

PULMONARY FIBROSIS FOUNDATION


# breathe

SUMMER 2022



A walking journey across  
the U.S. in honor of  
**Mary E. Hesch**  
to raise awareness of  
**pulmonary fibrosis**

I am fundraising in honor of  
my mother to find a cure for  
**pulmonary fibrosis**.  
Read my story and donate at  
[bit.ly/maryhesch](https://bit.ly/maryhesch)

 Pulmonary Fibrosis Foundation™



A pilgrimage of love.  
Read Mary Hesch's  
story on page 18.

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## OUR MISSION

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

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



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### Pulmonary Fibrosis Foundation

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# Letter from Our President and CEO

## DEAR FRIENDS,

After more than two years of learning how to co-exist with COVID-19, I continue to be humbled and grateful for the dedication and resourcefulness we've all seen from our healthcare providers throughout the pandemic. And I remain impressed by the continued energy and resilience of the pulmonary fibrosis (PF) community. Our collective willingness to embrace new approaches has meant that we at the Pulmonary Fibrosis Foundation (PFF) have continued to progress in our mission of accelerating the development of new treatments and improving care for people living with PF, all while providing unequalled support to those who care for them.

One notable example of this embrace of new approaches was last year's success with pivoting our beloved PFF Walk from live gatherings to fully virtual events. Despite the challenges, the PFF Walk raised more than \$570,000 in 2021, which is a huge tribute to our donors and volunteers. And now I'm delighted to share that PFF Walk 2022 will return to the familiar series of live events we have all missed so much!

Another ongoing priority is our FDA engagement project, which is an ambitious effort to develop new, more clinically relevant ways for how we measure success in PF clinical trials. The PFF has convened a working group of key opinion leaders, including notable scientific researchers and leading industry voices, as well as a patient living with PF for the personal perspective that only someone with firsthand experience can provide. Once we have successfully summarized the current state of PF research and clinical care, along with recommendations for additional drug trial measures and trial designs, in a single document for publication, we will start to engage the FDA directly. If we can develop a new clinical trial endpoint acceptable to the FDA, that might help speed current and future clinical trials. This would be an enormous benefit to all in our community.

Regarding the all-important issue of supplemental oxygen, the PFF is continuing to work with other advocacy groups in respiratory medicine, including the American Thoracic Society, the American Association for Respiratory Care, the American Lung Association, the LAM Foundation, CHEST, and the COPD Foundation. We are developing a set of proposals that we believe would solve common supplemental oxygen-related access problems for people living with PF and other respiratory diseases. Ultimately, we hope to assist with developing new federal legislation to address the strong concerns and frustrations of people who depend on supplemental oxygen to survive. Additionally, we and our partner Three Lakes Foundation are working to stimulate discussions between advocacy groups like the PFF and the supplemental oxygen industry to brainstorm mutually beneficial ways to innovate and improve oxygen technology.

As always, we continue to strive to meet our ambitious goals and search for new ways to help people in the PF community. Thank you for your unwavering support through these pandemic years and beyond. Please support the PFF with a financial gift if you're able and know that we appreciate the trust you have given us to help you navigate throughout your journey with PF.



**William T. Schmidt**  
PRESIDENT AND CHIEF EXECUTIVE OFFICER





## Finding Hope and Giving Back

Mike Henderson, Chair Emeritus of the PFF Board of Directors, celebrated his 16th lung “transplantiversary” this March. Henderson, who was diagnosed with idiopathic pulmonary fibrosis (IPF) in 2004, said the disease gave him a new purpose in life. He has led two PF support groups, a lung transplant support group, and has devoted himself to making a difference for people living with PF.



Henderson was 57 years old when he was diagnosed. After experiencing recurring shortness of breath and a persistent cough, he was misdiagnosed with

asthma and given inhalers to treat it. Then he was told he needed a stent for his heart. But those treatments didn't help.

Henderson was shocked, angry, and confused with his IPF diagnosis and terminal prognosis. But almost immediately, he began looking for hope. The first glimmer came when he joined a PF support group which Henderson refers to as a blessing. “They become your second family,” he said. “The purpose is to help each other deal with the disease and you get very close to one another. It's very rewarding.”



Henderson also discovered that Dr. Ganesh Raghu, one of the world's leading interstitial lung disease experts, was in Seattle, not far from Henderson's home in Portland.

But shortly after his first visit with Dr. Raghu, Henderson's condition deteriorated. Henderson was put on the lung transplant list.

His wish for new lungs came on March 19, 2006, when he received a double lung transplant at the University of Washington. “What an amazing, incredible gift,” said Henderson. He calls his lungs “the best part of me.”

Henderson was eager to give back after his transplant. He joined the PFF Board of Directors in 2011 and served on the Executive, Finance, and Governance Committees before becoming Vice Chair, then Chairman of the Board. Henderson is proud of the Board and the organization. “I believe that our strategy and management team will provide patients the resources they need, and will lead to new therapies and hopefully a cure for PF. The Board really represents the community,” he said. “It's the strongest it's ever been.”

## PFF Advocates Raise the Community's Voice on Hill Day

More than 40 patients living with PF, lung transplant recipients, caregivers, and healthcare providers met with congressional representatives on March 10 for the PFF's annual Hill Day. They shared their personal stories and the urgent need for increased research funding as they participated in 70 virtual meetings throughout the day.

Kate Gates, Vice President of Advocacy and Programs for the PFF, was proud of the community's strong turn out and the reception they received. “More members of Congress are aware of lung diseases and that research is the path to better treatments,” she said. “Because of increased media coverage of the importance of lung health, people

understand that the federal government needs to fund more PF research.”

Advocacy is a key element of the PFF's strategic plan and Hill Day provides a major opportunity to communicate the needs of the PF community to elected officials. The Foundation's primary requests were for language in the annual congressional funding report that emphasizes the need for PF-related research at the National Institutes of Health, and for continued funding for PF-related research through the U.S. Department of Defense's Peer Reviewed Medical Research Program.

The PFF's advocacy efforts take place year round. If you are interested in participating, please sign up at [pulmonaryfibrosis.org/advocacy](https://pulmonaryfibrosis.org/advocacy) or email [advocacy@pulmonaryfibrosis.org](mailto:advocacy@pulmonaryfibrosis.org).



## You are invited!

### Join a PFF Support Group on Zoom

The PFF hosts four monthly Zoom support groups for anyone who is affected by pulmonary fibrosis. If you are not able to attend an in-person group, or simply want more opportunities for support between meetings, consider joining one of the PFF's monthly support group calls. All groups offer the PF community a valuable forum to share information and provide support to one another from the comfort of their own home. Registration is not required to participate, and call-in information and meeting times are the same each month.

**PFF Voices** offers a chance to learn from healthcare providers and discuss topics and concerns related to the disease. This group meets on the third Thursday of every month at 1:00 p.m. CT.

**PFF Caring Conversations** is specifically for those caring for individuals with PF and gives participants the opportunity to share experiences and information related to their caregiving role. This group meets on the first Tuesday of every month at 1:00 p.m. CT.

**PFF Lung Transplant Community Support Group** is intended for those who have had, or are awaiting, a lung transplant due to pulmonary fibrosis. This group provides an opportunity for discussion and dialogue around transplant-related challenges and celebrations. Meetings feature guest speakers as well as an open forum approach. This group meets on the fourth Tuesday of every month at 1:00 p.m. CT.

**PFF Coloquio** es un grupo de apoyo para los que son afectados de la fibrosis pulmonar. Este grupo da espacio para discutir temas y preocupación relacionado con la fibrosis pulmonar. Un grupo de apoyo que se reúne cada segundo martes de cada mes a la 1:00 p.m. CT.

## 1:00 p.m. CT

### HOW TO JOIN:

To join a PFF virtual support group meeting via Zoom, go to:

**[bit.ly/pffsupportgroup](https://bit.ly/pffsupportgroup)**

or call one of the telephone numbers provided, at or just prior to **1:00 p.m. CT** on the scheduled day.

**Meeting ID: 898 3066 3004**

### DIAL IN BY PHONE:

US Chicago	+1 312 626 6799
US Washington DC	+1 301 715 8592
US New York	+1 929 436 2866
US Houston	+1 346 248 7799
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## The PFF Help Center: Your Trusted Hub for Information



PFF  
Help Center™

Have you ever had a question about pulmonary fibrosis and wondered where you'd find an answer?

Have you wanted to connect with other people living with PF, but weren't sure how? Are you looking for a physician who is skilled in treating PF patients?

There is a place you can go for assistance with all of these questions, and more. The **PFF Help Center** is a dedicated support resource that provides patients, caregivers, and healthcare providers with up-to-date medical information, links to supportive services, and ways to access other essential resources. Below are some of the most common questions that the Help Center receives.

- I was just diagnosed with PF and I'm overwhelmed. What do I do now?
- Can you send me printed information about pulmonary fibrosis?

- I really need to talk with other people who are living with PF. Can you help me find a support group?
- How do I find a doctor who has experience caring for PF patients?
- What should I do if I want to participate in a clinical trial?
- How can the Pulmonary Fibrosis Foundation help me?

Our PFF Help Center staff are dedicated to making sure you get the answers that you need. We can also help you access all of the programs and resources the PFF has created to help the PF community live better with pulmonary fibrosis. Connect with us in the PFF Help Center to learn more about our warm and inviting community, and how we can support you in your PF journey.

PFF Help Center staff are available Monday through Friday from 9:00 a.m. until 5:00 p.m. Central Time at **844.TalkPFF** (844.825.5733) or via email at **[help@pulmonaryfibrosis.org](mailto:help@pulmonaryfibrosis.org)**. We hope to hear from you!

# PFF Expands Commitment to Diversity, Equity, and Inclusion



When the PFF launched ***Accelerating the Pace of Progress***, the updated three-year Strategic Plan, one short-term goal was to create and implement a Diversity, Equity, and Inclusion (DEI) plan for the Foundation. In addition, the PFF is actively working to increase diversity of representation in PF research. You can learn more about this topic in our webinar, “Diversity in Research: Benefits for All” at [bit.ly/3mmPweT](https://bit.ly/3mmPweT). Further, the PFF has engaged the Ivy Planning Group, a Maryland-based consulting firm specializing in strategy development and change management to guide us through the process. Ivy Planning Group is currently working with the PFF to develop and field a DEI and culture survey in the coming months. This survey will help us explore and understand the PFF’s culture through the lens of DEI as a workforce, workplace, and community. Ivy Planning Group will use the survey results to run a series of focus groups with PFF staff, Board members, and volunteer and scientific leadership. Stay tuned for an update in the next issue of the Breathe Bulletin!

## The PFF Lung Transplant Community Support Group

The Pulmonary Fibrosis Foundation hosts four monthly Zoom support groups for anyone who is affected by pulmonary fibrosis. One of the groups is the PFF Lung Transplant Community Support Group led by lung transplant recipient, and PFF Board member, Heather Kagel.

To Heather, the PFF Lung Transplant Community Support Group is “for anyone in the lung transplant spectrum.” Whether one is thinking about transplant, has been approved for it, or has already received one, she invites you to join the group. “There are friends to be made, hope to be had, questions to be answered, comradery, and kinship. You are not alone in this journey. Bring your part of the journey to share with us so we can learn from you!”

The Lung Transplant Community Support Group provides an opportunity for discussion and dialogue around transplant-related challenges and celebrations. Meetings feature guest speakers as well as an open forum approach. This group meets virtually on Zoom the fourth Tuesday of every month at 1:00 p.m. Central Time.







## Session Highlights

The PFF Summit 2021 registered a record of nearly 1,200 attendees on the first ever all-virtual platform. The program offered 40 sessions over the course of the week. The top-viewed sessions designed for the patient and caregiver audience included the first plenary session, *Beyond Drugs: Therapies to Improve Quality of Life; Dealing with a Cough; and Caring for Yourself When Caring for Others*. Top sessions for healthcare professionals were *New Diagnostic and Management Guidelines, Research Updates: COVID-19 and More*, and *Expanding Our Clinical Understanding of ILD*.

Special sessions for community pulmonologists were also popular as were sessions held for the Nurse and Allied Health Network.



All sessions for PFF Summit 2021 are currently online to view for free. You can watch them on our YouTube channel at: **[youtube.com/pulmonaryfibrosisfoundation](https://youtube.com/pulmonaryfibrosisfoundation)**. Make sure to “like” the videos and subscribe to the PFF YouTube channel!

## Plenary Sessions



Kathleen O. Lindell, PhD, RN

The plenary sessions took place on Tuesday and Friday, both designed for all audience members. Tuesday’s plenary session was titled *Beyond Drugs: Therapies to Improve Quality of Life* and featured keynote speaker Kathleen O. Lindell, PhD, RN, who spoke about the critical importance of the caregiver during palliative care. Three other speakers joined her

to present talks on integrative therapies, psychological well-being, and evidence for pulmonary rehabilitation benefits for patients with ILD. The panel discussion also featured Sandra Bennet Pagan, a caregiver who provided valuable real-world insight.



Gary Gibbons, MD

Friday’s plenary session focused on *Moving PF Care Forward: Updates from Ongoing Research*. The keynote speaker, Gary Gibbons, MD, Director of the National Heart, Lung, and Blood Institute (NHLBI), addressed the importance of PF-related research to the NHLBI. Once again, three experts joined and

gave talks on the PRECISIONS trial, PFF Registry research results, and racial disparities in healthcare outcomes for those living with PF. Lung transplant recipient and PFF Support Group Leader Sean Keoni Craig joined the panel discussion to lend his perspective and experiences on participation in clinical trials and more. The full program and speakers is available to view at [pffsummit.org](https://pffsummit.org).

# PFF Summit Poster Winners

Academic posters were reviewed in advance of the Summit by a panel from the PFF's Research Review Committee, who selected the top five posters for awards. All five poster winners received cash awards and were recognized at the poster awards ceremony following the virtual poster session. The poster awardees also presented a summary of their research during a dedicated poster awardee scientific session later in the week.

## AND THE AWARDS GO TO...

### 1ST PLACE

**Jason Gokey, PhD**

Vanderbilt University Medical Center (VUMC)

**Poster Title:** YAP regulates alveolar epithelial cell differentiation and AGER via NFIB, KLF5, and NKX2-1

### 2ND PLACE

**Luis Rodriguez, PhD**

Perelman School of Medicine at The University of Pennsylvania

**Poster Title:** Leveraging The Sftpc173T Mutant Surfactant Mouse Model For Preclinical Intervention Studies To Benchmark Idiopathic Pulmonary Fibrosis Therapeutics: Effect Size of Nintedanib and TGF-beta Pathway Inhibitors

### 3RD PLACE

**Yi Yao, PhD**

Henry Ford Health System

**Poster Title:** Loss of miRNAs in alveolar macrophages attenuates bleomycin-induced pulmonary fibrosis

### HONORABLE MENTION

**Margaret Thomas Freeberg, PhD**

Virginia Commonwealth University

**Poster Title:** Mechanosensing by Piezo2 is associated with metabolic reprogramming in human lung fibroblasts

### HONORABLE MENTION

**Bhavika Kaul, MD**

University of California, San Francisco

**Poster Title:** Agent Orange Exposure is Associated with Subsequent Development of Idiopathic Pulmonary Fibrosis Among United States Veterans



## LOOKING AHEAD TO PFF SUMMIT 2023

We are excited to announce that PFF Summit 2023 is heading to Orlando, Florida! The conference will be held at the JW Marriott Orlando Grande Lakes Resort from November 9 through 11, 2023. We look forward to bringing the PF community together, surrounded by Florida sunshine at this award-winning property. Co-chairs for the next Summit will be Dr. Patricia Sime from Virginia Commonwealth University, Dr. Tracy Luckhardt from the University of Alabama at Birmingham, and Ann Lucas, a PFF Ambassador, Support Group Leader, and lung transplant recipient from Charlottesville, Virginia.

Stay tuned for further details at [PFFSummit.org](https://PFFSummit.org)!

## Diamond Sponsor



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## Silver Sponsors







# PFF Community Registry Set to Launch This Summer

Excitement is building as the new PFF Community Registry is getting ready to welcome everyone who has been touched by PF. Years in the making, this innovative research database will complement the existing PFF Patient Registry to gather self-reported data from patients living with PF from across the U.S. The Community Registry will also collect information from family members, caregivers, and lung transplant recipients who have had PF.

## Make Your PF Experience Matter

The PFF Community Registry database, which is safe and secure, uses the same technology that is used in the current PFF Patient Registry and is trusted by doctor's offices, hospitals, and clinical trials worldwide. The PFF will send monthly emails and periodic newsletters with research updates to those enrolled in the PFF Community Registry.

## Participate from the Comfort of Home

Once enrolled, participants will complete an enrollment questionnaire. They will receive follow-up surveys every six months and can also participate in optional surveys on specific PF issues. "Individuals should be able to answer most survey questions without consulting their medical provider or records," said Junelle Speller, MBA, Vice President, PFF Registry. "And they can stop participating at any time."

## 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.

## THE PFF PATIENT REGISTRY TO REOPEN

Now in its sixth year, the PFF Patient Registry collects medical data from patients with PF who receive care at participating PFF Care Centers throughout the U.S. The PFF Patient Registry collects deidentified data on patients' clinical care, and researchers use these data to answer questions to improve the care and outcomes of patients with PF.

The PFF Patient Registry will continue as the new and rebranded PFF Care Center Registry to patients who receive their care at a participating PFF Care Center. Enrollment will begin next year.

Learn more at [pffregistry.org](https://pffregistry.org)

# PFF Research at a glance

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The mission of the Pulmonary Fibrosis Foundation is to accelerate the development of new treatments and ultimately a cure for pulmonary fibrosis. To fulfill our mission, we have developed a robust and multifaceted research program. Here is a snapshot of the many ways we're harnessing the power of science and working to end PF and save lives.

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**PFF Registry**<sup>™</sup>

Patient powered.  
Data driven.  
Research results.

## PFF PATIENT REGISTRY

Now in its sixth year, this observational database tracks the real-world care of patients who receive their care at a participating PFF Care Center. Researchers have already used Registry data for nearly 40 studies to answer key questions about PF that may translate into improvements in patient care. In 2023, the PFF Patient Registry will continue as the new and rebranded PFF Care Center Registry and resume enrollment to patients who receive care at participating PFF Care Centers.

**Status: set to resume enrollment next year.**

## PFF COMMUNITY REGISTRY

PFF Community Registry participants will report their own data from home via a series of regular questionnaires uploaded through a secure, easy-to-use online portal. Everyone who is touched by PF will be able to enroll, including patients living with PF, lung transplant recipients who have had PF, caregivers, and family members across the U.S.

**Status: set to open for enrollment this summer.**

**Learn more at [PFFRegistry.org](https://PFFRegistry.org).**

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## PFF CARE CENTER NETWORK

Through the PFF's network of medical centers, patients living with PF have the opportunity to participate in research studies at one of the 68 centers nationwide. The Care Center Network has reopened applications from medical centers and will welcome new members soon.

**Status: accepting applications from institutions now.**



**PFF Care Center Network**<sup>™</sup>

Care. Education. Innovation.



## PRECISIONS

The PRECISIONS trial, which received an unprecedented \$22 million in funding from the National Institutes of Health and Three Lakes Foundation, is the first ever to apply precision medicine principles to diagnosing and treating IPF. Among its aims, PRECISIONS studies whether the over-the-counter supplement N-acetylcysteine (NAC) can treat people with IPF who have a specific gene variant. The trial is due to be completed in 2025.

**Status: currently enrolling!**

## PROLIFIC CONSORTIUM

Now in its second year, this partnership between 12 industry partners and two foundations (including the PFF) is working to cooperatively develop and validate tests that can detect biomarkers in patients living with PF. To date, PROLIFIC is studying 12 potential biomarkers of IPF in four categories: epithelial damage, fibrosis, inflammation, and thrombosis. This year researchers will screen blood samples from the PFF Patient Registry to identify and validate blood protein biomarkers.



# PROLIFIC

**Status: active.**



## 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.

**Status: next application cycle to open in fall.**

Thanks to your support, we are pushing forward with enhanced educational resources, expanded patient programs, new advocacy initiatives, and larger research investments.

**Please donate if are able at [pulmonaryfibrosis.org](https://pulmonaryfibrosis.org). Your donations make a difference!**



# PFF Makes an Impact at the ATS Annual Meeting

Researchers with ties to the PFF always make a good impression at the annual meetings of pulmonology medical societies. This year was no exception.

The American Thoracic Society (ATS) is a leading medical society dedicated to advancing global respiratory health through multidisciplinary collaboration, education, and advocacy. When the ATS' 16,000 members gather for their annual meeting, it becomes one of the highlights of the year in pulmonology.



**DR. ANDREA OH**  
**Presents at ATS 2022**

Current PFF Scholar Andrea Oh, MD, Assistant Professor of Radiology at UCLA, overcame steep competition to be chosen to present an abstract of her work at an oral presentation at the ATS annual meeting. Her session "Visual and Quantitative

CT Derived Parameters Predict Transplant-Free Survival in Patients with Interstitial Lung Disease: Results from the Pulmonary Fibrosis Foundation Registry" explored the relationship between CT pattern, fibrosis extent, and transplant-free survival among patients with ILD.

"My research is focused on using CT methods to diagnose and better predict outcomes in patients with interstitial lung disease. We are using the PFF Patient Registry to help us create a risk prediction model for patients with fibrosis," Dr. Oh said. "I feel fortunate and grateful to have been chosen to present my abstract as an oral presentation. Our research using visual and quantitative CT parameters to predict transplant-free survival in patients from the Registry is a novel and important finding for this patient population."



**DR. HYUN KIM**  
**Presents at ATS 2022**

Hyun Kim, MD, Director of the Interstitial Lung Disease program at the University of Minnesota, presented an abstract at the ATS annual meeting that uses data from the PFF Patient Registry. Her goal was to determine how many people in the Registry

live in rural areas, as well as the breakdown of different types of ILDs between rural and urban populations.

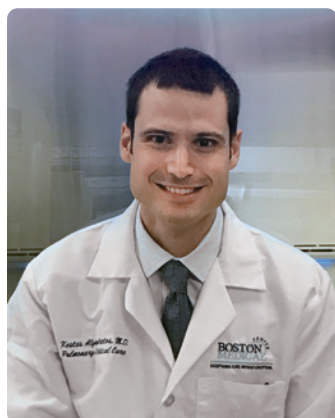
Dr. Kim and colleagues worked with a statistician at the Registry's data coordinating center, SABER at the University of Michigan, to compare Registry data with public U.S. Census data. "We were able to determine that 12% of people in the PFF Patient Registry live in rural areas," she said. "That's better than I expected because rural/urban was not considered when the Registry was set up." According to the USDA's Economic Research Service, 14% of the U.S. population lived in rural areas in 2020.

The study also found that hypersensitivity pneumonitis is more common in rural residents than urban residents. "We found that people who live in rural areas have more environmental exposures from manufacturing and mining and using coal," she said. "We also know that hypersensitivity pneumonitis is caused by environmental exposures, so this is starting to create a picture of this disease that we may ultimately use to improve diagnosis and treatment," she said.

Dr. Kim is also hoping to learn if there are disparities between access to care and outcomes for people with interstitial lung disease who live in rural areas versus nonrural areas. Results of this research will directly impact the CCN Rural Health Outreach Committee in developing tools and resources for rural communities.

# PFF Research Awardees Continue to Excel

The premise behind the PFF Scholars program is that providing early-career investigators with financial support can help catapult them to ever-greater research accomplishments even after the PFF Scholars' two-year awards end.



## **DR. KONSTANTINOS ALYSANDRATOS** **Publishes in Cell Reports**

Konstantinos Alysandratos, MD, PhD, is a 2018 PFF junior investigator awardee who is now an Assistant Professor at the Boston University School of Medicine. A researcher in BU's Center for

Regenerative Medicine, Dr. Alysandratos is the first author on a paper that appeared recently in the peer-reviewed journal *Cell Reports*.

Dr. Alysandratos and his co-authors created an in-lab model using stem cells to show how dysfunction of type 2 pneumocyte air sac cells started the fibrotic cascade found in many adult and pediatric lung diseases, including IPF. They used two groups of patient cells, one with an altered gene that made them dysfunctional and one engineered to correct the altered gene. They compared the cells using a variety of different methods.

"This understanding may result in the development of novel targeted therapies for this devastating disease," said Dr. Alysandratos. "The model has the potential to serve as a platform for testing new therapeutics. Until now, drug development efforts have suffered from a lack of access to living cells from patients."

"This understanding may result in the development of novel targeted therapies for this devastating disease."

- Konstantinos Alysandratos, MD, PhD



## **DR. JOHN KIM** **Publishes in Respiratory Medicine Journal**

John Kim, MD, is a 2020 PFF Scholar and Assistant Professor at the University of Virginia. He was recently first author on a new paper in the *American Journal of Respiratory and Critical Care Medicine*.

He and his co-authors measured the number of monocytes, a white blood cell and part of the immune system, in 7,400 people who were already taking part in other clinical trials. They found that people who had more monocytes in their blood were more likely to have interstitial lung abnormalities and disease progression as shown on CT scans. These findings suggest monocytes may have a critical role in the early development of interstitial lung disease.

"Higher blood monocyte count was associated with a greater burden of interstitial lung abnormalities and its progression on CT imaging and lower forced vital capacity among adults," Dr. Kim said.

In an accompanying editorial, Michael Kreuter, MD, of the University of Heidelberg in Germany wrote that "the work presented by Kim and colleagues adds support to the notion that monocytes have the potential to be important biomarkers for aiding detection of individuals with interstitial lung abnormalities and early ILD."





## PFF Care Center Lauds the Benefits of the PFF Registry

“When your job focuses on clinical research, every week is Clinical Trials Week,” said Timothy Sheehan, MS, a Research Project Manager at Milton S. Hershey Medical Center at the Penn State College of Medicine in Hershey, Pennsylvania. Sheehan is proud to assist with the collection and management of the patient data his Care Center submits to the PFF Patient Registry.

Sheehan was onsite in Hershey for the Registry from the beginning, assisting with its 2016 launch. After working in this role for several years, he moved to Charleston, South Carolina, briefly before returning to Hershey and resuming his prior role. “The PFF Patient Registry was the first research study I ever worked on, so coming back and seeing it still running full force nearly six years later is just great,” he said. “I always called it my baby, so being able to pick up again where I left off has been rewarding. We hired a new research coordinator and the Registry will be a great way for her to get up to speed with research, as well.”

The Hershey site originally enrolled 54 patients in the Registry. For Sheehan, the required two visits per year to collect new data for the Registry are a great way to stay in touch with some of his favorite patients. “Of course, they

come in as needed throughout the rest of the year, but those Registry visits are a nice way to engage,” he said. “What the Registry does is so important, I know it gives our patients a sense of pride to participate.”

### PFF CELEBRATES CLINICAL TRIALS WEEK

From May 14-20, the PFF once again celebrated Clinical Trials Week to highlight the importance that clinical trials have in improving diagnosis and care for all people, including those who are living with PF.

The PFF participated in a social media campaign on all five of its social media channels—Facebook, Twitter, Instagram, YouTube, and LinkedIn—to show some love to the hardworking research teams who make a difference and increase human knowledge, and to encourage patients to seek out clinical trials. Many PFF Care Center Network medical centers also participated this year.

In honor of Clinical Trials Week, ask your pulmonologist about participating in clinical research. You can visit [trials.pulmonaryfibrosis.org](https://trials.pulmonaryfibrosis.org) to use the PFF Clinical Trials Finder.

## Care Center Network Video Debuts; Spanish Available

Living with pulmonary fibrosis can be difficult, but knowing what options, treatments, and resources are available and how to find them can be its own challenge.

That’s why the PFF Care Center Network recently introduced a video that showcases the specialists on your PF care team. Your core team—including a nurse, pulmonologist, radiologist, and pathologist—has extensive expertise in treating adults with fibrotic lung disease. They will meet to discuss your diagnosis and care plan. You may also see other specialists like a cardiologist, infectious disease specialist, transplant surgeon, or genetics counselor, depending on your circumstances. This video is also available in Spanish. You can watch the video on the PFF’s YouTube channel.



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## Meet New PFF Board Member Heather Kagel

Members of the Pulmonary Fibrosis Foundation Board of Directors lay the groundwork for the PFF's strategic vision, contribute significantly to resource development, and promote awareness the pulmonary fibrosis community. The Foundation recently welcomed longtime PFF volunteer Heather Kagel to the Board.

The Foundation recently welcomed longtime PFF volunteer Heather Kagel to the Board.

Kagel is best known within the PF community for creating the highly successful *Ready.Set.Breathe.* walk in Dallas, which became an official PFF Walk site in 2019. She is also a former PFF Ambassador, a role that both her husband and daughter have also filled.

When Kagel was diagnosed with familial pulmonary fibrosis (FPF), she feared the worst, having watched her father decline from the same disease in just months. Fortunately, her PF journey has been quite different. In 2013 when a cough lingered, her longtime primary care doctor took a chest X-ray, recognized it as abnormal, and immediately referred Kagel to a pulmonologist. She was fortunate to find a pulmonologist with expertise in FPF and



was able to identify the cause, a *TERC* gene mutation. Relieved to learn that her form of PF often advances slowly, she was able to avoid going onto supplemental oxygen until 2015.

However, the *TERC* mutation threw a curveball in 2016, when Kagel was diagnosed with oral squamous cell

carcinoma, a known possibility. Surgery to remove the tumor on her tongue was successful, but by 2019, she needed a double lung transplant. Her team's concerns about Kagel's bout of oral cancer nearly derailed the transplant, but everything came together in time to save her life, and she continues to thrive nearly three years later.

From nearly her earliest days living with PF, the PFF has been a source of support. "The PFF's resources for doctors, patients, medical professionals, and the general public are all remarkable. From the support groups to the PFF Help Center to the PFF Summit, they're all amazing," Kagel said. "I've always been proud to be part of the PFF and it's an honor to be asked to join the Board. The PFF is an organization very close to my heart."

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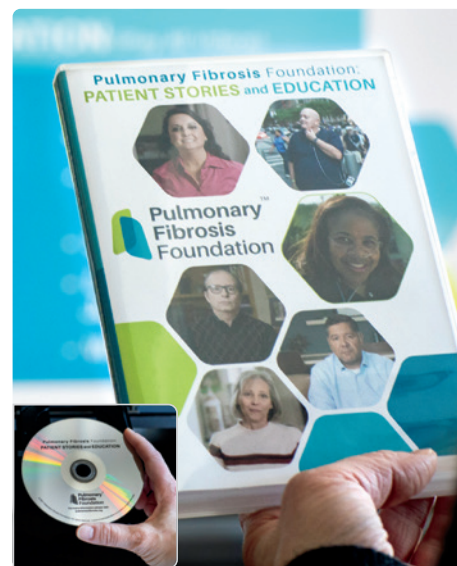
## PFF Video Collection Now Available on DVD

The PFF has an all-new "Patient Stories and Disease Education" DVD featuring 23 of the Foundation's popular informational and documentary style videos. Each DVD is free of charge.

"We are pleased to offer this valuable new resource free to our community," said Kate Gates, PFF Vice President of Advocacy and Programs. "The content has been very well received through our digital channels and we are eager to share it with those who would like it in DVD format."

Each DVD contains a variety of content. Viewers can learn about different types of interstitial lung disease from a pulmonologist and hear from patients who are living with PF, or discover the importance of support groups and receive step-by-step instructions on how to start one. Included in the collection is the PFF's highest-viewed video entitled "What is Pulmonary Fibrosis?" which has more than 124,000 views on YouTube.

To order your **free** Patient Stories and Disease Education DVD, contact the PFF Help Center at **844.TalkPFF** (844.825.5733) or **help@pulmonaryfibrosis.org**.





# Veteran With PF Reaches New Heights

Adam Faatz is no longer in the U.S. Army, but he is using his acquired training and discipline in a battle he never anticipated. Faatz, a 34-year-old veteran from New Jersey, was diagnosed with pulmonary fibrosis in 2018. Not only is he fighting PF, but he is literally climbing mountains to raise funds for the PFF. And he's enlisting everyone he can to join him.



Faatz began experiencing PF symptoms during Army boot camp in 2006. He was prescribed steroids to treat his severe chest pain and difficulty breathing. Determined to complete his tour of duty, Faatz lived with his symptoms for nearly 10 years. But when his shortness of breath became intolerable, he went to a pulmonologist

who ordered a chest CT. The scan revealed more than 17 nodules in his lung.

When Faatz was told that he had PF, he was numb. He had never heard of the disease.

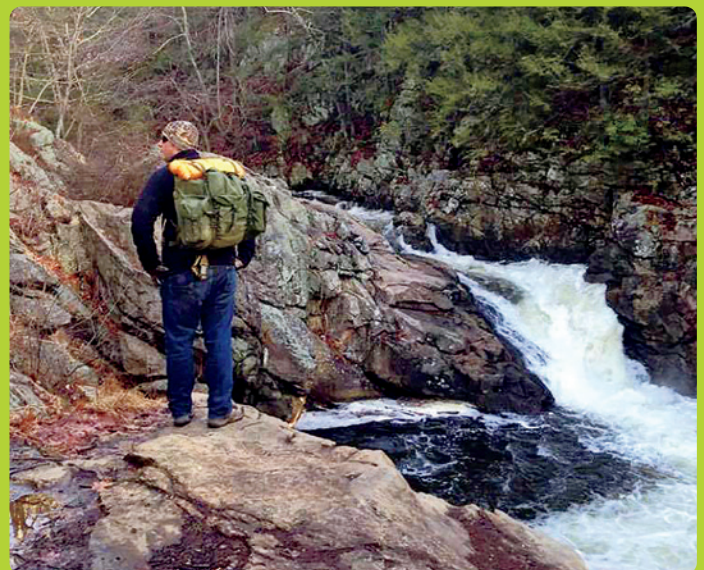
"I had to quickly learn what my journey would look like," Faatz said. "I became passionate about raising money for the PFF while challenging myself physically to achieve new goals."

Faatz partnered with a friend who is an avid hiker and they trained together for three months. The training was grueling and included daily workouts at the gym and a weekly regimen of squats, pushups, and sit ups.

Last December, Faatz hiked to the summit of Mount Marcy, the highest mountain in New York, to raise money for the PFF. The arctic conditions and icy trek took nine hours to complete, but Faatz made it to the mountain top with a renewed sense of joy.

"I really had to push myself," said Faatz. "But this was one of the most rewarding experiences of my life."

Now, through the PFF Spring Appeal, Faatz is partnering with the PFF to raise \$75,000 to help the more than 250,000 Americans living with PF. If you would like to make a gift, please visit [bit.ly/sapff2022](https://bit.ly/sapff2022).







# A Pilgrimage of Love

When Mary Hesch of Stevens Point, Wisconsin was in her 20s, she told a friend that one day she would like to walk to the ocean. More than three decades later, Hesch made that journey in memory of her mother and namesake, who she lost to idiopathic pulmonary fibrosis.



Mary Hesch

"My mother was an amazing human being who raised six children with love and kindness," said Hesch. "Her life was cut far too short and I want to do anything I can to help others with this disease."

Hesch's goal was to honor her mother by raising awareness of PF and \$50,000 for the PFF. On September 15, 2021 after joining the Foundation's Team PFF program, she set out on her 1,450 mile trek from her home in Stevens Point to Port Aransas, Texas. This was one of her mother's favorite places because she found it easier to breathe at sea level. It was also the place her mother's ashes were scattered after her death 25 years earlier.

Hesch was joined by two friends who accompanied her on the journey in an RV with a photo of her mother and a message about PF on the back. They walked through Wisconsin, Illinois, Missouri, Arkansas, and Texas. Hes

sch spoke with media outlets along the way and shared her story about her mother and the crucial need for funding for research and better treatments for those living with PF.

Near the end of her journey, Hesch received a heartbreaking call that her father, who was her biggest cheerleader, died from a heart attack. She was devastated, but her walk took on a bigger purpose to honor both of her parents.

On December 30, after 107 days of walking, Hesch stepped onto the beach in Port Aransas and was greeted by her siblings and other family members. They celebrated her tremendous achievement and held a ceremony for both of their parents.

Hesch was overwhelmed with gratitude for the support and generosity from people she knew and from those she never met. Please consider supporting Mary and help her reach her fundraising goal by donating at [pulmonaryfibrosis.org/maryhesch](https://pulmonaryfibrosis.org/maryhesch).





# ***Broadway Belts For PFF!***

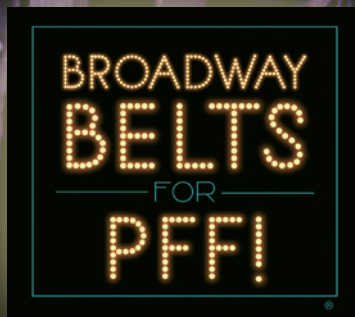
## **Raises Record \$475,000!**

Tony Award winner and PFF Board member Julie Halston and a star-studded cast presented the 12th annual ***Broadway Belts for PFF!*** on April 29 at the Edison Ballroom in New York City. The gala was a hybrid celebration with guests joining in person and virtually from home. A record \$475,000 was raised to support PF research and programs for individuals living with PF.

Tom Viola, Executive Director of Broadway Cares/Equity Fights AIDS (BC/EFA), was honored with the 2022 Ralph Howard Legacy Award. Viola, who has supported Broadway Belts for PFF! since it began, has contributed significantly to health and family service organizations nationwide.



Derrick Davis



From left to right: Telly Leung, Ruby Locknar, Beth Malone, Lillias White, Robert Creighton, Julie Halston, Ann Harada, Beth Leavel, Arielle Jacobs, Derrick Davis



Beth Leavel



Beth Malone



Lillias White

Photos: Rebecca J. Michelson





PFFWALK

# Together Toward a Cure: PFF Walk 2022



The sixth annual PFF Walk returns this summer in cities across the country! After two years of virtual walks due to the coronavirus pandemic, the Walk is set to take place both in person and virtually from July through October.

"We are thrilled to invite the community to come out and join the PFF Walk this summer," said Amy Wardzala, Vice President of Development. "This is a major celebration for our community, and we encourage everyone to gather their friends and family, build a team, and raise funds so we can drive research and support those living with PF."

Since its inception in 2017, the PFF Walk program has raised over \$2.5 million. The Walk has expanded over the years with new cities added to the lineup each year. The San Francisco Walk, originally scheduled to launch in 2020, was delayed and will take place for the first time this year.

"The indomitable spirit of our community continues to enable us thrive, and we are so grateful," Wardzala said.

## **Pittsburgh**

North Shore Riverfront Park, Pittsburgh, PA | July 23

## **New York City**

Liberty State Park, Jersey City, NJ | July 30

## **Chicago**

Diversey Harbor, Chicago, IL | September 10

## **Bay Area**

Crissy Field, San Francisco, CA | September 17

## **National Walk Day**

Virtual | September 24

## **Washington D.C.**

National Harbor, Fort Washington, MD | October 8

## **Dallas**

Cypress Waters, Dallas, TX | October 22

For more information and to register yourself or your team, please visit **[pffwalk.org](https://pffwalk.org)**.



# Pulmonary Fibrosis Awareness Month 2022: Here For Each Other

Each September, join with those who have been impacted by pulmonary fibrosis worldwide to unite for Pulmonary Fibrosis Awareness Month (PFAM). This year's theme is "Here For Each Other," and we'll be showcasing how the pulmonary fibrosis community has stepped up throughout the years in support of one another. From attending PFF events, to starting and joining support groups, and everything in between, your participation is what makes the PF community stronger than it's ever been. And we want to celebrate **you**.



**30 Facts In 30 Days**

**PULMONARY FIBROSIS awareness month SEPTEMBER**

The word "pulmonary" means lung and "fibrosis" means scar tissue. So in it's simplest sense, pulmonary fibrosis means "scarring of the lung." More than 250,000 Americans are living with PF, and more than 50,000 new cases are diagnosed annually. There is no known cure.

Beginning September 1, join us on social media on the PFF's official Facebook, Instagram, and Twitter accounts at [@pfforg](https://twitter.com/pfforg)!

To kick off the campaign, we'll be empowering the community through

education with our "30 Facts In 30 Days" campaign. In this feature, the PFF shares a medically-accurate fact about pulmonary fibrosis every day at 11:00 a.m. CT.

Further, we'll be sharing a story from someone who has been impacted by pulmonary fibrosis as a part of our "Portraits of PF" series every day at 1:00 p.m. CT. Sharing stories is the most powerful way to raise awareness. Whether you're living with PF, a caregiver, a lung transplant recipient, a healthcare provider, or if you've lost a loved one, your story makes a difference. Submissions are currently open, and you can share your story at

[pulmonaryfibrosis.org/mystory](https://pulmonaryfibrosis.org/mystory).

Additionally, the PFF will celebrate the community through the popular #BlueUp4PF campaign. The PFF loves the creativity and passion of the community. You can #BlueUp4PF by wearing as much blue as possible, dyeing your hair blue, and posting a selfie on social media telling the world what PFAM means to you. Use the hashtag #BlueUp4PF and tag us!

Finally, every evening at 7:00 p.m. CT we'll post a stunning photo of a building or landmark that shines its lights blue in recognition of PFAM and the #BlueUp4PF activity. Last year, more than 65 landmarks participated.

Every *like*, *share*, and *comment* makes a difference. You can help our messages reach the community by engaging with each post during September. The more *likes* and *comments* a post receives, the more likely it is to show up in newsfeeds everywhere.

It's not too early to start planning for PFAM. Read more about the activities this year, download the toolkit, and find social media graphics at [pulmonaryfibrosis.org/pfam](https://pulmonaryfibrosis.org/pfam).



# 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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Register today at [pffwalk.org](https://pffwalk.org)



## **Pittsburgh**

North Shore Riverfront Park, Pittsburgh, Pennsylvania, July 23

## **New York City**

Liberty State Park, Jersey City, New Jersey, July 30

## **Chicago**

Diversey Harbor, Chicago, Illinois, September 10

## **Bay Area**

Crissy Field, San Francisco, California, September 17

## **National Walk Day**

Virtual, September 24

## **Washington, D.C.**

National Harbor, Fort Washington, Maryland, October 8

## **Dallas**

Cypress Waters, Dallas, Texas, October 22

**Register today at [PFFWalk.org](https://PFFWalk.org)**



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