

PULMONARY FIBROSIS FOUNDATION

breathe

ISSUE 01 SUMMER 2020



Pulmonary Fibrosis Foundation 2020

Two Decades of Progress
Toward a World Without PF

Table of Contents

Letter From Our President and CEO	3
Keeping the Community Safe: Addressing Patient Health During the COVID-19 Pandemic	4
True or False? Myths and Misconceptions Debunked	4
PFF Ambassador Program Adapts to a Virtual Meeting for Annual Training Program	5
PFF Hill Day Continues Despite COVID-19	6
New Telephonic Support Groups Serve Those in Need	7
The Patient Communication Center is Here to Help	7
With Telemedicine, Patients in Rural Areas Can Make Clinic Visits Remotely	8
PFF Position Statements Offer Guidance to Healthcare Providers and Patients	9
Benchmarking Project is Setting Standards for ILD Clinics	9
Why Research Matters and How the PFF Supports It	10
Meet the New Experts on the PFF Medical Team	10
PROLIFIC Research: New Consortium May Speed Up Targeted IPF Treatments	11
First Broad Study of American Anti-Fibrotic Use Reaches Publication Stage	12
PFF to Fund Six New PFF Scholars	13



PFF Patient Registry Research Studies	14
PFF Summit will Return to the Windy City in 2021	15
PFF 2020: Two Decades of Progress Toward a World Without PF	16
Meet McKenzie Swider: A 28-Year Old Mom with IPF Who Finds New Meaning as a PFF Ambassador	18
Community Fundraisers Make Every Dollar Count	19
A Decade of <i>Broadway Belts for PFF!</i> Raises \$2 million for the PFF	20
Moving the Needle on PF Awareness	21
Ways to Get Involved	22
Meet the Staff	23

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.

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Letter from Our President and CEO

DEAR FRIENDS,

The world's attention has been focused on the COVID-19 pandemic—and at the Pulmonary Fibrosis Foundation (PFF), we've turned our own efforts to continuing our important work during this period of uncertainty.

Recognizing that people with chronic medical issues, including pulmonary fibrosis (PF), are at higher risk for serious illness from COVID-19, we're sharing multiple resources to help patients and their families stay informed and prepared. Please visit pulmonaryfibrosis.org/covid19 to find PFF guidance on COVID-19, two PFF webinars on the coronavirus, answers to frequently asked questions from PF patients, information for transplant candidates and recipients, tips on preparing your home, help with managing anxiety, and much more.

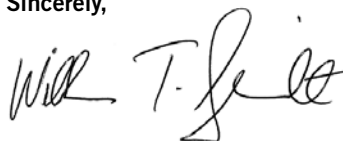
The Foundation scored a significant win for PF patients when we recruited other pulmonary and respiratory disease organizations to join us in a letter asking the Centers for Medicare and Medicaid Services (CMS) to issue new oxygen prescription and delivery guidelines during the pandemic. For the length of this public health crisis, CMS has waived the in-person testing requirement for patients receiving supplemental oxygen for the first time. To eliminate unnecessary contact, CMS has also waived the signature requirement when oxygen is delivered.

During this time, we're being creative with our approach to sharing information, spreading awareness, and raising funds for PF. For instance, we held our annual Washington, D.C. Hill Day via phone calls rather than in person. A scheduled training for PFF Ambassadors took place online. And the popular PFF Walk in New York City was held virtually this year.

Beyond our response to the pandemic, the Foundation's daily work continues, including our dedication to supporting research. This spring, we announced the creation of PROLIFIC, a consortium with industry partners that could speed up the development of targeted treatments—precision medicine—for individuals with idiopathic pulmonary fibrosis (IPF). Our success in building a robust PFF Patient Registry and Biorepository is bearing fruit in this and many other research endeavors that are leading us closer to effective treatments—and, eventually, a cure.

Thank you for your ongoing support of the Foundation and for everything you do to increase PF awareness, education, advocacy, and research. Together, we're making a difference even in this challenging moment—and building toward an even more productive and life-changing future.

Sincerely,



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER

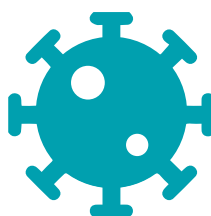


Keeping the Community Safe: Addressing Patient Health During the COVID-19 Pandemic

As the COVID-19 pandemic spread throughout the U.S., the PFF took swift action to keep the PF community informed. The Foundation closely monitored the situation, developed new online resources, and advocated on behalf of patients.

Under the leadership of the PFF medical team, a comprehensive COVID-19 page was created on the PFF website with a guidance statement, patient FAQs, and links to important organizations including the Centers for Disease Control and Prevention, Johns Hopkins University, and the World Health Organization. These resources are also available in Spanish.

On April 1, the PFF launched a COVID-19 webinar series to share the latest information and most effective ways to prevent infection from the virus.



Top pulmonologists in the field addressed topics such as what to do if you get sick, how to cope with social distancing, and misconceptions about the virus.

The Foundation also took important measures on the government relations front by composing a letter signed by national healthcare organizations urging the Centers for Medicare and Medicaid Services (CMS) to waive certain requirements for supplemental oxygen. On March 30, CMS adjusted its policies and waived the in-person testing and signature requirements for delivery of supplemental oxygen. You can read more about this on page 6.

Finally, in response to the flood of COVID-19 stories on social media, the PFF launched a Positivity Project on Facebook. PFF Ambassadors were profiled, and they shared how they remained positive and spent time indoors during the crisis.

To access the PFF's statements, additional resources, webinars, and more, visit pulmonaryfibrosis.org/coronavirus.

TRUE OR FALSE? PULMONARY FIBROSIS MYTHS AND MISCONCEPTIONS DEBUNKED

Myth: Oxygen is addictive.

Fact: Everyone needs oxygen to live. Supplemental oxygen is not addictive and can reduce the stress on the heart caused by low oxygen levels.

Myth: No one knows what causes interstitial lung disease (ILD).

Fact: While some types of ILD don't have a known cause, many do. These include environmental factors, radiation treatment, certain medications, occupational exposure, and autoimmune disease.

Myth: There are no effective treatments for pulmonary fibrosis.

Fact: Medications, supportive treatments such as oxygen therapy, pulmonary rehabilitation, and lung transplantation are among the treatments available for PF.



These statements are just three of the myths exposed in the "PF Myths and Misconceptions Debunked" webinar available on the PFF's YouTube channel. The webinar, presented by former PFF Senior Medical Advisor, Dr. David Lederer, provides facts about pulmonary fibrosis while clearing up confusion about numerous aspects of the disease. You'll learn that people with PF can exercise, palliative care does not mean hospice care, and survival rates from lung

transplant vary by age group. Watch the webinar today and become a PF mythbuster at bit.ly/pffmyths!

Subscribe to the PFF's YouTube Channel for the latest Disease Education Webinars and Life With PF videos.

PFF Ambassador Program Adapts to a Virtual Meeting for Annual Training Program



When the PFF Ambassador Program opened its annual application cycle in January, plans were already in place to bring the newest class of PFF Ambassadors to Chicago in April to meet one another, interact with staff members, and undergo volunteer training.

As 14 new PFF Ambassadors from across the country were selected to join the program in early March, the PFF staff forged ahead with logistics to offer them the same in-person training opportunity attended by previous PFF Ambassador classes in 2018 and 2019.

The country faced a new reality due to COVID-19 in March and all training plans were disrupted. PFF staff and public speaking coach, Lisa Braithwaite, quickly adapted to offer the training session in a virtual capacity for the first time in the program's history. The newest class of PFF Ambassadors virtually gathered to meet one another and undergo public speaking training in early April from the comfort and safety of their own homes utilizing



the GoToMeeting platform. Webcams were used to create a more personal level of connection. During this training session, attendees learned how to create an engaging and personal presentation and also had the opportunity to write and deliver a three-minute speech about their connection to pulmonary fibrosis, receiving feedback from fellow attendees and the trainer. Despite the distance and virtual component, Ambassadors remained committed to this training program and left feeling more prepared for their volunteer role and emotionally fulfilled after the two-day session.

Despite the distance and virtual component, Ambassadors remained committed to this training program and left feeling more prepared for their volunteer role and emotionally fulfilled after the two-day session.

Once public speaking training is complete, new PFF Ambassadors then work with an author to draft a formalized version of their story to share at events. They also participate in monthly teleconference calls with the full PFF Ambassador roster to receive Foundation updates, share best practices and discuss PFF Ambassador opportunities. Once fully trained, the newest class of PFF Ambassadors look forward to attending events, both in-person and virtually, to share their story, connect with the pulmonary fibrosis community and offer a message of inspiration and hope.

With Phone Calls Replacing Visits, PFF Hill Day Continues Despite COVID-19



The Pulmonary Fibrosis Foundation's spring Hill Day is an opportunity for patients and their families to advocate in Washington, DC, for legislation that will improve the lives of people living with pulmonary fibrosis (PF). When the rapid spread of COVID-19 made it impossible for the usual in-person meetings to take place this year, Foundation volunteers and Capitol Hill staff found a way to keep the connection going.

"We knew it wasn't prudent to ask anyone, especially people with PF, to travel to Washington—so at our request, the provider who set up our meetings with legislators graciously switched to telephone meetings," says Kate Gates, PFF senior director of programs.

Pairing up to call in groups of two (one constituent and one person providing extra perspective), volunteers were able to participate in phone meetings with their own members of Congress or their staffs. Callers had two requests of their representatives:

- For Congress to include language about the importance of PF research in the 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
- For Congress to continue including PF in the list of research areas for the Peer Reviewed Medical Research Program at the Department of Defense

The response to the calls was extremely positive, Gates reports. "Overall, people on the Hill are very supportive of medical research," she says. "It's really helpful to have patients or family members with direct experience with the disease, because it puts a face to the numbers and drives home the importance of having better options for people living with PF."

Want to join the ranks of PFF Advocates? Visit pulmonaryfibrosis.org/advocacy to learn more, sign up for alerts, and find out more about reaching out to your own members of Congress.

New Telephonic Support Groups Serve Those in Need

The PFF Support Group Network has 150 support groups located across the country led by passionate volunteer group leaders. Despite the size of this network, there are still areas in the U.S. where members of the PF community do not have access to or cannot attend a support group due to distance, schedule conflicts, or language barriers. The PFF hosts three telephone-based support groups for patients, caregivers, family members and anyone affected by this disease. **PFF Voices**, a group for all members of the PF community, provides a chance to discuss different topics and concerns related to the pulmonary fibrosis.

PFF Caring Conversations, a group created specifically for those who are caring for individuals with PF, provides participants an opportunity to share experiences and information related to their caregiving role. **PFF Coloquio**, a group created for Spanish speaking patients, caregivers and families affected by PF to discuss various topics and concerns regarding pulmonary fibrosis. All groups allow participants to share personal stories and information, ask questions, and provide support to one another. Call-in information and meeting times are the same each month.

PFF VOICES



Meets the third Thursday of each month

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

Phone number: 1-571-317-3116
1-866-899-4679 (Toll-free)
Access Code: 124-558-453

PFF Caring Conversations



Meets the first Tuesday of each month

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

Phone number: 1-646-749-3129
1-877-309-2073 (Toll-Free)
Access Code: 220-929-629

PFF Coloquio



Meets the second Tuesday of each month

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

Phone number: 1-312-757-3117
(866) 899-4679 (Toll-Free)
Access Code: 741-967-613

Do you have questions about pulmonary fibrosis? The PCC Is Here to Help

Looking for a support group, medical center, or even a clinical trial? For those living with pulmonary fibrosis, it is important to have access to the most accurate and current information.

The **PFF Patient Communication Center (PCC)** is a dedicated call center that provides patients, caregivers, and healthcare providers with the most up-to-date medical information, available support services, and other essential resources. While our PCC staff cannot give medical advice to individuals, they can answer questions about pulmonary fibrosis and share helpful resources. In addition to answering questions that you may have, the Patient Communication Center can also share free disease education literature.



To get in touch with our Patient Communication Center, please call 844.TalkPFF (844.825.5733) or email pcc@pulmonaryfibrosis.org.

With Telemedicine, Patients In Rural Areas Can Make Clinic Visits Remotely



When it established its Care Center Network (CCN), the Pulmonary Fibrosis Foundation sought to have a medical center with expertise in treating pulmonary fibrosis within a two-hour drive of most Americans.

In sparsely populated states, that goal is a challenge—so CHI Creighton University Medical Center-Bergan campus (CUMC-Bergan) and its innovative telemedicine program has been an especially welcome addition to the CCN.

For some time, the Omaha, Nebraska-based university health system has used telemedicine to connect satellite providers to its main hospital. In outlying hospitals' ICUs, for example, cameras and video monitors allow physicians and advanced practice nurses to talk to the nurse on duty and perform detailed visual assessments—right down to assessing the patient's pupils.



"It provides us with extra sets of eyes at the bedside," says Douglas Moore, assistant professor of medicine and medical director for critical care, CUMC-Bergan.

Now, CUMC-Bergan is leveraging its telemedicine infrastructure for interstitial lung disease patients' ongoing

care. Moore, who established CHI Health's ILD clinic, is working with colleagues to establish remote clinics that will save patients multiple-hour drives to and from Omaha. Pulmonary function tests or other activities that require a patient to be present will continue to be performed locally.

The Centers for Medicare and Medicaid Services (CMS) has relaxed its rules on telemedicine reimbursement in response to COVID-19, creating a rare silver lining to the public health crisis. "Reimbursement has been a big hurdle in expanding telemedicine," says Moore. "Now that CMS is on board with this, we may see a change in our healthcare system. That's good news for patients."

PFF Position Statements Offer Guidance to Healthcare Providers and Patients

In an effort to share knowledge of pulmonary fibrosis with the medical community at large, the Foundation has collaborated with healthcare professionals from the Care Center Network to develop PFF Position Statements on topics of interest.

Four statements have been published to give healthcare providers and patients perspective on various topics. The statements are now available on the PFF website at pulmonaryfibrosis.org/healthproviders.

GENETIC TESTING AND COUNSELING IN PULMONARY FIBROSIS

A diagnosis of familial pulmonary fibrosis should be suspected when a patient with idiopathic pulmonary fibrosis has at least one other close relative affected by the disease.

SURGICAL LUNG BIOPSY

While surgical lung biopsy is an important diagnostic procedure in the evaluation of patients with fibrotic interstitial lung disease (ILD), it is often not necessary to achieve a confident diagnosis.

STEM CELL

Though research is promising, stem cell and cell-based therapies are currently unproven and may be detrimental for patients with PF.

HIGH-RESOLUTION COMPUTED TOMOGRAPHY (HRCT)

A recommended protocol designed for HRCT imaging is available for diagnosing people with suspected ILD.

The PFF will continue to publish informational Position Statements as a resource to complement ongoing research.



Benchmarking Project Is Setting Standards For ILD Clinics



Each of the Pulmonary Fibrosis Foundation's Care Center Network sites provides diagnosis and management of interstitial lung diseases. The PFF understood there were variances in the 68 centers, but, with this survey, it further elucidated the differences and commonalities.

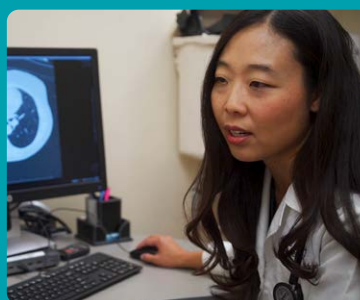
Christophe He, MD, who recently completed a fellowship at the University of Colorado, is interested in starting an ILD center in his home country, Canada. To discern what CCN sites across the US are doing and create best-practices guidelines to share with other medical centers, He and his UCHHealth colleagues decided to survey all CCN sites.

"We started by asking basic questions: everything from whether they have an ILD-dedicated nurse to how long they spend on a first consult to what ancillary staff—such as social workers and respiratory therapists—they have on board," says Joyce Lee, MD, who directs UCHHealth's ILD Clinic. The group's conclusion from the 72-question survey, which received a 58% response rate, is that "ILD clinics throughout the CCN are heterogeneous in their volume and support staff.

However, all participate in research and clinical trials, and nearly all utilize a multidisciplinary conference for diagnosis and care," Lee says.

A second phase of the project used the Delphi process, which involves asking a panel of experts—in this case, CCN ILD clinic directors—questions in rounds until consensus for each question is achieved. Through this process, Lee and her fellow researchers will determine which aspects of ILD clinics a solid majority of directors deem essential. In a separate project element, a focus group will provide detail on what clinic offerings patients believe are key to include.

The project "is helpful for us in developing common clinic standards that are absolutely essential to becoming a CCN site," says Pauline Bianchi, RN, PFF senior vice president for research and programs. "We're hoping to take what we're learning and apply it to our criteria for future sites."



Joyce Lee, MD is an Associate Professor of Pulmonary Sciences and Critical Care and Director of the Interstitial Lung Disease Program at the University of Colorado School of Medicine

Why Research Matters and How the PFF Supports It

For people living with pulmonary fibrosis, research is the most important tool leading to an improved quality of life—and eventually, a cure. Recognizing the critical role of increased research in transforming the lives of people with PF, the Pulmonary Fibrosis Foundation has significantly heightened its research commitment over the past several years.



With the establishment of the PFF Patient Registry and Biorepository, researchers now have a robust, consistent body of data for use in studies exploring drug therapies and other potential treatments. The Foundation has also increased the amount of funding it provides to researchers. Many others in the research community are making innovative use of Registry data. Some are going on to secure major grants from the National Institutes of Health and other external funding bodies, creating

an important return on investment with the “seed money” provided by PFF research awards.

In this section, read more about current PFF research efforts, including the first publication based on Registry data, current research studies using the Registry, the funding of six new PFF Scholars, and a new industry consortium focused on developing precision medicine approaches to PF.

MEET THE NEW EXPERTS ON THE PFF MEDICAL TEAM

The PFF is delighted to welcome three highly respected pulmonologists to its expert PFF Medical Team. Dr. Amy Hajari Case of Piedmont Healthcare in Atlanta; Dr. Sonye Danoff of the Johns Hopkins University School of Medicine in Baltimore; and Dr. Joyce Lee of the University of Colorado Anschutz Medical Campus in Aurora, Colorado, bring a combined 40-plus years of expertise in treating individuals with interstitial lung disease.



Amy Hajari Case, MD, FCCP established the ILD program at Georgia Lung Associates, which became part of the Piedmont Pulmonary, Critical Care, and Sleep Division in 2013. She leads the Advanced Lung Disease at Piedmont directs the ILD program, which became part of the Pulmonary Fibrosis Foundation's Care Center Network in 2014. She is also the Medical Director for Pulmonary and Critical Care Research and serves as principal investigator for numerous clinical trials for pulmonary fibrosis.



Sonye Danoff, MD, PhD is an Assistant Professor in the Division of Pulmonary and Critical Care Medicine and Co-Director of the Interstitial Lung Disease Clinic at Johns Hopkins Medicine. She is a specialist in diseases causing fibrosis in the lung, particularly those associated with autoimmune diseases including myositis. Dr. Danoff actively participates in local, regional, and international collaborative groups in the study of ILD.



Joyce Lee, MD is an Associate Professor of Pulmonary Sciences and Critical Care and Director of the Interstitial Lung Disease Program at the University of Colorado School of Medicine. She established the University's ILD program which is now part of the PFF Care Center Network. She has developed clinical-translational research programs with both NIH and non-NIH funded investigator-initiated studies and clinical trials.

PROLIFIC Research: New Consortium May Speed Up Targeted IPF Treatments

Precision medicine—treatments targeted to the genes, environment, and lifestyle of specific individuals with a particular condition—are at the forefront of medicine. This spring, the PFF announced a collaboration with industry partners that could speed up the development of targeted treatments for individuals with idiopathic pulmonary fibrosis (IPF).

The PFF and Bristol Myers Squibb, formerly Celgene, have organized a consortium called PROLIFIC (Prognostic Lung Fibrosis Consortium). “The PROLIFIC collaboration is an example of the innovative and intensive research underway with the PFF and industry partners to identify additional therapies for PF,” says Gregory P. Cosgrove, MD, chief medical officer for the PFF.

PROLIFIC will develop assays—investigative laboratory procedures that assess or measure the presence, amount, or functional activity of a particular entity. These assays will detect important peripheral blood protein biomarkers (indicators of a disease or other physiological state) in patients with PF. The research will be used to uncover early indicators of a drug’s activity and performance.

PROLIFIC industry members include Biogen, Genentech Inc., Lung Therapeutics, Inc., OptiKira LLC, Pliant Therapeutics, Inc., RespiVant Sciences GmbH, and Three Lakes Foundation. The group has selected 12 biomarkers based on published scientific reports describing their prognostic use for the disease itself and their potential for predicting how well a drug will work. The biomarkers may also be useful for comparing the biological activity of different therapeutic interventions across trials.

Of the 12 biomarkers, five are markers of epithelial (cells from body surfaces like organs) damage, three of fibrosis, three of inflammation, and one of thrombosis (blood clot formation).

BIOMARKERS UNDER STUDY

The 12 biomarkers PROLIFIC has identified for study may indicate better or worse prognoses for disease progression or mortality. These include indicators of:

- 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)



The PFF Patient Registry and Biorepository is playing a vital role in PROLIFIC’s work. Using samples from the 2,000-patient Registry and Biorepository, researchers will identify and validate the biomarkers. In addition to the blood samples, investigators will use baseline data related to symptoms, demographics, and social traits, as well as data showing variation over time, to characterize proteins affected by the disease.

Says Saurabh Saha, MD, PhD, senior vice president of translational medicine at Bristol-Myers Squibb, “Biomarker research plays a fundamental role in our precision medicine approach to treating some of the most challenging diseases. Through the PROLIFIC consortium, we’re collaborating with industry leaders to help put translational discoveries into clinical practice.”

Additional organizations, including pharmaceutical and biotech companies, patient advocacy and non-profit organizations, and academic institutions, will be invited to apply for membership to the PROLIFIC consortium.

Broad Study of American Anti-Fibrotic Drug Use Reaches Publication Stage



It's an investment that's paying returns. The PFF Patient Registry and Biorepository was designed to provide a significant body of long-term data and samples that can be used by investigators to study pulmonary fibrosis.

Currently, 24 studies at various stages are making use of Registry data (see story, page 10). The first of these studies “Patient and Site Characteristics Associated with Pirfenidone and Nintedanib Use in the United States; An Analysis of Idiopathic Pulmonary Fibrosis Patients Enrolled in the Pulmonary Fibrosis Foundation Patient Registry” will appear in the December 2020 issue of *Respiratory Research* 21 (1).

The study was based at the University of Michigan and also included researchers from the University of Minnesota and industry partner Genentech, Inc.

ADDRESSING A KNOWLEDGE GAP

Although two anti-fibrotic medications, nintedanib and pirfenidone, slow disease progression in idiopathic pulmonary fibrosis (IPF), little is published about use of anti-fibrotic medications in a real-world

US setting. Many persons with IPF were excluded from clinical trials leading to approval of these two medications—such as the INPULSIS study of nintedanib and the ASCEND study of pirfenidone—due to their severity of lung function impairment, inability to walk with specific diseases, or comorbidities.

Although IPF patient registries are being developed worldwide and some other countries have conducted pragmatic research into use of these drugs, “Use of an anti-fibrotic in persons with IPF failing to meet clinical trial inclusion criteria is not well defined in the US,” the authors write. “This study is a descriptive analysis of early use of anti-fibrotic medications in the US. We aimed to describe the relationship between patient- and Registry site-level characteristics and a) the likelihood of using anti-fibrotic therapy and b) the specific anti-fibrotic medication used

by patients enrolled in the PFF Patient Registry. This work is intended to generate hypotheses to guide future research regarding variations in use of these medications.”

“More research is needed to better understand variations in medical decision-making regarding use, including at different stages of disease severity, and selection of anti-fibrotic medication.”

REVEALING PATTERNS OF PRESCRIBING

The investigators learned that 60.7% of Registry patients whose medication information is on file were taking at least one anti-fibrotic medication. Among the 57.8% taking a single medication, 44.4% were taking nintedanib and 55.6% were taking pirfenidone. Many persons with severe IPF who may not have qualified for a clinical



trial were being treated with an anti-fibrotic in clinical practice.

“In general, more severe lung disease was associated with anti-fibrotic use,” the investigators write. “This

may be due to providers and patients deferring anti-fibrotic initiation in patients with less severe disease. Such a strategy is not supported by research that shows anti-fibrotic use prevents irreversible lung function loss at all levels of disease severity.”

The authors add, “One surprising finding is that nearly 40% of persons with IPF were not prescribed one of these disease-altering medications. It is possible that provider unfamiliarity with these newer medications, concerns about side effects, or concerns about cost may be reasons for deferral of medication initiation.”

Strengths of the study “include analysis of detailed patient information for a cohort of well-characterized persons with IPF,” the co-authors note. The study was somewhat limited by lack of provider-specific information, “which required use of Registry site as a proxy for physician,” they add. “However, a single influential provider may influence peer and trainee practice [at a Registry site] indirectly and directly.”

A STRONG FIRST STEP

Among the investigators’ conclusions: “There was variation in odds of anti-fibrotic medication use between Registry sites that was incompletely explained by examined characteristics.”

For instance, “Pirfenidone was used by a small majority of patients with IPF and was associated with patient history of cardiovascular disease, anticoagulant use, recent clinical trial participation, and enrollment at a Midwest region Registry site.”

Compared to studies based on a limited number of US clinical sites or a single-payer healthcare system in another nation, “This analysis provides a more detailed and inclusive characterization of US treatment patterns,” the co-authors conclude. “More research is needed to better understand variations in medical decision-making regarding use, including at different stages of disease severity, and selection of anti-fibrotic medication.”

Co-authors of the first published study based on PFF Patient Registry data

Colin H. Holtze MD, Kevin Flaherty MD, MS—Department of Internal Medicine, Division of Pulmonary and Critical Care Medicine, University of Michigan

Elizabeth A. Freiheit—Department of Biostatistics, University of Michigan

Susan L. Limb MD, John L. Stauffer MD, Karina Raimundo MS—Genentech, Inc.

Wayne T. Pan MD, PhD, MBA —Genentech, Inc.

Hyun J. Kim MD—Department of Medicine, Division of Pulmonary, Allergy, Critical Care, and Sleep Medicine, University of Minnesota

PFF TO FUND SIX NEW PFF SCHOLARS



The PFF Scholars program engages emerging researchers in the field of pulmonary fibrosis, supporting and enabling promising researchers to obtain independent funding, and to continue

their cutting-edge research. This program also provides supplementary sponsorship to the awardee as an additional resource throughout their award period by actively advocating on behalf of the awardee and working to create opportunities for leadership, networking, and visibility in the field. The program always funds at least four awardees per cycle, but for the second year in a row, the Foundation will select six PFF Scholars for an award of \$50,000 each over a two-year period.

“We’re always looking for ways we can increase both the number of awards and the dollar amount provided based on funding we receive,” says Zoe Bubany, PFF vice president for board and external relations. “With the continued generous support of the PF community, we are able to commit to increase the number of these important early-career awards for the 2020 cycle, which lay the foundation for these researchers to obtain additional, independent funding.”

Although slightly delayed due to COVID19—some investigators’ labs are temporarily closed and others are working on the front lines of healthcare—this year’s grant cycle continues, with final selections scheduled for mid-summer.

PFF Patient Registry Research Studies



The investigators using PFF Patient Registry and biorepository data are a mix of gifted early-career and established researchers.

Through the combined efforts of university-based and industry-supported researchers—many studies are a collaboration between academia and industry—investigators are making meaningful progress in the fight against pulmonary fibrosis. Combined funding for these studies is an impressive amount to come.

The 24 studies currently making use of PFF Patient Registry data are at a variety of stages. Many investigators have already presented their research at prestigious conferences including the American Thoracic Society annual meeting and the PFF Summit.

A sampling of current research using the PFF Patient Registry and Biorepository:

- **Registry Design and Baseline Characteristics of Patients**
- **Autoimmune Testing Patterns Associated with IPF Diagnostic Confidence**
- **Racial Differences in Age at Diagnosis and Mortality**
- **Patient Factors and Disease Severity Impact Cough-specific Quality of Life**
- **Association of Supplemental Oxygen Therapy With Hospitalization and Lung Transplant Events in Patients With Interstitial Lung Disease (ILD) Enrolled in the Pulmonary Fibrosis Foundation (PFF) Patient Registry**
- **PRECISIONS (Prospective tReatment EffiCacy in IPF uSIng genOtype for Nac Selection)**
- **Role of Fatty Acids in ILD**
- **Role of Body Mass Index in ILD**
- **Acute Exacerbations and Hospitalizations in IPF**
- **Association of Supplemental Oxygen Therapy With Hospitalization and Lung Transplant Events in Patients With Interstitial Lung Disease (ILD) Enrolled in the Pulmonary Fibrosis Foundation (PFF) Patient Registry**

These are samples of the important research being conducted utilizing the patient data and biospecimens from the PFF Patient Registry.

The next step is to re-open enrollment for clinically-captured data and samples, along with an expansion of the PFF Patient Registry to engage patients and caregivers directly, outside of the clinical environment. This expansion will allow investigators to have access to this valuable research tool to take critical steps towards a cure.

The success of the PFF Patient Registry relies upon funding from everyone in our community.

If you would like to support this important research initiative, please contact Seth Klein at 312.224.2670 or sklein@pulmonaryfibrosis.org.

PFF Summit Will Return to the Windy City in 2021

Save the date! The PFF Summit, held biennially, will be returning to Chicago on November 11-13, 2021 at the breathtaking Sheraton Grand Chicago. Our first PFF Summit was held in Chicago in 2011.



The PFF Summit is not only the largest PF healthcare conference in the world, but it is unlike any other, welcoming anyone who has been impacted by the disease. The Summit provides an unparalleled opportunity to network with patients, caregivers, healthcare providers,

researchers, thought-leaders, and industry representatives—all in one setting. The goal of Summit is to foster collaboration that will help enhance patient care and stimulate research that will lead to better treatments for PF.

“The PFF Summit offers the entire community a truly unique opportunity to join forces against pulmonary fibrosis,” said Jeri Webb, Associate Vice President, Conferences and Meetings. “Newly diagnosed patients and their caregivers in particular discover the depth of knowledge available at the conference while making strong connections with others who have been living with the disease.”

At PFF Summit 2019, the conference saw record-breaking participation with 950 attendees from 44 states and 10 countries. Attendees enjoyed sessions such as “How Should We Approach GERD in ILD/IPF Now?”, “Emergency Preparedness,” “Clinical Trials: Empowering People to Participate,” “Translational Genomics: The Future is Now,” and much more.

All PFF Summit 2019 sessions were recorded and are available on the Foundation’s YouTube channel at [youtube.com/pulmonaryfibrosisfoundation](https://www.youtube.com/pulmonaryfibrosisfoundation). To view information about past events, visit pffsummit.org.

CO-CHAIRS TO PROVIDE NEW INSIGHTS FOR 2021

The PFF is pleased to announce the co-chairs for the PFF Summit 2021. 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.

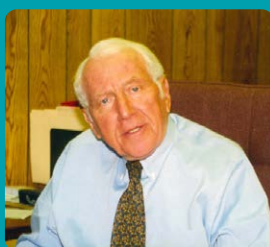
INTERESTED IN BECOMING A SPONSOR?

We offer a wide range of sponsorship levels and benefits for this event with a 2021 Prospectus anticipated to be released by the end of 2020. To learn more about PFF Summit, visit PFFSummit.org, or for inquiries, send an email to Jennifer Mefford at jmefford@pulmonaryfibrosis.org.

2020

2020 marks the 20th anniversary of the establishment of the Pulmonary Fibrosis Foundation. Because of your commitment and support, what started as a small family-operated foundation with a staff of two has now evolved into a \$12 million organization with 34 employees.

2000 **FOUNDING OF THE PULMONARY FIBROSIS FOUNDATION**



The PFF was established in Denver by Albert Rose and Michael Rosenzweig after they lost their sister to the disease. Albert pledged \$1 million to start the Foundation, and this commitment is memorialized today through the PFF's planned giving program, the Albert Rose Legacy Society.

2002 **PFF HEADQUARTERS RELOCATES FROM DENVER TO CHICAGO**



The PFF is still headquartered in Chicago today.

2011 **PFF SUMMIT UNITES COMMUNITY**



The first PFF Summit was held in Chicago. The biennial conference, the only one of its kind focused solely on PF, welcomed 300 patients, caregivers, researchers, healthcare professionals and industry partners.

2013 **CARE CENTER NETWORK LAUNCHES**



The PFF Care Center Network (CCN) was established with nine medical centers that provide comprehensive care and support to people living with PF. Today, the CCN includes 68 centers in 33 states.

2017 **HUNDREDS PARTICIPATE IN FIRST PFF WALK**



The first PFF Walk in Chicago raised funds and visibility as the centerpiece event of Pulmonary Fibrosis Awareness Month in September. Since then, the Walk has expanded to New York City, Washington D.C., Dallas and in 2020, San Francisco.

2018 **PFF SCHOLARS PROGRAM LAUNCHES**

After identifying a need to allow more early-stage researchers study PF, the research grant program was revamped and became the PFF Scholars program. The PFF Scholars program is designed to support and enable promising researchers to obtain independent funding and continue their cutting-edge research. Scholars receive up to \$50,000 each over a two-year period.

Together with the pulmonary fibrosis community, the PFF has achieved many important milestones in the fight against this disease. Today, we are stronger than ever and continue to advance research, advocate for patients, and develop trusted resources for families.

2005 LEANNE STORCH JOINS THE PFF



Leanne Storch, who was diagnosed with idiopathic pulmonary fibrosis, joined the PFF as a volunteer. Leanne worked with Michael Rosenzweig as a liaison for patients and their families. She later served as Executive Director of the PFF. The Leanne Storch Support Group Fund was established in her

name in 2012 to honor her extraordinary commitment to patient support. The program provides grants to PF support groups nationwide. The PF community was saddened by the passing of Leanne in 2019.

2010 THE CURTAIN GOES UP AT THE INAUGURAL BROADWAY BELTS FOR PFF!



Broadway Belts For PFF! was created by actress and comedienne Julie Halston, her late husband Ralph Howard, and others in the Broadway community. The event honored acclaimed theater critic Michael Kuchwara, who

succumbed to idiopathic pulmonary fibrosis. *Broadway Belts For PFF!* has become the single largest fundraiser for the PFF.

2014 FDA APPROVES TWO THERAPIES FOR IPF

The FDA approved nintedanib and pirfenidone to treat IPF. This major advancement led the Foundation to begin new partnerships with Boehringer Ingelheim and Genentech, a member of the Roche Group. Through these partnerships, the Foundation launched the PFF Ambassador program and the Patient Communication Center.

2015 PFF PATIENT REGISTRY AND BIOREPOSITORY ENROLLMENT BEGINS



The PFF Patient Registry began enrolling patients to gather data and blood samples to advance research for better therapies and a cure. A major milestone, the enrollment of 2,000 patients, was completed in 2018.

2020 FORGING AHEAD



The PFF is paving the way to a world without pulmonary fibrosis. We are aggressively investing in research, advocating for federal support for the community, expanding resources for

patients and caregivers, and educating health care providers about PF. We are raising more money and awareness to fight this disease than ever before. Together, with you, we WILL beat it.

Be The Difference.

Join IPF Patient McKenzie Swider To Raise Funds in the PFF Spring Appeal



A few years ago, McKenzie Swider was enjoying a full life. She was running 5Ks, taking care of her five children, and volunteering at church.

But in 2018, Swider's world was turned upside down. Symptoms of dizziness, dry cough, and loss of vision became severe and she struggled to breathe. At age 26, Swider was diagnosed with idiopathic pulmonary fibrosis. Doctors told her that she had lost half of her lung function.

As Swider and her husband, Keith, tried to come to grips with the reality of the diagnosis, the disease began to impact their family life. She had to slow down. She became depressed. She was too exhausted to go grocery shopping and play with her kids.

Her need for supplemental oxygen rose from two, to four, to six and then ten liters at a time.

But while she struggled to accept her new reality, Swider was inspired to use her experience to help others. She called the Pulmonary Fibrosis Foundation and received educational resources and information about a local support group.

"It was during the lowest point of my life that I was able to turn to the PFF and finally find the strength I needed to live with this disease," Swider said. "The best place we can go for support and understanding of the disease is the Pulmonary Fibrosis Foundation."

Please donate to help McKenzie and others win the fight against PF. You can make your gift now by going to bit.ly/springpff2020.

McKenzie's mission is to raise funds for the Pulmonary Fibrosis Foundation. With your support, McKenzie and thousands like her who live with pulmonary fibrosis can move one step closer to finding a cure.

Community Fundraisers Make Every Dollar Count

Each year, more than 100 volunteers nationwide hold fundraisers for the Foundation. From bake sales and happy hours to golf outings and yoga classes, PFF volunteers raised over \$400,000 for the community last year alone.

Through our Community Events programs, volunteers create their own events and activities to generate funds to advance research and provide educational resources for patients and families. These imaginative efforts have a tremendous impact on individuals living with PF.

For example –

- A lemonade stand that raises \$30 provides funds for mailing four information packets to newly diagnosed patients;
- A bowling tournament that generates \$900 can send a PFF Ambassador to a patient education event;
- A walk that produces \$1,250 covers the cost of monitoring one patient in the PFF Registry for one year; and
- A golf outing that raises \$45,000 funds the production and distribution of a new healthcare provider education material.

Another great way to get involved is by creating a fundraising page. Whether you're celebrating a birthday or anniversary or participating in an athletic event, we can help you create your own personal fundraising page where you can share your story and collect donations.

Best of all, the PFF supports you every step of the way. A member of the PFF's fundraising staff will provide consultation on logistics, templates for requesting donations, and additional online resources.

For more information, contact Jackie Williams at 312.224.4667 or jwilliams@pulmonaryfibrosis.org.



Walkers in Meridian, Idaho welcomed over 80 attendees for the third annual Breath-a-Palooza community walk.



The 2018 Peter Coode Memorial Golf Tournament, held in Raleigh, North Carolina, brought together sponsors and golfers.



The Funds for Lungs Bowling Tournament held in Modesto, CA welcomed over 50 attendees.

A Decade of *Broadway Belts for PFF!* Raises Over \$2 Million for the PFF



Lisa Howard (*Escape to Margaritaville*) belts *Jenny's Blues*



Hostess Julie Halston, 2020 Ralph Howard Legacy Awardee Daryl Roth, and Bernadette Peters

The PFF and Broadway community came together on February 24th at New York City's Edison Ballroom to celebrate the monumental 10th-anniversary of *Broadway Belts for PFF!*



Jason Gotay performs the all-new *Something to Hold On To* from the upcoming *Between the Lines*



Bernadette Peters (*Hello Dolly!*) dazzles with *When You Wish Upon a Star*

More than 300 attendees gathered for this year's star-studded event and raised over \$380,000, bringing the 10-year total to more than \$2 million! The evening featured Julie Halston as the dynamic hostess, a special performance by Bernadette Peters, and a dazzling lineup of Broadway's top performers.

An especially poignant moment in the evening was the presentation of the Second Annual Ralph Howard Legacy Award to legendary Broadway producer, Daryl Roth. Roth was honored for her commitment to the Foundation's mission and her dedication to inspiring others through her mentorship.

"I am beyond grateful to my incredibly talented and generous friends for performing with me to raise funds for a cause that is so near and dear to my heart," Halston said.

Plans are already underway for next year's *Broadway Belts for PFF!* The evening will once again showcase Broadway's hottest performers belting out their favorite tunes to benefit the PFF.

This special night of lavish cuisine, premium cocktails, and unforgettable performances is an extraordinary celebration of the PF community.

Be sure to check out this year's phenomenal cast and photos at **BroadwayBeltsforPFF.org**! We'd love for you to join us in 2021. Would you like to learn more about our unique sponsorship opportunities and other ways to get involved? Send an email to Jackie Williams at **jwilliams@pulmonaryfibrosis.org**.

THANK YOU TO OUR GENEROUS SPONSORS:

LEADING ROLE

Doug & Gay Lane
Charitable Foundation

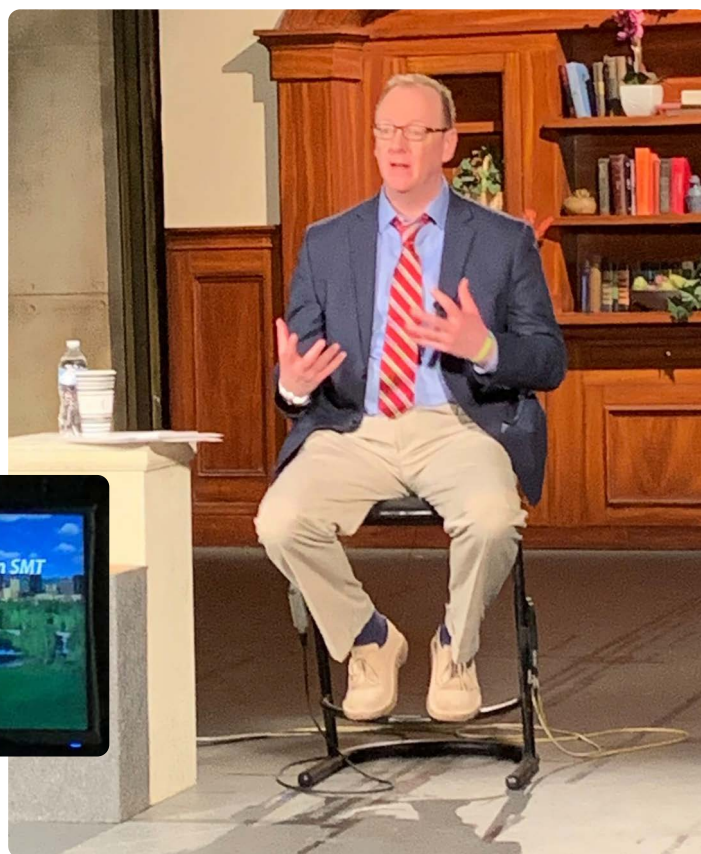
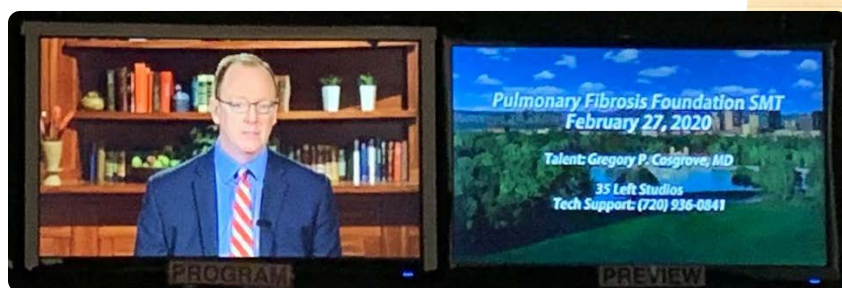
Diane & Dave Steffy

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Moving the Needle on PF Awareness



As part of the “Not Everyone Breathes Easy” awareness campaign, the PFF hit the ground running this year with a national consumer survey

revealing that 86% of Americans do not know the symptoms of PF. In an effort to highlight the need for more awareness of PF, key findings from the survey were announced to national healthcare journalists, resulting in coverage in outlets including U.S. News & World Report, Physicians Weekly, and Healio.com.

Results were also highlighted in a satellite media tour with TV and radio stations nationwide during Rare Disease Week. Dr. Gregory Cosgrove, PFF Chief Medical Officer, conducted 20 taped and live interviews about pulmonary fibrosis and the PFF as the trusted resource for those affected by the disease. The tour produced 753 interview airings generating more than 23 million impressions.

Full-page Not Everyone Breathes Easy print ads ran in winter issues of Outdoor Life, Garden Guide, VFW Magazine, Field and Stream and WebMD.

THREE LAKES FOUNDATION

The PFF and the Three Lakes Foundation (formerly Three Lakes Partners) expanded the “More Than A Cough” campaign into the new test markets of Birmingham, Alabama, Scottsdale, Arizona, and Nashville, Tennessee. Through a special partnership with Google, numerous iterations of ad creative and messaging were tested to identify the best performing ads. Insights from these markets, in addition to Chicago, will be utilized in developing a national campaign next year.

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

ATTEND AN EVENT

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

FUNDRAISE FOR TEAM PFF

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

PFF WALK

Join us for the PFF Walk 2020 in Chicago, Washington D.C., Dallas, virtually, and new in 2020, San Francisco! 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.

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](https://twitter.com/pfforg) as we share facts, stories, videos, and much more to spread the word far and let the world know. During September, 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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The Pulmonary Fibrosis Foundation rates among top charities in the U.S. The PFF has a three-star rating from Charity Navigator and is a Better Business Bureau accredited charity. The Foundation has met all of the requirements of the National Health Council Standards of Excellence Certification Program®.



Pulmonary Fibrosis

FOUNDATION

230 EAST OHIO STREET SUITE 500 CHICAGO, ILLINOIS 60611

Unite. Celebrate. **Walk.**



Mark your calendars and join us virtually for one of our five PFF Walks across the country.



CHICAGO
Saturday, September 12



NEW! SAN FRANCISCO
Saturday, September 19



VIRTUAL
September 26 & 27th, or a date of your choice



WASHINGTON D.C.
Saturday, October 10



DALLAS
Saturday, October 24



NEW YORK CITY
Spring 2021

Visit **PFFWalk.org**
today to get started.

To join the walk or for
sponsorship opportunities, email
pffwalk@pulmonaryfibrosis.org.