

PULMONARY FIBROSIS FOUNDATION

breathe



Table of Contents

| | | | |
|---|----|--|----|
| Letter from our Interim President and CEO | 3 | Revolutionizing Research: Celebrating One Year of Empowering Change with the PFF Community Registry! | 11 |
| Beacons of Strength, Positivity and Hope – Meet the PFF Ambassador Class of 2023 | 4 | APPLe Study Targets Early Detection of Pulmonary Fibrosis | 12 |
| Support Group Leader Network Encourages Leaders to Lean In | 5 | PFF Summit 2023: We went to Orlando! | 14 |
| Questions about Palliative Care? This New Resource Can Help! | 5 | Key Sessions and Topics | 16 |
| New Emergency Preparedness Resource Helps PF Community Weather the Storm | 6 | Meet Our Co-Chairs | 17 |
| PFF Advocates Rally for Oxygen Reform, Inspiring Change Nationwide | 6 | 2020 PFF Scholar Award Recipient Discovers a Novel New Finding | 18 |
| Friends and Family Card Makes Sharing Disease Information Easier | 7 | PFF Walk 2023: Miles of Momentum | 19 |
| Bridging the Gap: Expanding the PFF Care Center Network to Rural Communities | 8 | Embrace Your Breath: Pulmonary Fibrosis Awareness Month | 22 |
| Bringing PF Unity to the Community | 10 | Meet the New Members of the PFF Board of Directors... .. | 23 |
| PFF Advocates Raise Awareness on Hill Day 2023 | 11 | In Memoriam: Dr. Daniel Rose | 25 |
| | | Ways to Get Involved | 26 |
| | | Leadership | 27 |

OUR MISSION

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

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



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

DISCLAIMER:
The material contained in this newsletter is for educational purposes only and should not be considered as medical advice. Consult your healthcare provider for treatment options.

© 2024 Pulmonary Fibrosis Foundation. All rights reserved.

Pulmonary Fibrosis Foundation

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

pulmonaryfibrosis.org

Letter from Our Interim President and CEO



DEAR FRIENDS,

Welcome to the latest edition of the Breathe Bulletin! We are excited to bring you our first fully digital issue as part of our ongoing commitment to environmental sustainability. By transitioning to a digital format, we aim to reduce our carbon footprint and minimize energy consumption while continuing to deliver engaging content to our readers. Please feel free to share the link with anyone who would enjoy our magazine.

In this issue, we highlight remarkable individuals whose contributions are shaping the landscape of our community. From dedicated patients-turned-volunteers serving as Ambassadors, Support Group Leaders and Advocates, to the inspiring updates on the PFF Community Registry and the impactful work of our new Scholars, there is much to celebrate!

We also bring you recaps from the successful PFF Summit 2023 and Walk season, along with other updates that underscore our commitment to advancing research and enhancing the lives of those affected by PF and ILD.

Within these pages, you'll witness firsthand how the PFF's unwavering dedication to patients remains at the forefront of everything we do. We're deeply grateful for your continued support in furthering our mission.

Thank you for being an integral part of the Foundation's journey. Together, we're making a difference.

A handwritten signature in black ink, appearing to read "Scott Staszak". The signature is fluid and cursive, with a long horizontal stroke at the end.

Scott Staszak

Interim Chief Executive Officer
and Chief Operating Officer

Beacons of Strength, Positivity, and Hope – Meet the PFF Ambassador Class of 2023



With a record number of applicants, the PFF proudly welcomed its new class of PFF Ambassadors last spring. After completing a series of trainings on public speaking and storytelling, the 13 new members will begin sharing their inspiring stories with newly diagnosed patients, support groups, healthcare providers, and others. While PFF Ambassadors have unique experiences with the disease, they rally around the common goals of raising awareness of PF and instilling hope wherever they go.

Comprising ten patients, one caregiver, one lung transplant recipient, and one individual who has lost a loved one, the 2023 class brings a diverse range of perspectives on the disease. Among the patients, diagnoses include autoimmune interstitial lung disease (ILD), familial pulmonary fibrosis, idiopathic pulmonary fibrosis (IPF), and post-COVID ILD. This group of passionate advocates has lent their voices to the PF cause in various ways, engaging in impactful discussions with elected officials during PFF Hill Day, and leading support groups that serve as lifelines for those navigating the challenges of PF.

But the Class of 2023's mission extends beyond advocacy alone. With backgrounds spanning education, business, and medicine, they possess a skill set that will make a tangible difference in the lives of others. Their collective mission is to empower individuals to embrace life to the fullest while navigating the challenges of PF. As

Ambassador Julie Rossignol, who lost her mother to PF, said, "We have to find ways to enjoy the special moments and happiness every day."

Through their powerful stories, these PFF Ambassadors are poised to support others impacted by the disease. They understand the ups and downs of living with PF, relying on friends and family members, and ultimately accepting their diagnoses. They stand as proof that life after diagnosis can be meaningful, purposeful, and fulfilling. Each ambassador is committed to not only sharing their personal journey but also providing invaluable guidance on how arming themselves with the knowledge and connections from the PFF has motivated them.

This cohort continues the tradition of representing the PFF by engaging audiences to understand more about the plight of people living with PF. Our new ambassadors are ready to change lives, alter perceptions, and inspire a spirit of resilience.

For more information on the PFF Ambassador program or to request a PFF Ambassador for your next event, contact the PFF Help Center at **844.TalkPFF** (844.825.5733) or email help@pulmonaryfibrosis.org.

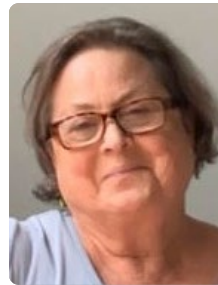
Thank you to our sponsors



Support Group Leader Network Encourages Leaders to Lean In

How do 150 support group leaders across the country develop monthly discussion themes, create tools for recruiting and communicating with members, and conduct peer-to-peer conversations about running a support group? They actively participate in the PFF Support Group Leader Network (SGLN)! This program is a one-stop resource for meeting topics, distribution of PFF educational materials and community resources, plus much more.

such as webinar notifications, videos, and articles. She also suggests having a one-on-one phone call with new members to learn about their personal story.



Networking is also a valuable benefit of the SGLN, especially for new leaders. "I received good advice about potential speakers and topics at the last SGLN meeting," said Anna Risdorfer, founder and leader of the Breathe Maryland Support Group. Risdorfer, who is living with PF, launched her group in 2020 as a

Facebook page then transitioned it into a virtual group the following year. She is interested in meeting more leaders, particularly those in her region.

Risdorfer enjoys the breakout sessions during the quarterly Support Group Leader Network meetings, as she finds it easier to talk about specific issues in smaller groups. She encourages support group leaders to speak up and utilize the network as much as possible.

To learn more about the PFF Support Group Leader Network and support groups available to you, to start a support group in your area, or to join the SGLN as an already established support group, contact the PFF Help Center at [844.TalkPFF](tel:844.265.7333) (844.825.5733) or email help@pulmonaryfibrosis.org.



Mary Ann and Mike Kinsky stepped in to lead the support group, Breathe Easy Rochester, after receiving training from the group's previous leader, Mary Pollock. The PFF's mission is particularly close to the hearts of the Kinskys, as Mary Ann is a caregiver to her husband, Mike, a lung transplant recipient. Their

leadership was tested at the start of the pandemic after they had to learn how to conduct meetings virtually. Yet, they ultimately found the virtual format made it easier for patients to join and for speakers to participate.

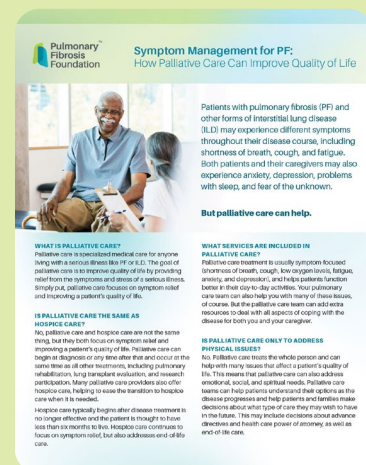
"Being part of the Support Group Leader Network has enriched our lives and challenged us to be better advocates and supporters of the PF community," said Mary Ann. She encourages new support group leaders to be consistent with emails and to share the PFF's resources

Thank you to our sponsors



Questions about Palliative Care? This New Resource Can Help!

The Pulmonary Fibrosis Foundation created a new education resource on the topic of palliative care. *Symptom Management for PF: How Palliative Care Can Improve Quality of Life* aims to help patients, caregivers, and family members understand more about this unique service. Palliative care is specialized medical care for anyone living with a serious illness, including pulmonary fibrosis and interstitial lung disease, with the goal of improving one's quality of life. Palliative care can begin as early as the time of diagnosis and treatment is usually symptom-focused. To learn more about palliative care, including how to request it, differences between palliative and hospice care, and where to find additional resources on palliative care, please contact the PFF Help Center at [844.TalkPFF](tel:844.265.7333) (844.825.5733) and request a free copy. This item is also available for download at pulmonaryfibrosis.org/education.



New Emergency Preparedness Resource Helps PF Community Weather the Storm



Facing hurricanes, floods, wildfires, and other natural disasters can be scary, especially for people living with PF, but it's also an opportunity to enhance preparedness. The potential loss of access to critical healthcare, medication refills, electricity, and oxygen supplies underscores the importance of emergency readiness. That's why the Pulmonary Fibrosis Foundation has launched a comprehensive new resource: "Preparing for Emergencies: A Guide for People Living with Pulmonary Fibrosis."

Before an emergency strikes, ensuring that your phone can receive alerts from government and local authorities is paramount. Additionally, assembling a well-equipped "go-kit" containing essentials like food, water, medication, and vital documents is essential. Engaging in discussions with your healthcare provider about your unique health needs prior to emergencies is equally important.

Imminent emergencies like hurricanes may require planning to stay with family or friends outside the affected area. Keeping your vehicle's gas tank full and acquainting yourself with nearby shelter options can provide peace of mind. In the event of a power outage, promptly notifying your electric company about your reliance on home oxygen can help expedite the restoration of power. Ensuring an ample supply of oxygen for emergencies is imperative for those who depend on it. Individuals residing in flood-prone regions should take proactive measures to safeguard their homes against water damage. Similarly, in areas affected by wildfire smoke, adopting precautions such as staying indoors and using masks when venturing outside is recommended.

The "Preparing for Emergencies: A Guide for People Living with Pulmonary Fibrosis" is designed to empower individuals to stay safe and prepared during challenging circumstances, providing support to the PF community as they weather the storm with resilience and readiness. Special thanks to Boehringer Ingelheim, Genentech A Member of the Roche Group, and United Therapeutics for their support of the guide.



PFF Advocates Rally for Oxygen Reform, Inspiring Change Nationwide

Across the country, a groundswell of support is surging as PFF Advocates urge Congress to pass comprehensive supplemental oxygen reform. This growing movement is significant as it seeks to ensure that individuals living with PF and ILD can access the oxygen they need for their medical well-being and quality of life. The PFF is at the forefront of this effort, dedicated to making a positive impact.

Recently, we reached a major milestone when the Supplemental Oxygen Access Reform (SOAR) Act was introduced in Congress. The SOAR Act will increase access to supplemental oxygen for Medicare beneficiaries. The bill includes a patients' bill of rights and a new payment system to make sure that patients can get liquid oxygen. Now, we are building momentum by calling on the PFF community to contact their members of Congress in support of the SOAR Act. Over 700 PFF Advocates have already sent this urgent alert to their members of Congress but we need many more people to take action to make sure that the SOAR Act is voted on and passed this year.

Please add your voice to our effort and help demonstrate the vital need to pass legislation addressing the challenges associated with supplemental oxygen. Your voice will contribute to a future where everyone has equitable access to the oxygen they need. Stand with us and become a PFF Advocate today! Sign up for alerts at pulmonaryfibrosis.org/advocacy.



Friends and Family Card Makes Sharing Disease Information Easier

When you or a loved one is diagnosed with pulmonary fibrosis, sharing this news and explaining the disease with family members and friends can be quite a challenge.

The Pulmonary Fibrosis Foundation created the Talking About PF with Friends *and* Family card to help ease this burden. These small notecards include a detailed explanation of the disease, list various causes, and direct readers where to find more information. Cards can be ordered at no cost by calling the PFF Help Center at **844.TalkPFF** (844.825.5733) and are available for download at pulmonaryfibrosis.org/education.



Thank you to our sponsors



Bridging the Gap: Expanding the PFF Care Center Network to Rural Communities

In 2023, the PFF celebrated 10 years of providing top-tier specialized care to individuals living with PF. We also launched a new facet of the Care Center Network (CCN) — the Clinical Associate sites!

Celebrating a Decade of Revolutionary PF Care

Today, the CCN comprises 81 centers across the United States. The designation of “Care Center” indicates that the institution provides specialized, multidisciplinary interstitial lung disease care, conducts ILD research, and offers educational events for the community to help patients and their loved ones. Thanks to the ongoing efforts and collaboration of the PFF and the PF healthcare community, the CCN will now include both Care Centers and Clinical Associate Sites.

“I’m most excited about the energy that was expressed in the applications and the dedication these new centers have shown to improving the lives of patients living with PF,” Jessica Shore, PhD, RN, Senior PFF Vice President, Clinical Affairs and Quality said. “They’ll all be providing access to support groups, serving on CCN committees and working groups, and participating in the continued expansion of the Nurse and Allied Health Network.”

More Access, More Care

In May of last year, the PFF presented research at the American Thoracic Society (ATS) International Conference highlighting the healthcare disparities that patients with ILD face. Data collected by the CCN Rural Health Outreach Committee suggests that more rural-inclusive databases are needed to better understand how to improve access to care for rural patients. The study found that while ILD patients in rural areas may endure inequalities, they did not contribute to more frequent hospitalizations or emergency department visits.



Early diagnosis, specialized care, cutting-edge research, and increased awareness play vital roles in the battle against PF. The PFF Clinical

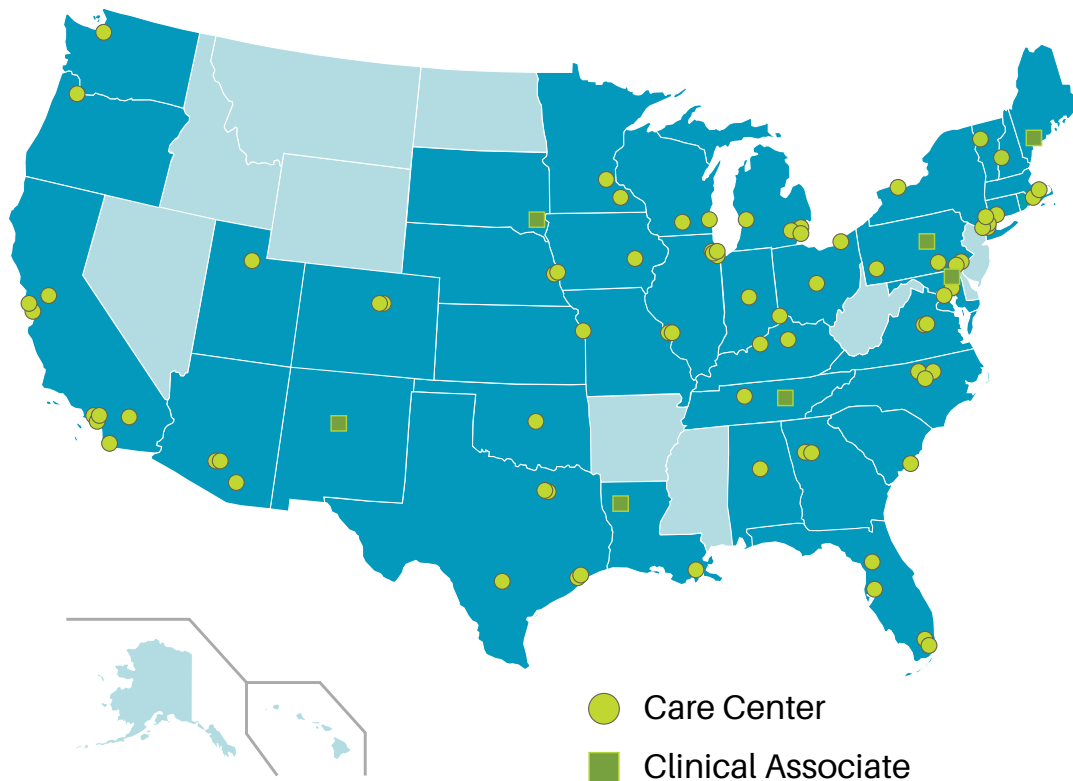
Associate site is a more inclusive iteration of the CCN that aims to transform the landscape of PF care. The overarching goals of this program are centered around expanding impact, enhancing care, driving research, and advancing advocacy and provider engagement.

The addition of the PFF Clinical Associate Sites welcomes the diverse perspectives of community providers, often located in rural areas, to enrich PF research. These centers, staffed by expert care teams, collaborate to improve the quality of care provided to PF patients. By working together, they share knowledge, best practices, and resources, ultimately enhancing the patient experience and outcomes.

“We’ve been planning this expansion for a few years as part of our strategic plan to expand beyond the large academic medical centers that typically make up our 81 centers, and that are currently providing specialized lung disease care,” Shore said. “We’re looking at more community-based programs, smaller academic centers – centers that are providing care in places that aren’t currently being represented by our Care Centers.”

One of the Clinical Associate primary objectives is to reduce the time it takes to accurately diagnose PF and ensure that PF patients have access to high-quality care within a two-hour radius of their homes. Through the expansion of the CCN and partnerships with local care providers, the PFF aims to broaden the Network’s reach, making specialized care easily accessible to patients across the nation. This commitment to quality care reinforces the Foundation’s dedication to improving patient outcomes and quality of life.

“We want the perspectives of providers to inform our research,” said Jessica Shore. “We have had patients and caregivers join our working groups



● Care Center
■ Clinical Associate

and committees. But we don't have space yet for community-based providers or providers that don't meet the strict criteria that currently upholds the CCN."

We have invited a targeted list of medical centers in communities lacking representation to apply for the Clinical Associate pilot program. Our initial goal is to secure about 10 medical centers across the Northern Plains and Southwest regions that do not currently have access to the CCN.

Driving Research and Scientific Discoveries

The CCN serves as a hub for research collaboration, fostering scientific discoveries that propel forward the understanding and treatment of PF. By facilitating research within the network and leading research efforts, the PFF aims to expand our knowledge of PF, expedite clinical trials, and identify effective therapies. This dedication to research is instrumental in driving advancements in the field and offering hope to those affected by PF.

Expanding Opportunities

By welcoming new partners, the PFF seeks to provide more opportunities for community care providers to collaborate with designated Care Centers, fostering expertise sharing, and creating a more comprehensive and cohesive care experience for patients nationwide.

The CCN is leading the way in combating this challenging disease by uniting expert care teams, promoting early diagnosis, enhancing quality care, driving research initiatives, and advocating for the PF community. With the PFF's dedication and the continued expansion of the Network, the future holds promise for improved outcomes, increased awareness, and a brighter future for all those affected by PF. The PFF Care Center Network was first established in 2013 with nine Care Centers. This year, we are celebrating the history of those founding Care Centers and the subsequent expansion of the CCN thanks to the ongoing efforts and collaboration of the PFF and PF healthcare community.

The Nine Founding Care Centers from 2013 include:

National Jewish Health
University of California at San Francisco
University of Chicago
University of Louisville School of Medicine
University of Michigan Health System

University of Pittsburgh
University of Washington Medical Center
Vanderbilt University Medical Center
Yale School of Medicine



Bringing PF Unity to the Community

The PFF Community Registry is an invaluable resource that collects vital information from patients, caregivers, and family members like you. By participating in the Community Registry, you become a crucial part of a groundbreaking initiative that aims to advance our understanding of PF and improve the lives of current and future patients.

How does your participation make a difference? Your information, combined with that of others, creates a comprehensive dataset that researchers can utilize to uncover patterns, identify trends, and develop innovative treatments. Your contribution directly empowers care providers to make informed decisions, enhancing the quality of care for individuals battling PF.

Enrolling in the Registry is a simple process that takes approximately one hour. You don't have to answer all the questions in one sitting, and you can save your progress and return to complete it at your convenience. Rest assured, your responses are 100% confidential, and you will never be personally identified in any research findings or publications.

The process is designed to be as straightforward and easy as possible. You fill out medical and life experience surveys centered around your journey, then, researchers will review and analyze your responses.

The biggest reason people join the Registry is to help their community and support individuals experiencing PF. Together, we can find the answers that researchers seek. By sharing your journey, you provide a voice for the PF community and ensure that your experiences and challenges are seen and heard.

To make the Registry even more effective, we encourage you to stay engaged. Every six months, you'll receive a new survey so you can update your information and provide new insights into your PF journey. Your ongoing involvement allows researchers to stay up to date and capture the evolving nature of the disease, ultimately leading to more targeted and effective treatments.

We currently have more than 1,900 enrollees but we need many more. And with your help, we know we can do it!

The Community Registry is for you or someone you know that meet any of these requirements:

- Patient living with PF or ILD
- Lung transplant recipient who had PF or ILD
- Caregiver or a biological family member of patients with PF or ILD, including those who have passed away

No one can predict how fast a patient's PF will progress. But we know that each response and each piece of data brings us one step closer to unlocking the mysteries of PF and improving the lives of those affected. We are grateful for the trust, courage, and willingness of our supporters to be part of the solution.

Join the PFF Community Registry today and be a catalyst for change. Visit our website at pffregistry.org to enroll or reach out to our dedicated team at registry@pulmonaryfibrosis.org if you have any questions or need assistance.

Together, we can make a lasting impact and offer hope to individuals and families affected by pulmonary fibrosis.

Take it from our current enrollees — your participation matters!



"I'm all about trying to find a cure, so I signed up for the PFF Community Registry as a lung transplant recipient. I'm lucky to get a transplant, but so many of us still need a cure."

MELISSA WHEELER

PF lung transplant recipient



"Alay Kapwa is a Filipino way to be an active participant in the PFF Community Registry. In essence, it means I am actively offering many ways that I can share and give a helping hand to others in the community."

BO PUNZALAN

Living with PF



"I hope my participation in the PFF Community Registry can ultimately help other patients understand and plan for what their disease may bring. By filling out surveys for the Registry, my responses will help healthcare providers help their patients work through their struggles."

KEN VELLA

Living with PF



"I know the power community has. And if we're all able to come together and join this registry to offer our insights, that is where the real power lies. We need all of our voices to be able to answer the questions that we have."

SAMANTHA KAGEL

PF caregiver

PFF Advocates Raise Awareness on Hill Day



In March, 71 participants met with congressional representatives for the annual PFF Hill Day. Patients living with pulmonary fibrosis, lung transplant recipients, caregivers, those who have lost a loved one to PF, and healthcare providers from 31 states spread awareness on the Foundation's policy priorities.

PFF Hill Day advocates met with 95 congressional offices, sharing their personal experiences and how important it is to provide strong federal funding for PF research. Advocacy is a key element of the PFF's strategic plan, and PFF Hill Day provides a major opportunity to communicate

the needs of the PF community to elected officials.

Together, community members highlighted the urgent need for federal funding for PF research by including appropriations language in the annual congressional funding report for the National Institutes of Health, and maintaining PF as a research topic area in the U.S. Department of Defense's Peer Reviewed Medical Research Program. Participants also addressed the need to improve patient's access to supplemental oxygen, bringing awareness to the reform efforts that the PFF is addressing with a coalition of 23 other advocacy organizations. Connecting with elected officials is the key to effecting legislative change. PFF's advocacy efforts take place year-round, and we want to keep you informed on the next steps for moving this legislative momentum forward.

To stay up to date on our advocacy efforts, register as a PFF Advocate for future campaigns and communications at pulmonaryfibrosis.org/advocacy or email advocacy@pulmonaryfibrosis.org.

APPLe Study Targets Early Detection of Pulmonary Fibrosis



The Advancing Prevention of Pulmonary Fibrosis (APPLe) study represents a critical nationwide PF research endeavor funded by the National Institutes of Health (NIH) and the National Heart, Lung, and Blood Institute (NHLBI). Its primary objective is to revolutionize the detection and diagnosis of idiopathic pulmonary fibrosis (IPF), a debilitating lung disease characterized by progressive scarring of lung tissue. By delving into the intricate mechanisms underlying the development and progression of IPF, the study aims to pave the way for early diagnosis and intervention strategies that could potentially halt or slow down the disease process.

The study seeks to enroll 1,000 participants across the country, carefully selected based on specific criteria. Eligible individuals cannot be currently diagnosed with PF, but they must have at least two family members who have been diagnosed with PF. One family member with PF needs to be a first-degree relative (parent, sibling, or child). Study participants must be between the ages of 40-75. This strategic selection of participants allows researchers to focus on a cohort with a heightened genetic predisposition to the disease, shedding light on the interplay between genetic factors and environmental influences in the development of PF.

A key aspect of the APPLe study is its comprehensive approach to understanding the multifaceted nature of PF. Researchers aim to dissect the roles of both genetic risk factors and environmental risk factors in predisposing individuals to the development of PF. By examining both the genetic profiles and environmental exposures of participants, the study seeks to elucidate how these factors interact and contribute to the pathogenesis of pulmonary fibrosis. This comprehensive approach is crucial for understanding the complexities of the disease process and identifying potentially novel targets for intervention.

Through longitudinal assessments and careful monitoring, the APPLe study will track the progression of pulmonary fibrosis over time within the enrolled cohort. By analyzing changes in lung health and disease trajectory, researchers hope to identify early indicators of disease onset and progression, ideally before irreversible lung scarring occurs. This proactive approach not only holds promise for improving early detection and diagnosis but also opens avenues for developing personalized treatment strategies tailored to the specific needs of individual patients.

In essence, the APPLe study represents a groundbreaking effort to transform our understanding of PF and revolutionize

patient care. If you are interested in enrolling in the APPLe study, send an email to Rachel Warren, Clinical Research Program Manager, at rachel.warren@cuanschutz.edu with the subject line "APPLe study."

What is it Like Being a Research Participant?

Featuring Kelley McAllister

Why did you join this study?

My mother, grandmother, and youngest aunt all died from PF, and at least one other family member has the disease currently. My mom found out about the study just shortly before her death and I know it would have meant a great deal to her that I participated. That's why I joined initially...however, my current reasoning is that it turns out it matters an incredible amount to ME. I get to take action to possibly help myself, my children, and my extended family, and it makes me feel closer to my mom. My first set of bodily fluid donations happened to coincide with the month of my mother's death and it actually helped me in my grieving process.



What has been your experience with the FPF research group?

I've been pleasantly shocked by how responsive and caring each member of the team has been. I feel like they all actively care about me and about my family's story, which has given me a sense of belonging. So few people out in the world are familiar with PF and sometimes it can feel like no one really understands what it's like to experience the disease. This is a group of people who know and who really want to make a difference, and it shows.

What do you value about the FPF research studies?

Participating in moving forward a better understanding of the disease, as well as the comfort of knowing that I'm in the loop, somehow. I feel safer knowing that I have a baseline for comparison should I ever get diagnosed, and that I can communicate with those in the forefront of the research. I'm the sort of person who believes that knowledge is power and this study makes me feel as if I'm gaining personal knowledge as well as participating towards advancing the collective knowledge. Plus, it's heartening to feel as if I'm doing something about it rather than just waiting for the day when I might possibly get diagnosed myself.

What have you learned after participating in our studies?

I've learned what these diagnostic tests (CT scan and full PFTs) are like. My mom was scared of these tests and it's comforting to experience them theoretically first, so that if I ever have to experience them as a diagnosed patient they won't be an unknown. Plus, now I know all of my baseline results, so I know I'll have something to refer to if I ever need that.

Has any part of being a research participant surprised you?

I've been surprised by how meaningful it feels to me. I've found myself seeking out other medical studies I can participate in, such as myconnect.cancer.gov. It's easy for me to feel hopeless, as if there's nothing I can really do to change all the suffering in the world, and these studies give me a sense of purpose that I wouldn't have expected as well as that same little rush that you get from doing a good deed. This just happens to be a good deed that could also actively benefit my daughters or my future self!

What would you tell someone who's considering joining?

That this is a chance to do something good for the world with very little work. That it can bring meaning to the loss of a loved one, or meaning to living with a terrifying diagnosis. That none of it has been scary or stressful (in fact, it's been the opposite).

What are your hopes for the future of IPF research?

I'd love to be able to see this disease coming from further away. The only good news about my family members having had PF is that we're well-informed and know how to protect ourselves to the degree possible—and I hope that the research will help all of us eventually learn additional preventive measures. In a perfect world I'd love to someday be able to test myself to know if I'm at risk — and do the same for my children. Imagine how we'd feel if those tests could relieve us of fear, or if the research leads to more effective treatments? I actively experience comfort just imagining those outcomes, and knowing that I'm acting to bring them about to the best of my ability.

PFF Summit 2023: We went to Orlando!

**Thank you to all who
joined the PF Community
from November 9 - 11**



The PFF Summit is the world's largest conference focused on pulmonary fibrosis and interstitial lung disease research and education. Held every other year, it unites the community to come together as one to learn about this disease from globally recognized experts. We warmly welcomed patients, caregivers, lung transplant recipients, those who have lost loved ones to ILD, physicians, researchers, nurses, industry representatives, and anyone who has been impacted by PF to attend the conference.

With a focus on fostering collaboration and knowledge exchange, the PFF Summit 2023 aimed to make significant strides in improving the lives of those affected by pulmonary fibrosis.



Networking Opportunities

The PFF Summit 2023 featured a range of sessions, including keynote speeches, panel discussions, workshops, and interactive sessions. These formats are designed to engage participants and encourage active participation, ensuring a rich and dynamic learning experience for all attendees.

The conference also offered various social opportunities — such as the Welcome Reception and Poster Presentation and the Networking Dinner — allowing participants to meet other attendees.

During the Welcome Reception and Poster Presentation on Thursday, November 9, attendees were able to browse scientific posters created by researchers. The posters provided a glimpse of what is currently underway for a variety of research projects and anyone was able to ask questions and learn more about the research. At the end of the evening, we awarded ribbons to five researchers with the most dynamic research. On Saturday, November 11, the top three ribbon recipients presented a summary of their research.

The Networking Dinner on Friday, November 10, featured a delicious buffet and cocktails or mocktails. During the evening, attendees had the chance to visit with old friends and meet new ones.

Key Sessions and Topics

The PFF Summit covered a wide range of themes and topics related to pulmonary fibrosis. These include:

- 1 Understanding PF:** Sessions focused on the underlying mechanisms of pulmonary fibrosis, as well as an overview about key programs at the PFF. Sessions included topics about understanding the disease, an introduction to the Foundation, how to live with PF in a COVID world, and genetics and PF.
- 2 Treatments and Therapies:** Presentations and panels addressed current and emerging treatments for pulmonary fibrosis. Topics included supplemental oxygen, preparing for a lung transplant, and improving pulmonary fitness.
- 3 Patient Care and Quality of Life:** Sessions dedicated to enhancing patient care, symptom management, and quality of life for individuals living with pulmonary fibrosis. Sessions included discussions about environmental factors that can affect PF, as well as the Plenary Session, "It Takes a Village: The Critical Role of Federal Agencies in PF Research and Care."
- 4 Research and Clinical Trials:** Discussions on ongoing research studies, clinical trials, and the development of novel therapies. The Summit provides a platform for researchers to present their findings and discuss potential collaborations for future investigations. Sessions included the Plenary Session, "Clinical Trials: Accelerating Finding a Cure," current therapies in the pipeline, the future of clinical trials, and more.
- 5 CME Sessions:** The conference provided a large selection of continuing education credits for physicians, physician's assistants, respiratory therapists, pharmacists, nurse practitioners, and registered nurses engaged in the care of patients with pulmonary fibrosis. Some key sessions included a full-day session for community pulmonologists, a half-day session for nurses and allied health professionals, and regular conference topics pertaining to disparities in ILD, multidisciplinary discussions, and more. To view the CME requirements, visit pulmonaryfibrosis.org/summit-CME.

There were many more sessions that took place at this year's Summit. All sessions at the PFF Summit were recorded and will be available through the PFF's YouTube channel in the spring of 2024.



We Welcomed Keynote Speakers Dr. Banu Karimi-Shah and Dr. D. Clark Files!

On Friday, November 10, in the plenary session titled “It Takes a Village: The Critical Role of Federal Agencies in PF Research and Care,” Dr. Banu Karimi-Shah from the FDA presented the FDA’s perspective on accelerating new treatments while maintaining clinical trial safety.

On Saturday, November 11, in the plenary session titled “Clinical trials: Accelerating finding a cure,” Dr. D. Clark Files spoke about adaptive clinical trials as the wave of the future.



**BANU
KARIMI-SHAH, MD**



**D. CLARK
FILES, MD**

Meet Our Co-Chairs



PATRICIA J. SIME, MD, FRCP, VCU Health

Dr. Sime is the Chair of the Department of Internal Medicine at Virginia Commonwealth University in Richmond, Virginia. She has published more than 150 manuscripts and has been continuously funded by the NIH, foundations, and philanthropy. Dr. Sime holds patents for her discoveries, has served as a standing member of an NIH study section, has contributed to journal editorial boards, and serves leadership roles in the American Thoracic Society, Pulmonary Fibrosis Foundation, and the Parker B. Francis Foundation. Her goals are to continue to develop innovative and impactful clinical, research, and education programs across Divisions and Departments while helping to support the next generation of researchers, educators, and clinicians.



TRACY LUCKHARDT, MD, UAB Medicine

Dr. Luckhardt has particular interests in evaluating and treating patients with interstitial lung disease at the University of Alabama at Birmingham. She is working to build collaborations with rheumatology and cardiology to treat patients with interstitial lung disease and in particular patients with connective tissue disease-associated ILD. Dr. Luckhardt is also the Medical Director of the inpatient Pulmonary Services and the Specialty Care Unit and has interest in the management of patients with advanced lung disease and chronic respiratory failure.



ANN LUCAS, PF Advocate

Ann was diagnosed with RA-ILD in 2008 and continued working until 2014. She received a double lung transplant in 2017 at UVA. Since transplant, she has focused on supporting others diagnosed with ILD as well as those preparing and recovering from lung transplant. Ann served as a PFF Ambassador from 2018 to 2022, and is currently an Emeritus Ambassador. She also volunteers as a lung transplant mentor at UVA and leads several support groups for patients and families.



Inclusion and Advocacy

The PFF Summit strongly emphasizes inclusivity and the involvement of all patients, caregivers, and advocates in shaping the conversation around pulmonary fibrosis. Your unique perspectives and experiences are recognized as essential components in driving research, improving care, and raising awareness about this often devastating disease.

Thank you to our Sponsors!

DIAMOND LEVEL



GOLD LEVEL



SILVER LEVEL



MEDICAL CENTER SPONSOR



Recorded sessions are coming soon!

Visit our website at PFFSummit.org for updates on when recorded sessions will be available and general information about the conference.



2020 PFF Scholar Award Recipient Discovers a Novel New Finding



Avraham Unterman, MD, MBA, one of the 2020 PFF Scholar awardees, created a single-cell atlas of the peripheral immune system in idiopathic pulmonary fibrosis patients to study differences between the stable and

progressive forms of the disease. The soon-to-be-published results are now available online as a preprint.

“It’s obvious to study the lung; it’s less obvious to look at the peripheral blood system,” said Dr. Unterman, who heads the Interstitial Lung Disease Program and runs a lab at Tel Aviv Sourasky Medical Center in Israel. “Blood has many advantages because it’s accessible and less invasive than studying a lung biopsy.”

Dr. Unterman used single-cell RNA sequencing to analyze 38 peripheral blood mononuclear cell samples from 25 patients with IPF and 13 matched controls, yielding nearly 150,000 cells segregated into 23 sub-populations. Naftali Kaminski, MD, Professor of Medicine at Yale School of Medicine and a world expert in genomics of chronic lung disease, biomarkers discovery, and molecular mechanisms of IPF, supervised the work. “Single-cell RNA sequencing allows us to profile in high-resolution different cell subtypes of monocytes and lymphocytes in the

peripheral blood immune system,” Dr. Kaminski said.

Dr. Unterman found that compared to the controls, classical monocytes were increased in stable IPF, and to a greater extent in progressive IPF. An increased level of classical monocytes was associated with decreased survival. He said the increase in classical and intermediate subtypes was likely related to the receptor CCR2, which hones in on diseased tissues.

“Because non-classical monocytes lack this receptor, they aren’t attracted to the lungs like classical monocytes,” he said.

Regulatory T-cells, or Tregs, were also increased in progressive IPF and were associated with decreased survival.

“This is a novel finding,” Dr. Unterman said. “We expected all lymphocyte populations to be decreased in progressive disease. But some types of lymphocytes are not part of the herd.”

Dr. Imre Noth, Professor of Medicine at the University of Virginia School of Medicine and a premiere translational researcher in ILD, served as Dr. Unterman’s PFF sponsor through the PFF Scholar Award program. The PFF assigns a sponsor to each PFF Scholar as an additional feature of the award. PFF sponsors actively advocate on behalf of the awardee and work to create opportunities for leadership, networking, and visibility in the field.

“I am very privileged to work with Dr. Noth,” said Dr. Unterman. “It’s exciting to have the opportunity to connect with one of the leaders in the field.”



PFF Walk 2023: Miles of Momentum

Who doesn't love a walk in the park? For the Pulmonary Fibrosis Foundation, a simple walk through Chicago's Lincoln Park in 2017 has grown exponentially, and the 2023 walks included events in Pittsburgh, the NYC Metro, San Francisco, Chicago, National Walk Day, Washington D.C., and Dallas! On National Walk Day, those who were unable to participate in person created their own experiences and gathered family and friends in their hometowns choosing a location and time that was just right for them.

"After the first PFF Walk in Chicago six years ago, we knew we had a hit on our hands and we wanted to expand so that more members of the PF community could join the experience," said Seth Klein, PFF Chief Development Officer. Since 2017, the PFF has added five more walk destinations, plus created an opportunity for those outside of these locations to expand the footprint of the event and bring the spirit of the Walk to their communities. To date, the PFF Walk program has raised over \$5 million, and more than 10,000 walkers have participated to date. Participants can walk as individuals or create a team, and can choose from a 1-mile or 2-mile route. Those who raise more than \$100 receive a commemorative PFF Walk T-shirt, and bigger incentive

prizes are awarded for higher fundraising levels.

The series of walks are an opportunity for people living with PF and their caregivers and families to help raise money and awareness for the development of new treatments and research needed to someday find a cure for the disease.

"The walks really bring home the fact that we have the ability to accelerate finding a cure when we come together as a united front. The momentum generated by this program is extremely impactful," said Klein.

Each city's walk takes place along a waterfront and taps into unique aspects of each locale. For example, at the NYC Metro Walk, participants enjoyed views of the Statue of Liberty, Ellis



Island, and the Manhattan skyline as they strolled along lower Manhattan's waterfront. And in San Francisco's Bay Area, walkers celebrated with the PF community with views of the Golden Gate Bridge as part of the scenery.

The Washington, D.C. Walk began near The Carousel at National Harbor on the Potomac River and the final walk of the season in Dallas guided walkers along a peaceful course on the Cypress Waters Trail.

In addition, participants in each of the six cities enjoy family-friendly activities, entertainment, and light refreshments.

A new experience was created called the "Mission Moment," designed to recognize all members of the PF community —people living with PF, caregivers and family members, and those who are remembering someone lost to the disease.

The Mission Moment is an interactive opportunity and at each walk, registered participants were given a spirit stick whose color corresponded to their relationship with PF. Then during their walk's Mission Moment, they were called on to wave their spirit sticks in the air. Each color was representative of how the Walker is connected to the cause. Patients and transplant recipients received a blue spirit stick, those who lost a loved one to the disease received a white spirit stick, and caregivers, family



members, healthcare professionals and friends received a blue and white spirit stick. On National Walk Day, walkers were also encouraged to start their walks with a Mission Moment that was personally meaningful to them. It was truly a sight to remember!

Klein said there are many reasons for the success of the PFF Walk. "This community likes being with one another. They share stories and tips on how they are succeeding in living with PF. And they feel a sense of urgency to raise money today, not just for current PF patients but for future generations. The altruism of the PF community is a remarkable thing."



Registration for the PFF Walk 2024 is now open!

Register, donate, and find dates and locations at PFFWalk.org





Embrace your

Breath



In September, the worldwide pulmonary fibrosis community united for Pulmonary Fibrosis Awareness Month (PFAM)! In 2023, the theme was “Embrace Your Breath” showcasing how you, the pulmonary fibrosis community, stand together in the fight against this disease.

On September 1, the PFF posted content every day on social media. Thanks to your likes, shares, and comments, we reached more than 130,000 people online! This number is important, because it helps people find the PFF so they can connect with the community and access our valuable resources.

The PF community strikes a pose

New this year, we asked the community to strike the lung pose. Our expectations were exceeded, and more than 40 people shared their images and stories about why they're striking the lung pose. You can find the new Lung Pose images and stories from the community on Facebook and Instagram at [@pfforg](https://www.pff.org).



Our most popular activities returned

Each September, there are a wide variety of activities that take place. All the posts are still available on our social media accounts, so head on over to your favorite platform and find us at [@pfforg](https://www.pff.org) to see all the content from the last PFAM.

Here's what happens every September:

- **30 Facts In 30 Days:** Each day on social media at 11:00 a.m CT, we'll post a fact about PF and ILD. *Like, share, and comment* on the facts.
- **Portraits of PF:** Every day at 1:00 p.m. CT, we'll post a story from someone in the community who has been impacted by PF. *Like, share, and comment* on each of the stories, or submit your own story to be featured in the campaign.
- **#BlueUp4PF:** If there's a unique building or landmark in your community that can shine blue at night, reach out to the building's management and ask them to participate by changing their evening lighting to blue. Don't forget to share use this hashtag to share with the entire PFF community!
- **Post on social media:** Post on your feed or change your profile picture with one of our PFAM images! Download them to your desktop or mobile, upload them to social media, and tell the world why you are raising awareness in September.
- **Donate:** You can show your support to the PF community by making a donation to the Foundation each September.

Meet the Newest Members of the PFF Board of Directors



DEVI KUMAR-NAMBIAR, JD, MBA

The Pulmonary Fibrosis Foundation may be new to Devi Kumar-Nambiar, but she has been supporting PF patients for nearly a decade. Her husband, Dr. Anoop Nambiar, co-directs a support group based in San Antonio to offer information

and sharing opportunities for PF patients and their families throughout Texas. Dr. Nambiar founded and has been the Director of the PFF Care Center at the University of Texas Health San Antonio since 2012.

“When we were first married, I started attending support group meetings to better understand Anoop’s passion for PF,” said Kumar-Nambiar, Deputy General Counsel for CPS Energy, the country’s largest city-owned gas and electric utility.

The ongoing PF support group soon provided no-cost medical services like on-site pulmonary function and six-minute walk testing and medical records review, including CT chest scans – a first-of-its-kind. Over time, it became clear to Kumar-Nambiar that many of the support group members would also benefit from legal assistance. In 2021, she established a partnership with the San Antonio Legal Services Association to offer free legal services to eligible group members.

“It’s important for everyone to prepare legal documents, such as wills and advanced directives, but especially so for patients with PF,” she said.

As a PFF Board member, she hopes to replicate a similar medical or legal clinic framework for patients and their loved ones in other US cities.

“There’s something so encouraging about local, grassroots-level support,” said Kumar-Nambiar.

“By participating in the support group, I have seen firsthand how patients and their families value the understanding they get through shared experiences.”

She would like to work on increasing awareness of PF among community pulmonologists.

“Pulmonary fibrosis and other ILDs are such nuanced diseases,” she said. “So often, they are difficult to diagnose, and community-based physicians need to know when to refer patients to a specialist for additional diagnostic testing and treatment.”



WAYNE T. PAN, MD, PHD, MBA

Although Dr. Wayne T. Pan started his career in orthopedic surgery, it has evolved over the past two decades to include significant experience in managed care, health information technology, and biotechnology.

Dr. Pan is a Medical Director at San Francisco Health Plan, an award-winning, Medicaid-managed care plan. He is also a Co-Founder and Chief Medical Officer of Verbal Voice Technologies, a company that harnesses artificial intelligence and behavioral change techniques to enhance virtual healthcare services.

Using machine learning and natural language processing, the company is building a platform to increase the effectiveness and efficiency of virtual care for patients with chronic conditions. The system prompts a clinician with standards of care appropriate to a patient’s condition and with words and phrases that are easiest to understand.

“Instead of searching through a database for an answer to a question, suggestions are automatically populated, allowing the clinician to focus on the conversation and the patient,” Dr. Pan said.

In a previous role at Genentech, Dr. Pan used the PFF Patient Registry to perform quality of care and health economic and outcomes research on nintedanib (Ofev®) and pirfenidone (Esbriet®). His research revealed the degree of variability in patient outcomes — and the need for biomarkers that can better measure drug effectiveness.

“Joining the PFF Board was one way to give back to the Foundation for using the Patient Registry for that research,” he said. “It’s critical that we continue to sustain our Registry.”

As a member of the Board of Directors, Dr. Pan will work to address funding to maintain the Registry to support the development of drugs to treat fibrotic lung diseases.

“Ongoing clinical research is so important to getting drug companies interested in uncommon diseases,” he said.



KENNETH C. FANG, MD

Dr. Kenneth C. Fang has enjoyed a long career in medicine, translational research, and biotechnology. He began as an academic clinician at the University of California, San Francisco, where he worked in bench science, intensive care medicine, and lung fibrosis management.

“At that time, there were limited therapeutic options for pulmonary fibrosis,” he said. “A key clinical challenge of lung fibrosis then, and still now, is determining what type of fibrosis a patient has.”

Dr. Fang said the development of the first two FDA-approved PF drugs has heightened the interest of the pharmaceutical industry and early-stage biotechnology companies, much like the early success of targeted molecular therapy changed the perception of lung cancer as a lethal disease.

“I think lung fibrosis has in the last decade really started attracting a lot of attention not just from big pharma companies, but also from startup companies looking at different scientific pathways to explore as alternative treatment strategies,” he said.

To match those efforts, Dr. Fang said we need more sophisticated diagnostics and greater investment in understanding the basic science of lung fibrosis.

“My perspective is that developing better drugs requires understanding the disease at the molecular level,” said Dr. Fang. “If you look at cancer in general, the therapeutic advances have resulted from a better scientific understanding of the biology of the disease. I think that’s where we’re at now in lung fibrosis.”

After leaving academia, Dr. Fang began working in biotechnology, focusing on translational research — making him a timely addition to the PFF Board of Directors.

“I look forward to helping the PFF play a role at the national level and really making an impact,” he said.

Participate in a committee!

Are you interested in participating in a Board of Directors sub-committee? The PFF welcomes members for the Development and Finance & Audit committee, and various working groups addressing timely needs of the Foundation. Please reach out to [Zoe Bubany](#) with a cover letter and attached CV or resume.



IN MEMORIAM:

Dr. Daniel Rose

OCTOBER 20, 1947 - JULY 11, 2023

The Pulmonary Fibrosis Foundation mourns the passing of Dr. Daniel “Dan” Rose, former President, CEO, and Chair of the PFF Board of Directors.

Dan’s father and uncle founded the PFF in 2000 after his father and aunt were diagnosed with pulmonary fibrosis. Shortly after the formation of the PFF, Dan’s uncle was also diagnosed with PF. Their commitment and foresight shaped the PFF into what it is today – the nation’s leading advocacy organization supporting pulmonary fibrosis patients through research, education, and advocacy.

Dan was born in Denver, Colorado, where he lived until he completed high school. He graduated from Wesleyan University in Connecticut and University of Colorado Medical School. Dan completed his residency in cardiac surgery at New York University.

In 2002, after retiring from his career as a cardiothoracic surgeon, Dan became Chair of the PFF Board of Directors, and he served as the PFF’s CEO from 2009-2015. Under his leadership, the PFF became a unifying force and trusted resource in the PF community. Dan was a visionary who spearheaded numerous innovative education and research

programs. His unwavering drive to support the pulmonary fibrosis community led to the development of some of the PFF’s most impactful initiatives – the PFF Registry, PFF Summit, and the PFF Care Center Network. Together, these initiatives reach thousands of patients, families, and health care providers.

During Dan’s tenure at the PFF, the first two antifibrotic therapies, nintedanib and pirfenidone, were approved by the FDA. This was a transformational milestone in the treatment of IPF.

After serving as President, CEO, and Chair of the PFF, Dan continued to support the Foundation by participating in the Development Committee. He was a fearless fundraiser and never shied away from a difficult solicitation. Dan was also a valuable member of the PF Warriors, and he served on the steering committee of the Clinical Trials Transformative Initiative (CTTI).

Dan will be dearly missed by his wife, Ellen, children, grandchildren, and many friends. While we still have far to go in our fight against PF, patients and their families are in a better position because of Dan’s efforts.

Ways to Get Involved

Together, we can make a difference. You can help the PF community and lead the way toward a world without pulmonary fibrosis by getting involved with the Foundation. Below are just some of the ways that you can make an impact. To learn more, visit pulmonaryfibrosis.org or call us at **844.TalkPFF** (844.825.5733).



ADVOCACY

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

FUNDRAISE FOR TEAM PFF

Join Team PFF and be a part of a committed group of volunteers across the country. Turn your passions and interests into a unique fundraising campaign to advance vital research and support patient programs that help patients and their families live longer, healthier lives. For questions, contact Alyssa Athens at aathens@pulmonaryfibrosis.org or **312.224.8112**.

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 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 online event or find inspiration for creating an event of your own. To find an event, visit bit.ly/pffevents.

ENGAGE WITH US ON SOCIAL MEDIA

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

PFF WALK

Together toward a cure: Registration is open for the PFF Walk 2024 season! Join us in Pittsburgh (July 20), NYC Metro (August 3), the Bay Area (September 7), Chicago (September 14), National Walk Day (September 28), Washington, D.C. (October 12), and Dallas (October 19)! Register, learn more, and donate at PFFWalk.org.

Leadership

BOARD MEMBERS

David McNinch

CHAIR

Laurie Chandler, CFP

VICE-CHAIR, TREASURER

Pat Rosa

SECRETARY

Martin Attwell

Kenneth C. Fang, MD

Terence Hales

Julie Halston

Jeff Harris

Susan S. Jacobs, RN, MS

Heather Kagel

Devi Kumar-Nambiar, JD, MBA

Wayne T. Pan, MD, PhD, MBA

CHAIRMAN EMERITUS

George Eliades, PhD

Michael C. Henderson

Daniel M. Rose, MD

MEMBERS EMERITUS

Colleen Attwell

Joseph Borus, Esq.

Thomas E. Hales

Dave Steffy

Stephen A. Wald, PhD

MEDICAL ADVISORY BOARD

Michael F. Beers, MD*

Timothy S. Blackwell, MD

Amy Hajari Case, MD*

Sonye Danoff, MD, PhD*

Kevin R. Flaherty, MD, MS*

Christine Kim Garcia, MD, PhD

Marilyn Glassberg, MD

Susan S. Jacobs, RN, MS*

Naftali Kaminski, MD

David W. Kamp, MD

Melanie Koenigshoff, MD

Martin Kolb, MD

Joseph Lasky, MD

Joyce Lee, MD*

Kathleen O. Lindell, PhD, RN*

James E. Loyd, MD

David A. Lynch, MB, BCh

Fernando J. Martinez, MD, MS

Imre Noth, MD

Jesse Roman, MD

Ganesh Raghu, MD

Patricia J. Sime, MD*

Charlie Strange III, MD

Janet Talbert, MS, CGC

RESEARCH REVIEW COMMITTEE

Bethany Moore, PhD

CHAIR

Mitchell Olman, MD

VICE CHAIR

Ayodeji Adegunsoye, MD

Michael F. Beers, MD*

PAST CHAIR

Zea Borok, MD

Sonye Danoff, MD, PhD*

Joao De Andrade, MD

Wonder Drake, MD

Carol Feghali-Bostwick, PhD

Marilyn Glassberg, MD

David Kamp, MD

Melanie Koenigshoff, MD, PhD

Joseph Lasky, MD PAST CHAIR

Andrew Limper, MD* PAST CHAIR

Kathleen O. Lindell, PhD, RN*

David A. Lynch, MB, BCh

Fernando J. Martinez, MD, MS

Joshua Mooney, MD, MS

Imre Noth, MD

Mauricio Rojas, MD

Jesse Roman, MD PAST CHAIR

Mary Beth Scholand, MD

Jessica Shore, PhD, RN

Patricia Sime, MD*

Mary Streck, MD

Paul Wolters, MD

PFF TEAM OFFICERS

Scott Staszak

INTERIM CHIEF EXECUTIVE OFFICER,

CHIEF OPERATING OFFICER

Janet Bianchetta, CPA

CHIEF FINANCIAL OFFICER

Amy Hajari Case, MD, FCCP

INTERIM CHIEF MEDICAL OFFICER,

SENIOR MEDICAL ADVISOR, EDUCATION AND

AWARENESS

Seth Klein

CHIEF DEVELOPMENT OFFICER

STAFF

Zoë D. Bubany, MBA

VICE PRESIDENT,

BOARD AND EXTERNAL RELATIONS

Sonye Danoff, MD, PhD*

SENIOR MEDICAL ADVISOR,

PFF CARE CENTER NETWORK

Kevin R. Flaherty, MD, MS*

STEERING COMMITTEE CHAIR,

PFF CARE CENTER NETWORK AND

PFF REGISTRY

Kate Gates

VICE PRESIDENT, ADVOCACY AND PROGRAMS

Joyce S. Lee, MD, MS*

SENIOR MEDICAL ADVISOR, RESEARCH AND

HEALTH CARE QUALITY

Jennifer Mefford

VICE PRESIDENT, CORPORATE PARTNERSHIPS

Jessica Shore, PhD, RN

SENIOR VICE PRESIDENT, CLINICAL AFFAIRS

AND QUALITY

Amy Wardzala

VICE PRESIDENT, DEVELOPMENT

Alyssa Athens

Misha Cadet

Alvin Coleman

Diana DeRosa

Laura Devitt

Naomi Edwards

Roberto Espino

Tamaris Jeune

Sarah Brandywine Johnson

Sheena Kelly

Mary Kiener

Anna LaValle

Kelly Lynch

Jake Meding

Sharon Reed

Diana Rincon

Ingrid Schwab

Samantha Simmons

Jennifer Simokaitis

Ashley Smith

Leah Sorini

Meredith Taylor

Sean Thinnis

Aubrey Trecek

Andrea Young

* A member of the Medical and Scientific Advisory Committee. Additional members include:

David J. Lederer, MD

Harold R. Collard, MD



230 EAST OHIO STREET
SUITE 500
CHICAGO, ILLINOIS 60611

The Breathe Bulletin is digital!

We are excited to announce that all upcoming issues of the Breathe Bulletin will be fully digital.



By going digital, we're reducing our carbon footprint. Digital magazines eliminate paper and ink usage, as well as energy consumption associated with printing and transportation.

Further, digital magazines can be accessed from anywhere with an internet connection, allowing us to reach an even bigger audience. You can read the Breathe Bulletin on your smartphone, tablet, and computer, making it convenient and easily accessible.

New issues of the Breathe Bulletin can now include embedded videos, hyperlinks, and so much more.

All issues of the Breathe Bulletin, including this issue, are available on our website at pulmonaryfibrosis.org/breathebulletin.