

PULMONARY FIBROSIS FOUNDATION

breathe

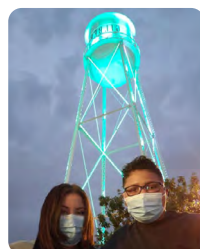
ISSUE 02 WINTER 2020



**Pulmonary
Fibrosis
Foundation**TM

A New Era, A New Identity

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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 a Better Business Bureau accredited charity. The Foundation has met all of the requirements of the National Health Council Standards of Excellence Certification Program®.



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Pulmonary Fibrosis Foundation

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Letter from Our President and CEO

DEAR FRIENDS,

The COVID-19 pandemic has changed some of the ways we approach our important work at the Pulmonary Fibrosis Foundation (PFF). But it's also renewed and strengthened our commitment to the fight against pulmonary fibrosis (PF).

We continue to offer a range of online COVID-19 resources. From patient guidance and Disease Education Webinars to frequently asked questions and virtual support groups, our website provides wide-ranging help for PF patients and caregivers in navigating the unique challenges the coronavirus presents.

In September, we observed Pulmonary Fibrosis Awareness Month with a new twist: virtual events. Although our PFF Walk celebrations took place on computer and phone screens, you showed the same energy and enthusiasm in our shared goal of raising funds and awareness. We are grateful for your creativity and dedication to this impactful fundraising effort.

We continue to advocate for legislation that will improve the lives of people living with PF, especially during the pandemic. Our current advocacy initiatives include asking elected representatives and governmental organizations for emergency funding for the National Institutes of Health and Medicare reimbursement for remote pulmonary rehabilitation.

The Foundation's dedication to supporting life-changing research is deeper than ever. After a short delay resulting from many labs being closed during the early days of COVID-19, six outstanding researchers have received grants through our PFF Scholars program. In 2019, the Foundation introduced this program—which replaced the Established and Junior Investigator awards—to focus on supporting early-career investigators in the field of PF. With the goal of advancing research that could translate into successful therapies for PF, the PFF Scholars program enables promising researchers to obtain critical early funding that will position them to compete for larger grants from the National Institutes of Health and other sources.

You'll find details on the Foundation's other research progress, including ongoing studies, a pioneering paper, and the PFF Registry in this issue.

These past months, we've also been working behind the scenes on a bright, engaging new logo for the PFF. Our goal was to develop an identity that represented all of our connected patients, caregivers, researchers, healthcare providers, and supporters. Our new logo, which features powerful lettering with an abstract pair of lungs in the PFF's signature teal and green colors, is positive, forward-thinking, and illustrates the close-knit community the PFF fosters.

We're inspired by all the dedicated healthcare providers who've brought creativity and flexibility to caring for PF patients during this extraordinary time. Thank you for your continued dedication to our mission, and the patients that we serve.

Sincerely,



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER

PS: More than ever, we're grateful to all of you, the PF community, for sustaining the Foundation's irreplaceable work. The best antidote for a challenging present is an investment in a brighter future. Please consider making a gift before year's end at **PFFGive.org**.

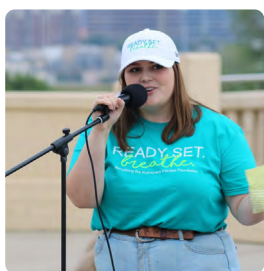


PFF Ambassadors Share Words of Wisdom in the Social Media-Based Positivity Project

When COVID-19 began making around-the-clock headlines in March, the Pulmonary Fibrosis Foundation wanted to help combat the feelings of anxiety, negativity and despair generated from the news cycle.

Staff turned to the PFF Ambassadors to serve as role models for the community and to share messages of hope in a new way.

PFF Ambassadors participated in what was named “The Positivity Project” on the PFF’s social media channels. They were asked to share how they were staying positive, what activities they were doing while staying home or social distancing, and what message they would like to send to the pulmonary fibrosis community.



RECOGNIZING AND ACCEPTING YOUR EMOTIONS

PFF Ambassador Samantha Kagel, caregiver and daughter of a pulmonary fibrosis patient turned lung transplant recipient, shared with the community the importance of feeling and recognizing different emotions.

“When I am feeling sad, angry, frustrated, or confused, I try to tune in to what my mind needs,” says Kagel. “Sometimes I angry-journal and let everything out on paper, sometimes I close my eyes and listen to podcasts for a few hours to think about something else, and sometimes I call my friends and cry a little bit. I try not to sit in the feelings for longer than I have to, but I know acknowledging them is critical to me in staying positive in the big picture.”

Through her story, Kagel reminded the community to keep track of joyful moments. “It is these little moments that amount to the bigger moments and create a life of joy and happiness despite the circumstances we find ourselves in now, as well as the circumstances our community faces daily.”



FOSTERING NEW HOBBIES

PFF Ambassador Jose Tamayo, a caregiver who lost a loved one, fostered a new hobby during his city’s shelter-in-place order.

“I have a black thumb but my mom was just the opposite,” says Tamayo. “She loved to garden but after her lung

transplant, the doctors told her to stay away from the soil and it broke her heart. So, she began to teach me all her tricks!”

Tamayo began by using his mom’s gardening tools to build a small elevated garden. “I didn’t really know what I was doing at first but, like most things, if you put in the time, care, and patience, good things will come,” he says. “I started tending to my garden and made it a point to put in at least 20 minutes a day, every day. I now have three different types of roses and herbs, and tomatoes and peppers. Sometimes, in the morning or the evening, I’ll have a cup of coffee—my mom’s choice of beverage—and look over the garden. It’s not only an amazing process but I feel connected to her in a very spiritual and physical way. By replaying my mother’s lessons and putting in 20 minutes a day, my black thumb is slowly turning green.”



LOOKING FORWARD TO A BRIGHT FUTURE

PFF Ambassador Sam Kirton, a pulmonary fibrosis patient, had a message to share with the community as uncertainty around the future of COVID-19 continues.

“Do not become so comfortable in the isolation of social distancing that you no longer miss doing the things you love to do,” says Kirton. “Instead, look forward to being able to do them again and make plans for when you can do them again. I have come to appreciate every breath I am able to take and I intend to continue to make every breath count.”

Support Groups Connect Virtually Amidst COVID-19

With the onset COVID-19 in March, the Pulmonary Fibrosis Foundation quickly reached out to its support group leaders nationwide and helped them transition to a virtual format. Support group leaders received Zoom accounts and attended virtual trainings provided by the PFF.

While many of the PFF's 150 support groups are now meeting virtually, some have decided to pause their gatherings until they can go back together in person.

"We have all had to change and adapt during this time," says Laura Devitt, director of programs for the PFF. "We are grateful to our volunteers for their efforts to learn new communication vehicles to help keep their support groups going."

Ken Vella runs the "Pulmonary Fibrosis Together" support group in the Triangle Area of North Carolina. His group meets monthly on Zoom.



Support group leader Ken Vella and his wife Eileen

"I try to make the Zoom meeting feel like we're meeting in person and everyone gets a chance to participate," says Vella, who encourages members to use the video option so participants can see each other. "The main thing is to show up. We don't care if you're in your pajamas. Just show up so we know how you're doing."

PFF COVID-19 Resources

The PFF's Medical Team has been closely monitoring the impact of COVID-19 and its spread throughout the United States to assure that the PF community has the most current information. The PFF has created and curated guidance and resources to help you navigate these challenging times.

Life has felt uncertain for nearly everyone since the beginning of the COVID-19 pandemic. Individuals who have pulmonary fibrosis are at higher risk for developing severe illness if they contract COVID-19, which is why access to reliable information is particularly important. Our resource page includes:

- PFF Guidance and Frequently Asked Questions documents that include an overview of how the virus is transmitted, symptoms, and precautions. English and Spanish versions are available for download
- Links to our Disease Education Webinar Series presentations that provide in-depth information about the COVID-19 pandemic
- Short videos produced by the PFF on COVID-19 Guidance and Everyday Precautions




- Press releases about post-ARDS fibrosis and Centers for Medicare & Medicaid Services (CMS) home oxygen requirements
- Resources from reliable organizations like the National Institutes of Health (NIH), U.S. Food and Drug Administration (FDA), World Health Organization (WHO) and others. Topics include lung transplant, mental health, pulmonary rehabilitation, and more

You can view all available resources online at **pulmonaryfibrosis.org/covid19**.

In addition to these resources, the PFF now offers free Safety Kits through **ShopPFF.com**. The kit includes two reusable face coverings, hand sanitizer, sanitary wipes, and tips on preparing for your doctor visit. Limit two per household while supplies last.

Have questions about the resources on our COVID-19 Resources page?

Contact our Patient Communication Center at **844.TalkPFF** (844.825.5733) or **pcc@pulmonaryfibrosis.org**.



PF Advocacy Continues Despite COVID-19 Barriers

House Highlights PF Research In Key Report

When pulmonary fibrosis patients and their families connected with Congress this spring in a virtual version of Hill Day, they succeeded in convincing legislators to promote PF research in a key report.

Thanks in part to these advocates' dedicated efforts, language on the importance of PF research was included in the House of Representatives' FY21 Labor, Health and Human Services, Education, and Related Agencies report for the National Heart, Lung, and Blood Institute at the National Institutes of Health.

Hill Day is a Pulmonary Fibrosis Foundation opportunity for patients and their caregivers to advocate in Washington, DC, for legislation that will improve the lives of people living with PF. This spring, the COVID-19 pandemic made it impossible for the advocates to meet with their Congressional representatives and their staff members in person, so this year's well-received meetings took place by phone.

Seeking Reimbursement for Remote Rehabilitation

Particularly during a pandemic, many people living with PF have difficulty attending in-person pulmonary rehabilitation. Along with organizations including the American Association for Cardiovascular and Pulmonary Rehabilitation and the American

Association for Respiratory Care, the PFF joined an informal coalition supporting Medicare coverage of remote pulmonary rehabilitation in letters to the Centers for Medicare & Medicaid Services (CMS).

Spotlight On Emergency Research Funding

During the COVID-19 pandemic shutdown, many medical researchers have had to delay their work or even temporarily close their labs. "These researchers need extensions and additional funding to keep their important projects going," explains Gates, "so the PFF has been advocating for emergency funding for the National Institutes of Health in Congressional emergency funding bills."

"The Foundation has asked its advocates to reach out to their members of Congress to request this emergency funding. More than 170 people have participated," Gates says.

Join The Ranks of PFF Advocates

You can make a difference in the PFF's advocacy initiatives. Visit pulmonaryfibrosis.org/advocacy to learn more, sign up for alerts, and find out how to reach out to your own members of Congress.

PFF Insights Addresses Timely Topics

Are you interested in the latest medical insights in research, patient care and news about pulmonary fibrosis? If you answered yes, add PFF Insights, the PFF medical team's new blog, to your reading list.

Launched this spring, PFF Insights has covered topics ranging from staying safe during COVID-19 to news of the U.S. House of Representatives highlighting the need for more PF research in its appropriations report.

Dr. Gregory Cosgrove, chief medical officer for the PFF, is the editor and primary contributor to PFF Insights. "This is an



important new way for us to communicate with our patient community," said Cosgrove. "We develop posts based on issues of medical importance and from questions raised by our Patient Communication Center."

Future blog posts will also feature guest contributors. Check out PFF Insights at pulmonaryfibrosis.org/blog.

Order Free Educational Materials from the Patient Communication Center

Did you know that the PFF provides free educational materials? The PFF is proud to serve as the trusted resource for the PF community. Our educational materials provide reliable information about pulmonary fibrosis to support and empower patients, their families, and friends while living with PF.

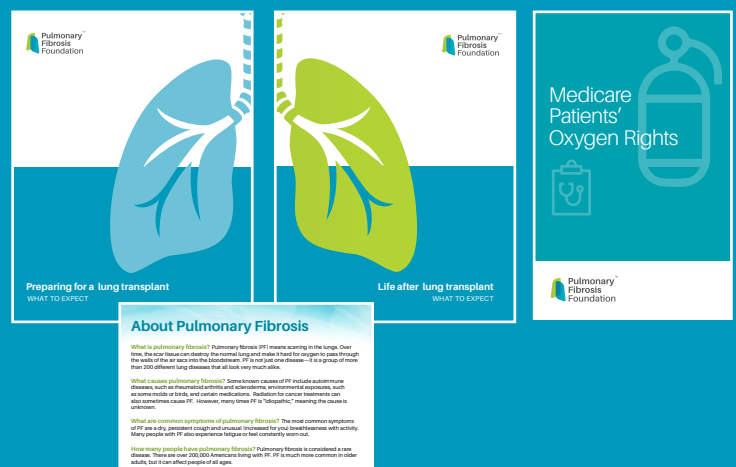
Complimentary copies are available of our Pulmonary Fibrosis Information Guide, Oxygen Basics Booklet, About the Pulmonary Fibrosis Foundation Brochure, and many more!

New this year, we are excited to offer the following materials:

- **Preparing for a Lung Transplant: What to Expect**
- **Life after Lung Transplant: What to Expect**
- **PF Family and Friends Postcards**
- **Medicare Patients' Oxygen Rights**

Contact the PFF Patient Communication Center (PCC) to request free copies of any of our printed materials. The PCC can be reached at **844.TalkPFF** (844.825.5733) or pcc@pulmonaryfibrosis.org.

Our educational materials are also available for download from our website. You can access these electronic documents at pulmonaryfibrosis.org/resources.



Preparing For CCN Expansion

Care Center Network Continues Building Momentum

The unprecedented healthcare demands created by the novel coronavirus have highlighted the extraordinary work of the healthcare providers at Pulmonary Fibrosis Foundation Care Center Network (CCN) sites.

"Our care centers do outstanding work all the time, but they've really gone above and beyond during the current situation," says Luis Arellano, manager, PFF CCN.

This year, the PFF was unable to open the application cycle for CCN expansion due to the COVID-19 pandemic. Barring unforeseen complications, the Foundation expects to reopen the expansion process for interested centers in the second quarter of 2021. "Our medical team is currently finalizing new criteria for a CCN center," says Arellano. "We're looking forward to continuing the great momentum of the network—and to welcoming new centers into our fold."



Staff at University of Washington Medical Center

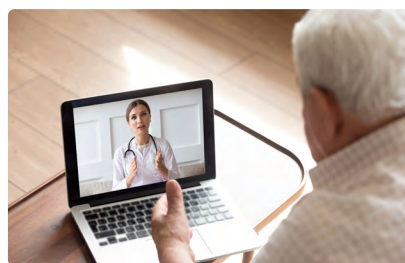
Benchmarking Project Update

The PFF benchmarking project, designed to develop common ILD clinic standards for CCN sites, has moved into its next phase.

This working group chaired by Joyce Lee, MD, director of UHealth's ILD Clinic, has already surveyed CCN sites for details on their components, staffing makeup, treatment approaches, and more. Other process phases involved seeking consensus from CCN ILD clinic directors and patients on what clinic offerings are essential. Now, the working group is using information from the PFF Patient Registry and new survey platforms to incorporate additional data to the previously self-reported information.

"Benchmarking is really driving the strategic planning of the network," says Arellano. "It's crafting how the CCN will be shaped and the level of expectations we're hoping centers will adhere to in coming years."

Boosting Rural Health Outreach



The PFF is working to put a Care Center within a few hours' drive of most Americans—but vast open spaces in the U.S. landscape mean that many patients

will still have geographic challenges. A working group on rural health outreach aims to address some of these obstacles.

Chaired by Rebecca Bascom, MD, MPH, professor of pulmonary, allergy, and critical care medicine, Penn State Health, and Tejaswini Kulkarni, MD, instructor in critical care medicine and pulmonology, UAB Medicine, the group is exploring a range of solutions, says Arellano.

"Telemedicine is an emerging option that's been rapidly adopted because of the COVID-19 pandemic," he notes.

"The group is also looking at CCN member sites sharing their expertise with local pulmonologists through education and webinars. And when we reopen CCN expansion next year, we'll be adding still more centers to the network."

Improving ILD Training

Many important innovative initiatives are born at the PFF's annual Volunteer Meeting. Out of discussions at the 2018 gathering, a working group of pulmonologists specializing in interstitial lung disease was created to better understand what components constitute high-quality clinical education for an ILD pulmonologist.

The working group, co-chaired by Maryl Kreider, MD, MSCE, director of the ILD program at Penn Medicine, and Tristan J. Huie, MD, associate director of pulmonary, critical care, and sleep medicine at National Jewish Health, surveyed pulmonary and critical care medicine fellowship directors nationwide to gather input on best practices in training. A resulting article, "Fellowship Education in Interstitial Lung Disease: A National Survey of Program Directors and Trainees," was recently published in *ATS Scholar*. The authors define their objective "to characterize the present state of ILD training during fellowship and to determine graduating PCCM fellows' perceived abilities to diagnose and manage ILD." Read the article at bit.ly/pff-ats-2020.

Journal Club Sparks Discussion, Builds Bonds

Sharing and discussing relevant professional research is an effective and enjoyable way to build bonds while embracing best practices. The Pulmonary Fibrosis Foundation Nurses and Allied Health Professionals Network (NAHN) Journal Club offers opportunities to learn, make connections, and even destress during a tumultuous time in healthcare.

Journal Club members take turns choosing a recent scholarly article relevant to pulmonary fibrosis to share, present, and discuss with their peers. The hour-long or shorter gatherings take place on the Mobilize app about every other month after attendees are polled on the best date and time to meet. All are welcome; attendees need not be network members to attend.



"I learn so much, both from the literature and from hearing what colleagues are doing," says Journal Club Chair Lori Flint, BSN, RN, a nurse in Michigan Medicine's Pulmonary Clinic. "One of our members called it her nurses' support group, and that's what we want it to be."



Past Journal Club topics have included oxygen, palliative care, and antifibrotic medicines, among others. The most recent meeting included research presented by its author, Divya Patel, DO, clinical assistant professor, sarcoid program director, and ILD program associate director, UFHealth. Patel routinely recruits patients

for both single-center and multi-center clinical studies, including industry-sponsored and investigator-initiated clinical trials. She has expertise in a broad range of interstitial lung diseases.

To learn more about the Journal Club and upcoming meetings, email Flint at lzaremba@med.umich.edu.



PFF Launches Virtual Toolkit for Care Center Network

A new toolkit has been developed to support the PFF Care Center Network sites nationwide in hosting virtual patient education webinars and events during COVID-19. Through a webinar platform provided by the PFF, medical centers can now utilize numerous resources to virtually raise awareness, educate, and connect with patients, caregivers, and family members who are affected by pulmonary fibrosis.

The PFF developed the toolkit to assist CCN sites that would typically host in-person patient education events. "The toolkit offers a conduit for experts at our Care Centers to present important information to the patient community," said Luis Arellano, manager of the PFF Care Center Network. "Our platform prioritizes patient safety and eliminates geographic boundaries."

The toolkit was previewed successfully at a Pulmonary Fibrosis Awareness Month event. On September 19, seven CCN sites hosted the Southeast Regional Pulmonary Fibrosis Symposium, which was attended by 176 patients and caregivers. This online educational event was a collaborative initiative between the PFF and experts from Duke University

Medical Center, Emory University School of Medicine, Medical University of South Carolina, Piedmont Healthcare, Pulmonix at Cone Health Medical Group, UAB Medicine, and Vanderbilt Health.

The toolkit is available free of charge to Care Center Network sites. For more information, contact Lindsey Basset at lbasset@pulmonaryfibrosis.org.

RESEARCH FROM THE CCN

PFF CCN member sites participated in a survey led by Dr. Lisa Lancaster to investigate the impact of COVID-19 on the function of the CCN sites and the changes in practice that have been implemented. This research will help clarify the effect of the pandemic on the ongoing clinical care of patients with PF and identify gaps in care that can help be addressed by the PFF. "This is a great example of the ability of the PFF CCN sites to engage in research that will move the care of PF patients forward," says Sonye Danoff, MD, PhD."

PRECISIONS Trial Will Lay Foundation for Personalized Medicine in PF

Biomarkers—biological molecules found in blood that convey information about disease status—play a critical role in PRECISIONS. This ambitious clinical trial is the first ever to apply the principles of precision medicine to the diagnosis and treatment of IPF. And it will use data and blood samples from the PFF Registry.

Personalized medicine is the approach of selecting the best therapy for an individual patient, the therapy that is most likely to aid them and at the same time least likely to cause any harm,” explains co-principal investigator Fernando Martinez, MD, MS, Weill Cornell Medicine and New York-Presbyterian Weill Cornell Medical Center. “PRECISIONS is the first time the principles of personalized medicine will be applied and tested in an interventional study of pulmonary fibrosis patients.”

PRECISIONS trial and Molecular Endophenotyping in Idiopathic Pulmonary Fibrosis and Interstitial Lung Diseases study has received a \$22 million grant from the National Institutes of Health and Three Lakes Foundation.

PRECISIONS has three main goals:

- 1. Determine whether N-Acetyl-cysteine (NAC) is an effective treatment for people with IPF who have a gene variant known to play a role in lung immunity.** NAC is inexpensive and already available over the counter as a supplement.
- 2. Develop blood tests to help distinguish IPF from other lung diseases with similar symptoms.** These tests could identify molecular signatures linked with IPF, with hopes that eventually researchers can predict an individual’s disease course and response to therapy.
- 3. Identify subtle differences in the genetic code that influence an individual’s risk of developing IPF,** which may help identify high-risk people even before they show symptoms.



PFF’s PROLIFIC Consortium Aims to Break Down Barriers in IPF Research

What if proteins in your blood known as biomarkers could give your doctor information about what your future with PF might be? And what if the presence or absence of a biomarker could predict whether a specific medication would help you? That’s the promise of precision medicine.

It’s also the goal of PROLIFIC Prognostic Lung Fibrosis Consortium, a new group created by the PFF and Bristol Myers Squibb Company to facilitate drug development. Peter H. Schafer, PhD, of Bristol Myers Squibb, explains that PROLIFIC is needed because, until now, companies haven’t had a way to share basic scientific information with competitors. Pharmaceutical companies currently develop proprietary versions of laboratory tests for drugs in development. “It doesn’t really make sense for each company to develop its own tests,” he says. “It’s more efficient for us to combine efforts to develop tests we all can use.”

These biomarkers have been chosen for their potential to predict the disease course of PF and how well a drug will work in a specific individual. The biomarkers may also be useful for comparing results across different clinical trials, which could speed regulatory approval.

PROLIFIC MEMBERS

Bristol Myers Squibb Company	OptiKira LLC
Galapagos	Pliant Therapeutics, Inc.
Genentech, Inc.	Pulmonary Fibrosis Foundation
Lung Therapeutics, Inc.	Three Lakes Foundation
Novartis Institutes for Biomedical Research Inc.	

An Inside Look: How the Registry Advances PF Research

As a large, all-cause pulmonary fibrosis registry that includes participants from across the United States, the PFF Registry is an essential database for PF researchers.

Kevin Flaherty, MD, MS, steering committee chair of both the PFF Registry and the PFF Care Center Network, explains that the Registry captures participants' experiences with PF to broaden physicians' knowledge about the disease and how to treat it. "Participants don't have to change their medications or how often they see their physician," he says. "The Registry follows thousands of participants for as long as they are able to participate. This means huge amounts of patient data are available to researchers who are eager to answer key questions about PF."

In order to access the Registry's data and blood samples, researchers must apply to the PFF's Ancillary Studies Committee with a detailed research proposal.

Data scientists at the Registry's data coordinating center at the Statistical Analysis of Biomedical Education and Research (SABER), University of Michigan, review each proposal to confirm that the Registry data can support the proposed study and answer the researchers' main questions. If needed, SABER data scientists work with applicants to further hone their hypothesis. The proposal goes to the Registry's review committee, where expert physicians review each proposal for scientific clarity and relevance. Does the study seek to answer an important question about how PF is diagnosed or treated? Will the study paint a more complete picture of who gets PF and what life is like for them and their families?

Finally, the review committee notifies the applicant and SABER of their decision. SABER sends the necessary data or blood samples to each successful applicant so that research can begin. SABER data scientists continue to offer support throughout the research process, up to and including preparing



manuscripts for publication.

PFF chief medical officer Gregory P. Cosgrove, MD, reports that 33 studies are underway using Registry data and/or blood samples. Of these, eight studies are either basic or translational in nature. Basic research can lead to general knowledge that provides the means of answering many important scientific problems, though it may not provide a complete answer to any one of them. Translational research builds on basic scientific research to create new therapies, medical procedures, or diagnostics.

Both the PRECISIONS clinical trial and the PROLIFIC consortium are translational research projects. Additionally, six other Registry-based studies are currently focusing on biomarker exploration.

Further diversifying the scope of research, eight current Registry research projects focus on patient-centered research questions.

These include patient quality-of-life factors related to oxygen supplementation, antifibrotic medications, hypersensitivity pneumonitis, and lung biopsy.

The remaining 17 studies are clinical in nature, meaning that they focus on different aspects of PF diagnosis or patient care. Some examples include the path to initial diagnosis, antifibrotic medication effectiveness, and the role of cough, obesity, and air pollution in PF.

"Having Registry data at the ready for innovative researchers helps smooth the path to scientific publication, often shaving months or even years from the process," Cosgrove says. "And patients are the ones who benefit most when we can help accelerate research."

To learn more about the PFF Registry and its exciting developments, download or order copies of the full-length PFF Registry report at bit.ly/registryreportfall2020 or call 844.TalkPFF.

PFF Registry Prepares to Reopen, Relaunch, and Broaden Its Focus

The PFF is proud to announce that the PFF Registry is preparing to reopen patient enrollment. Data collection will continue from the original participants and patient enrollment will reopen for new participants at PFF Care Centers.



And, for the first time, the Registry will include a direct-to-community feature to begin collecting data not only from patients within the Care Centers, but patients in other settings as well as lung transplant recipients, caregivers, and family members. As more people contribute data, a clearer picture of life in a PF family will emerge.

The improved Registry will also include:

- **Expanded protocol and data collection to answer more questions about pulmonary fibrosis**
- **Simplified clinical data recording to streamline the process for medical staff**
- **Coordinated direct-to-community registry to examine PF's effects on patients, caregivers, and families across all care settings**
- **Increased engagement via additional email communications and surveys on health and quality-of-life topics**

PFF chief medical officer, Gregory P. Cosgrove, MD, emphasizes that direct-to-community participants need not be affiliated with a PFF Care Center Network medical center. "This change will allow even greater geographic diversity by including responses from people in areas that may be rural or underserved," he says. "With direct outreach, we can also encourage those from underrepresented communities of color to participate, which will give us a truer picture of who gets PF and what their experiences are with it."

Annals of the American Thoracic Society Publishes PFF Registry Study

PFF Registry data have played a key role in nearly 40 research projects to date. Now, one recent study has turned the spotlight on the Registry itself. In August, the peer-reviewed journal, *Annals of the American Thoracic Society*, published "The Pulmonary Fibrosis Foundation Patient Registry: Rationale, Design, and Methods." The study gives detailed information about the demographics and clinical data of Registry participants as of December 2019.

Lead author Bonnie Wang, MD, of the University of Michigan, hopes this study will increase awareness of the PFF Registry among thoracic physicians. "One of our goals is for researchers and clinicians to use Registry data and blood samples to answer many of the unanswered questions we still have when caring for patients with

interstitial lung diseases," she says. "A rich clinical registry representing a wide range of ILDs is an important first step towards improving care for these patients."



Second Annual PFF Registry Report Highlights New and Current Initiatives

In September, the PFF released its second edition of the annual report of the PFF Registry. The report highlights the Registry's accomplishments including its successful launch, enrollment of over 2,000 patients, and facilitation of important research.

For example, PRECISIONS, a groundbreaking clinical trial, will use clinical data and blood samples from the Registry to assess the effectiveness of a medication for IPF. Also included is information about our newest initiative, the PROLIFIC Consortium. In this Consortium, the PFF joined forces with Bristol Myers Squibb and other industry partners to develop tests to identify important biomarkers in patients with pulmonary fibrosis.

The report also provides testimonials from Registry participants, researchers, and sponsors and looks ahead at the next phase of the Registry.

"I hope my participation in the PFF Registry can ultimately help other patients understand and plan for what their disease may bring," said Ken Vella, IPF patient and support group leader.

"By filling out quality-of-life questionnaires for the Registry, I want to provide enough data points so that healthcare providers can help their patients work through their struggles."

In 2021, the PFF Registry will, for the first time, open to caregivers, family members, and those patients who have received a lung transplant. Participants in all categories will be able to engage with the Registry remotely, an important feature during this time of COVID-19 when many medical studies are on hold. The PFF will launch this expanded Registry soon.

You can sign up to be the first to know when the PFF Registry reopens for enrollment at bit.ly/registrynews.

The PFF Registry Annual Report is available for download at bit.ly/registryreportfall2020. Hard copies are available to order by calling 844.TalkPFF or emailing pcc@pulmonaryfibrosis.org.

PFF Summit 2021 is Headed to Chicago

Next year, you're invited to join the world's largest pulmonary fibrosis conference from Thursday, November 11 through Saturday, November 13, 2021 at the Sheraton Grand Chicago!



With more than 950 attendees and 44 states and 10 countries represented in 2019, the biennial PFF Summit is a unique opportunity to meet patients, caregivers, healthcare providers, researchers, industry professionals and many more—all in one setting.

PFF
SUMMIT
2021

PFF Summit 2021 will be co-chaired by members of the PF community. Representing the professional community are Mary Strek, MD from the University of Chicago Medicine, Daniel Dilling, MD from Loyola University Medical

Center, and Rade Tomic, MD from Northwestern Medicine, each of whom represent Chicago-area Care Center Network sites. Representing the patient community are transplant recipient, Gary Cunningham and his wife Marianne Sarazin, both of whom are PFF Ambassadors. Along with the Summit 2021 Program Organizing Committee, the co-chairs will work with the PFF to create another innovative program that will address current and growing educational needs for the greater PF community.

Registration will open in April 2021. For more information about PFF Summit 2021, visit pffsummit.org or email pffsummit@pulmonaryfibrosis.org. Sponsorships and exhibit space is available. Contact Jennifer Mefford at partnerships@pulmonaryfibrosis.org or 312.546.4105 for details.

PFF Research Continues to Expand with New PFF Scholars

The Foundation continues to expand its commitment to broadening its research portfolio. The PFF Scholars program supports early-career investigators with two-year research grants that should position them to earn funding from the National Institutes of Health (NIH) and other prestigious funders in the future.

"Through the PFF Scholars, the Foundation is supporting potentially lifelong research interests by enhancing investigators' ability to secure K-level (career development awards) or R-level (research grants) funding from the NIH," says Michael F. Beers, MD, chair of the Research Review Committee. "Further, our research funding program creates a significant return on donors' and the Foundation's research investment."

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



JOSEPH E. DRUSO, PHD
University of Vermont
Medical Center

TITLE: Collagen S-glutathionylation promotes pulmonary fibrosis through myofibroblast activation.

Funded by Boehringer Ingelheim Pharmaceuticals, Inc.

As a developmental biologist, Druso studies how cells communicate with each other. He participated in research that discovered a specific type of oxidation process in mouse lung cells with idiopathic pulmonary fibrosis that differed from normal mouse lung cells. Oxidation is a modification of a protein that involves adding or removing oxygen, which in turn can affect how lung cells function. For his PFF Scholars study, Druso will explore the effect of the newly discovered protein S-glutathionylation on mouse cells and human cells. His preliminary data show that the new protein activates myofibroblasts, the cell type most responsible for collagen deposits in the lungs of IPF patients. "Does S-glutathionylation activate this cell type to deposit more collagen in the lungs of IPF patients?" Druso asks. "If the protein affects how cells interact in the lung, targeting it might reformat how cells react to that environment and each other, thereby offering a new therapeutic target."



JASON GOKEY, PHD
Vanderbilt University
Medical Center

TITLE: YAP/Wnt interactions regulate epithelial cell proliferation and differentiation leading to abnormal repair and progression of IPF

Funded by Boehringer Ingelheim Pharmaceuticals, Inc.

The lung has a remarkable capacity to regenerate after injury. However, failure of these repair mechanisms contributes to development of diseases including idiopathic pulmonary fibrosis. Gokey and colleagues believe that the YAP signaling pathway that activates genes within cells is involved in forming and multiplying abnormal cell types in the lung. For his project, he will use mouse lung cells to make alveoli organoids, a simplified version of the lung's gas exchange cells, to mimic the IPF disease process. After activating the YAP pathway in the organoids, Gokey will then use the YAP-blocking drug vertoporphin to study its effects on the cells. Once successful, he can then repeat the process using lung cells from human donors. "We think the YAP pathway being upregulated makes disease progress rapidly," Gokey says. "If we can inhibit that process, we might be able to give patients more time and a better quality of life."

**GILLIAN GOOBIE, MD****University of Pittsburgh***Funded by the The Peter L. O'Neill Memorial Fund*

Patients with interstitial lung diseases are especially vulnerable to the harmful effects of air pollution. Environmental factors may affect disease by controlling

how genes result in protein production without changing the genetic code (also known as epigenetics). DNA methylation is one the most common epigenetic changes that can occur due to environmental exposures such as air pollution. Goobie will combine de-identified patient data from the PFF Registry with location-based air pollution data from the U.S. Environmental Protection Agency. She can then track patient outcomes in the context of how much air pollution the patient's location experienced over time. "There is likely a link between pollution and ILDs but we still need to clarify how strong that link is and how patients can reduce their risk," Goobie says. "It's important to show whether an association exists so we can impact public policy to reduce air pollution exposure for everyone."

**BRIDGET GRANEY, MD****University of Colorado****TITLE:** Improving Patient and Caregiver Outcomes in Pulmonary Fibrosis: a Novel, Dyadic Assessment of Caregiver Burden

This award is partially funded by the Jenny H. Krauss and Otto F. Krauss Charitable Foundation Trust, in memory of Stephen N. Dirks

Individuals with pulmonary fibrosis live with intrusive, bothersome symptoms and impaired quality of life. Caregivers of individuals with PF can also experience significant physical, social, and emotional impacts in their own lives, a concept termed "caregiver burden." Currently, we do not know if caregiver burden is a significant problem for caregivers of individuals with PF or what the impact of burden is for both caregivers and patients. To study which factors about PF contribute to caregiver burden, Graney will recruit 50 PF patient-caregiver pairs to complete a survey about their experiences. She will then conduct individual interviews with the 25 pairs experiencing the highest level of caregiver burden. "From the cancer literature, we know that patients who get palliative care live longer and their caregivers had better outcomes," Graney says. "Ultimately, my long-term goal is to lessen caregiver burden and improve outcomes, including quality of life, for both patients and their caregivers. We in medicine should do more to support caregivers."

**AVRAHAM UNTERMAN, MD, MBA****Tel Aviv Sourasky Medical Center, Tel Aviv, Israel****TITLE:** Single-cell Immunophenotyping of Chronic Fibrosing Interstitial Lung Diseases*Funded by the Chuck and Monica McQuaid Family Foundation*

With a new pulmonary fibrosis diagnosis, doctors must determine whether the patient has an immune-based form of PF. Patients with a connective tissue interstitial lung disease can take anti-inflammatory medications. Those with idiopathic pulmonary fibrosis should not. Connective tissue ILD often resembles IPF on CT scans, requiring an invasive lung biopsy to know for sure. Unterman will use a new technology—single-cell RNA sequencing—to study the gene expression profile of individual blood cells. The cells will come from people with either connective tissue ILD or IPF. Each RNA molecule will receive a barcode that identifies its source in the patient's body. "We will be able to identify specific immune system changes in the blood that reflect the specific cause of fibrosis in the lungs," Unterman explains. "These changes could later be used as biomarkers to better diagnose the cause of PF, without the need for a lung biopsy."

**ELEANOR B. VALENZI, MD****University of Pittsburgh****TITLE:** Investigating the Master Regulators of Myofibroblasts in Systemic Sclerosis-Associated Interstitial Lung Disease*Funded by the The Peter L. O'Neill Memorial Fund*

Interstitial lung disease is the leading cause of death in patients with systemic sclerosis, an autoimmune disease. Myofibroblasts are involved in pulmonary fibrosis due to its overproduction of the collagen that leads to fibrotic tissue in the lungs. Unfortunately, no treatments currently exist to target these overactive cells. Valenzi will use single-cell sequencing to isolate individual cells from the lungs of systemic sclerosis patients. She will study the RNA molecules and DNA structure encoding for collagen and other proteins, as well as all the cell's active genes. She will then compare the RNA and DNA structure in diseased myofibroblasts with normal fibroblasts. This will allow Valenzi to determine which specific transcription factor proteins are overproduced in the diseased form. "My goal is to be able to determine the parts of the DNA the myofibroblasts are interacting with to ultimately design new therapies targeted at these specific cells," she says.

Julie Halston and Martin Attwell Join PFF Board

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 and advocate for the pulmonary fibrosis community. The Foundation recently welcomed two new members to the Board.



JULIE HALSTON: **Bringing Broadway to the fight against PF**

Actress and comedienne Julie Halston has supported the PF community for a decade as host and co-founder of *Broadway Belts for PFF!* in New York City. The gala annual benefit, which

has raised more than \$2 million since its 2010 inception, features legendary Broadway stars singing their favorite show tunes. It's now the PFF's single largest fundraiser.

Halston's late husband, veteran radio broadcaster Ralph Howard, was diagnosed with PF in 2008. He received a life-extending lung transplant in 2010, but ultimately lost his battle in 2018.

"Ralph received his transplant on our 18th wedding anniversary—the best anniversary present anyone could ask for," Halston says. "I was so grateful for the connections I'd made with other patients, caregivers, physicians, and the Foundation that I made it my mission to fundraise as long as I could for the PFF. Becoming a Board member gives me another platform for spreading awareness, fundraising, and continuing to make those connections among people touched by this disease."

The rise of COVID-19 has had an unexpectedly positive effect on her PF activism, reports Halston. She recently launched a half-hour comedy talk show, *Virtual Halston*, and has used the show in part to encourage support of the PFF. "I've always wanted to do more, but because I'm an actress, it's been hard for me to schedule time. The pandemic has allowed me to reassess my commitment to the PFF and I realized this is the right time to join the Board," she says.

"I believe the next 10 years are going to be exponentially important," she adds. "I think we're going to see major developments in the treatment of PF—and possibly steps toward a cure."



MARTIN ATTWELL: **A deepening involvement**

Martin Attwell's family has been deeply affected by pulmonary fibrosis: both his father and his father-in-law passed away from the disease. Attwell became involved with the PFF in 2014. He's served on the Finance Committee, was a

key member of the Strategic Planning Committee that developed the PFF 2020 Strategic Plan, and is a frequent attendee at the PFF Summit, and *Broadway Belts for PFF!*

"It's been a journey of deepening my involvement with the Foundation," says Attwell, who has worked within the energy and health insurance sectors for more than 30 years, holds MBA and law degrees, and is certified as both a project management and change management professional. His expertise in finance and organizational change complements the development background of his wife, Colleen, who has also served on the PFF Board.

"Colleen and I bring different things to the table, but we've always had the point of view that we wanted our involvement with the PFF to be a joint endeavor," Attwell says.

During the six years the couple has been active with the PFF, "We've seen it grow in maturity and stature," he says. "To see the PFF Care Center Network and PFF Registry come to fruition has been very satisfying, but I also see a big journey ahead." Two initiatives he sees as most critical: expanding the CCN's reach by helping community healthcare providers understand best practices in the diagnosis and treatment of PF, and continuing strong research support—particularly studies involving the Registry.

"It's really important that we keep bringing a holistic approach, engaging patients and caregivers on the importance of clinical trials and other research activities," he says.

"It's really important that we keep bringing a holistic approach, engaging patients and caregivers on the importance of clinical trials and other research activities."

Fighting PF With Research, Awareness and Advocacy

With a substantial gift from the Three Lakes Foundation (TLF) last fall, the partnership between the Pulmonary Fibrosis Foundation and TLF has yielded record disease awareness and fueled new research into the causes and treatments of pulmonary fibrosis.

"Our investment and partnership with the PFF are a catalyst to increase awareness and drive innovation to help patients living with this horrific disease," said Dana Ball, executive director of the Three Lakes Foundation.

The partnership's first effort, the *More Than A Cough* campaign, successfully drove awareness of PF among the general population, symptomatic individuals, diagnosed patients and family audiences. Launched in Chicago last fall, the campaign was selected for an innovative Google partnership that enabled ad testing in Birmingham, Scottsdale and Nashville. Over a six-month period, the campaign generated more than 62 million impressions on Google and resulted in over 53,000 downloads of the PF risk list from the microsite.

THREE LAKES FOUNDATION

The campaign was presented to the national and international PF community when it was introduced at the PFF Summit 2019 in San Antonio. Three Lakes Foundation was a diamond sponsor of the conference.

"We are committed to our shared goal — to shorten the timeline to a cure," said Bill Schmidt, president and CEO of the PFF.

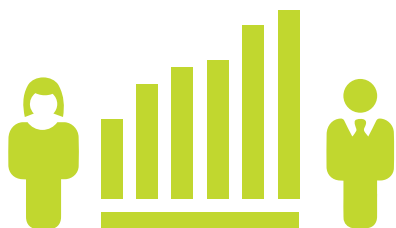
Funding from TLF also supported an extension of the PFF's *Not Everyone Breathes Easy* campaign including the first-of-its kind national consumer PF awareness survey, satellite media tour, digital ads and traditional print ads.

On the research front, the PFF Registry and Biorepository will be utilized in the PRECISIONS clinical trial, funded by the National Institutes of Health with significant support from TLF. In 2021, the Registry will expand and feature an online direct-to-community tool to include patients, caregivers, family members and those who have received a lung transplant.

Currently, the PFF and TLF are also working together with advocacy groups and professional organizations to address the problem of Medicare patients' lack of access to liquid oxygen.

Additional projects are under development as both organizations pledge to make the partnership as productive as possible for the PF community.

Mission Possible: Meet the Faces of Fundraising



In the battle to conquer PF, every dollar makes a difference. The PFF is fortunate to have an arsenal that includes thousands of patients, families, healthcare providers, and those who have lost a loved one. These dedicated individuals have made it their mission to raise funds to drive

research and support patient programs. And by sharing their stories, they have personally raised hundreds of thousands of dollars through the PFF Walks, appeals, tributes, and community fundraising events. They've reached out and engaged personal and professional networks to support a cause that needs urgent attention—better treatments and a cure for pulmonary fibrosis.



Tom Frey: A 9/11 Hero Shares His Personal Story

Tom Frey, a 9/11 first responder and former New York City police detective, sacrificed his health to save others and to support the rescue and recovery efforts from the World Trade Center attacks. Frey worked at Ground Zero and at the site on Staten Island where the debris was moved. While Frey survived the immediate devastation, he has suffered immensely.

In 2016, Frey was diagnosed with Hodgkin's lymphoma. His illness was attributed to exposure from his work in the aftermath of 9/11. Frey underwent chemotherapy and developed shortness of breath. A pulmonologist then diagnosed him with bleomycin lung toxicity resulting in pulmonary fibrosis.

Frey now serves as a PFF Ambassador and shared his story through a portrait-style video at *Broadway Belts for PFF!* and in a special appeal on September 11. The appeal raised more than \$35,000.

"I'm sharing my story because I want to help people living with this disease," says Frey. "If you want to get involved, fundraising for the PFF is a good way to start."

Watch Tom's video at bit.ly/tomfreyppf

Todd Tullis:

Leveraging *Broadway Belts for PFF!* in His Mother's Honor



After his mother Kathy's diagnosis of PF in 2012, Todd Tullis began using the PFF's educational resources to learn more about the disease.

Unfortunately, Kathy passed away from PF just a year later.

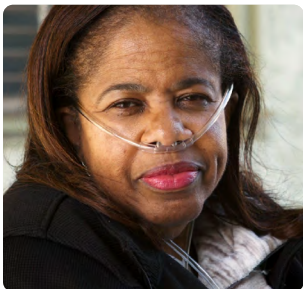
In her memory, Tullis makes a monthly gift to the PFF. He invites friends and colleagues to give to the PFF on special occasions such as his birthday, his mom's birthday, and the anniversary of her passing. "My friends adored my mom," says Tullis. "Fundraising for the PFF gives everyone who loved her an opportunity to remember her while contributing to help others living with the disease."

Tullis attended his first *Broadway Belts for PFF!* in 2015 and discovered that he could make an even bigger impact as a sponsor and through inviting friends to attend. As a lifelong Broadway fan and an executive in the travel industry, it was the perfect event to support.

"I'm inspired by this community," he adds. "We need more people sharing their personal stories of life with PF. When you hear what it's like, you can't help but want to get involved and make a difference."

Valeria Hatcher:

Using Her Story to Give Back



Once diagnosed with pulmonary fibrosis, Valeria Hatcher finally understood why she had felt breathless for so long. At age 48, she was exhausted and unable to work. "But when I found the PFF, they were such a great resource," says Hatcher. "I had questions and they had answers."

Hatcher got involved by sharing her story to motivate others to support the PFF. Her journey was showcased in a 2017 appeal and a recent Portraits of PF video. She continues to advocate while managing her disease. "With more funds for research, the PFF will be able to answer even more questions about this horrible chronic disease."

Watch Valeria's video at bit.ly/valeriahatcherpff

Gretchen Hupke:

Creating a Tribute for Her Cherished Father



It's hard to imagine the pain of losing a loved one during the COVID-19 pandemic when hospital visits are curtailed. That's what happened to Gretchen Hupke. Her father, James McWethy, passed away this summer after a two-year battle with PF. McWethy, who was always on the move and enjoyed working into his 70s, passed away on June 22.

Hupke and her family took advantage of the PFF's tribute program. "We created a tribute page in memory of our father with the hope that others will not have to endure the pain we felt," says Hupke. "The PFF is the only organization that provides families suffering from this disease with the quality care we need. It is essential that we support the PFF's work in finding a cure."

Lindsay Ezykowich:

Remembering Robert with Lucky 7's

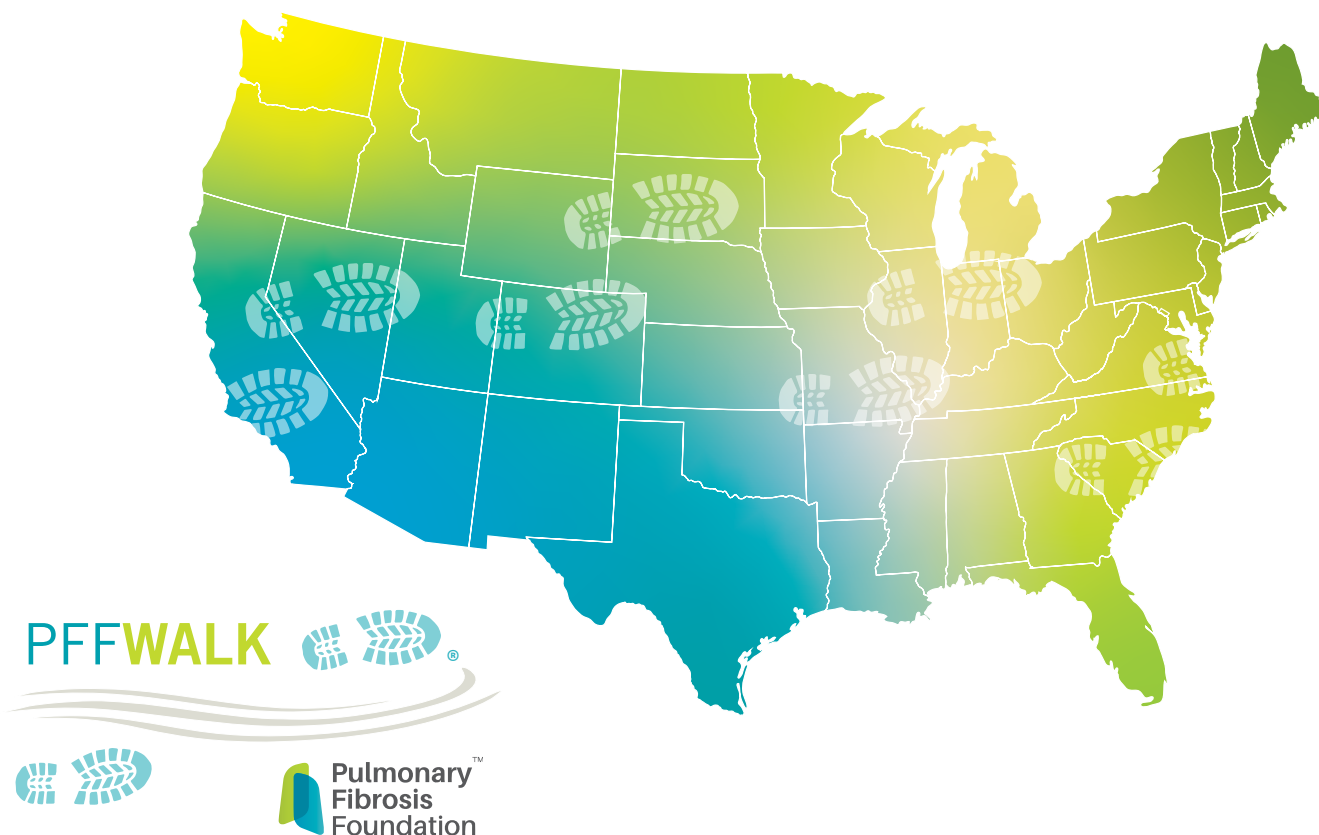


Lindsay Ezykowich, an event planner and recently certified personal trainer, lost her father, Robert, to PF in 2019. She supported the PFF over the years by participating in PFF Walks, hosting Facebook fundraisers, and volunteering at *Broadway Belts for PFF!*.

But this year, Ezykowich decided to do something different to commemorate the one-year anniversary of her father's passing.

Using her passion for fitness and wellness, she created the "Breathe Ezy Fitness Challenge" by asking her network of personal trainers to join her in hosting virtual fitness classes for a suggested donation of \$7 (her dad's lucky number) to benefit the PFF. Throughout September, top trainers from all over the world held 12 sessions and raised over \$1,500 to support the PF community.

PFF Walk 2020 Unites Walkers Across the Nation Virtually



As the COVID-19 pandemic took hold of the U.S. this spring, the PFF pivoted from live Walk events to a fully virtual experience. With just a few weeks to make the shift, the New York City Walk on April 25 was the first in which participants successfully found new ways to actively share their passions and fundraise for the PF community.

Creativity was the name of the game with people participating in activities ranging from indoor workouts, to mask-making, to drawing PFF signs and hanging them in windows for all to see. The New York City Walk, which raised more than \$94,000, set the tone for the fall walk season.



To encourage Walk registration and keep the community connected, the PFF hosted a virtual PFF Walk Kickoff in August. PFF board member and *Broadway Belts for PFF!* host Julie Halston and PFF senior director of development, Amy Wardzala, co-hosted the live-stream event on YouTube and Facebook. The program featured special appearances by PFF Walk stars and celebrities including Bernadette Peters, Robert Creighton, Mitchell Tenpenny, and Bernie Williams. PFF Walk **national presenting sponsor, Genentech**, joined in with others to describe how they planned to stay safe and healthy while fundraising for the PFF.

The virtual series continued with the PFF Walk - At Home Edition on September 26 during Community Walk weekend, and a final celebration party on November 7.



You can watch the full recordings of the PFF Walk - Kickoff and the PFF Walk - At Home Edition on Facebook and YouTube.

Walk stars across the country participated in unique ways. Three interviewees shared their stories with the community.



JUNE MCCONNELL

June McConnell and her brother, Rick Garnett, launched the “Two Cities - One Cause” Walk after they both received the devastating diagnosis of idiopathic pulmonary fibrosis. McConnell lives in Montesano, Washington, and Garnett lives in Denver. Their walks take place on the same day in their respective communities. Together, their common purpose has raised almost \$15,000 for the PFF since they launched the event in 2019.



HEATHER KAGEL

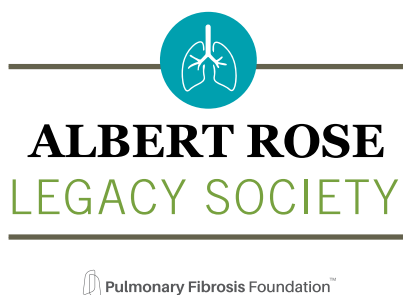
One year after receiving a double-lung transplant, Heather Kagel remains committed to the PFF. Kagel created the *Ready.Set.Breathe Walk* in Dallas which raised over \$65,000 before evolving to become the PFF Walk - Dallas. Kagel is a PFF Ambassador Emeritus who shared her story near and far to help others living with the disease. Her daughter, Samantha, followed in Kagel's footsteps and now volunteers as a PFF Ambassador.



STEPHANIE GOLDEN

PFF Ambassador and Walk team leader Stephanie Golden and her family honored their beloved mother, Olga, as Team Golden Turner in the PFF Walk - Dallas. Each team member chose a different place to walk this year—in the neighborhood, on the treadmill and in the park. Golden and her team also created a video to help others in the PF community with fundraising tips.

Albert Rose Legacy Society



Join the PFF's fastest-growing program, the Albert Rose Legacy Society. With this planned giving program, you can leave a life-giving legacy and help the PFF achieve its goal of finding a cure for pulmonary fibrosis. For more information, visit pulmonaryfibrosis.org/plannedgiving or contact Seth Klein, vice president of development, at sklein@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/get-involved** 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.

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 patient programs that help patients and their families live longer, healthier lives.



PFF WALK

Join us in 2021 for the next edition of the PFF Walk! The PFF Walk offers an inclusive opportunity for those who have been touched by pulmonary fibrosis to unite in the search for a cure while sharing stories and celebrating loved ones with our community of patients, caregivers, healthcare professionals, and friends. 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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A Family's Lost Generation

Pulmonary fibrosis wiped out an entire generation of Sisi Suarez's family. Suarez lost her mother and all five of her mother's siblings to the disease.

The heart-wrenching pain of her mother's death, combined with Suarez's fear that PF will affect others in her family, motivated her to become a team leader in the PFF Walk - New York City.

"I walk for my mom," says Suarez. "Pulmonary fibrosis is lethal but people don't know about it and that's scary. My mother would be proud of us for trying to make an impact."



Suarez is the face of the PFF's fall appeal. Read more of her story and join the fight with a gift to the PFF today at bit.ly/sisisuarez.

