mother.



Dave and Candace took steps from Willis, TX

Thank you to everyone who participated in Pulmonary Fibrosis Awareness Month (PFAM) this past September. As a community, we made a tremendous impact in raising both awareness and funds to accelerate our mission forward

- Achieved one million impressions through your likes, shares, and comments on our social media channels
- Connected virtually through your stories and the creative ways that you took on our #BlueUp4PF campaign

Together, we strengthened our community. We are thrilled to announce that Pulmonary Fibrosis Awareness Month raised more than \$750,000 and garnered 810 million impressions through national media outlets!

Thank you for making these milestone accomplishments possible! It's never too early to start planning for PFAM. To get ready for 2022 and learn how you can make a difference, visit pulmonaryfibrosis.org/pfam.

Because of YOU, we:

- Launched our first ever National Walk Day and more than 1,200 participants brought the spirit of the walk to communities across the country
- Hosted 24 Team PFF events that included endurance challenges, golf tournaments, happy hours, and fitness classes
- Shined bright with 70 buildings and landmarks that turned blue in recognition of our signature color
- Showcased 30 facts about PF over 30 days to help educate the public about the symptoms and risk factors of the disease



Susan joined the PFF Walk from Moscow, ID.



The Savoca Family walked in Deer Park, IL

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.

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.

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, and Instagram at **@pfforg**, and on LinkedIn and YouTube at **/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** today.

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Broadway Belts for PFF!

**RETURNING FOR
ONE-NIGHT-ONLY
Monday, March 7, 2022
Edison Ballroom, New York City**

NEW this year, you can join virtually and stream the show LIVE from your living room!

To learn more or to purchase tickets, please visit ***BroadwayBeltsForPFF.org***.

