

PULMONARY FIBROSIS FOUNDATION

Breathe

BULLETIN

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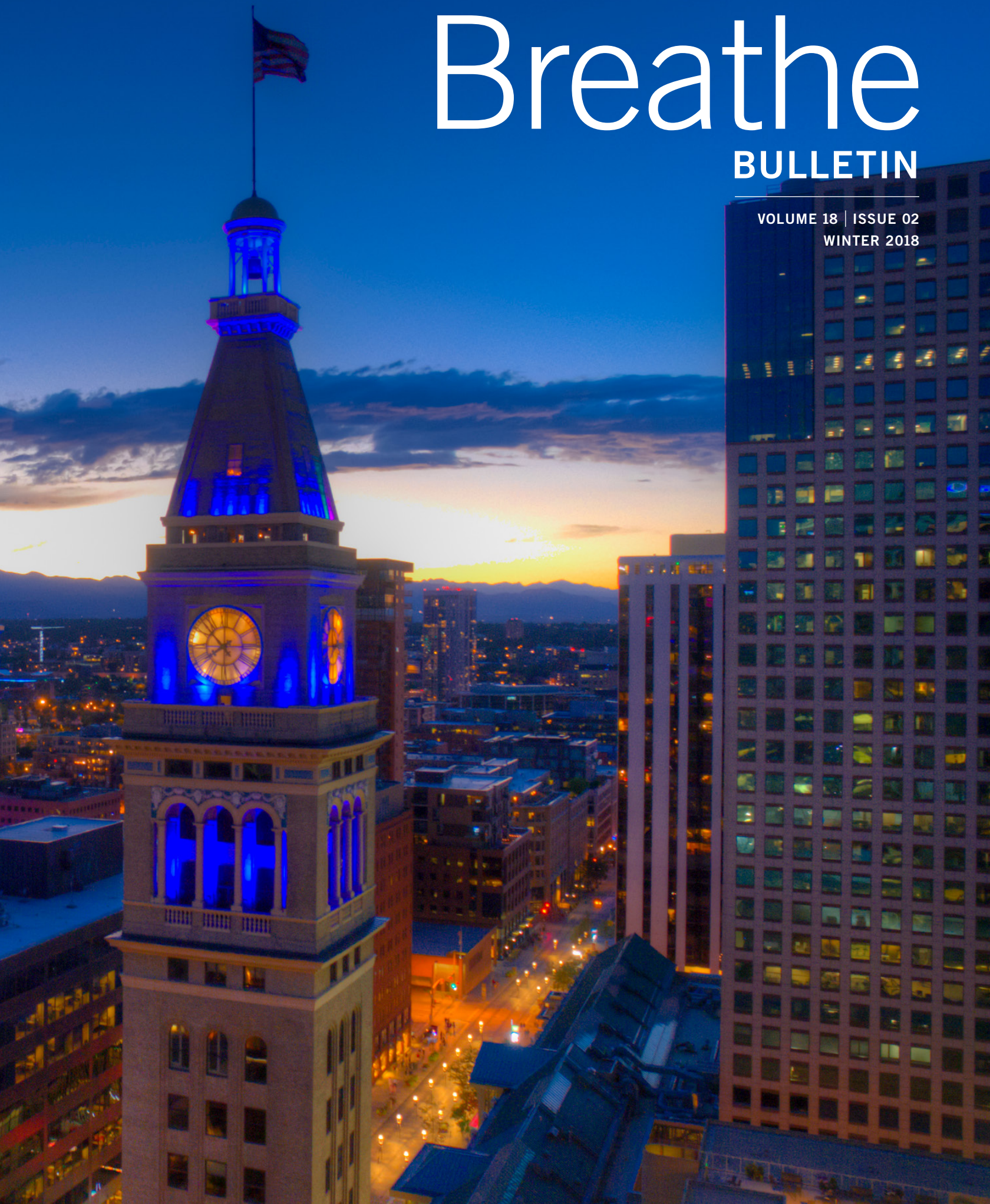


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Our Mission

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.

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

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Pulmonary Fibrosis Foundation

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

Letter from our President & CEO

DEAR FRIENDS,

I recently marked my first anniversary as president and CEO of the Pulmonary Fibrosis Foundation (PFF). It's been an invigorating and inspiring year. I've enjoyed meeting and building deeper relationships with patients, caregivers, physicians, and other health professionals, volunteers, and staff. The pulmonary fibrosis (PF) community is truly passionate about improving the lives of people living with this challenging disease, and I am quite optimistic about the progress we can make together.

As I begin my second year at the PFF, I'm so pleased that we are celebrating many milestones the Foundation has reached in our programs and initiatives. We recently enrolled the 2,000th participant in the PFF Patient Registry, completing our foundational first phase of enrollment. The data collected by the Registry is already being used in a variety of research and will significantly improve our ability to understand and treat PF (page 10).

We achieved another milestone at the second annual PFF Walk (page 16). Enthusiasm for the Walk was high—more than 2,100 people living with PF, caregivers, friends, and families were in attendance, and the walk raised more than \$635,000, far above the original goal. Our warmest thanks to all who participated.

This March, we welcomed Pauline Bianchi, RN, BSN, as Vice President for Research and Development. Her responsibilities include leading the PFF Care Center Network and PFF Therapeutics Network, both key elements of our strategic goal to bring high-quality care to patients and accelerate the development of clinical trials. Pauline, a veteran nurse and pharmaceutical industry expert, has hit the ground running: she's already visited more than 30 CCN sites and is strengthening the connections that

will significantly improve education, treatment, and research.

Access to supplemental oxygen continues to be an issue for PF patients. The PFF's new Oxygen Information Line at 844.825.5733 will provide valuable information and resources to supplemental oxygen users and their caregivers. As part of our increased emphasis on government relations and advocacy, the PFF is one of 20 organizations that recently urged the Centers for Medicare and Medicaid Services to enhance access to liquid oxygen and address a range of other issues relating to supplemental oxygen. (page 6).

Your support—whether it's professional, personal, or financial—powers the momentum the Foundation is experiencing. As 2018 winds down, please consider making a gift to the PFF to support our important initiatives. Thank you for all the ways you join us on the path to a cure for PF—we're honored to share the journey with you.

Sincerely,



William T. Schmidt

PRESIDENT AND CHIEF EXECUTIVE OFFICER



The pulmonary fibrosis community is truly passionate about improving the lives of people living with this challenging disease.

PFF Ambassadors Hit the Road & Airwaves During Pulmonary Fibrosis Awareness Month



A dynamic group of 16 PFF Ambassadors from across the country embarked on their official duties during Pulmonary Fibrosis Awareness Month in September. From securing proclamations to sharing their stories on local news stations and at patient symposiums, PFF Ambassadors actively identified and participated in opportunities to engage a wide range of audiences about PF.

“Our Ambassadors are very eager to get involved with all aspects of the Foundation,” said Laura Devitt, Manager of Volunteer Programs for the PFF. “They are ready and willing to help educate and support the PF community.”

By speaking about their individual experiences with pulmonary fibrosis, PFF Ambassadors promote disease awareness, and provide up-to-date information, hope, and inspiration to patients, caregivers, healthcare professionals, and others in the PF community.

MEET A FEW OF OUR AMBASSADORS

Paul Hilliard of Richland, Washington shared the story of his family's battle with PF on KNDU-TV in early September. Hilliard's father and two uncles succumbed to idiopathic pulmonary fibrosis

(IPF). Hilliard, who was diagnosed with IPF at age 45, recounted his shock at the diagnosis and his subsequent life-saving double lung transplant at the Interstitial Lung Disease Clinic at University of Washington Medical Center, a PFF Care Center Network site. Hilliard has started a new support group in his community to help others living with PF.

In Birmingham, Alabama, PFF Ambassador Glenda Trail Rouland described her journey with PF on ABC 33/40's *Talk of Alabama*. She appeared with Dr. Tracy Luckhardt of University of Alabama's Interstitial Lung Disease Clinic, a PFF Care Center Network site. Luckhardt explained the difficulty with diagnosing and limitations of treating the disease.

Jim and Karen Carns of Harrisburg, Pennsylvania became PFF Ambassadors to help educate people about the disease, especially with finding a “new normal” after lung transplant. Jim, who visited a support group in New York City during PF Awareness Month, wants patients to understand the importance of advocating for themselves every step of the way. Karen is focused on helping caregivers and even started a support group for loved ones of people affected by PF. She joined fellow Ambassador Debbie Herndon for a caregiver-focused meeting at the Oahu IPF Support Group in Hawaii!

Former firefighter Frank Pross of New Jersey was diagnosed with IPF after his doctor heard crackles in his lungs. Pross received a bilateral lung transplant but lost one of the lungs after getting an infection in the hospital. He and his wife, Debbie, are anxious to give back to others who are facing similar challenges to the ones they once faced.

Ambassador Steve Edwards of suburban Atlanta suggests learning as much as possible about the medications, treatments and

By speaking about their individual experiences with pulmonary fibrosis, PFF Ambassadors promote disease awareness, and provide up-to-date information, hope, and inspiration to patients, caregivers, healthcare professionals, and others in the PF community.

We are extremely grateful for the commitment of our entire group of PFF Ambassadors who will spend the next few years representing the PFF in their communities and beyond.

therapies for PF. He has a strong interest in research.

“By participating in studies, you can help the research community come up with new drugs or treatments,” said Edwards. “Knowing that I have helped makes me feel better about myself.”

Mary Pollock of Rochester, New York lost her husband Greg Thomas to PF after more than 40 years of marriage. Thomas started the ‘Breathe Easy Rochester’ support group in 2014 and Pollock promised to help make it successful. Her commitment to helping people live with PF has led her to take on the roles of support group leader and advocate for PF research.

As a former policeman and a 9/11 first responder, Ambassador Tom Frey was exposed to dust, ash, and debris around the World Trade Center. During chemotherapy treatment for Hodgkin’s lymphoma in 2016, Frey developed shortness of breath. He was diagnosed with PF and looked on the Internet for information. Frey says he “almost hit the floor” based on what he learned from a typical Google search. Fortunately, he found the PFF website, and subsequently, a support group. “The PFF network is great,” said Frey. “Awareness of the disease is getting better than it was when I was diagnosed two years ago.” Frey encourages people to support the PFF through its fundraising initiatives.

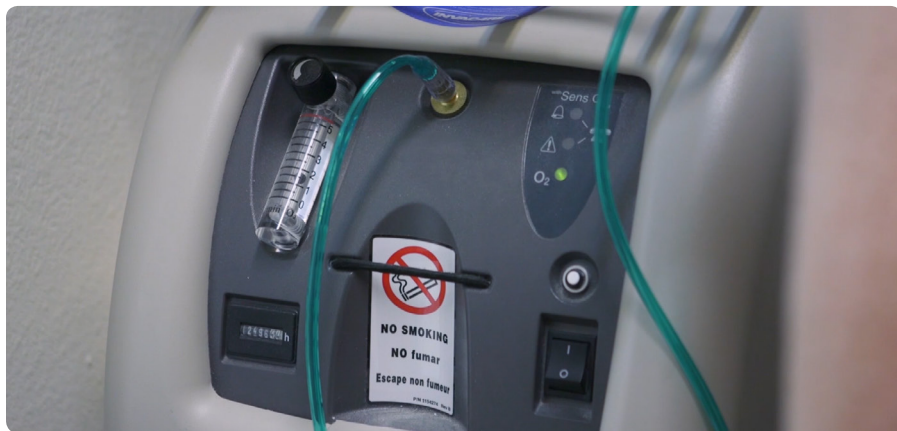
“We are extremely grateful for the commitment of our entire group of PFF Ambassadors who will spend the next few years representing the PFF in their communities and beyond,” said Devitt. “They will work to empower patients and remind them of the resources and support available through the PFF.”

LEFT:
PFF Ambassadors gathered for a group photo.

RIGHT, TOP TO BOTTOM:
Paul Hilliard (left) with a therapy dog at the University of Washington Medical Center prior to transplant.
Tom Frey (right), a 9/11 first responder and former policeman.
A training event was held for PFF Ambassadors in April.
Glenda Trail Roulund (right) joins Dr. Tracy Luckhardt (center) with host Nicole Allshouse on *Talk of Alabama*.



PFF Steps Up Oxygen Education & Access Efforts



Oxygen can help PF patients maintain an active lifestyle while preventing breathlessness and reducing stress on other organs—but many patients have difficulty accessing and using this vital resource. With a new Oxygen Information Line and heightened advocacy work, the Foundation recently expanded its efforts to help the PF community obtain and safely use supplemental oxygen.

OXYGEN HELP IS A PHONE CALL AWAY

In a study published in the October 2017 issue of the *Annals of the American Thoracic Society*—the first large survey of oxygen users—respondents cited frequent and varied problems, particularly a lack of access to effective instruction and adequate portable systems.

“The study found that patients who are educated about oxygen have better outcomes, so the Foundation wanted to make sure those struggling with supplemental oxygen have the education, answers, and resources they need,” says Kate Gates, Director of Programs for the PFF. The new PFF Oxygen Information Line, 844.825.5733, will provide information and resources to individuals using supplemental oxygen and to caregivers. Staffed by trained representatives, the Oxygen Information Line is available 9 a.m. to 5 p.m. CST Monday through Friday.

On its website, pulmonaryfibrosis.org, the PFF also offers a downloadable *Quick Start Guide for Supplemental Oxygen* and a *Traveling with Supplemental Oxygen Guide*. Print versions of the guides are available free of charge from the Patient Communication Center.

THE PATIENT COMMUNICATION CENTER

The PFF Patient Communication Center (PCC) serves the PF community by providing up-to-date information and resources. We offer webinars on a variety of topics through our Disease Education Webinar Series and Advocacy in Action Webinar Series. Register at pulmonaryfibrosis.org for a live broadcast or to watch an archived webinar from anywhere. Past webinars are available on the PFF website and on the Pulmonary Fibrosis Foundation's YouTube channel.

Our newest resource, the About PFF Brochure, gives readers an overview of all the programs and services the Foundation offers to help those affected by PF. The PFF now has an array of materials translated into Spanish including the Pulmonary Fibrosis Information Guide, the Physician Notepad, and brochures about supplemental oxygen and traveling with oxygen. The Quick Start Guide for Supplemental Oxygen is available in Simplified Chinese and Russian.

Contact the PFF at **844.TalkPFF** (844.825.5733) or pcc@pulmonaryfibrosis.org to receive free educational materials today!

PFF.
patient
communication
center

Pulmonary Fibrosis
FOUNDATION

For too long, patients who require a high-liter flow of oxygen have not been able to leave their homes, jeopardizing their physical and mental health and quality of life.

In addition, a new video about supplemental oxygen is available on the PFF's *Oxygen Therapy* webpage, and on the official YouTube Channel.

Before entering into a contract with an oxygen company, patients should check with their healthcare providers to make sure the equipment offered by the supplier is right for them.

PFF URGES CMS TO PROTECT PATIENTS WHO USE SUPPLEMENTAL OXYGEN

Leading organizations, including the PFF, are urging the Centers for Medicare and Medicaid Services (CMS) to use its statutory authority to improve the lives and treatment for Americans who require supplemental oxygen. In early November, the group of patient and physician organizations reacted to a final rule from CMS issued on durable medical equipment (DME) and its application to supplemental oxygen:

“While our organizations appreciate that members of Congress and the Centers for Medicare and Medicaid Services (CMS) recognize the numerous problems associated with patient access

to oxygen in general and liquid oxygen systems, we believe that CMS's decision today will not ultimately solve the problems facing patients who require supplemental oxygen.”

“For too long, patients who require a high-liter flow of oxygen have not been able to leave their homes, jeopardizing their physical and mental health and quality of life. Other patients have also encountered countless other problems, including delivery issues and insufficient amounts of portable oxygen for them to continue working or simply running routine errands. Everyone deserves the opportunity to live a full and healthy life.”

Starting January 1, 2019, CMS is also suspending the DME Competitive Bidding Program for an expected period of two years. Most patients will be able to remain with their current suppliers. CMS recommends that patients ask any prospective suppliers if they accept assignment as the patient may be responsible for paying a higher coinsurance if the supplier does not accept assignment. For more information about the Competitive Bidding Program gap period, contact the PFF Oxygen Help Line at 844-825-5733.

You are invited! PFF Voices

PFF Voices is the Pulmonary Fibrosis Foundation's telephone-based support group for people living with pulmonary fibrosis, caregivers, family members, and anyone else affected by this disease. Each monthly meeting provides a chance to discuss different topics related to PF, share personal stories, ask questions and provide support to one another from the comfort of your own home.

**Meetings are held on 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

Call-in information for PFF Voices

Phone Number: 1-571-317-3116
Access Code: 124-558-453

For more information, visit
pulmonaryfibrosis.org
or call 844.TalkPFF.

Thank you to our sponsors:



Care Center Network Highlights

As the PFF Care Center Network (CCN) expands, about 80 percent of U.S. pulmonary fibrosis patients are within a two-hour drive of a CCN site—growing ever closer to the PFF’s goal of 90 percent.

Since she joined the Foundation in March, Pauline Bianchi, PFF Vice President for Research and Development, has been criss-crossing the country to visit CCN sites and forge even stronger connections between the PFF and the health professionals serving the PF community day to day.

“I’ve been to more than 30 of the 60 sites, meeting the staff, attending multidisciplinary meetings, touring hospitals and research labs, and visiting pulmonary rehab centers,” Bianchi says. “It’s been a great way to let the sites know about all the resources the PFF has for them, and bring back practical ideas we can use in our educational materials and resources.”

Here are brief snapshots of just three CCN sites that are taking a creative approach to patient care, education, and research. The Foundation will highlight more CCN sites in future publications.

UNIVERSITY OF ALABAMA AT BIRMINGHAM

Team-based approach offers consistent & coordinated patient care



One of the top interstitial lung disease programs in the nation, the University of Alabama at Birmingham has replaced the traditional model of one provider per patient in favor of a team-based approach.

“A few years ago, we changed our model as a way to increase access and make practice more uniform,” says Joao de Andrade, MD, founder and director of the UAB Interstitial Lung Disease Program. Now, his team offers half-day clinics at which a team of health professionals sees multiple patients.

Before each clinic, the team—physicians, patient care coordinators, nurse practitioners, research coordinators, fellows, and residents—meets to discuss each patient’s plan of care. “Everyone on the team hears the same things at the same time, ensuring better patient care and research,” de Andrade says.

In the next year or so, UAB is looking to help create regional associated care centers in its referral area. “We’d like to disseminate best practices as well as compare our team-based patient care model with the traditional model to see how outcomes are affected,” de Andrade says. The data collected will not only aid UAB and associated centers, but also benefit the PFF CCN at large.

UAB’s patient education efforts include an informative website, a quarterly support group meeting, and an annual conference—a smaller version of the *PFF Summit*—during PF Awareness Month.

Interstitial lung disease research activities are extensive at UAB, with several major funded studies underway. As part of its research commitment, the program has been very successful in enrolling patients in the PFF Patient Registry as well as in a local registry and biorepository.

“What differentiates us philosophically is the idea that every patient who comes through our doors should be offered the opportunity to participate in the effort to know more about the disease,” de Andrade says. “Our patients feel vested in the fight against PF.”

“PF nurses are out there doing amazing things for their patients... The network is a great way to bring them deeper into the PFF fold to brainstorm, share best practices, and avoid reinventing across our CCN.”

PIEDMONT HEALTHCARE

Strong regional program has a “passion for patients”



Piedmont Healthcare is a Georgia-based regional health network with 11 hospitals, primarily in the Atlanta metropolitan area.

Piedmont offers high-quality clinical services, standardized diagnostics, and biopsy services, says Amy Hajari Case, MD, FCCP, Chief of the Advanced Lung Disease Program and Medical Director for Pulmonary and Critical Care Research. Piedmont uses Mayo Clinic thoracic pathology consultative services to augment its internal multidisciplinary conference, and Piedmont lung transplant patients are also referred to other centers.

Under Hajari Case's leadership, the program has improved patient education, adding a support group for the patients who live in the western suburbs of Atlanta to complement an existing Atlanta group. Once a year, Piedmont hosts the daylong Pulmonary Fibrosis Educational Symposium for patients, caregivers, and health care providers. The educational event covers different aspects of living with and treating PF.

When Hajari Case joined Piedmont, COPD and similar disorders were the focus of the organization's well-developed clinical trial program. “We changed the focus to advanced lung disease, particularly for a patient audience with limited FDA-approved therapies,” she says.

Piedmont has also recruited heavily for the PFF Registry. “Our patient population wants to help researchers learn more about the disease process, and most of them are willing and excited to be able to contribute, even though they know they may not personally benefit,” she says.

“I'm very proud of our program,” Hajari Case adds. “Our people have a passion for patients and providing great care for them.”

CONE HEALTH MEDICAL GROUP/ LEBAUER HEALTHCARE

Expanding services for greater patient satisfaction



Ten years ago, Murali Ramaswamy, MD, FCCP, came to LeBauer Health Care at Cone Health in Greensboro, North Carolina, a specialty medical practice. He immediately determined Cone's pulmonary fibrosis patients were underserved. For almost all pulmonary services, they were referred to Duke University Medical Center, a CCN site in Durham, North Carolina, nearly 55 miles away.

“We're the only pulmonary practice for the community and the region, and I knew we could do more,” says Ramaswamy, who directs the PF program at LeBauer Healthcare at Cone Health. He and his team improved diagnoses by involving Cone's forensic radiologists, as well as founding the first PF support group in North Carolina. Through the program's research arm, Pulmonix Research LLC, Ramaswamy, and colleagues began conducting a variety of industry-sponsored clinical trials, including participating in the ASCEND trial of pirfenidone.

“With improved patient support, diagnosis, and research, we've been able to make a difference in the community,” Ramaswamy says. “Second opinions, complex cases, and transplants still go to Duke with fully integrated patient records, but there's much more we can do at Cone now. That's improved our patient satisfaction because they have to travel less.”

Becoming a CCN site has garnered fuller resources for the program, Ramaswamy says. “For the first time, we've been able to get a Cone geneticist involved, which is significant because up to 20 percent of our patients have a family history of PF. Becoming a CCN site is resulting in more comprehensive care for our patients.”

PFF Patient Registry Meets First Enrollment Goal

The PFF Patient Registry has completed its first phase, meeting its initial goal of 2,000 participants.

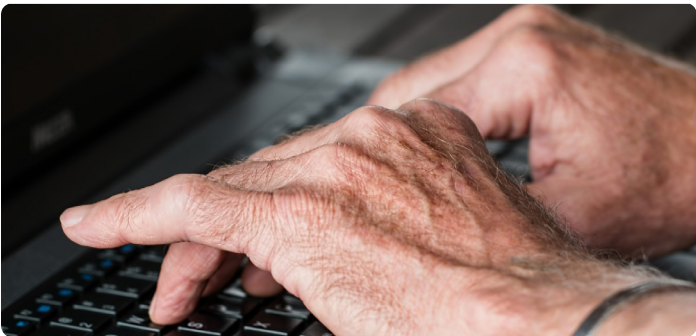
As one of the most important PF research initiatives to date, the Registry allows PF patients to voluntarily share their medical data and HRCT images (without information that could identify the participant). The result is a continually expanding set of data that can be used in a variety of research studies. Registry participants may also choose to provide blood samples for a research-supporting biorepository.

“Completing the first phase of enrollment is a significant milestone for the PFF Patient Registry,” says Rex Edwards, PFF Vice President for the Registry. “The Patient Registry will be instrumental in improving the health and quality of life for people living with PF. To make those strides in research and clinical best practices, data from a diverse group of of PF patients from all across the United States of America is required. We’re very pleased with our progress and momentum, and look forward to our next chapter.”

The PFF is currently evaluating funding to resume enrollment for the Registry’s second phase, Edwards says.

PFF REGISTRY STATS*
TOTAL ENROLLMENT: 2,003
*At time of publication

CLINICAL TRIAL FINDER EASES PATIENTS’ PARTICIPATION IN RESEARCH STUDIES



Clinical trials are a critical step to determining if an experimental treatment is safe and effective for treating a specific medical condition. The PFF Clinical Trial Finder, which debuted earlier this year, raises awareness of and increases participation in clinical trials, accelerating the development of new treatment options for patients with pulmonary fibrosis.

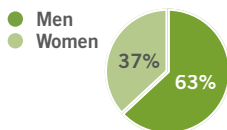
Unlike the government website ClinicalTrials.gov, which is challenging for searchers to use, the PFF Clinical Trial Finder makes it easy for patients to find appropriate information. Searchers can filter information from ClinicalTrials.gov by zip code, how far they’re willing to travel, age, gender, disease status, and type of trial. There’s even a keyword option to further narrow results.

A feature soon to be piloted allows users to sign up for notifications when trials that meet their particular interests are added to the Clinical Trial Finder.

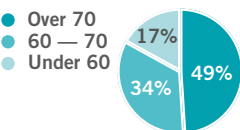
Visit trials.pulmonaryfibrosis.org to search for a clinical trial that’s right for you. For more information, call the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or email pcc@pulmonaryfibrosis.org.

Who’s in the Registry? 2,003 total participants

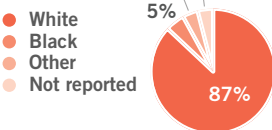
Gender



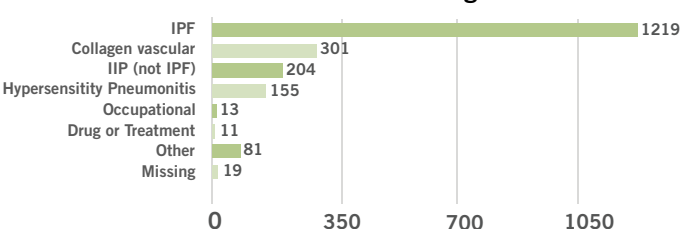
Age



Race



ILD Diagnosis



ILD Nurse and Allied Health Network Shares Resources, Best Practices

Nurses are key to the successful treatment and support of PF patients and their caregivers. As the PFF's Care Center Network expands and strengthens, a Foundation working group, the *ILD Nurse and Allied Health Network*, is bringing together nurses and allied health professionals from across the CCN to pool their extensive expertise.

"Nurses really take on the majority of PF patient education and support," says Pauline Bianchi, PFF Vice President for Research and Development, who regularly meets with nurses on her visits to CCN sites. "They're the ones doing the interfacing with patients, so they have a lot of creative ideas for resources the PFF can develop and distribute."

Led by Wendi Mason, RN, MSN, ACNP, Program Director of Vanderbilt University's Idiopathic Pulmonary Fibrosis Program and a PFF Board of Directors member, the *Nurses and Allied Health Professionals Network* includes a core group of nurses and allied health professionals who are well known and respected in the PF community. While the group is still newly launched, it's already taking active measures to broaden access to valuable information—such as using a central Dropbox to share high-quality patient education materials and other tools.

"PF nurses are out there doing amazing things for their patients," says Bianchi. "The network is a great way to bring them deeper into the PFF fold to brainstorm, share best practices, and avoid reinventing resources across our Care Center Network."



MEET ALANNA KAVANAUGH: A NURSE PRACTITIONER LEADING THE WAY IN PATIENT CARE



"Nurses have a really special role in medicine—and we're still sculpting it," says Alanna Kavanaugh, MSN, APRN, FNP-BC, CCRN. "We have unique insights into our patients and we should use that."

As the first nurse practitioner in Weill Cornell Medical's outpatient pulmonary and critical care department, Kavanaugh has been helping physicians and other colleagues understand where her expertise can be used. She's already made significant improvements to patient care, including her work with oxygen therapy.

"A lot of patients have trouble obtaining and using the kind of oxygen they need," Kavanaugh says. "Although I never wanted to become an insurance specialist, I am one now." A professor of nursing at her alma mater, the College of Mount Saint Vincent, Kavanaugh worked with a student and intern to draft a comprehensive patient booklet on procuring and safely using oxygen. She's a favorite resource across departments at Weill Cornell—a member of the PFF's Care Center Network—when patients have complex oxygen needs.

Patient education is a passion of Kavanaugh's. She obtained funding to start Weill Cornell's pulmonary support group, which serves patients with PF and other lung diseases. She also created a handout that helps patients navigate potentially complicated anti-fibrotic regimes. "Pirfenidone and nintedanib can be titrated differently depending on the patient, so we created a template that can be tailored to each patient, explaining drug management, side effects, and more," she says.

"I always say that nurses are the practicality of medicine," Kavanaugh says. "We don't just get things done efficiently; we also understand the caring, humanistic side of medicine. If you want to get the patient's view of a problem, ask a nurse."

PHOTOS:

The ILD Nurse and Allied Health Network enjoys dinner after its first planning meeting; Nurses in the ILD Nurse and Allied Health Network, including: Susan Jacobs, RN, MS; Jennifer Hayes, RN, BSN; Kathleen O. Lindell, PhD, RN; Carolyn Spada, RN, BSN; Anne Turner, RN4, BSN, J.D; Wendi Mason, RN, MSN, ACNP

Eyes on a Cure: 2018 Research Awardees Seek a Deeper Understanding of PF

A key part of the PFF's mission is to fund research that will enhance PF patient care and identify potential treatments for the disease. The Research Fund to Cure Pulmonary Fibrosis was created to fund innovative grants for projects that may widen the base of knowledge about PF. The PFF is pleased to announce recipients of two PFF Research Awards: the Albert Rose Established Investigator Award and the I.M. Rosenzweig Junior Investigator Award. (See page 14 for details on how PFF research awards are changing.)

THESE AWARDS ARE MADE POSSIBLE BY PRIVATE GIFTS TO THE PFF AND THROUGH THE GENEROUS SUPPORT OF BOEHRINGER INGELHEIM PHARMACEUTICALS, INC.

ALBERT ROSE ESTABLISHED INVESTIGATOR AWARDEE

Nabeel Hamzeh, MD, University of Iowa

CD4 T-cell Immunophenotype in Hypersensitivity Pneumonitis



Hypersensitivity pneumonitis (HP) is a form of PF caused by inhalation of organic materials, such as mold spores and other particles. Depending on the type of exposure, HP can go by other names including farmer's lung, pigeon breeder's lung, and hot tub lung.

HP causes inflammation and scarring (PF) that leads to breathlessness and low oxygen levels. In some cases, HP can be as severe as idiopathic pulmonary fibrosis (IPF). Current therapies for HP are based on clinical experience, not on rigorous clinical trials. "Not fully understanding the type of inflammation seen in HP and the cells involved in this inflammatory response limits our ability to choose drugs to study in HP that can stop the inflammation and limit scar formation," Hamzeh says.

"By better understanding the type of cells involved in the inflammatory response and what drives them, we can begin to study drugs that can limit the inflammation and subsequent scarring," he says. In this preliminary study, Hamzeh's team will recruit patients with HP and, with their consent, perform a scope of the lungs (bronchoscopy) with lung washing to remove inflamed cells from the lungs and further study them in the lab.

I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARDEES

Ayodeji Adegunsoye, MD, University of Chicago

Impact of Race on Genetic Predisposition to Radiologic Honeycombing in Pulmonary Fibrosis



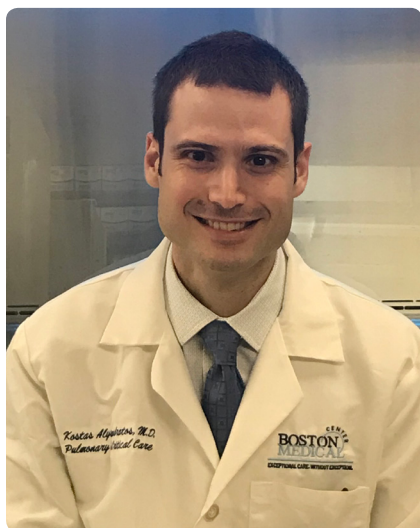
While the cause of PF is frequently unknown, recent studies conducted in non-African-Americans suggest one's genetics contribute to the risk of developing PF.

"African-Americans, the largest U.S. minority race with more than 40 million people, have worse survival rates in numerous lung diseases," Adegunsoye says. "However, the role of genetic markers and their associations with PF in African-Americans is unknown." Adegunsoye's study will use clinical and genetic data collected across diverse races to identify genetic markers associated with the most severe form of PF in African-American and non-African American patients.

"By applying this approach to precision medicine, we expect to identify new genes and gene pathways that may one day serve as targets for the treatment of PF across African American and non-African American populations," Adegunsoye says.

Konstantinos-Dionysios Alysandratos, MD, PhD, Trustees of Boston University, Boston University Medical Campus

Utilizing a Pluripotent Stem Cell Model System to Unravel the Pathogenesis of Pulmonary Fibrosis



The cells that line the inside of the air sacs (called type 2 alveolar epithelial cells) help keep the lung healthy. Changes in the function of these cells are a possible cause of PF.

Genes that increase the risk of PF seem to be activated in type 2 alveolar epithelial cells. Capturing these cells for research has been difficult. "We sought to engineer a disease model using induced pluripotent stem cells (iPSCs) from patients with PF," says Alysandratos. iPSCs are made by "reprogramming" blood or skin cells so they can become any cell type in the body – including type 2 alveolar epithelial cells.

Alysandratos's team generated iPSCs from patients with PF who carried an abnormal PF gene. By comparing cells with and without the abnormal gene, Alysandratos hopes to learn how this gene leads to PF.

Linlin Gu, PhD, University of Alabama at Birmingham

Metabolic Reprogramming and Mitochondrial Biogenesis Are Regulated by Macrophage MCU in Pulmonary Fibrosis



The lungs contain cells called "macrophages" that are an important part of the body's immune system. Abnormalities in these macrophages, including difficulty making new mitochondria (the "powerhouses" of the cell), may lead to PF.

"In this proposal, our team will use innovative strategies to determine if abnormalities in macrophages and mitochondria in the lung might lead to PF," Gu says. "The results may support the notion that metabolism and mitochondria in macrophages are potential therapeutic targets for PF."

Revamped Research Program Focuses on Rising Investigators



The PFF's commitment to supporting early stage researchers is expanding with the new PFF Scholars Program. The program is designed to support and enable promising researchers to obtain independent funding and continue their cutting-edge research. PFF Scholars will debut with the 2019 research cycle.

Awards of up to \$50,000, granted by the PFF over a two-year period, support early stage investigators—within five years of completion of their formal training — allowing them to continue performing PF research while they seek funding from the National Institutes of Health and other sources.

“With the launch of the PFF Scholars program, we are unleashing powerful new talent to study this complex and devastating disease,” said William T. Schmidt, PFF President and CEO. “We are eager for the first group of Scholars to begin their work to improve the care and quality of life for people living with pulmonary fibrosis.”

In addition to providing financial support, the program facilitates professional development, networking, and career opportunities. PFF Scholars are provided supplementary mentorship by a PFF Advisor, participate in PFF Scholars activities throughout the year and at the *PFF Summit* and Annual Volunteer Meeting, and have the opportunity to invite a PFF Visiting Professor to their home institution.

The stages of the PFF research cycle—from an open call for letters of intent through the PFF Scientific Advisory Committee's selection of final proposals—will remain the same. For more information, please email grants@pulmonaryfibrosis.org.

PFF SUMMIT PROGRAM ORGANIZING COMMITTEE PROVIDES IMPORTANT INPUT

The *PFF Summit* Program Organizing Committee is meeting monthly to help plan a diverse program and select faculty for the *PFF Summit 2019*. With members representing PFF staff, physicians, nurses, people living with pulmonary fibrosis, caregivers, and others in the PF community, the committee is an inclusive and important resource to the PFF as the Foundation designs the next *Summit*.

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Team PFF Leads the Way with Fundraising

From Michigan to Miami, and Idaho to New York, Team PFF event leaders produced everything from softball and bowling tournaments to happy hours with family and friends.

These motivated volunteers pushed Pulmonary Fibrosis Awareness Month to new heights with innovative fundraisers to support critical research and sustain vital programs that help people with PF and their families live better lives.

During PF Awareness Month in September and throughout the year, extraordinary team leaders worked tirelessly to elevate awareness and inspire hope through their efforts on behalf of the PF community.

Melissa Rivers, Scott Wholley, and their family hosted the second annual event for the PFF, *Bowl for Breath* in Andover, Massachusetts. Complete with prizes, auction items, and fun for the whole family, the event raised \$3,700.

Dr. Kori Ascher of Jackson Memorial Hospital at University of Miami, a PFF Care Center site, hosted a special happy hour. She promoted *Just Breathe, an Event for Pulmonary Fibrosis*, on the radio and welcomed medical professionals, patients, or family and friends to the event, which raised over \$8,300.

Johnny Pace of Charlestown, Indiana, broke out the bats and balls for a softball tournament with friends and family. *Playing for Pops*, an event in memory of his father, raised \$1,000 for the PFF.

Korey and Kelly Partenheimer and the Douglas R. Partenheimer Foundation hosted their ninth Annual *Cruisin' Toward a Cure for PF Car Show and 5K*. This year's event included a 5K, car and bike show, family fun with a slime-zone, face painting, trivia, and much more! The event in Holland, Indiana raised over \$12,000, bringing the nine-year total to over \$100,000.

Each year, Team PFF Event Leaders host more than 100 events in cities across the country. The goal for 2018 is to raise \$300,000, and Team PFF leaders are well on their way to reaching their goal. Funds support research, advocacy, awareness, education, and important programming for the PF community.

The PFF is most grateful to these dedicated leaders who are leading the way toward a world without pulmonary fibrosis.

You too can lead the way. Hosting your own Team PFF event has never been easier! The PFF offers extensive resources to support your fundraising efforts. Visit the PFF website, pulmonaryfibrosis.org for details or contact Jackie Williams at jwilliams@pulmonaryfibrosis.org or **312.224.4667**.



ABOVE, CLOCKWISE:

Dr. Kori Ascher speaks to attendees at *Just Breathe, An Event for Pulmonary Fibrosis* in summer 2018.

Melissa Rivers speaks at her event.

Attendees take a break at *Cruisin' Toward a Cure for PF Car Show and 5K*.

An attendee goes to bat at *Playing for Pops*.

PFF Walks in New York City, Chicago & Washington D.C. to Raise Funds

What started with a goal of raising \$70,000 for an inaugural fundraising walk in Chicago last year has blown past its initial expectations in both size and scope. The PFF Walk, which took place in New York (June 23), Chicago (September 15) and Washington D.C. (October 14) this year, attracted more than 2,100 participants and raised over \$635,000. In addition, more than 200 people participated in the PFF Walk virtually across the country and overseas, raising \$50,000 while walking for PF in their hometowns.

“This event has become a powerful fundraising initiative, as well as a tremendous awareness builder,” said Bill Schmidt, President and CEO of the Pulmonary Fibrosis Foundation. “The PFF Walk empowers our community to tell others about PF and to come together for the unifying experience of the Walk. There was a desire within our community for this type of event and we look forward to expanding it even further.”

Sponsorship of the 2018 PFF Walk grew substantially with the commitment of Genentech, a Member of the Roche Group, as a national sponsor.

“Genentech is honored to be the national sponsor of the 2018 PFF Walks,” said Dean Alford, Vice President, Respiratory. “We understand the crucial need for the pulmonary fibrosis community to share experiences together, raise awareness of this devastating disease, and help sustain programs that support patients and their families. We appreciate the opportunity to support and connect with people impacted by pulmonary fibrosis and thank PFF for the opportunity.”

NEW YORK CITY: CENTRAL PARK



Fifty-eight teams and 500 patients, caregivers, friends, families and volunteers kicked off the PFF Walk in Central Park on June 23. The event raised more than \$165,000, far exceeding the initial goal of \$130,000. Created by PFF Board of Directors

member Terence Hales in 2007 as the **NYC Run-Walk-Hike for Pulmonary Fibrosis**, the event is now an official PFF Walk site.

“The experience of the Walk was really about the support that was shown to Maureen with our family being there and reconnecting with people we met at *Summit*,” said Jack Sheedy, whose wife, Maureen has pulmonary fibrosis.

“I felt so much support and love on the day of the Walk,” Maureen Sheedy said. “With my family, friends and all who came out to be with us, I am reminded that, as scary as this journey is, I never walk it alone.”

CHICAGO: DIVERSEY HARBOR



Sunny skies and warm temperatures greeted walkers at Chicago's Diversey Harbor on September 15. For the second year, the PFF Walk - Chicago surpassed expectations, raising more than \$300,000 toward a cure for PF.

Linda Conran, whose husband was diagnosed with IPF in 2014, led one of the top fundraising teams at the PFF Walk - Chicago. “Our hope is that this awareness will help raise funds that are used for research towards better treatments and a cure,” said Conran. “Bringing people together that have the same disease, along with their families and friends helps build the community of PF in a unique way. It is so important to the patient, caregivers and families and friends.”

WASHINGTON D.C.: NATIONAL HARBOR

The PFF Walk in Washington D.C. at National Harbor, previously known as the **MollyK 5K Walk/Run**, took place on Oct. 14 and raised more than \$124,000. The walk began in 2012 by Nita Zalavadia, who lost her mother Mradula “Molly” Kalathia to IPF.

Annie Kubler was the Team Captain of Galloping for Gudda. They

“I felt so much support and love on the day of the Walk... With my family, friends and all who came out to be with us, I am reminded that, as scary as this journey is, I never walk it alone.”



raised over \$6,000, doubling their original goal. “Since losing my dad to pulmonary fibrosis over five years ago, I have been wanting to get involved with the PFF, and this walk was a way for me to do this,” said Kubler. “The PFF Walk brought my entire family together to honor and remember my father, Greg Bigham, while simultaneously raising funds to help support an amazing

foundation that is doing so much to help others affected by pulmonary fibrosis. We’re grateful to the PFF for this opportunity and all the Foundation is doing to raise awareness, provide support, and fund research for this terrible disease.”

VIRTUAL WALK

Many members of the PF community joined the PFF Walk virtually from their hometowns.

Virtual walk participant Rebecca Lucente from the Boston area said her family has been dramatically affected by PF. Lucente has lost several family members to the disease, most recently her mother, who succumbed to PF in March of 2017.

“We have wanted to get involved with the PF community for some time now and when I heard about the ability to be a part of the virtual walk for PF, it sounded like the perfect opportunity,” said Lucente. “It would have been difficult for us to travel to Chicago to be at the walk, but being a part of this event virtually allowed us to still be involved in such an important cause,” It felt good to do something, not only in mom’s memory, but in honor of those still battling this disease. We could not be more proud to be a part of such a special community of people.”

COMMUNITY WALKS

Dozens of PFF Community Walks popped up across the country this year, thanks to an active group of fundraisers committed to supporting the PFF’s efforts. A community walk provides an opportunity for those who are not near a physical walk-site to launch an event in their hometown. Community walks help us expand our footprint across the country and take on many shapes and sizes.

The PFF has all of the tools and resources that you’ll need to create a successful walk! If you’d like to launch a PFF Community Walk, please contact Emily Smith at esmith@pulmonaryfibrosis.org or **312.273.4991** to receive a copy of the planning guide.

Sponsorship opportunities for the PFF Walk 2019 are available now and registration will open in early spring. Stay tuned for updates by subscribing to our e-newsletter at pulmonaryfibrosis.org or following us on social media at [@pfforg](https://twitter.com/pfforg).

COMING IN 2019: PFF WALK – DALLAS!



The PFF is pleased to announce the expansion of the PFF Walk with a new location in Dallas, Texas on October 26, 2019.

The new PFF Walk - Dallas will build upon the momentum created by PFF Ambassador Heather Kagel, whose Ready. Set. Breathe. walk raised over \$65,000 in its first year.

Diagnosed with idiopathic pulmonary fibrosis in 2013, Kagel is dedicated to helping raise awareness of PF as a PFF Ambassador.

As a runner, Kagel wanted to create something that allowed individuals with PF to stay active. Although each breath is a struggle, Kagel says “the best thing we can do for ourselves is keep our lungs and bodies strong.”

The PFF looks forward to partnering with Kagel at the PFF Walk - Dallas 2019!

PHOTOS:

New York City: Attendees in Central Park take a selfie during the PFF Walk.

Chicago: Melissa King, PFF Ambassador, speaks to attendees at the PFF Walk – Chicago.

Washington, D.C.: Nita Zalavadia began the MollyK 5k Walk/Run in 2012 after her mother passed away from IPF. Today, Zalavadia’s walk is an official PFF Walk held at National Harbor in Washington D.C.

Coming Soon to the Edison Ballroom: Broadway Belts for *PFF!* 2019

Mark your calendars: *Broadway Belts for PFF!* makes its triumphant return to the Edison Ballroom in New York City on Monday, February 25th for an exclusive evening of glitz, glamour and unforgettable star performances. Created and hosted by Broadway star and comedienne Julie Halston, *Broadway Belts for PFF!* features extraordinary entertainment, premium cocktails, and lavish cuisine, making it a once-in-a-lifetime, genuine New York experience.

Now in its ninth year, Halston helped create this uniquely special evening in honor of Michael Kuchwara, former theater critic for the Associated Press who succumbed to PF in 2010. Halston's husband, Ralph Howard, was also diagnosed with the disease shortly after the inception of *Broadway Belts for PFF!* and sadly passed away in August 2018.

With help from Halston and her star-studded network of Broadway greats, *Broadway Belts for PFF!* has become a wildly successful annual benefit for the PFF. In recent events, award-winning talent including Marissa Jaret Winokur (*HAIRSPRAY*), Daveed Diggs (*HAMILTON*) and Stephanie Mills (*The WIZ*) belted out their favorite tunes for a sold-out show.

The ninth annual *Broadway Belts for PFF!* is certain to be nothing short of spectacular.

Tickets to *Broadway Belts for PFF!* sell-out quickly and can be purchased at BroadwayBeltsforPFF.org.

Sponsorship opportunities are available now and feature a range of benefits including event tickets, premium branding benefits, and more. For more information on sponsorships and to receive a copy of the package, please contact Amy Kozyra-Wardzala at awardzala@pulmonaryfibrosis.org or [312.878.2351](tel:312.878.2351).



Spotlight on Philanthropy



During this season of giving, the Pulmonary Fibrosis Foundation gratefully recognizes the tremendous contributions from individuals throughout the community. By offering time, talent and treasure, supporters of the PFF provide the crucial resources needed for the Foundation to deliver on its mission of raising awareness, providing disease education, and funding research.

Gary Cunningham, a PFF Ambassador, has both received and provided support during his journey with PF. In our year-end campaign, Gary shares how pulmonary fibrosis has played a part in his life and why he supports the Pulmonary Fibrosis Foundation.

"I serve as a PFF Ambassador and one of my life passions is to raise awareness so others have the tools they need to advocate for themselves and live their lives to the fullest," said Gary. "When I was first diagnosed, I was terrified, but then I went to a support group and met many wonderful people. We need to understand that there's always hope."

To learn more about Gary and to make your year-end donation, please visit bit.ly/fallpff2018. Thanks to the generosity of donors nationwide, the PFF is able to drive research of the disease and provide important programs to improve the quality of life for people living with PF today.



THE ALBERT ROSE SOCIETY PLANNED GIVING

In 2000, Albert Rose and his family were touched by pulmonary fibrosis. Mr. Rose didn't want the disease to continue to impact other families, so he pledged \$1 million to form the Pulmonary Fibrosis Foundation. We are proud to honor Mr. Rose and his legacy by introducing the *Albert Rose Society*.

Planned giving is one of the most meaningful ways you can make a life-giving impact. Like Mr. Rose, you can leave a lasting benefit and help the PFF one day achieve its mission, a world without pulmonary fibrosis.

Over the next few months, please be on the lookout for more information regarding the Albert Rose Society. If you have any questions or would like to join the society by making a bequest, please contact Seth Klein at sklein@pulmonaryfibrosis.org or **312.224.2670**.

Pulmonary Fibrosis Awareness Month Reaches Record Audience

We are incredibly overwhelmed by the time, hard work, and passion that you put into making this September a Pulmonary Fibrosis Awareness Month to remember.

Through your time and effort, you reached more than *1.2 million* people in spreading the word about pulmonary fibrosis. You really outdid yourselves this September! We genuinely can't thank you enough for the impact you've made on this community. We are honored to have you join us in the fight for raising awareness of pulmonary fibrosis. Thank you again and again.

PROCLAMATIONS: A record 36 city and state Pulmonary Fibrosis Awareness Month proclamations, and a United States Senate resolution, were declared thanks to PF advocates throughout the United States and Canada. New this year are proclamations from Alaska, Arkansas, Hawaii, Kentucky, Michigan, Minnesota, Nebraska, New Mexico, New York, Nevada, Ohio, Tennessee, Wyoming, and Wisconsin.

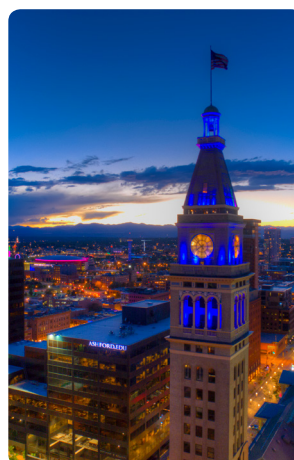
BLUE LIGHTING CAMPAIGN: Each day in September from coast-to-coast, a building or landmark shined blue for PF Awareness Month. This year, 34 landmarks participated in the campaign, ranging from skyscrapers, clock towers, fountains, Ferris wheels, and more.

SOCIAL MEDIA: Our daily *30 Facts In 30 Days* campaign on social media allowed followers to quickly and easily share facts about PF to friends and family. Facts ranged from symptoms, to treatment options, to information about the PFF's programs. The daily *Portraits of PF* series shared real stories from people who have been touched by pulmonary fibrosis. Thanks to your likes, shares, comments, re-tweets, and more, the PFF's social media channels helped us reach new and existing audiences.

#BLUEUP4PF: People everywhere who have been affected by PF joined the cause by wearing as much blue as possible, taking a photo, and telling the world why they are raising awareness with the hashtag, #BlueUp4PF. From wearing blue t-shirts, to dyeing hair, to sharing blue treats at support groups, the PF community rallied together to "go blue."

MEDIA: Pulmonary fibrosis advocates throughout the United States reached out to local media to tell communities about the impact of PF. With the help of people just like you, in September more than 16 news outlets covered stories about pulmonary fibrosis.

You can still engage with us all year. We are happy to share stories and photos of the different journeys people in the PF community experience. To learn how you can stay involved all year long, reach out to us at socialmedia@pulmonaryfibrosis.org.



ABOVE LEFT, TOP TO BOTTOM:

Navy Pier's Centennial Wheel in Chicago shined blue on September 15, the same evening as the second annual PFF Walk – Chicago.

Employees at Spad's Twister's Soft-Serve Ice Cream in Lansing, Michigan wore blue #BlueUp4PF t-shirts all month long.

The Daniels & Fishers Clock Tower in Denver, Colorado participated in the blue lighting campaign.

Support group leader Mal Doyle received a proclamation from Shari Cantor, Mayor of West Hartford, Connecticut.

ABOVE RIGHT, TOP TO BOTTOM:

Ray from Toronto, Canada, dyed her hair blue in memory of her father.

Tanya, who is living with IPF, dyed her hair and painted her nails blue and green.

Hershey's IPF Support Group gathered outside of Penn State Hershey Medical Center in Pennsylvania, which went blue as a part of the lighting campaign.

Sean and Nicolle received a state proclamation from Governor David Ige of Hawaii.

Save the Date: PFF Summit 2019 is heading to San Antonio

PFFSUMMIT2019



Join us in San Antonio, Texas from November 7-9, 2019 at the *PFF Summit 2019*! We look forward to bringing the PF community together for our fifth biennial conference at the JW Marriott San Antonio Hill Country Resort—surrounded by rolling, oak-covered hills and stunning views. Registration will open in spring.

PFF Summit is the largest international conference on pulmonary fibrosis designed to bring the entire PF community together. The *Summit* will feature an innovative continuing medical education (CME) program for health care professionals and a continuing education (CE) program for nurses, respiratory therapists, and pharmacists.

People living with pulmonary fibrosis, caregivers, transplant recipients, and those who have lost a loved one are encouraged to attend the *Summit*. Sessions are tailored for everyone in the PF community.

The *Summit* provides an opportunity to network with others who have shared experiences. Numerous roundtable discussions, networking breaks, and the Networking Dinner allow attendees to mingle and make meaningful connections. In addition, the Poster Presentation held during the welcome reception allows all attendees to interact with leading researchers in the PF field. In 2017 a total of 76 posters were presented.

In 2017, sessions such as “*Understanding ILD and IPF*,” “*Oxygen Therapy, Pulmonary Rehabilitation, and Symptom Management*,” and “*What’s in the Pipeline: Current Clinical Trials, Potential Therapies, and How the Process Works*” were designed to address questions and growing educational needs among people living with PF and their caregivers.

Several “*Call To Action*” sessions for transplant recipients and

those who have lost a loved one brought people together in 2017 to learn how to take action. Session topics included transitioning after a transplant or after the loss of a loved one, planning for the future, contacting legislators, how to host a fundraiser, and more. All sessions are available to watch in full on the PFF’s YouTube channel.

WATCH FULL PFF SUMMIT SESSIONS ON YOUTUBE

Want a glimpse of what the *PFF Summit* has to offer? You can view more than 70 full-length *Summit* sessions on the PFF’s YouTube channel. Visit youtube.com/c/pulmonaryfibrosisfoundation to watch today. Don’t forget to subscribe so that you can be the first to know when new videos are available.

VISIT OUR BRAND NEW PFF SUMMIT WEBSITE

Our *Summit* website is bigger and better than ever before. Check out the brand new look at pffsummit.org to learn about the *Summit*, view the full 2017 program, watch archived videos, and read testimonials.

SPONSORSHIP OPPORTUNITIES ARE AVAILABLE

To learn more about becoming a *PFF Summit 2019* sponsor please contact Jennifer Mefford at jmefford@pulmonaryfibrosis.org or **312.546.4105**.



Meet the PFF Summit 2019 Co-Chairs



Dr. Anoop Nambiar

Dr. Anoop M. Nambiar is an Associate Professor of Medicine and founding director of the Center for Interstitial Lung Disease at the University of Texas Health San Antonio. Born and raised in New Jersey, he attended college at Rutgers University, medical school at the University of Medicine & Dentistry of New Jersey, internal medicine residency and completed pulmonary/critical care fellowship at the University of Michigan in 2009. Following a locum tenens year in New Zealand, he joined the faculty at UT Health San Antonio in 2010. Over the past 8 years, Dr. Nambiar's clinical and research efforts include: the first dedicated ILD/IPF clinic at UT Health San Antonio in 2011; development of a fortnightly multidisciplinary ILD/IPF conference in 2014; active past and present research program with involvement in a number of important multicenter investigator-initiated and industry-sponsored clinical trials; and community outreach as medical director of the SA PF Support Group with a semi-annual "Free ILD Clinic," the only one of its kind. These initiatives served as the foundation for the center's selection as a PFF Care Center Network Site in 2015.



Dot Delarosa

It took three years for Dot Delarosa of San Antonio, Texas, to learn that the breathlessness, dry cough, and tightness in her

chest weren't something she could shake off. At 41, she learned she had idiopathic pulmonary fibrosis, a progressive and deadly lung disease with no known cause and no known cure. Eighteen months after diagnosis, Dot received a life-saving transplant. This experience compelled her to establish a pulmonary fibrosis support group and the only free interstitial lung disease clinic in the world. Dot is now a volunteer PFF Ambassador who encourages other patients to consider transplantation and take advantage of available treatments.



Dr. Joseph Lasky

Dr. Joseph Lasky is currently the Director of the Interstitial Lung Disease Program and Section Chief of Pulmonary/Critical Care at Tulane University in New Orleans, Louisiana. He also serves as the Chair of the Scientific Advisory Committee for the PFF. Understanding the pathogenesis of pulmonary fibrosis has been the focus of his research career, which began at the National Institute of Environmental Health Sciences (NIEHS) investigating the pathobiology of asbestosis 28 years ago. His past research involved the study of growth factors, such as PDGF and CTGF, in promoting pulmonary fibrosis. His recent efforts have been directed toward understanding the role of RNA splicing, and also the effects of protein acetylation, in modulating lung fibrogenesis. Dr. Lasky's research has bridged from mechanistic studies in cell culture and animal models to the design and implementation of human trials. He has been involved in clinical trials as site-investigator, steering committee member, data safety monitoring board member and Chair, and co-principal investigator on an investigator-initiated trial.

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Pulmonary Fibrosis

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230 EAST OHIO STREET SUITE 500 CHICAGO, ILLINOIS 60611

