

PULMONARY FIBROSIS FOUNDATION

breathe

ISSUE 01 SUMMER 2021



 PULMONARY FIBROSIS[®]
awareness month
SEPTEMBER

PRESENTED BY  Pulmonary Fibrosis Foundation[®]

In our home, we #BlueUp4PF
in September. Learn more at
pulmonaryfibrosis.org

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OUR MISSION

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

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



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Pulmonary Fibrosis Foundation

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

Letter from Our President and CEO

DEAR FRIENDS,

As we move past the first year of the COVID-19 pandemic and as vaccines bring hope for a future that's nearer to normal, I've been reflecting on the energy and resilience of the pulmonary fibrosis (PF) community. The patients and caregivers, healthcare providers and researchers at the Pulmonary Fibrosis Foundation (PFF) Care Center Network sites, our PFF staff, and the community at large have all shown incredible spirit in overcoming obstacles and embracing new approaches. This extraordinary positivity and flexibility mean we've continued to make strides in patient care, education, research, and raising awareness about the ongoing challenges of PF.

Although the coronavirus has brought new complexity to our work, we continue to find silver linings in our practice of meeting virtually. At the PFF Hill Day in March, we remotely visited more than 100 offices of Congressional representatives in Washington, D.C., to raise awareness of the importance of PF research. The virtual event allowed more patients and caregivers than ever to participate — many told us they wouldn't have been able to come to Washington but enjoyed being part of PFF advocacy from their homes. Further, to ensure all who want to can attend, the PFF Walk and the biennial PFF Summit will go all-virtual this year. We look forward to welcoming attendees from all over the world.

In a major development that promises to power new research, the next generation of the PFF Registry is here. Now split into "PFF Care Center" and "Community" divisions, the PFF Registry has two distinct data sets. The PFF Care Center Registry collects medical data from up to 2,000 patients and is administered by PFF Care Centers across the country. The PFF Community Registry, launching this summer, will rely on ongoing participant-reported data provided directly by the enrollee. All PF patients, PF patients who are lung transplant recipients, caregivers, and family members are invited to participate in the PFF Community Registry.

Building on the new PFF logo and colors we debuted last year, recently we launched a bright, engaging new website with a more modern design. The new site is easier to navigate, more interactive, and built with accessibility to all users in mind.

Visit us online at pulmonaryfibrosis.org to explore our new website.

As always, the PFF continues to provide support and tools to the community as we navigate the pandemic together. Visit pulmonaryfibrosis.org/COVID19 for frequently updated COVID-19 resources, and read the Q&A in this issue about the safety and efficacy of COVID-19 vaccines.

The support created by our close-knit community fuels the Foundation's progress every day, no matter what challenges that day may bring. Thank you for your courage, commitment, and constancy through a difficult year — you are a valuable and valued ally in our fight to identify new treatments, improve patient quality of life, and find a cure for pulmonary fibrosis.



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER

PS: Remembering the PFF in your estate planning is one of the most meaningful ways you can make an impact. A gift to the PFF creates a life-giving legacy for generations to come — and might even benefit someone close to you. Visit pulmonaryfibrosis.org/plannedgiving to learn more.



Giving and Getting Virtual Support

While virtual meetings and celebrations now seem to be the way of the world, it didn't happen overnight. Just ask Jane Thompson and Chris Behringer who lead the Pulmonary Fibrosis Support Group in Minnesota.



Jane Thompson

"It took us a while to figure out the best way to keep our group together during the pandemic," the co-leaders said. "We eventually turned to the wonders of Zoom."

With 30-40 people who regularly attend meetings, they came up with a rotating schedule to meet every member's needs. Meetings always feature an educational speaker followed by Q&A, a PF-related discussion topic to share collective knowledge, and small breakout group discussions.

While Thompson and Behringer recommend structured meetings, they are always thinking of new ways to make virtual get-togethers interesting. For example, they are planning a Zoom chair yoga session as part of an upcoming group wellness discussion.



Chris Behringer

Chair yoga is a recommended alternative for those who are less flexible. It can help loosen and stretch muscles, reduce stress, and improve circulation.

Moving and staying connected are activities that Thompson and Behringer consistently recommend to their support group. In between meetings, they keep their group engaged by emailing noteworthy information from the PFF and other helpful sources. They also created a private Facebook page as a way for members to share more personal information and keep in touch.

Throughout the country, PF support groups are discovering innovative ways to help their members stay informed and engaged. If you are interested in joining or starting a support group, please contact the PFF Help Center at **844.TalkPFF** or **help@pulmonaryfibrosis.org**.

New Virtual Pulmonary Rehabilitation Toolkit Available



The PFF and the American Association of Cardiovascular and Respiratory Care (AACVPR) have partnered to launch a new digital Pulmonary Rehabilitation

(PR) Toolkit for PF patients. The toolkit features videos and written pieces explaining what pulmonary rehab is, as well as mindfulness resources. It also includes exercise videos and tools enabling users to track exercise and vital signs. While it includes resources that you would receive through a PR program, it is not meant to be a substitute for an in-person PR visit.

"The benefits of pulmonary rehab are significant and many PF patients have been without access to it for over a year," said Kate Gates, PFF Vice President, Advocacy and Programs. "We are grateful to the AACVPR for their efforts to make the Pulmonary Rehabilitation Toolkit available to our community."

The Pulmonary Fibrosis Foundation would like to thank Boehringer Ingelheim for sponsoring the toolkit.



Visit pulmonaryfibrosis.org/PRtoolkit for more information.

Volunteers Advocate For PF Research at Virtual Hill Day



The PF community flexed its collective muscle in Washington D.C. during the PFF's annual Hill Day. On March 10, 60 participants "traveled" to D.C. and met virtually with representatives to advocate for increased support for PF patients.

Specific requests to government officials included the addition of language in the congressional funding report for the National Heart, Lung, and Blood Institute on the importance of pulmonary fibrosis research and maintaining pulmonary fibrosis as a topic area in the Peer Reviewed Medical Research Program at the U.S. Department of Defense.

PFF Hill Day made the local news in several cities across the nation, including the Kennebunk Post (Maine), The Central Virginian (Virginia), and The Idaho Press (Idaho).

The PFF Help Center is Here for You!

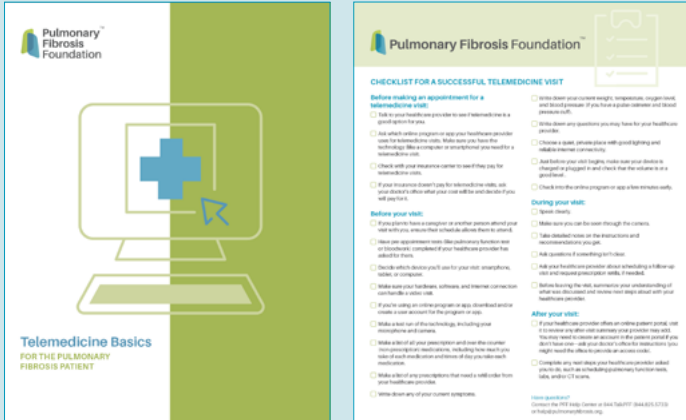


We are excited to announce that the Patient Communication Center has a new name — the **PFF Help Center!** The PFF Help Center will continue to provide patients, caregivers, and healthcare providers with the most up-to-date medical information, communicate the availability of support services, share free educational materials, and offer information about other essential resources.

We believe the name "PFF Help Center" will give context to the services that our call center provides and also clarify that we provide help and support to all members of the PF community. The PFF Help Center is a great resource for new and returning patients, transplant recipients, caregivers, and healthcare providers to contact when looking for support and information from the PFF. The PFF Help Center is also a place where those in the PF community who have lost a loved one can learn how to get involved with the Foundation.

You are welcome to contact the PFF Help Center at **844.TalkPFF** (844.825.5733) or **help@pulmonaryfibrosis.org** to speak to one of our dedicated staff members. The operating hours of the PFF Help Center are 9:00 a.m. – 5:00 p.m. Central Time, Monday through Friday.

New Telemedicine Materials Make Virtual Healthcare Easier For You



to prepare for a telemedicine appointment, and what to expect during and after a virtual visit. Additional topics include the pros and cons of telemedicine, when to see a provider in person, insurance coverage, and troubleshooting technology.

The PFF’s **Telemedicine Checklist** can help patients and caregivers prepare for a successful visit with their provider. This checklist includes action items for patients to consider before making a telemedicine appointment, as well as before, during, and after the virtual visit. There is space to jot down notes on the back of the checklist — whether it’s questions you have for your provider, information to share, notes from your appointment, or follow-up instructions — and room to note when your next appointment will be.

The PFF has developed a Telemedicine Basics booklet and Telemedicine Checklist to help members of the PF community navigate the world of virtual healthcare with ease.

Telemedicine is the use of technology—smartphone, tablet, laptop, or desktop computer—to connect patients directly with their healthcare providers. Telemedicine has become increasingly popular over the last few years, and since the beginning of the COVID-19 pandemic it has become much more common. The use of technology to access healthcare can be difficult for some, so it was important for the PFF to develop resources to educate and empower our community members and set them up for success.

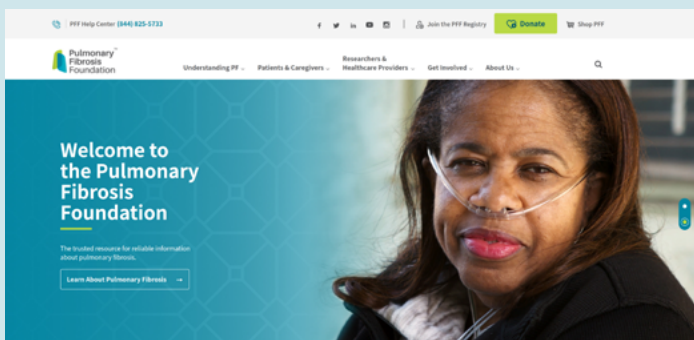
In the **Telemedicine Basics** booklet, patients can learn how to connect with their healthcare providers in a virtual format, how

Access our new telemedicine materials and other PFF educational materials on our website at pulmonaryfibrosis.org/education. Hard copies of the Telemedicine Basics booklet and Telemedicine Checklist are available upon request via the PFF Help Center at **844.TalkPFF** (844.825.5733) or help@pulmonaryfibrosis.org.

The PFF would like to thank Boehringer Ingelheim for their generous support of these important educational resources.



Introducing Our Brand New Website



The Pulmonary Fibrosis Foundation recently unveiled its new website at pulmonaryfibrosis.org. The new website is more interactive than ever before, with accessibility for web users of all experience levels at the forefront of its design. Developed with feedback from those impacted by PF, the site navigation is intuitive and the PFF’s trusted content comes to life in a clear and compelling design. The bright, engaging, and easy-to-use website will help the PF community find information and resources more efficiently, learn about our robust programs, ways to get involved, and how to get in touch with the PFF. Visit the new website today!

Pivoting During the Pandemic: PFF Care Center Network Finds Positive Side To New Approaches



“The COVID-19 pandemic has brought sweeping changes to the way patient care is delivered. For the PFF Care Center Network (CCN), some of those changes have been surprisingly positive!”

– Jessica Shore, PhD, RN, PFF Vice President of Clinical Operations and Quality

An important piece of Shore’s job is visiting CCN sites to learn how they treat adult patients with fibrotic lung diseases and take a multidisciplinary approach to delivering comprehensive patient care, engaging in patient-oriented pulmonary fibrosis research, working with the PFF to provide educational materials, and interact with the local community through PFF programs. As the pandemic brought a temporary end to travel and on-site visits, Shore and the CCN staff at the PFF began conducting virtual visits to CCN sites “to hear how COVID-19 is affecting them, what’s going well and what isn’t, and what the PFF can do to support them,” she said.

The ability to visit many more sites than usual is a big plus. “Even if we traveled to one center each week, we wouldn’t get to them all in a year,” Shore explained. “This way, we can do multiple visits in a week, and I can bring other PFF staff onto the call who wouldn’t have been able to join an on-site visit.”

Shore’s team has heard many success stories from sites that have pivoted effectively during COVID-19. “Centers shifted quickly

to telehealth and, when appropriate, brought patients into the clinic,” she said. “Many have reached out to engage patients in support groups and research. We’re gaining a lot of information about our network and how strong it really is.”

Solving problems together

Besides sharing formal guidance, the PFF has acted as a conduit for shared problem-solving. “Sometimes a center talks about the same problem or challenge I heard from another site the week before,” Shore explained. “We’re happy we can help those on the front lines connect with each other to say, ‘We have the same problem; let’s talk it through.’”

For instance, two centers with which the PFF recently conducted virtual visits, University of Kentucky Healthcare and the University of Vermont Medical Center, have done a particularly good job with rural health outreach during the pandemic. “Both have continued to do extraordinary outreach to patients, even when it’s by telephone, given that internet isn’t always reliable in rural areas. They’re sharing their expertise with other centers,” Shore said.

“The pandemic has shown us that we can bring PFF Care Centers together in a way we hadn’t envisioned before,” she added.

When the pandemic ends, Shore expects some of those new practices to continue.

“A lesson we’ve learned is that virtual events can be much broader and more frequent because they’re not using the resources of in-person gatherings,” she said. “We’re now thinking of ways we may be able to implement some virtual CCN meetings throughout the year, not necessarily waiting for the PFF Summit or the PFF Volunteer Meeting.”

A Parade of Hope: Cleveland Clinic Walk Energizes Patients and Providers



Healthcare providers within the PF community are among the hundreds of event leaders who take action and host events in their hometowns annually. Cleveland Clinic is just one example of the many dedicated nurses, practitioners, and researchers who are actively raising funds and awareness within their communities.

Dozens of community walks for the PFF take place nationwide every year. In fact, these events have raised funds to support the Foundation's mission to serve as the trusted resource for all those impacted by pulmonary fibrosis.

Jessica Glennie, a nurse practitioner at the Cleveland Clinic—a PFF Care Center Network site—launched a community walk in 2019 that has raised over \$9,000 in just two years. Physicians, nurses, patients and their families, friends, and pets walked together in their local neighborhood in 2019 and pivoted to a hybrid event in 2020.

Glennie, who is also a support group leader, developed two opportunities that were both safe and fun. Participants were invited to walk together — while masked and socially distanced — or take steps in their own neighborhoods. Their creativity and commitment is an important reminder that together, we can make a difference even when we're physically apart.

"This has been such an exciting event, allowing us to bring together members of our interstitial lung disease center, people living with PF, and the community to raise awareness and funding for this under-recognized disease," said Glennie.

The PFF provides tools and resources to help CCN sites and PF community members interested in building a community walk. Email templates, how-to-videos, recruitment strategies, and more are at your fingertips at pffwalk.org.

Are you interested in starting a local walk or fundraiser in your area? For more information, please contact Jackie Williams at jwilliams@pulmonaryfibrosis.org.

PFF Position Statements Expand To Include Information For Patients

Resources summarize available evidence on aspects of pulmonary fibrosis

As part of its growing resource library for healthcare providers, the Pulmonary Fibrosis Foundation produces position statements that provide clinicians with insights based on currently available evidence. Now, position statements are being developed with both providers and patients in mind.

“As we provide information to clinicians, we want to make sure we also bring those perspectives to patients and their caregivers in appropriate, easy-to-understand language,” said Jessica Shore, PhD, RN, PFF Vice President, Clinical Operations and Quality. “The position statement on genetic testing, published in April 2020, has information for both providers and patients. That’s our model as we move forward.”

Working groups comprised of physicians, nurses, allied health professionals, and researchers pull together published research and expertise from across the PFF Care Center Network to create the position statements. In addition to helping develop new, separate versions for patients, the PFF Nurse and Allied Health

Network aims to expand the clinician versions to incorporate care protocols from across the continuum of providers.

“We’re looking at what information should be included, not just for physicians, but also for nurses, pharmacists, respiratory therapists, and others,” Shore explained. “Our goal is to better understand best practices in care from these different practice perspectives.”

Two new position statements are currently in development. A statement on rural health will examine ways to improve care of interstitial lung disease patients in sparsely populated areas of the country. A statement on palliative care will clarify the difference between palliative care — managing symptoms and maximizing comfort — and hospice for patients with PF. In parallel with developing position statements, the goal is to publish clinical recommendations for ILD patients in scientific journals. The Surgical Lung Biopsy recommendation was recently published in the ATS Annals.

To determine topics for the next group of position statements, “We’ve polled and surveyed across the CCN to identify needs and gaps,” said Shore. “In creating these statements, we’re really listening to the CCN to learn where we should go next to share best practices and really improve care delivery.”

READ PFF POSITION STATEMENTS

Visit pulmonaryfibrosis.org/healthproviders to read and download PFF position statements.

NOW AVAILABLE	CLINICIAN VERSION	PATIENT VERSION
Genetic Testing in PF	✓	✓
Surgical Lung Biopsy	✓	
Stem Cell	✓	✓
High-Resolution Computed Tomography	✓	

COMING SOON	CLINICIAN VERSION	PATIENT VERSION
Rural Health	✓	✓
Palliative Care	✓	✓

Join Us Virtually in November for the PFF Summit 2021!



Join us November 8 -13, 2021!
The PFF Summit 2021 will be presented virtually this year with a robust program planned for all attendees.

Our engaging faculty will include keynote speakers Dr. Gary Gibbons, Director of the National Heart, Lung, and Blood Institute (NHLBI), who will present “The Importance of PF Research to the NHLBI”, and Dr. Kathleen Lindell, Associate Professor and Mary Swain Endowed Chair in Palliative Care Health at Medical University of South Carolina, who will deliver “Palliative Care: Spotlight on the Caregiver.” Registration will open on June 14, and the first 1,000 registrants will receive a surprise swag bag in advance of the Summit 2021 opening day.

Academic and industry researchers are invited to submit abstracts of their scientific research for poster presentation, which will be open for submission from June 14 to September 10 through the online portal ProposalCentral. For healthcare professionals, the Summit will feature a continuing medical education (CME) and Maintenance of Certification (MOC) program in addition to a continuing education (CE) program for nurses, respiratory therapists, and pharmacists.

Program

The PFF Summit will span six days of engaging live and on-demand programming through the online platform MedscapeLIVE! On November 8, the Summit will kick-off with introductory sessions and will conclude with an interactive poster session highlighting research from around the world, a live awards ceremony for the top five academic posters, and the ability to chat 1:1 with the presenting authors.

The remainder of the week will feature two plenary sessions on Tuesday and Friday, three days of the Clinical Trials Innovation Series (CTI), two half day sessions for community pulmonologists and ILD fellows, two half day sessions for nurses and allied healthcare workers, a fireside chat with our President and CEO, William T. Schmidt and our esteemed medical team, and a networking event you don't want to miss! The full program is available to view at pffsummit.org.

Clinical Trials Innovation Series

The popular CTI Series provides the opportunity to highlight updates in drug development and clinical trials. Speakers in the CTI Series will have a unique 10-minute opportunity to share information directly with patients, key opinion leaders, and all other stakeholders in the PF community.

PFF Summit Co-Chairs

The PFF extends a very special thanks to our PFF Summit 2021 co-chairs. Representing the health care provider community are: Mary Strek, MD from the University of Chicago Medicine, Dan Dilling, MD from Loyola University Medical Center, and Rade Tomic, MD from Northwestern Medicine. Representing the patient and caregiver community are: Gary Cunningham, a former patient and transplant recipient, and his caregiver and wife Marianne Sarazin. Both Gary and Marianne are PFF Ambassadors Emeritus and serve as support group leaders in Sterling Heights, MI. The PFF also extends our thanks to the entire Summit Program Organizing Committee (SPOC) who have helped develop this year's stimulating program, along with the thoughtful selection of expert faculty from around the world. To view the full list of SPOC membership, please visit pffsummit.org.

For more information, visit pffsummit.org or email questions to summit@pulmonaryfibrosis.org. For questions about sponsoring, exhibiting, or additional marketing opportunities, please contact Jennifer Mefford at partnerships@pulmonaryfibrosis.org or 312.546.4105.

Community Pulmonologists and ILD Fellows

The PFF will present two half-day sessions designed specifically for community pulmonologists and ILD fellows. These sessions have been very popular in the past, but had caps on attendance. The PFF is excited that this year we have the ability to open this programming to anyone who wishes to attend.

PROLIFIC Consortium Welcomes New Members, Continues to Break Down Barriers



PROLIFIC

Prognostic Lung Fibrosis Consortium

In 2019, the Pulmonary Fibrosis Foundation and Bristol Myers Squibb launched the PROLIFIC Prognostic Lung Fibrosis Consortium to facilitate drug development for pulmonary fibrosis. PROLIFIC is based on precision medicine, which looks at the genetics, environment, and lifestyle of a patient to select treatment that could work best for them.

Until now, companies haven't had a way to share basic information with competitors, so pharmaceutical companies have developed their own tests. "It's more efficient for us to combine efforts to develop tests we all can use," said Peter H. Schafer, PhD, of Bristol Myers Squibb.

Using samples from the PFF Registry, PROLIFIC will develop tests focused on 12 different biomarkers (measurable indicators of a disease's presence or severity), chosen for

their potential to predict the course of pulmonary fibrosis and how well a drug will work in a specific individual.

Biomarker selection includes:

- Epithelial damage (CYFRA 21-1, SP-D, CA-19-9, CA-125, KL-6)
- Fibrosis (MMP-7, TN-C, POSTN)
- Inflammation (CCL 18, CXCL13, sICAM-1)
- Thrombosis (PAI-1)

Jennifer Mefford, PFF Vice President, Corporate Partnerships, said PROLIFIC has welcomed four new partners: Galapagos NV, Galecto Biotech AB, Novartis Institutes for BioMedical Research, and Three Lakes Foundation. These companies join existing consortium members Bristol Myers Squibb, Genentech, Lung Therapeutics, OptiKira, and Pliant Therapeutics.

"PROLIFIC has a scope of work for 2021 in place with a plan to begin testing of PFF Registry samples by January 2022," Mefford said.

For information on joining PROLIFIC as an industry partner, contact partnerships@pulmonaryfibrosis.org.

New Clinical Trials Newsletter Helps Spread the Word

Clinical trials, research studies that test the safety and effectiveness of medical treatments, will be the key to solving the mysteries of interstitial lung disease (ILD). Knowing that, many patients with ILD are eager to do their part for science by participating in one or more clinical trials.

How can patients find out about clinical trials that might be a good fit? One option is to visit the PFF's Clinical Trial Finder (trials.pulmonaryfibrosis.org), a database of nearly 300 ILD clinical trials imported from the National Institute of Health's ClinicalTrials.gov.

To help make it even easier for the PF community to find relevant clinical trials, the PFF launched the Clinical Trials Newsletter last fall, a monthly newsletter that highlights enrolling clinical trials for the PF Community. Each newsletter contains a broad cross-section of trials, including:

- Late-phase trials that need to recruit larger numbers of patients
- Trials that plan to recruit participants over many months
- Trials studying a variety of different forms of ILD and related conditions such as chronic cough, pulmonary hypertension, and lung transplant

Since its launch, the newsletter has been well-received. Trial sponsors — including PFF CCN sites — are eager to find new ways to tell patients about these trials. Additionally, patients enjoy having positive, engaging information that reminds them just how much research is being done in the ILD space.

PFF Registry Prepares to Add New Community Registry



PFF Registry™

Patient powered.
Data driven.
Research results.

The Pulmonary Fibrosis Foundation is proud to announce that the PFF Registry is preparing to enter a new phase, and when it does, the Registry for the first time will have two distinct data sets.

The PFF Care Center Registry is the new name for the existing registry that collects medical data from 2,000 patients with ILD. The PFF Care Center Registry is open only to patients who receive care at Care Center Network sites. Since 2016, PFF Care Centers throughout the U.S. have submitted data from participating patients to the Registry. Enrollment will resume this fall.

The PFF Community Registry, launching this year, will rely on ongoing participant-reported data that is provided directly by the participant.

"We're especially excited about being able to add the PFF Community Registry," says Junelle Speller, Vice President of the PFF Registry. "We invite all PF patients, PF patients who are lung transplant recipients, caregivers, and family members to participate in the PFF Community Registry. As more people contribute data, a clearer picture of PF will emerge to help improve health care and outcomes."

Spotlight on the PFF Community Registry

The Registry captures participants' experiences with PF to broaden physicians' knowledge about the disease and how to treat it. The new PFF Community Registry will take that one step

further by allowing patients, families, and caregivers to make their voices heard.

"With the PFF Community Registry, patients and caregivers can report their outcomes with medications and how they are managing life with PF," says IPF patient and Registry participant Ken Vella. "People can discuss what is working for them and make recommendations directly to the medical community."

Kevin Flaherty, MD, MS, Steering Committee Chair of the PFF Registry, explains that the new PFF Community Registry will have a special role to play. "We hope that removing barriers will make it easier for patients and caregivers to enroll in the PFF Community Registry so we can deepen and enrich our understanding of ILD," he says. "Academic medical centers tend to be located in metropolitan areas but PF occurs everywhere. This is our chance to learn more about how PF is diagnosed and treated among patients who don't have easy access to a CCN institution."

Make Your Voice Heard

The PFF Community Registry will collect information via an easy-to-use online portal. "Surveys will average less than 30 minutes to complete, and we will tell you at the start how much time each will take," says Speller. "You should be able to answer most questions in our surveys without consulting your medical provider or records, and you can stop participating at any time."

For Vella, participation is too important to even consider withdrawing from the Registry. "We still have a lot to learn about pulmonary fibrosis and interstitial lung disease," he says. "Opening the Registry to patients, family members, and caregivers will quickly increase the data and with more information, we can improve patient outcomes."

To sign up for the PFF Registry and to learn more, visit pffregistry.org. For questions, email registry@pulmonaryfibrosis.org.

Diversity in Research: Benefits for All

What do we know about how patients' race and ethnicity might affect clinical outcomes in pulmonary fibrosis? Not nearly enough, as a recent PFF webinar makes clear.

Junelle Speller, Vice President of the PFF Registry, introduced guest speakers Amy Hajari Case, MD, FCCP, Shalini Mohan, MD, and Anna María Nápoles, PhD, MPH. They explained how including a more diverse patient population in clinical research can benefit everyone. Benefits to society include better and safer treatments, faster and less expensive clinical trials, better participation rates in clinical research, and increased trust in study results.



Amy Hajari Case,
MD, FCCP

A recent report in the *New England Journal of Medicine* compared pulse oximetry measurements with arterial oxygen saturations in hospitalized patients. Researchers found that, compared with more accurate blood gas levels, pulse oximetry sometimes failed to detect hypoxemia, or low oxygen levels. This happened to Black patients three times as often as it did to White patients, leading the FDA to issue a warning in February 2021 that over-the-counter oximeters might be less accurate in dark-skinned users.



Shalini Mohan, MD

Dr. Case, who is Chief of the Advanced Lung Disease Program at Piedmont Healthcare in Atlanta and Senior Medical Advisor for Education and Awareness for the PFF, opened the webinar by discussing recent research results that have implications for patients with interstitial lung disease.

Dr. Mohan began her presentation by shedding light on Genentech's EMPACTA trial. When news of COVID-19 health disparities hit, their Medical Affairs team met with physicians in hospitals that treat a high proportion of underserved and minority patients and quickly developed a randomized, placebo-controlled study. While speed was a priority, it was important to not

lose sight of creating the study with equity in mind. Researchers chose eligibility criteria that took variation among racial and ethnic groups into account.

"We call on all those working in biopharma to join us in developing and studying treatments that can benefit all patients," said Dr. Mohan. "Scientifically and morally, we need to place diversity and inclusion at the forefront."



Anna María Nápoles,
PhD, MPH

Next, Dr. Nápoles discussed how to engage minority populations in research. As a scientific director at the National Institute on Minority Health and Health Disparities, her work involves developing and testing interventions to reduce racial and ethnic health disparities. She explained that women and members of minority groups must be included in all NIH-funded clinical research. Despite this mandate, minority representation remains extremely low.

Dr. Nápoles also shared evidence about what works to enhance minority representation in research. Successful techniques include using multiple recruitment strategies, research personnel with cultural similarities who form ongoing relationships, and making participation seem desirable.

For PFF President and CEO William T. Schmidt, the webinar illuminated many important points. "We know that PF does affect people of color but we're getting a limited picture by not being more diverse in PFF Registry enrollment," he says. "If the Registry is not sufficiently diverse, that diminishes the overall value of the data, so we need to do better. The soon-to-launch PFF Community Registry will help by encouraging broader enrollment."

On a larger level, Schmidt says the PFF has formed a Diversity, Equity, and Inclusion Task Force to look at all aspects of the organization. "Over time, we'll have more of a story to tell on this," he says. "It's the right thing to do and it's overdue."

The entry in the PFF Disease Education Webinar series, "Diversity in Research: Benefits for All," is now available for viewing at bit.ly/pffdiversityinresearch.

PFF Scholar Gillian Goobie, MD: Zeroing in On Air Pollution



Gillian Goobie, MD

The PFF Scholars program supports early-career investigators with competitive two-year research grants. The goal is to prepare them to earn funding from the National Institutes of Health (NIH) and other prestigious funders in the future. PFF Scholars receive expert mentoring and, if approved, can use PFF Registry data for their research projects.

We checked in with current PFF Scholar Gillian Goobie, MD, for an update on her PFF-funded research, “Air Pollution: Clinical Outcomes and Epigenomic Effects in Interstitial Lung Diseases.”

How does air pollution affect ILD?

Dr. Goobie wants to understand how exposure to airborne pollutants over time affects clinical outcomes in patients with fibrotic ILD. To do this, she will integrate air-quality data from across the U.S. with data from the PFF Registry. Specifically, she will look at how Registry patients with ILD have done in terms of lung function decline, exacerbations, and mortality. Then, she will put that information in the context of annualized air pollution levels near their homes.

Dr. Goobie originally planned to use ground-based data from the U.S. Environmental Protection Agency (EPA). But then she found an even better source: a database of satellite readings from the Atmospheric Composition Group at Dalhousie University in Halifax, Nova Scotia. This downloadable dataset includes data from throughout North America from 2000-2018. “They measure aerosol optical depth to estimate particulate matter levels, then combine those readings with data from ground-based EPA stations to validate them,” she says. “This produces a highly

accurate estimate of pollutants at the fairly precise location of one square kilometer.”

Better insights about rural patients

The Dalhousie data set does offer an important advantage: it offers more precise data for rural locations. That’s because satellite data can cover any place on earth, while the EPA’s ground-based data must rely on physical monitors to collect data. “There are often very few ground-based monitors in rural areas,” she says. “Satellite-based data are more likely to provide accurate exposure estimates for rural patients. We’re often making big assumptions about the exposures rural patients face because we just haven’t been able to collect good data.”

Dr. Goobie intends to compare her results using both the Dalhousie and EPA data, a technique known as a sensitivity analysis. “If the results are the same using each dataset, that might tell us that either approach is valid to use in future research,” she says. “By using more than one method, that increases the confidence that any significant results are real.”

Early data: more pollution, more deaths

Dr. Goobie, who is currently pursuing a PhD in human genetics at the University of Pittsburgh, explained that it’s too soon to know what the results will achieve. Dr. Goobie performed some preliminary research while awaiting samples from the Registry data coordinating center at the Statistical Analysis of Biomedical and Educational Research Group (SABER) at the University of Michigan. She cross-referenced the air-quality data with clinical data from her patients in Pittsburgh. “Those data aren’t published, but we have evidence that higher pollutant exposure during disease appears to be associated with increased mortality in patients with ILD,” she says.

This project is funded by The Peter L. O’Neill Memorial Fund.

A Lasting Legacy: One Family's Commitment to Research



Fred and Ginny Krauss of Raleigh, NC

Members of the pulmonary fibrosis community are generously and aggressively supporting the PFF in a variety of ways. One of the most important is through fundraising to accelerate research and expand patient programs. Meet Fred and Ginny Krauss, who have made a difference through their gifts and fundraising efforts.

Through the Jenny H. Krauss and Otto F. Krauss Charitable Foundation Trust, in memory of Stephen N. Dirks, Fred and Ginny support the PFF Scholars program because it's laying the groundwork for researchers to unlock answers and a cure for PF. Ginny lost her brother, Steve, to IPF in 2007.

From 2012-2018, the PFF supported researchers with two grant awards: the Albert Rose Established Investigator Award and the I.M. Rosenzweig Junior Investigator Award. In 2019, the PFF redefined its objectives for funding research and introduced the PFF Scholars program, which has replaced the Established and Junior Investigator awards. The program focuses on engaging early-career investigators in their emerging research in the field of pulmonary fibrosis. With the goal of advancing research that could translate into successful therapies for PF, the PFF

Scholars program is designed to support and enable promising researchers to obtain independent funding and continue their cutting-edge research.

Since its 2019 launch, the PFF Scholars program has awarded six junior investigator grants of \$50,000 each on an annual basis for a total of twelve new research awards. But thanks to the dedication of the PF community this year, the Foundation will begin awarding grants of \$75,000 over two years to at least four awardees each year—the most in the program's history.

When the Krausses learned about the PFF research program, they were eager to contribute. "We firmly believe in the PFF mission to support people with pulmonary fibrosis. Support encompasses education in managing the disease and education in better understanding the disease," says Ginny.

One of the most recent PFF Scholars awardees, Dr. Bridget Graney, is studying the interrelationship between patients with interstitial lung disease and their caregivers. Recognizing that none of us exist in isolation, Dr. Graney seeks to understand the impact of disease on caregivers of patients with ILD, specifically the degree of caregiver burden experienced that is frequently unrecognized but has negative health consequences for caregivers.

To learn more or to support the PFF Scholars program, please contact Seth Klein, Senior Vice President of Development, at sklein@pulmonaryfibrosis.org.

COVID-19 Vaccines and You: Answers to PF patients' questions about safety, effectiveness, and availability



Why is the vaccine important for PF patients?

In accordance with Centers for Disease Control and Prevention (CDC) recommendations, the PFF strongly encourages vaccination

for PF patients who are eligible. "Pulmonary fibrosis patients are at high risk of severe effects — hospitalization and mortality — with COVID-19," said Amy Hajari Case, MD, FCCP, PFF Senior Medical Advisor of Education and Awareness.

To ensure you're not part of the limited population for whom vaccination is not currently recommended, reach out to your primary care physician and pulmonologist. Some research indicates patients who are immunosuppressed after lung transplant may have a less robust immune response to vaccination than the general population. "Vaccination is still recommended for post-transplant individuals, but they should continue to be very careful to avoid exposure to COVID-19," Dr. Case advises.

What's the difference between the Pfizer, Moderna, and Johnson & Johnson vaccines?

The Pfizer and Moderna vaccines, each of which requires two shots given several weeks apart, use messenger RNA, or mRNA for short. These vaccines train your body to produce a harmless piece of the unique protein — called a spike protein — that COVID-19 uses to attach itself to your cells. Recognizing that the protein piece doesn't belong, your immune system begins making antibodies that protect you during a future exposure to COVID-19. The first dose primes the immune system and gives the recipient a fairly decent immune response. Similar to a "booster" shot, the second dose serves the purpose of improving the efficacy of the vaccine and increasing the recipient's immune response.

The Johnson & Johnson vaccine also uses genetic information to tell your body to produce a harmless piece of the COVID-19 spike protein, then build an immune response against it. The Johnson & Johnson vaccine, which requires only one shot, uses a strain of adenovirus — similar to a cold, but without disease-causing properties — as a viral vector for delivering this genetic information.

Neither mRNA nor viral vector vaccines ever reach the nucleus of your cells, where all your DNA resides, so they cannot alter your DNA.

Is there a difference in vaccine effectiveness? Should I wait for a particular one?

All three vaccines are extremely effective at preventing severe cases of COVID-19, including hospitalization and death. Each vaccination provider will usually have one type available at a time. To protect yourself and those around you as quickly as possible, the PFF recommends taking the earliest appointment available for any of the vaccines.

How were the vaccines developed so quickly?

The creation of three successful vaccines in less than a year is a significant achievement, but it builds on years of existing research into the family of viruses from which COVID-19 comes. "None of the steps ensuring safety and efficacy were skipped," said Dr. Case, noting that drug companies overlapped phases of clinical trials and prepared for accelerated manufacturing with the knowledge that some, not all, of the vaccines being tested would prove safe and effective. Only the vaccines that met those high standards have been approved for use.

"Because finding a vaccine was so important, a lot of people were motivated to quickly enroll in the clinical trials," Dr. Case added. "We owe our thanks for the rapid arrival of the vaccines as much to research participants as to scientists."

Can vaccines give me COVID-19?

Because the vaccines don't contain a live virus, you cannot contract COVID-19 from them. However, some people experience fever, muscle aches, headaches, or other flu-like symptoms for a day or two after receiving the vaccine, more commonly after the second shot in a two-shot series. Side effects after your second shot may be more intense than the ones you experienced after your first shot. These side effects are normal signs that your body is building protection and should go away within a few days. Some people experience no side effects at all.

How do I find a vaccine?

Vaccines are available at many medical centers, clinics, pharmacies, and special sites. Appointments are usually required. Visit vaccinefinder.org to locate an appointment in your area. If you don't find an appointment right away, check back often — new slots open frequently.

For even more frequently asked questions about the vaccine, visit PFF Insights at pulmonaryfibrosis.org/blog. For additional COVID-19 resources, visit pulmonaryfibrosis.org/COVID19.

How the PFF Registry Helps Research



In only a few years' time, PFF Registry data have played a key role in over 30 research studies that have been completed or are underway in basic/translational, clinical, and patient-centered research. If each of these studies had been conducted without the use of the Registry, the research costs would have totaled an estimated \$32 million.

"Early work on a topic generates abstracts and ultimately results in a manuscript once the data have matured," explains Junelle Speller, Vice President, PFF Registry. For example, a group of researchers built this series of successful studies:

- 2017 American Thoracic Society conference poster: clinical traits of Registry enrollees to that point
- 2018 European Respiratory Society conference presentation: updated clinical traits of Registry enrollees

- 2020 Annals of the American Thoracic Society journal article: "The Pulmonary Fibrosis Foundation Patient Registry: Rationale, Design, and Methods"

PFF Registry data also served as the basis for recent studies on factors contributing to cough severity, characteristics associated with antifibrotic use, and the association of anticoagulants and outcomes in patients with interstitial lung disease.

"The types of research questions that are being asked and answered within the Registry are incredibly diverse and speak to the collaborative nature of our community and the scope of the Registry data," says Joyce S. Lee, MD, MS, Senior Medical Advisor, Research and Health Care Quality at the PFF. "Work that comes out of the Registry will contribute to our understanding of pulmonary fibrosis and will ultimately help us better care for patients with pulmonary fibrosis."

PFF Appoints Healthcare Leaders To Key Roles

The PFF proudly welcomed two healthcare executives to the Foundation last year. Junelle Speller, MBA was appointed to the position of Vice President, PFF Registry and Jessica Shore, PhD, RN as the Vice President, Clinical Operations and Quality. Both positions are integral roles in the PFF's future successes.



Speller brings more than 20 years of experience in the field of healthcare policy and management. Her most recent position was with NeuroPoint Alliance, a non-profit

organization that specializes in developing and maintaining multiple clinical data registries on neurosurgical procedures. As VP of the PFF Registry, Speller will lead the expansion of the PFF Care Center Registry and the launch of the new PFF Community Registry, which will open this summer.



Shore has prior experience studying pulmonary fibrosis through her career as a nurse, performing clinical research, and through community engagement. She most

recently worked with the Pulmonary Trials Cooperative, an initiative established by the National Heart, Lung, and Blood Institute to facilitate efficient "real world" research into chronic lung disease. Shore's new position will involve leading the PFF Care Center Network.

PFF President and CEO William Schmidt notes that Speller and Shore have made an immediate impact and will pave the way for future success. "Junelle Speller and Jessica Shore each bring valuable expertise to the PFF at a time when we are developing robust new research and patient programs," Schmidt said.

Healthcare Heroes: Partners in the Battle Against PF



Fred Haley is a Pulmonary Fibrosis Support Group Leader at LeBauer HealthCare at Cone Health in North Carolina.

He was diagnosed with idiopathic pulmonary fibrosis in 2012 and largely credits his survival to his healthcare team, led by Dr. Murali Ramaswamy.

“Since the beginning of my journey with PF, Dr. Ramaswamy has been my hero. Because of his guidance and expertise, I have been able to fight PF while living my life to the fullest,” Haley said.

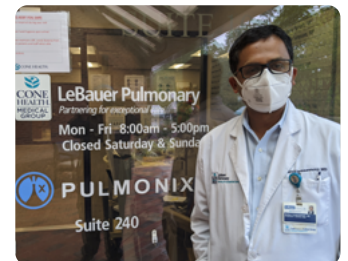
Haley is especially grateful to Dr. Ramaswamy and his team for their extraordinary care throughout the COVID-19 pandemic. As director of the interstitial lung disease clinic at Cone Health, Dr. Ramaswamy acted quickly when the clinic closed in March 2020. He and his staff worked tirelessly to implement the necessary safety measures needed to reopen the clinic and did so in less than four months.

Haley says Dr. Ramaswamy and his team of nurses, respiratory therapists and pulmonic researchers have been his champions throughout his journey with PF. Haley cites the referral to the PFF as one of the most important things Dr. Ramaswamy has done for him.

“Like so many other PF patients, I worry about what might happen in the future and the effect PF has on my family. The PFF



Fred Haley and his wife Cathy



Dr. Murali Ramaswamy

is the best place we can turn to for support and understanding of the disease, and the Foundation is determined to provide us with the quality support that we need to continue living with this disease,” Haley said.

The Pulmonary Fibrosis Foundation extends a heartfelt thanks to all healthcare heroes on the frontlines of the evolving pandemic. Your dedication and commitment to patients and their families will never be forgotten.

Do you have a story about a PF healthcare hero who has impacted your life? Please share it with us at development@pulmonaryfibrosis.org.

You can be a champion for the PF community by making a donation to the PFF today! Your support of Fred and patients like him will help the PFF provide vital support and drive research to find a cure for this devastating disease. Visit bit.ly/springpff2021 to make a gift.

VIRTUAL BROADWAY BELTS FOR PFF! REACHES THOUSANDS



The star-studded Broadway Belts for PFF! chorus performs a compilation of "For Good" from the smash-hit, *Wicked*.

In a magical showcase, the 2021 Broadway Belts for PFF! on March 12 successfully raised over \$346,000 in support of the Pulmonary Fibrosis Foundation.

"We were thrilled to bring the glitz and glamour of Broadway directly to living rooms across the country to help draw attention to pulmonary fibrosis, a devastating disease impacting hundreds of thousands of Americans," said Julie Halston, Broadway actress, comedienne, PFF Board Member, and the event's dynamic host. "People are beginning to understand lung health is a priority and they can help make a difference."

Broadway's brightest stars, including Robert Creighton, Christine Ebersole, Darlene Love, and more than 30 others delivered heartfelt performances that captivated a nationwide audience. For the grand finale, the Broadway Belts Chorus presented a glorious performance of "For Good" from the musical *Wicked*.

In addition to the outstanding musical entertainment, the third annual Ralph Howard Legacy Award was presented to Laurie Chandler. Chandler, who is a PF patient and lung transplant recipient herself, is a devoted advocate and PFF Board member. Her extraordinary volunteerism and leadership are making a great impact on the Foundation's efforts to accelerate research and improve patient care.

The virtual event was produced by Julie Halston, Jim Caruso, and D. Michael Dvorchak along with the technical direction of Ruby Locknar.

You can watch the Broadway Belts for PFF! chorus at bit.ly/broadwaychorus



Broadway's Julie Halston and Jim Caruso hosted the 11th annual Broadway Belts for PFF!



PF advocate and Board member, Laurie Chandler, named the 2021 recipient of the Ralph Howard Legacy Award

PFF Welcomes Three New Board Members

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 for the pulmonary fibrosis community. The Foundation recently welcomed three new members to the Board and bestowed Emeritus Director recognition upon one long-time former Board member.



Susan Jacobs, RN, MS, FAAN: **Always putting patients first**

Susan Jacobs, RN, a research nurse manager at Stanford Medical Center who helped launch the Interstitial Lung Disease Program there, is a leading authority on how to improve patient care for those who live with ILDs. "I always emphasize how much

we can do to decrease patients' symptom burden, in addition to treatment with their medications," she says. "We can't make breathlessness go away, but we can help patients cope with it better."

Jacobs has been involved with the PFF and the patient community for years in roles ranging from PFF Walk team leader to co-chair of the National Support Group Leader Network. She also serves on the PFF's Medical Advisory Board, on the PFF Summit Program Organizing Committee, and as multi-year Summit faculty.

Jacobs' passion is increasing patient access to supplemental oxygen. "On the Board, I plan to continue my advocacy on oxygen issues directly with patients and at the legislative level," she says. "I also want to work with Care Center Network nurses and allied health professionals to improve the standard of care we give our patients."



P.J. Kamani: Staying the course

Even before P.J. Kamani was diagnosed with IPF himself, he knew the devastation it causes, having already lost a parent and two siblings to the disease. His involvement with the PFF began in 2019 when he was invited to join the PFF Finance Committee. But he had first learned of

the PFF during his sister's illness a decade earlier. "The PFF has always done an excellent job of keeping us informed and

the amount of information offered is what drew me to them initially," he says. "The more information we have, the more progress scientists can make against this disease."

With a career spanning more than 30 years, Kamani currently serves as CEO of a language services company that provides interpreting and translation services to government, legal, and international clients.

For Kamani, attending the PFF Summit was a revelation: "It was oddly comforting to know there are a lot of people going through this," he says. "I feel a sense that we're all working together toward an ultimate goal. Success will come if we stay the course."



Pat Rosa: Carving out time in retirement

When Pat Rosa's husband, Tony, was diagnosed with IPF in 2005, the PFF was in its infancy. "It was very hard to find any information online about the disease," she says. "I felt like I was on my own throughout this very grueling experience." That's why Rosa began

volunteering for a local hospice shortly after Tony's death in 2007: "Everyone needs support when coping with a serious illness."

Eventually, Rosa found her way to the PFF and began participating in and organizing PFF Walks. She joined the PFF Development Committee in 2017. Shortly after joining the PFF Board in November 2020, she retired from a long career in cybersecurity at Wachovia/Wells Fargo. "Joining the PFF Board was part of my retirement plan because I knew I could finally give more time to it."

During her time on the Board, Rosa hopes to help raise public awareness of PF. "I volunteer in Tony's memory and to help prevent other families from going through what we did."

Colleen Attwell: Recognizing dedicated service

Colleen Attwell served on the PFF Board of Directors for five years, including serving as Vice-Chair of the Board, Chair of the Development Committee, and as a member of the Nominating and Governance Committee. Colleen served with distinction during a critical period in the PFF's growth. She demonstrated loyalty and devotion to the PFF mission and created a legacy that will extend long beyond her service on the Board. The PFF is delighted to recognize Colleen for her tireless passion and creativity. Thank you, Colleen!

Raising the Bar on Pulmonary Fibrosis Awareness: New Initiatives

DO YOU KNOW THE SYMPTOMS OF PULMONARY FIBROSIS?
Pinpoint early warning signs of PF – a disease that affects more than 200,000 Americans – to begin your diagnosis journey today.

Pinpoint PF

PULMONARY FIBROSIS SYMPTOMS INCLUDE:

- Shortness of breath
- Chronic cough
- Feeling run-down

WHO IS MOST AT RISK?

- Current or past smokers
- Age 60 or older
- Family history of interstitial lung disease

TALK TO YOUR DOCTOR TODAY

Pulmonary Fibrosis Foundation

Pulmonary fibrosis, an interstitial lung disease, is progressive, debilitating and hard to diagnose.

Visit AboutPF.org or call 844.Talk4PF (844.825.6733) to take action.

In December, the PFF unveiled its new “Pinpoint PF” education and awareness campaign aimed at individuals with symptoms and those at a higher risk for pulmonary fibrosis.

The campaign’s mission is to empower patients to “Pinpoint PF” symptoms and to take action early by

starting conversations with their doctors. According to a 2020 national survey by the PFF, more than 8 in 10 Americans do not know PF symptoms, which include shortness of breath, fatigue, and a dry, persistent cough. These symptoms are common and are often attributed to other causes, which can lead to late-stage PF diagnoses.

The campaign features targeted digital and traditional advertising supplemented by public relations efforts to further raise awareness of signs and symptoms of PF. “Pinpoint PF” enables at-risk patients, caregivers, and healthcare providers to ensure more accurate and timely diagnoses, improve patient outcomes, and maximize treatment options.

Pulmonary Fibrosis Awareness Month 2021: Growing Stronger

growing **STRONGER**

PULMONARY FIBROSIS awareness month SEPTEMBER
Presented by Pulmonary Fibrosis Foundation

Each September, join the PF community for Pulmonary Fibrosis Awareness Month (PFAM)! This initiative relies heavily on social media participation to spread the word about pulmonary fibrosis all over the world. One of the first steps you can take is to follow and interact with us on our social media channels. Find us online with our handle [@pfforg](https://www.facebook.com/pfforg) on Facebook, Twitter, and Instagram, and use the hashtags [#PFMonth](https://twitter.com/hashtag/PFMonth) and [#BlueUp4PF](https://twitter.com/hashtag/BlueUp4PF) to start getting social. Be sure to head over to our YouTube channel to like and subscribe so you never miss a new video.

Highlights of PFAM include:

- **Portraits of PF:** Every day, we share a story on social media from someone who has been touched by the disease. Participants include patients, caregivers, lung transplant recipients, healthcare professionals, and those who have lost a loved one. We are currently accepting story submissions.
- **30 Facts In 30 Days:** Each day, we share a fact about PF on social media. You can help us reach more people by liking, sharing, and commenting on the posts.
- **#BlueUp4PF:** Get creative! Have fun raising awareness by dressing up in as much blue as possible, taking a photo, and sending it to the PFF to share on social media. Further, you can ask the management of a local building or landmark to shine blue in our #BlueUp4PF lighting campaign. More than 30 landmarks shined blue in the lighting campaign last year.
- **Host a virtual fundraiser:** Gather your family and friends for a virtual trivia night, game night, or start a Facebook fundraiser.
- **And more!** PFAM can be completely unique to you. Find more ideas and learn how you can get started at pulmonaryfibrosis.org/pfam.

We have all the resources you need to get started with your PFAM planning. Visit pulmonaryfibrosis.org/pfam or contact us at socialmedia@pulmonaryfibrosis.org.

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).



LEGISLATIVE 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.

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 in your area or find inspiration for creating an event of your own.

FUNDRAISE FOR TEAM PFF

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

PFF WALK

Take one step forward in the search for a cure and join us in 2021 for the five year anniversary of the PFF Walk! You can unite with patients, families, and friends across the country for a fully virtual experience. Together, we'll take steps from communities from coast to coast and move toward our shared goal: a world without pulmonary fibrosis. Visit PFFWalk.org to learn more.

PULMONARY FIBROSIS AWARENESS MONTH

Each September, come together with all who have been impacted by pulmonary fibrosis worldwide and unite for Pulmonary Fibrosis Awareness Month. Follow the PFF on social media at @pfforg as we share facts, stories, videos, and much more to spread the word far and let the world know. During awareness month, the Foundation features stories on social media from people just like you. By sharing your story, you can help raise awareness and connect with others.

SHOP PFF

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

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Bring the spirit of the PFF Walk to your community and mark your calendar for a fully-virtual experience unlike any other!

Join us for National Walk Day September 25, 2021



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