

PULMONARY FIBROSIS FOUNDATION

breathe

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OUR MISSION

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

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

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Pulmonary Fibrosis Foundation

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Letter from Our President and CEO

DEAR FRIENDS,

As 2019 comes to a close, I'm taking stock of the Pulmonary Fibrosis Foundation's many accomplishments over the past year—and I'm very pleased to focus on two transformational partnerships.

At our very successful PFF Summit 2019, we discussed future plans for our exciting new partnership with Three Lakes Partners, which is focused on our shared goals of driving awareness, improving quality of care and support for patients with PF, and accelerating the development of new therapies and cures. With Three Lakes Partners' support, we plan to expand and maximize the PFF Patient Registry and have launched a multichannel print and digital marketing campaign to target patients, families, and caregivers. Three Lakes Partners also generously supported the PFF Summit this year.

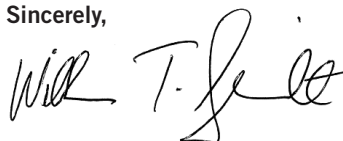
We're delighted, too, about our partnership in one of the largest research grants in the history of the pulmonary fibrosis community. The National Institutes of Health is awarding a \$22 million, six-year grant for the PRECISIONS study.

Led by co-principal investigators Fernando J. Martinez, MD, MS, and Imre Noth, MD, and incorporating many of the most prestigious researchers in pulmonary fibrosis and interstitial lung disease, PRECISIONS will use PFF Patient Registry data to move toward an innovative precision medicine approach to treating idiopathic pulmonary fibrosis. The study's aims include determining whether the drug known as NAC is an effective treatment for a subset of IPF patients, as well as converting the biorepository into data that will identify genetic risk, predict disease course, and calculate response to therapy for IPF and non-IPF ILDs. It's a project with enormous potential to change the course of IPF diagnosis and treatment.

The PFF's overall commitment to research continues to expand. The generosity of several longstanding and new donors enabled us to increase the number of PFF Scholars grants to six this cycle, representing a 50 percent increase. This issue also offers updates on the PFF Registry, Care Center Network, advocacy efforts, and other programming, as well as recaps of our successful Summit and PF Awareness Month activities. I think you'll enjoy reading about our multifaceted progress in all these areas.

And, as the calendar year winds down, please consider making a donation to support the PFF's critical and life-changing work. We celebrate all our accomplishments and your part in them—you're an important and irreplaceable ally in the fight against this deadly disease.

Sincerely,



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER



Topics for Support Groups:

Insight From Support Group Leader Mark McCormick



How do support group leaders decide what they're going to cover at meetings each month? It's easy—they ask the members.

“We’ve used flyers and surveys to ask members what they’re interested in learning about at the meetings,” said Mark McCormick, a PFF support group leader in Denver. “We discuss a myriad of topics and sometimes we repeat them after a year because we have new members coming on board.”

McCormick works with Katie Rosen, RN, MSN, ANP-C, a nurse practitioner and liaison between the support group and the staff at National Jewish Health. Rosen helps coordinate logistics, including speakers, and refreshments, for the meetings.

McCormick’s group typically features a presentation at every meeting. Often, the speakers are professionals such as dietitians, respiratory therapists, and researchers from National Jewish Health. “We’re very lucky because we have access to professionals right here in the hospital,” McCormick said.



Popular topics include pulmonary rehabilitation and breathing techniques, as well as how to use and travel with supplemental oxygen. A few years ago, McCormick reached out to the PFF to request an Ambassador to talk about the lung transplant journey. The presentation was a

hit, as several members at the time were facing the possibility of a transplant.

McCormick tries to find speakers who can address things that his members are concerned about, including support for caregivers. “It’s important for caregivers to understand they’ll burn out and they shouldn’t feel guilty because they need a break.”

“It’s important for caregivers to understand they’ll burn out and they shouldn’t feel guilty because they need a break.”

If a support group needs ideas or supplemental resources for a topic, McCormick says to look no further than the PFF’s Disease Education Webinar series. Not only will they find relevant content, but they will also find sources for additional information on each topic. The complete collection of webinars is available at pulmonaryfibrosis.org/webinars.

The PFF Support Group Network and the Leanne Storch Support Group Fund are sponsored by Friends of the Foundation and Genentech, a member of the Roche Group. The PFF Ambassador Program is sponsored by Boehringer Ingelheim and Genentech, a member of the Roche Group.



NEW EDUCATIONAL MATERIALS

PF Fact Sheet Series

Explore this collection of 13 fact sheets to learn about different types of pulmonary fibrosis and medication.

Oxygen Basics Booklet

The Oxygen Basics Booklet provides in-depth information about supplemental oxygen use.

The PFF also has two new resources for healthcare providers including the ILD Nursing and Allied Health Guide and the Pulmonary Rehabilitation Pocket Guide.

All of these materials are available for download at pulmonaryfibrosis.org. Reach out to the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or pcc@pulmonaryfibrosis.org to request free hard copies of these materials.



OXYGEN SURVEY UPDATE

Nearly 300 individuals participated in a Pulmonary Fibrosis Foundation follow-up survey gathering information from patients with lung disease who use supplemental oxygen. Many of the widespread problems with oxygen equipment delivery and service identified in the first survey, which took place in 2018, persisted into this year according to participants in the follow-up survey. Forty-seven percent of respondents reported problems with service, cost, flow rates, equipment reliability and convenience, or doctor's orders, and 52% reported no issues.

The PFF continues to monitor these issues, educate patients on effectively accessing and using supplemental oxygen, and advocate for more patient-friendly oxygen legislation and policy.



CONTACTING YOUR CONGRESSPERSON CAN YIELD BIG RESULTS

When pulmonary fibrosis patient Bill Burke of Williamsburg, Virginia, contacted his congressional representative's office requesting a meeting to advocate for PF patients' needs, he got a much bigger response than he expected. Burke's consultations with Rob Wittman's (VA-1) staff led to the congressman holding a town hall-style meeting with the Virginia Peninsula Pulmonary Fibrosis Support Group, founded and facilitated by Burke since mid-2017.

Wittman has a background in public health and is cosponsoring several health-related bills, including the Protecting Home Oxygen and Medical Equipment (HOME) Act of 2019. He has a solid understanding of challenges faced by home oxygen users—particularly those requiring liquid oxygen—following a drop in available suppliers resulting from recent Medicare reimbursement changes.

At the October 2 town hall, Wittman “spent more than 90 minutes listening to our group and stayed on for more discussion with me and the supplier,” Burke said. “Rep. Wittman mentioned adding a section about liquid oxygen to the home oxygen bill and exploring the possibility of setting up a capital investment tax credit to get more suppliers back into business.”

Of course, not every elected official already has Wittman's grasp of PF patients' issues—but by contacting your legislator, you can make a real difference in spreading awareness and advocating for greater research funding and more patient-friendly legislation.

“Out of this small meeting came some great ideas,” said Burke—and it wouldn't have happened unless Burke had taken the initiative to contact his congressional representative.

PFF Voices

A telephone-based support group held on the third Thursday of each month.

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

Dial In Phone Number: (571) 317-3116
Access Code: 124-558-453

PFF Caring Conversations

A telephone-based caregiver support group held on the first Tuesday of each month.

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

Dial In Phone Number: (646) 749-3129
Access Code: 220-929-629

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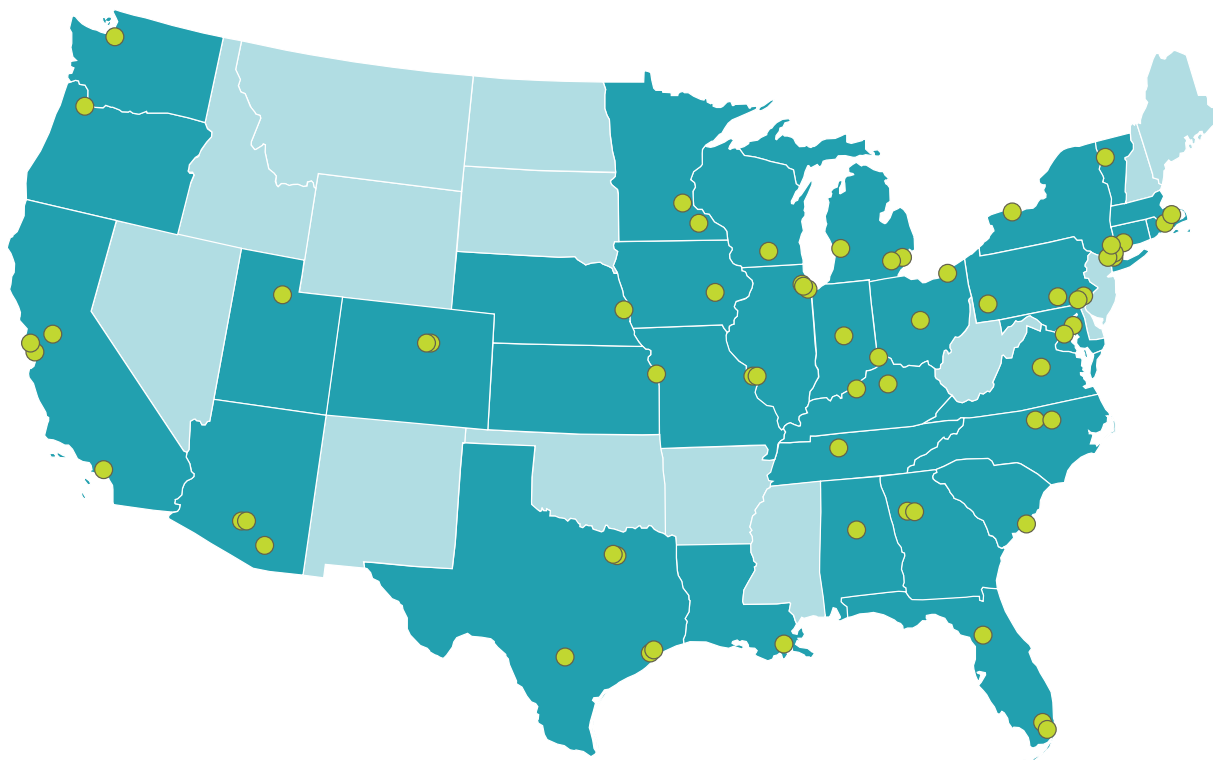


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For more information, call **844.TalkPFF**
or email pcc@pulmonaryfibrosis.org

PFF Adds Eight New Sites to Care Center Network



The Care Center Network now encompasses 68 medical centers in 33 states, following the addition of eight sites with recognized expertise in pulmonary fibrosis diagnosis, treatment, and patient support.

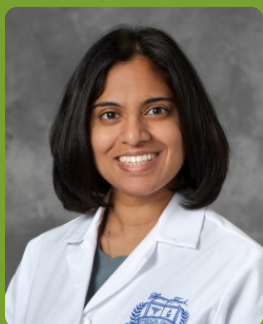
“Our growing network of centers has expanded to the states of Indiana, Nebraska, Oregon, and Vermont, increasing coverage in new geographic regions,” said Pauline Bianchi, vice president of research and development at the PFF.

The new sites include:

- Creighton University, Omaha, NE
- Emory University Hospital, Atlanta, GA
- Indiana University Health, Indianapolis, IN
- New York University School of Medicine, New York, NY
- The Oregon Clinic, Portland, OR
- The University of Vermont Medical Center, Burlington, VT
- Thomas Jefferson University Hospital, Philadelphia, PA
- University of Kentucky Research Foundation, Lexington, KY

Henry Ford Health System: Innovative Recordkeeping Improves Patient Care

Like many sites in the PFF Care Center Network (CCN), Henry Ford Health System holds multidisciplinary conferences—including pulmonologists, radiologists, pathologists, and others—to come to consensus diagnoses and establish care management plans. But Krishna Thavarajah, MD and her colleagues use an innovative means of recording those discussions that results in more complete and easily shareable information.



“For us, it’s really about using a team approach to guide patients,” says Thavarajah, director of the Henry Ford Health System’s interstitial lung disease program in Detroit.

Her partner, Jeffrey Jennings, MD, created a sophisticated website and database that tracks

care conferences, recommendations, patient history, and more. “Because this information is behind a firewall, we can document as we meet and easily share the information with other physicians,” Thavarajah says.

To complement the program’s ILD Clinic, the team has set up a combined ILD-Rheumatology Clinic as a one-stop resource for patients who have ILD related to a rheumatologic condition.

“Even for patients we won’t be following in the future, our goal is to provide a unified diagnosis and treatment plan for them and their health care providers,” Thavarajah says.

University of Vermont Health System: Country Music Concert Raises Funds and Awareness



When the University of Vermont Health Network’s recently formed PF support group—the first in Vermont—decided to put on a fundraiser, Prema Menon, MD, PhD, drew on her love of country music to help create a singular event.

Support group members wanted to increase local awareness of PF while raising funds for the travel costs of attendees from across Vermont, New Hampshire, and even rural New York. Menon, who directs UVM’s interstitial lung disease program, is a devoted fan of Nashville-based singer Jamie Lee Thurston, a native of Vermont. Thurston’s mother and aunt are both living with PF, as is the wife of support group member Moe Dubois, a performer in the classic rock band Quadra. Together, Thurston’s band and Quadra gave a concert in a Burlington IMAX theater seating more than 450.

“So many great things happened that day,” says Menon. “We sold out the concert, including standing-room only tickets. Jamie Lee and Moe told their family PF stories on stage. Our team was wearing aqua ‘Breathe Vermont’ shirts and shared PF information with all the people who came up to us. Jamie Lee even did a radio interview about PF and we got local news coverage.”

Besides boosting local awareness, the event raised funds to enable three support group families to attend the PFF Summit 2019—and will eventually support long-distance travelers to support group

meetings. “We’re thrilled and are already planning next year’s concert,” Menon says.



PF Research Grant Will Lay Foundation for Precision PF Medicine

The PFF Care Center Network (CCN) and PFF Patient Registry are central to a transformational National Institutes of Health-funded study that has the potential to move the diagnosis and treatment of idiopathic pulmonary fibrosis (IPF) into the era of precision medicine.

This study is supported in part by a \$22 million grant from the National Institutes of Health as well as contributions from Three Lakes Partners.

Led by co-principal investigators Fernando J. Martinez, MD, MS, and Imre Noth, MD, PRECISIONS (**P**rospective **t**reatment **E**fficiency in IPF **u**sing **g**enotype for **N**ac **S**election) study will include a number of prominent IPF and interstitial lung disease (ILD) researchers, including Kevin Flaherty, MD, MS, chair of the PFF CCN and Registry Steering Committee.

“Our overall objective is to efficiently conduct a novel precision genotype-based trial in IPF, while leveraging this unique biospecimen collection to molecularly characterize a broad range of ILDs, and identify genetic variants associated with IPF risk,” Noth says.

Building on previous research and using data from the PFF Patient Registry biorepository, the team will use a precision genotype approach to determine whether N-Acetyl-cysteine (NAC) is an effective treatment in a subset of patients with IPF.

Beyond this trial, the study will set the stage for a wide range of important future research. PRECISIONS’s investigators will characterize gene expression and protein biomarkers on the entire PFF registry cohort and define “signatures” for distinguishing IPF from non-IPF ILDs. This approach will help define individual diseases and predict disease course and response to therapy.

PRECISIONS will also conduct whole genome sequencing of the entire PFF cohort (estimated at 1,200 IPF and 800 non-IPF patients) to detect novel genetic associations for IPF and ILD risk. This matched genotypic and phenotypic data will create an open access biorepository for future investigations.

“As a principal investigator, I knew the PFF Registry was key to the success of the project,” says Martinez. “Studies such as PRECISIONS would be impractical without the Registry’s expert clinical and investigative groups, funding from both federal and non-federal sources, and a large number of patients with diverse PF disorders who have been recruited and characterized in a systematic fashion with stored biologic samples and consent for future research.”

PFF PATIENT REGISTRY 2.0: A MORE DIRECT RELATIONSHIP WITH PATIENTS



The PFF Patient Registry recently closed to new enrollments after reaching its initial registration goals. Now, the Foundation is defining next steps—nicknamed Registry 2.0 and set to launch in 2020.

“We’re seeking additional funding to continue and expand the Registry,” says Rex Edwards,

vice president for the PFF Patient Registry. “To reach its full potential, we need to reopen to patient enrollment to repopulate as patients leave the Registry.”

While planning and fundraising processes are still under way, Edwards notes that a major element of Registry 2.0 will be a more direct relationship with patients.

Previously, all Registry participants joined through their PFF Care Center Network sites. Future participants will be able to sign up directly with the Registry, sharing more patient-recorded information that may be useful to specific researchers now and in the future.

“We’re building a more robust data set for PF research questions we may not even have yet—that may develop down the road,” Edwards says.

Largest PFF Summit to Date Welcomes 950 Attendees



The PFF Summit 2019, held from November 7-9 in San Antonio, Texas provided an innovative educational program that focused on timely topics for all attendees.

The conference kicked off on Thursday with an all-day session tailored for community pulmonologists and ILD fellows, a new half-day session designed for nurses and allied healthcare professionals, and an afternoon session created for newly diagnosed patients and their caregivers.

Friday and Saturday began with plenary sessions designed for all audience members. Each plenary session featured engaging speakers who weaved their expertise into the session's theme and set the tone for an exciting and productive day of knowledge, sharing, and discussion.

Professional sessions new to this year concentrated on senescence, transcriptomics, and the importance of PF registries. Previous PFF research awardees presented summaries of ongoing projects to begin two of the scientific sessions.

For patients, caregivers, transplant recipients, and those who have lost a loved one, the PFF featured new content on grief writing, health and wellness with PF, emergency preparedness, and the value of meditation, mindfulness, and movement.

Friday evening featured a guitar performance by Bernie Williams, Four-time World Series Champion with the Yankees and IPF Breathless Spokesperson. Williams played a melodic rendition of "Take Me Out to the Ballgame" and invited the PF community to sing along.

The evening concluded with the inaugural Honoring Ceremony. Prior to the conference, registrants could opt to submit photos and names of any loved ones lost to the disease. Their names and photographs were displayed in a moving video at the end of the Networking Dinner.

To view the full program for PFF Summit 2019, please visit pffsummit.org. All sessions at PFF Summit 2019 were recorded and will be available on YouTube in early 2020.

"The PFF Summit was a well-organized, wonderful conference. There was so much positive energy and I walked away feeling like I had new tools to use. It was great."
– Attendee living with PF

"Networking with patients, physicians, and researchers is what I liked best about the PFF Summit. The cocktail hour on Thursday and dinner on Friday was outstanding!"
– PF Caregiver

Poster Winners and Honorable Mentions

Academic posters were reviewed by a panel from the PFF's Research Review Committee, who selected the top five posters. The top three presenting authors received cash awards, and all five received travel awards. The poster awardees were recognized at the Networking Dinner, and the top three presented a brief summary of their research during scientific sessions.

1ST PLACE

Jeremy Katzen, MD

Perelman School of Medicine, University of Pennsylvania
Poster Title: Transcriptional profiling of alveolar epithelial cells from distinct murine surfactant protein-c (SFTPC) mutation pulmonary fibrosis models reveals common changes in metabolic reprogramming and fibrogenic pathways

2ND PLACE

Farida Ahangari, MD

Yale University
Poster title: Saracatinib, a selective Src kinase inhibitor, blocks fibrogenic responses in in-vitro, in-vivo and ex-vivo models of pulmonary fibrosis



Poster winners from left to right: Dr. Jeremy Katzen, Dr. Tejaswini Kulkarni, Dr. Farida Ahangari, Dr. Avraham Unterman, and Mr. Arun Christian Habermann

3RD PLACE

Avraham Unterman, MD

Yale University
Poster Title: Single-cell RNA sequencing of peripheral blood mononuclear cells in IPF reveals immune cells changes reflective of disease progression

Honorable Mentions

Arun Christian Habermann, AB

Vanderbilt University Medical Center
Poster Title: Single-cell analysis of lung epithelial remodeling in pulmonary fibrosis

Tejaswini Kulkarni, MD, MPH

University of Alabama at Birmingham
Poster Title: Correlates of survival after autoantibody reduction therapy for acute IPF exacerbations

Clinical Trials Innovation Series

The Clinical Trials Innovation Series highlighted some of the most exciting advancements in drug development for the PF community. Over a two-day period, ten companies took the stage to present information in 10-minute slots.

The Friday portion featured Boehringer Ingelheim and Genentech, both with products approved by the FDA for the treatment of IPF. Veracyte presented information on its commercially available genomic classifier for IPF, and FibroGen and Galapagos NV each shared information about its phase 3 clinical trials.

On Saturday, attendees heard from Celgene, Galecto, Pliant, and Respivant—all with active Phase 2 clinical trials—and from Bristol-Myers Squibb, now recruiting for a Phase 1 study.

"Having been to other conferences, I found this one to be very well-organized and geared toward all facets of PF. My expectations were exceeded."
— Healthcare professional

CME/MOC/CE Information

The PFF Summit 2019 was an approved activity for continuing medical education (CME), Maintenance of Certification (MOC), and continuing education (CE) credits. CME consists of educational activities and opportunities which serve to maintain, develop, or increase the knowledge, skills, professional performance, and relationships that a physician, nurse, or allied healthcare professional uses to provide services for patients, the public, or the profession. This year's activity was designed to meet the educational need of physicians, physician's assistants, respiratory therapists, pharmacists, nurse practitioners, and registered nurses involved in the care of patients with pulmonary fibrosis.

For detailed information about how to obtain your CME, MOC, or CE credit for the PFF Summit 2019, please visit pffsummit.org.

FACULTY LISTING

Amy Case, MD
 Andreas Guenther, MD
 Andrew Limper, MD
 Anne Dimmock, MS
 Anne Turner, RN4,
 BSN, JD
 Anoop M. Nambiar,
 MD, MS
 Antje Prasse, MD
 Ayodeji Adegunsoye, MD
 Barbra Swanson, MS, ND,
 RDN, LD
 Bill Schmidt
 Bray Patrick-Lake, MFS
 Carolyn Spada, BSN, RN
 Christine Kim Garcia,
 MD, PhD
 Cory Hogaboam, PhD
 Dan Culver, DO
 Dave Sherry
 David Lynch, MB, BCH
 Debbie Herndon
 Deborah Gillman, PhD
 Deborah Levine, MD
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 Fernando Martinez, MD
 Ganesh Raghu, MD
 Gregory P. Cosgrove, MD
 Harold R. Collard, MD
 Imre Noth, MD
 Ivan Rosas, MD

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 Pam Tishendorf
 Patricia Sime, MD
 Pauline Bianchi, BSN, RN
 Prema Menon, MD, PhD



PFF Summit 2019 Co-Chairs from left to right:
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 FNP-C
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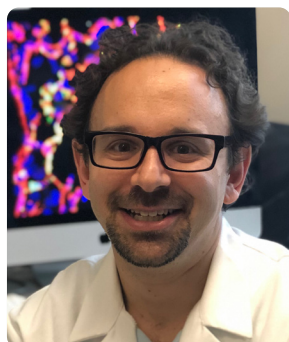


PFF Research Continues to Expand with New PFF Scholars

The Foundation continues to expand its commitment to broadening its research portfolio. The PFF Scholars program supports early-career investigators in research that may lead to prestigious grants from the National Institutes of Health (NIH) and other important funding organizations.

“Through the PFF Scholars, the Foundation is supporting potentially lifelong research interests by enhancing investigators’ ability to secure K-level (career development awards) or R-level (research grants) funding from the NIH,” says Joseph Lasky, MD, chair of the Research Review Committee. “Our research funding program creates a significant return on donors’ and the Foundation’s research investment,” he adds.

Thanks to special funding received from both new and longtime donors, the Foundation is able to support six PFF Scholars for the current research cycle. Read about their research projects below.



JEREMY KATZEN, MD

**Perelman School of Medicine,
University of Pennsylvania**

Funded by Boehringer
Ingelheim Pharmaceuticals, Inc.

Alveolar type-2 (AT2) cells are important cellular components of normal lung function and repair. It is believed that when AT2 cell function is impaired—for

example, in the way these cells process essential proteins—cellular death ensues. This may contribute to the initiation and progression of the fibrotic process in the lung. To investigate this process, Katzen’s team developed a mouse model in which human mutations in one of the essential genes produced in AT2 cells can be turned on and off and the abnormal processing of specific proteins with associated spontaneous fibrosis can be studied. “We hope this will lead to an enhanced understanding of the events regulating the initiation and progression of lung fibrosis,” Katzen says.



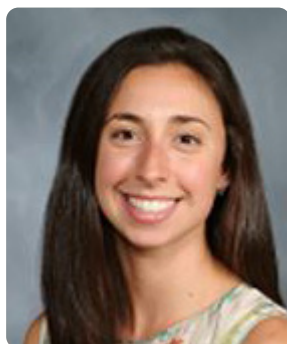
SARAH O’BEIRNE, PHD

**Joan and Sanford I. Weill
Medical College of
Cornell University**

Funded by Boehringer Ingelheim
Pharmaceuticals, Inc.

Hypersensitivity pneumonitis (HP) is a complex syndrome of lung diseases caused by the inhalation of a variety of organic particles

and low molecular weight chemical compounds. This provokes an exaggerated immune response in the airways and lung tissue of susceptible individuals and leads to the development of interstitial lung disease (ILD). To better understand the genes aberrantly activated or repressed in the lung, O’Beirne’s team is performing cell-specific RNA sequencing of activated cellular constituents—lymphocytes and macrophages—obtained during bronchoscopy. “We’ll obtain a better understanding of the mechanisms underlying the abnormal immune response to different inhaled proteins and particles and possibly identify a cellular signature for diagnostic and prognostic use,” O’Beirne says.



KERRI ARONSON, MD
Joan and Sanford I. Weill
Medical College of Cornell
University

Funded by Chuck McQuaid

Chronic hypersensitivity pneumonitis (CHP) may result in a diverse set of symptoms that impact patients' function and overall well-being. Standard

assessments of disease severity—pulmonary function testing, high resolution CT scans, and lung pathology—often do not correlate with the impact of the disease. Patient-reported outcomes, such as Health Related Quality of Life (HRQOL) questionnaires, offer patient-centered perspectives on disease severity and treatment effectiveness and enhance shared decision-making. Aronson's team is developing the first CHP-specific HRQOL tool to enable reliable and relevant patient assessments by uncovering disease effects and treatments specific to CHP. "Our long-term goal is to develop a reliable approach to assess and quantify therapeutic effects that are most important to patients living with CHP," Aronson explains.

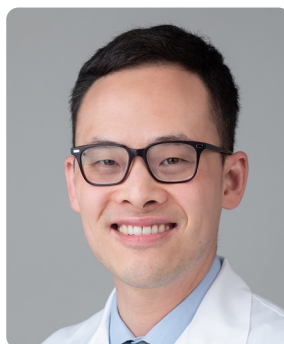


ERICA FARRAND, MD
University of California,
San Francisco

Funded by the Cohen, Veilleux, Tocher, and Feiger Families in fond memory of Eli Cohen.

Acute deteriorations or exacerbations of idiopathic pulmonary fibrosis (AE-IPF) are unpredictable and highly morbid

events, but only limited data guides AE-IPF treatment strategies, including the use of anti-inflammatory therapy. The use of real-world data methods is a novel approach to closing the evidence gap. Electronic health records provide powerful tools for clinical research that have proven successful in evaluating disease epidemiology, healthcare resource utilization, management patterns, and outcomes. "We'll use real-world data from two large healthcare systems, University of California San Francisco and Kaiser Permanente Northern California, to study AE-IPF epidemiology, the nature and variability of clinical management of AE-IPF across care settings, and the impact of recommended management strategies for AE-IPF on clinical outcomes," Farrand says.



JOHN KIM, MD
Rectors and Visitors
of the University of Virginia

Partially funded by the Otto F. Krauss and Jenny H. Krauss Charitable Foundation Trust in memory of Stephen N. Dirks

Modifiable risk factors may be therapeutic targets that slow and prevent IPF. Kim's research

has focused on components of lipids or "fat" in the blood, polyunsaturated fatty acids (PUFAs), as a potential risk factor in ILD. "My central hypothesis, based on my preliminary data, is that higher plasma levels of omega-3 fatty acids will be associated with less disease severity and progression in adults with IPF," he says. His team will evaluate the role of specialized pro-resolving lipid mediators in PUFAs and maintenance of the length of telomeres, structures that protect the ends of chromosomes. Both have been important modifying factors in other diseases and IPF.



ANDREW HAAK, MD
Mayo Clinic

Idiopathic pulmonary fibrosis is an aggressive and fatal disease of the lung characterized by uncontrolled deposition and diminished clearance of fibrous connective proteins (scar tissue). Therapies to treat this pathological process are limited, making

further investigations to understand the mechanisms which drive this fatal disease highly relevant. The processes which promote the chronic nature and prevent resolution of pulmonary fibrosis are not understood. Haak's team will investigate the role catecholamines—hormones made by our adrenal glands, including dopamine, norepinephrine, and epinephrine—play in regulating the pathology of pulmonary fibrosis and "set out to identify a potential therapeutic strategy that not only halts the progression of fibrosis but promotes reversal of the disease," Haak says.

Remembering Leanne Storch, Dedicated PF Patient Advocate

When life gives you lemons, make lemonade.” That’s what Michael Storch, husband of the late Leanne Storch, says was his wife’s philosophy of living. A tireless advocate for PF patients and an early pillar of the Foundation, Leanne passed away May 9, 2019.

When Leanne was diagnosed with IPF in 2003, she was laid off from her job—but she turned these setbacks into a new career and opportunity to help others. “By chance, the PFF was looking for an assistant to the executive director and one of the founders, Dr. Michael Rosenzweig,” Michael Storch remembers. “From answering the phones, consoling families, and giving advice to patients, Leanne became associate vice president of patient outreach and succeeded Dr. Rosenzweig as executive director of the Foundation.”

“Leanne put significant effort toward ensuring the patient voice was part of our organization,” says Scott Staszak, chief operating officer of the PFF. “She was devoted to speaking to newly diagnosed patients, sharing her own experiences to provide assurance that they weren’t alone in their journey.”

Leanne served as PFF executive director from 2008-10 and received a 2011 award for outstanding service to the organization. During her time at the Foundation and throughout her life, she remained a dedicated champion for the PF community. “Leanne traveled all over the U.S.—she was an expert in getting her oxygen needs met wherever she went—attending Summits and



helping patients and families do fundraisers and form support groups,” Michael remembers.

For many years, she hosted a suburban Chicago support group with her husband as her loyal assistant. The PFF’s Leanne Storch Support Group Fund, established in 2012, honors her extraordinary commitment to patient support through grants to support groups

across the nation. “Support groups were very important to my mom, and the fund is a beautiful way her name lives on,” says Leanne’s son, Brian.

Throughout her PF journey, which included a 2014 lung transplant, Leanne drew upon her deep spirituality and kept a positive outlook she passed along to other PF patients.

“She’d always been a caretaker. With the Pulmonary Fibrosis Foundation, she found a niche,” says Leanne’s daughter, Monica. “My mom got her happiness from helping other people. She was good at making every single person she interacted with feel important. She really listened, and sometimes that’s all a person needs. She gave hope to a lot of people.”

“She was caring, thoughtful, selfless, and tough,” Brian adds. “Even in a very challenging situation, Mom stayed positive, which helped her not only manage her own disease, but also help others with PF. She just kept fighting.”

“She was caring,
thoughtful, selfless,
and tough. She just
kept fighting.”

Welcome New PFF Board Member Dana Ball



At this year's PFF Summit, Ball (left) joined co-chair Dot Delarosa (center) and PFF President and CEO William T. Schmidt (right) at Friday morning's session, 'Moving Forward Together.'



Dana Ball is the Executive Director of Three Lakes Partners, a family founded philanthropic initiative dedicated to improving care and accelerating the development of promising

new treatments and technologies for pulmonary fibrosis.

Ball's career started more than 30 years ago as a patient advocate during the HIV/AIDS crisis and includes nearly two decades focused on advancing scientific and clinical programs in type 1 diabetes (T1D).

"My experience in HIV/AIDS and type 1 diabetes over the past 30 years has taught me that no single organization, researcher, or company can solve complicated diseases or deliver a cure," said Ball. "It takes a village to develop a plan to improve care today while we better understand the disease and develop new life-saving therapies."

Ball was co-founder and CEO of T1D Exchange, a patient-centered organization dedicated to improving care and patient

outcomes. Before founding T1D Exchange, Ball was selected as an inaugural executive and program director for the T1D program at The Leona M. and Harry B. Helmsley Charitable Trust. There, he played a leadership role in the development of the Trust's strategic and operational plans and led their T1D Program which focused on understanding the root cause of T1D and accelerating the development and delivery of novel devices, therapeutics, and technologies. Ball was first introduced to T1D through his work as Executive Director with the Iacocca Family Foundation.

Throughout Ball's career, he has formed successful collaborations and created partnerships with organizations such as the Juvenile Diabetes Research Foundation (JDRF), the Pulmonary Fibrosis Foundation, and a range of government and industry stakeholders.

"I know for patients and caregivers change can't come fast enough, but I believe we are at a critical tipping point for rapid awareness and progress that will allow us to diagnose PF earlier and intervene with more effective and tolerable therapies," said Ball. "I think now, more than ever, patients and family engagement is critical to ensure we can accelerate progress through participation in research studies and clinical trials. We know we can do this as we've done in other disease areas. The secret to success is the power of the patient community."

Stories of Action: Making an Impact on the Community

June McConnell of Montesano, Washington, and Rick Garnett, of Denver, Colorado, are siblings whose worlds were turned upside down in June 2017 when they both received a diagnosis of idiopathic pulmonary fibrosis.

“It took about a year to get my feet back on the ground,” said McConnell. “I thought, we’ve got to do something.”

They often talked about dealing with the disease. Then, they started to discuss an idea for an event that they could do together—but in their own communities.

The “Two Cities - One Cause” walk was born as a part of the community walk program. The two walks were held in Olympia, Washington (pictured above) and Denver, Colorado (pictured below).



They planned for August 11 with a goal to raise \$5,000.

McConnell contacted the PFF and received the Community Walk Guide, an instrumental tool in the planning of the event logistics, fundraising, and promotion.

“June’s idea to do two cities on the same day gave us a common cause,” said Garnett. “Getting the word out for early detection was my motivation.”

While each event was unique, both were successful. Now they’ve surpassed their fundraising goal with just over \$5,000 raised and have begun planning the event for next August.



Stacy Filion's father, Bernie Fudala, was diagnosed with pulmonary fibrosis in 2015. At the time, her family had never heard of PF and they were shocked when they learned how serious the disease was.



"We felt so lost when my dad was diagnosed," said Filion. "We didn't know what to do."

Filion and her family joined Team PFF and hosted "Bernie's 'Breathing Brigade'" in September 2017 to raise awareness and funds toward a cure. Held in Manchester, New Hampshire, Filion charged \$20 per person for a brunch at her family's home and raised \$1,500 the first year. Her father was in awe that so many people came to the event and donated to support the cause. Sadly, Fudala passed away on November 8 that year.

In 2018, Filion moved the event to a private venue and changed the theme from brunch to an afternoon bash, complete with raffle baskets, which were a hit. They welcomed 54 people and raised an amazing \$2,000.

Raise funds and
spread awareness -
start an event in your
community!

This year, nearly 100 people attended the bash. Filion introduced a giving wall with envelopes indicating dollar amounts for donations. The event topped out at \$4,850.

Filion always starts the event by greeting people and explaining what pulmonary fibrosis is. "We've educated a lot of family, friends and colleagues," said Filion.

"Once you start talking about it, you realize there are many people with a connection to this disease." Filion is already planning next year's bash.

"Even though my dad's gone, I want to help other people that are getting this diagnosis," said Filion. "This is my way of keeping his memory alive and telling him we're still in the fight for everyone else."

For more information or to start your community event, please contact Jackie Williams, development manager, at jwilliams@pulmonaryfibrosis.org.

A Wedding Wish In Honor of My Brother

By Chris Cosola



My brother, Carl Cosola, was surrounded by family when he passed away on June 25, 2019 in Walnut Creek, California. He was a vibrant 67-year-old who was slowed by PF but was engaged with others to the end. Carl was happy, industrious, loving, and talented.

Unfortunately, PF has affected at least two generations of our family. As my fiancée and I planned our wedding, which took place after Carl passed away, we realized that what we wanted most was to reduce the grief caused by pulmonary fibrosis. Our invitations asked that no direct gifts be given to us, but rather to the PFF as a tribute to Carl. It was heart-warming to see our friends grant our wish to honor Carl's memory.

PFF's tribute program is a heartfelt and impactful way to honor a loved one. Leave a lasting legacy to the community by considering donations in lieu of gifts, flowers, or in recognition of a lifetime event. For more information, contact Jake Meding, annual fund manager at jmeding@pulmonaryfibrosis.org.

The Albert Rose Legacy Society: Carmela's Story



My name is Carmela Vasta and in March 2016, I was diagnosed with IPF. After a long hospitalization and recovery from a serious exacerbation, I was released to my family's care. I am on 4.5 liters of oxygen 24/7 and will need oxygen

for the rest of my life. The diagnosis has changed my life in ways I could have never imagined.

Even now on a daily basis, I continue to adjust to the limitations and debilitation imposed by the disease. Recently, I joined the Albert Rose Legacy Society. Funding research and clinical trials through a planned gift is important to me as it will help improve the lives of those in need for many years to come. Please consider joining the Albert Rose Legacy Society by making your planned gift today at pulmonaryfibrosis.org/planned-giving.

For more information, please contact Seth Klein, Vice President of Development at sklein@pulmonaryfibrosis.org.

Stepping Toward a Cure with the PFF Walk



Record participation from 2,400 attendees at the PFF Walks nationwide show the strength and commitment of the PF community. Launched in 2017 with the PFF Walk Chicago, the event expanded

to New York and Washington D.C. in 2018, and to Dallas this year. Since its inception, the PFF Walk program has raised an astonishing **\$1.6 million dollars** to fund vital research and continue important patient programs.

San Francisco is the next destination to host a PFF Walk in 2020. "We are thrilled to bring the PFF Walk to San Francisco and the Pacific Northwest region," said Amy Wardzala, director of special events at the PFF. "We have a large, enthusiastic PF community there eager to join us in raising funds and awareness."

Virtual and community walks take place throughout the year. Visit the PFF website, pulmonaryfibrosis.org, to learn more about joining or hosting a walk.

For more information on how to get involved or to receive a copy of our save the date postcard, please contact Emily Smith, development manager, at esmith@pulmonaryfibrosis.org.

Remember the PFF During This Season of Giving

The PFF's annual Fall Appeal is underway with a goal of raising \$230,000. This annual fundraising campaign provides a special opportunity to support major PFF programs including research initiatives such as the PFF Patient Registry, educational resources like the new videos in the "Life With PF" series, and advocacy outreach to inform elected officials about the urgent issues facing the community.

In addition to making a donation to the PFF, you can help by inviting your family and friends to support the cause. People are often eager to step forward when they know a cause is important to a loved one.

Your support will bring us closer to a world without pulmonary fibrosis. Consider giving today at bit.ly/fallpff2019.



HITTING THE HIGH NOTES

10 Years of Broadway's Best

Broadway Belts for PFF! celebrates ten years of glitz, glamor, and Broadway's best on Monday, February 24, 2020 at the Edison Ballroom in New York City. Julie Halston, actress and comedienne, will once again host the star-studded evening which showcases Broadway's hottest performers belting out their favorite tunes to benefit the Pulmonary Fibrosis Foundation. Join us for the PFF's single largest annual fundraiser!



A star-studded cast of Academy, Tony, Oscar, and Golden Globe award-winning artists, including icons Joel Grey and Darlene Love grace the Birdland stage.

Broadway Belts for PFF! began as Songs for Mike: A Benefit Honoring Michael Kuchwara and featured a surprise performance from legendary Liza Minnelli.



2011

2012

Tony and Golden Globe award-winner, Linda Lavin, surprises guests as the featured performance.



Tony Danza charms guests as the headliner and the event breaks a record with more than \$100,000 raised.

2013

2014

Tony-winner Annaleigh Ashford joins a talented cast of performers for this special evening.



Tony-winner Daveed Diggs of *Hamilton* debuts his original rap, "Breathe," a piece he wrote for the event that detailed the difficulties of living with this debilitating disease.

2015

2016

R&B/pop-icon and Broadway star Stephanie Mills delivers an unforgettable, once-in-a-lifetime performance.



The original cast and creative team of *Hairspray* featuring Tony-winners Marissa Jaret Winokur, Harvey Fierstein, Marc Shaiman and Scott Wittman band together for Sweet-16 performance.

2017

2018

Introduced the Ralph Howard Legacy award in memory of Halston's husband, Ralph Howard, who passed away due to complications from PF in August 2018. The award recognizes individuals who have demonstrated commitment to the PF community, and embody Ralph's mission of supporting talent through mentorship, opportunity, and education.



2019

2020

SAVE THE DATE

Monday, February 24, 2020! Sponsorship opportunities and tickets are available now and will sell out. For more information and to secure your seat for this unforgettable evening, visit

BroadwayBeltsforPFF.org

Three Lakes Partners and the PFF Join Forces to Battle PF

In a new call to arms in the fight against pulmonary fibrosis, Three Lakes Partners and the Pulmonary Fibrosis Foundation have joined forces to combat the disease.

Three Lakes Partners, a philanthropic organization founded by a family affected by pulmonary fibrosis, has provided substantial funding to the PFF to expand programs focused on driving awareness and accelerating the development of new therapies and cures for the disease. The partnership was announced in September during Pulmonary Fibrosis Awareness Month.

“Together,
we can beat this
disease, but we
need your help.”

“The goal of the partnership is to establish a long-term collaboration designed to leverage each organization’s resources to generate the greatest impact on those affected by PF and their loved ones,” said Dana Ball, executive director of Three Lakes Partners.

Funding from Three Lakes Partners is helping to maximize the PFF Patient Registry. Three Lakes Partners also became a sponsor of the PFF Summit 2019 in San Antonio. In addition, the gift supported a multichannel public awareness campaign.

“Currently, many patients go years before finally getting an accurate diagnosis. We want people to not only know about PF, but to recognize the symptoms and risk factors so they can begin treatment as soon as possible,” said Ball.

The campaign featured two animated characters, Norm and Jennifer, designed to illustrate the experiences of patients and caregivers. They were introduced in digital, social media, broadcast, and print advertisements in Chicago this fall.

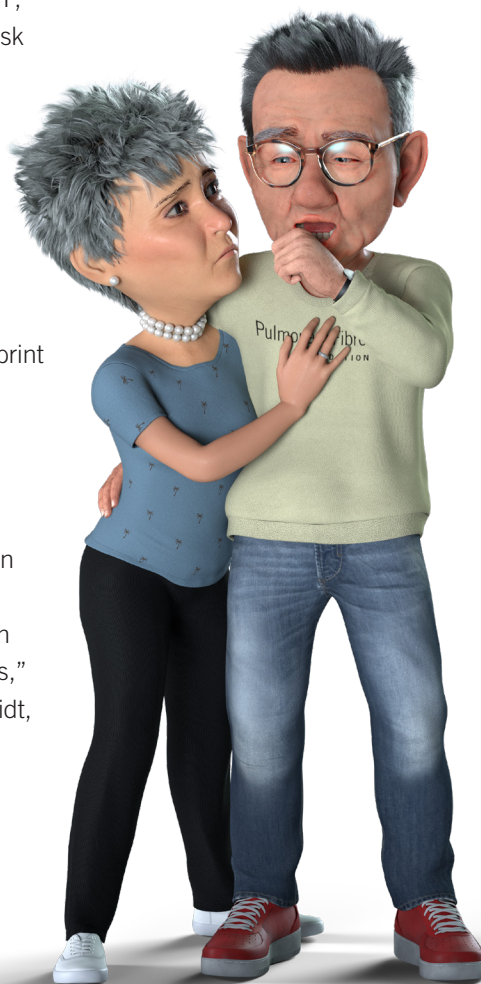
The campaign will expand into additional markets next year.

“We have already seen exciting results from our collaboration with Three Lakes Partners,” said William T. Schmidt, president and CEO of

the PFF. “The awareness campaign produced significant interest in our educational resources, online tools and support programs for patients and their families.”

The PFF and Three Lakes Partners are encouraging donors to support this important work by contributing to the PFF.

“Together, we can beat this disease, but we need your help,” said Schmidt. “We invite everyone to join us by becoming an advocate for better resources for the community, participating in studies and clinical trials, and donating to critical research and care programs.”



Pulmonary Fibrosis Awareness Month 2019



Pictured: The James S. McDonnell Planetarium in St. Louis, MO shined blue for Pulmonary Fibrosis Awareness Month on September 7th, 2019.

In September, the Foundation observed Pulmonary Fibrosis Awareness Month and celebrated the community through a robust campaign on Facebook, Twitter, and Instagram.

The PFF amped up its social media presence by sharing daily stories in the Portraits of PF series, 30 Facts In 30 Days, dozens of #BlueUp4PF images from the community and worldwide landmarks, event photos, and much more.

This year, the Foundation introduced a brand new call to action: making a gift on September 30, the Foundation's new Day of Giving. The goal of the inaugural Day of Giving was to raise \$25,000, but thanks to the dedication of passionate supporters like you, we surpassed our goal and raised nearly \$30,000!

The month wrapped up with unprecedented success. More than 1.6 million people on social media saw PFF content and learned about pulmonary fibrosis, and more than 10,000 people visited the PFF website to learn about the disease and how the Foundation can help.

Media coverage of PF and people impacted by the disease appeared in major outlets including the TodayShow.com, Chicago Tribune, Clinical Leader, and Healio.

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Thank you to everyone who made Pulmonary Fibrosis Awareness Month 2019 a resounding success. To learn how you can get involved with the Foundation, please see Ways to Get Involved on page 22.

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** and visit the “Get Involved” section or call us at **844.TalkPFF (844.825.5733)**.

ADVOCACY

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

ATTEND AN EVENT

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

FUNDRAISE FOR TEAM PFF

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



PFF WALK

Join us for the PFF Walk in New York City, Chicago, Washington D.C., Dallas, virtually, and new in 2020, San Francisco! Dates will be announced soon. The PFF Walk offers an inclusive opportunity for those who have been touched by pulmonary fibrosis to unite in the search for a cure while sharing stories, celebrating loved ones, and walking together with the community of patients, caregivers, healthcare professionals, and friends.

PULMONARY FIBROSIS AWARENESS MONTH

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

SHARE YOUR STORY

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

SHOP PFF

Shop PFF merchandise is an excellent conversation starter, perfect for handing out at awareness and fundraising events. From bracelets to t-shirts to mugs and more, Shop PFF has something for everyone.

Visit Shop-PFF.com today.



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The Pulmonary Fibrosis Foundation rates among top charities in the U.S. The PFF has a three-star rating from Charity Navigator and is a Better Business Bureau accredited charity. The Foundation has met all of the requirements of the National Health Council Standards of Excellence Certification Program®.



Pulmonary Fibrosis

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