

PULMONARY FIBROSIS FOUNDATION

# Breathe

**BULLETIN**

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BREATHE BULLETIN VOLUME 16 | ISSUE 01 SPRING 2016



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#### Disclaimer

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

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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**Pulmonary Fibrosis Foundation**  
230 East Ohio Street, Suite 304  
Chicago, Illinois 60611-3201  
844.TalkPFF (844.825.5733)  
or +1 312.587.9272  
pulmonaryfibrosis.org

# LETTER FROM OUR PRESIDENT AND CEO



## DEAR FRIENDS,

### **We continue to celebrate wonderful momentum at the Pulmonary Fibrosis Foundation (PFF)!**

This spring, the Foundation reached a much-anticipated milestone: the first patient enrolled in the PFF Patient Registry, the most comprehensive research tool available to help us in our fight against pulmonary fibrosis. This success was made possible thanks to the hard work of PFF Care Center Network colleagues, Registry funders, dedicated volunteers, and partners.

With this milestone realized, we are charging toward new goals, which you can read about on page 4. And as we continue to secure funds to fulfill and expand upon the important research conducted through the Registry, please consider contributing. Your donations help us sustain and grow the PFF Patient Registry and the PFF Care Center Network.

A record number of more than 700 individuals participated at the *PFF Summit 2015: From Bench to Bedside*. The *Summit* highlighted research opportunities with outstanding abstracts accepted for the Poster Presentation, and dug into critical issues through PFF Care Center Network and PFF Patient Registry meetings. This issue of the *Breathe Bulletin* also shares information about new *Summit* initiatives, which help us get closer to a world without PF (see pages 26–28).

Also during this incredible time of growth, we are pleased to welcome new Foundation board members: Former Coalition for Pulmonary Fibrosis (CPF) board member and corporate real estate agent Terence Hales (son of PFF board member Tom Hales); longtime fundraiser and development professional Colleen Attwell; and employment lawyer and seasoned volunteer/fundraiser Lauren Bruning. All three have a personal family connection to PF and we are appreciative of their leadership as part of our governing board.

We also welcome PFF Daughters, a former CPF support and information initiative. The PFF is committed to supporting caregivers of any gender or familial connection, and with that is expanding the Daughters program to include all caregivers. For more information, contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

Global Pulmonary Fibrosis Awareness Month is coming up in September. Visit [bit.ly/PFFGPFAM](http://bit.ly/PFFGPFAM) for ideas on how you can help spread the word about PF, raise funds, and advocate for change. The fight against PF is truly a universal effort—join us!

To improve our planning process and more closely align revenues with expenses, the PFF has changed our fiscal year to July 1–June 30. If you plan to make a gift during the Foundation's fiscal year 2016, we encourage you to do so before June 30, ensuring that your contribution is included in our year-end totals.

**We're extremely grateful for our supporters' commitment to the Foundation's work. Your continued dedication keeps us moving forward, expanding our reach, and leading the way to a cure for pulmonary fibrosis.**

A handwritten signature in black ink that reads "Patti Tuomey".

**PATTI TUOMEY, EdD**

PRESIDENT AND CHIEF EXECUTIVE OFFICER



# PFF CARE CENTER NETWORK, PATIENT REGISTRY TAKE BIG LEAPS FORWARD

Over the past three years, the Pulmonary Fibrosis Foundation (PFF) has worked with the pulmonary fibrosis (PF) medical community to establish the PFF Care Center Network (CCN), where people with PF can find experienced medical professionals who understand their disease and support services to improve the quality of their lives. Following two rounds of a competitive application process, the CCN has now expanded to 40 sites across the US. Hand-in-hand with the CCN, the PFF Patient Registry celebrated an important milestone when it enrolled its first patient this March.

“PFF Care Center Network sites are committed to improving the lives of those with PF by providing the highest quality care to patients,” explains Kevin R. Flaherty, MD, MS, Steering Committee Chairman, PFF Care Center Network and PFF Patient Registry (pictured right). “They embrace a multidisciplinary approach that involves experts in pulmonary medicine, rheumatology, radiology, and pathology—all specializing in interstitial lung disease.”

In addition to providing excellent clinical care, CCN sites offer numerous support and educational opportunities, which include providing resources and medical expertise to local support groups, sharing a range of PFF educational materials, and hosting an annual educational event for members of the PF community.

The PFF Patient Registry is a first-of-its-kind PF research study that will generate a database of de-identified (made anonymous) medical information, collected at participating CCN sites and gathered from at least 2,000 people living with PF.

Together, the CCN and Registry have the potential to significantly improve research relating to the diagnosis, treatment, and eventual cure for PF. This year, the PFF is increasing efforts to expand the reach and impact of these intertwined programs.

PFF PATIENT REGISTRY

PFF CARE CENTER NETWORK

Pulmonary Fibrosis  
FOUNDATION



## Partnering With Community Health Care Providers

In the next stage of its development, the CCN will develop plans for partnerships with community-based health care professionals to improve awareness of PF, reduce the time to an accurate diagnosis, and ensure that CCN sites and community medical centers can more effectively exchange information and share expertise.

“We see the CCN as a way to build bridges outward to raise awareness of PF and aid in the care of patients with pulmonary fibrosis,” Dr. Flaherty says.

“The PFF Patient Registry is a big step towards furthering PF research by leveraging the power of a large database of patient information with the prospect of identifying trends and relationships that would otherwise be undetectable.”

DAVID SHERRY / PF PATIENT, PFF AMBASSADOR,  
SUPPORT GROUP LEADER, AND LEANNE STORCH FUND  
REVIEW COMMITTEE CHAIR

**“The PFF Care Center Network provides the opportunity for patients to receive specialized disease management and participate in clinical research aimed at improving outcomes for patients with pulmonary fibrosis.”**

**KATHLEEN O. LINDELL, PHD, RN / PFF BOARD OF DIRECTORS**  
VICE CHAIR AND MEDICAL ADVISORY BOARD MEMBER

### **Together, We Envision a World Without PF**

Research is the pathway to a cure for pulmonary fibrosis. Many people living with PF have participated in a clinical trial, which is a research study designed to help understand whether an experimental treatment might help people living with PF. These clinical trials are critically important. While equally important, the PFF Patient Registry is quite different from a clinical trial. People enrolled in the Registry are not required to make any additional visits and do not receive experimental therapy as part of the Registry—the data is collected during each regular medical visit to a CCN site.

Information for the PFF Patient Registry is collected from the time of enrollment for as long as the patient continues to visit a CCN site. The de-identified data includes the patient’s age and gender, details on how the diagnosis was made, medical tests performed and their results, medications taken as well as medical outcome events such as hospitalization, transplantation, and death. The Registry will also capture high-resolution CT scan images, answers to short questionnaires about each patient’s symptoms, and information about how their lives are affected by their disease.

“This combination of data from so many patients, including those with less-studied forms of PF, will generate an unparalleled resource for future research toward additional treatments for these diseases,” Dr. Flaherty says. “It will also provide evidence to aid in answering important questions like ‘How often should patients visit their pulmonologists?’ or ‘Are annual CT scans important?’”

learn more  
visit [pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)

People who participate in the Registry will also have the option to contribute blood samples to a biorepository which will store these samples to be used in future research. When combined with the information in the Registry, these blood samples have the potential to help scientists find new causes of PF, identify ways of determining whether treatments are working, improve the ways doctors monitor the progression of PF, and help discover new ways to treat PF. The Registry and biorepository are critical next steps that will help transform research being performed by the PF community.

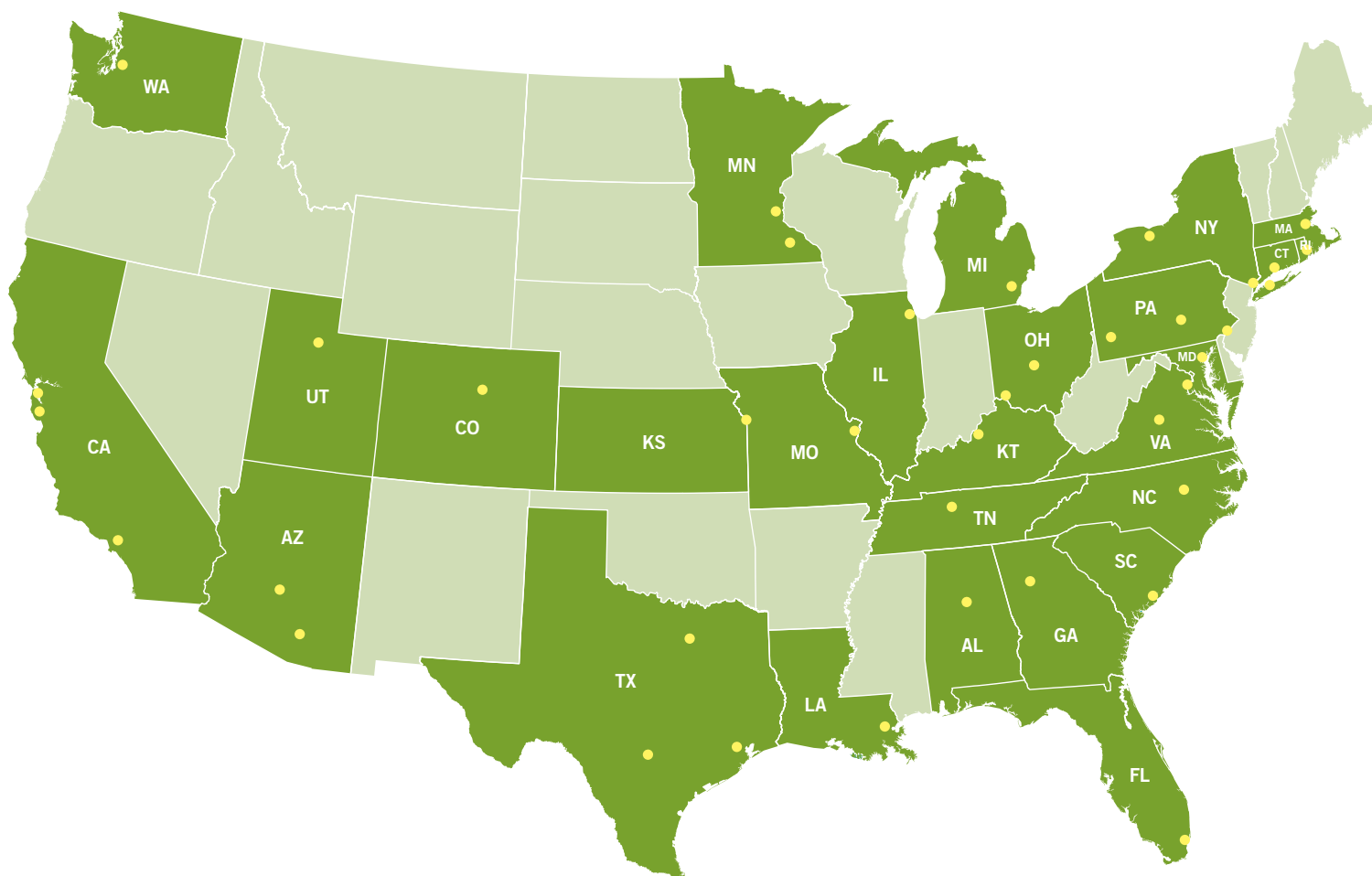
“Our vision is a world without PF,” explains Patti Tuomey, PFF President and CEO. “Before taking even our first step, we sought out PF clinician and scientific leaders and our patient community for their input on unmet needs in the PF community. It quickly became clear that the absence of a large nationwide patient registry and biorepository was holding back scientists and clinical investigators from taking the critical next steps toward a cure for PF.”

Now that the first patient has been enrolled in the PFF Patient Registry, the initiative is on track to fulfill its goals to enroll additional patients through PFF Care Center Network sites across the country and study a variety of data that will help the medical community unlock clues about this devastating disease.

**SEE PAGES 6–7 FOR A DIRECTORY OF PFF CARE CENTER NETWORK SITES.**

“We see the CCN as a way to build bridges outward to raise awareness of PF and aid in the care of patients with pulmonary fibrosis.”

KEVIN R. FLAHERTY, MD, MS / STEERING COMMITTEE CHAIRMAN,  
PFF CARE CENTER NETWORK AND PFF PATIENT REGISTRY



**78%** of the US metropolitan population is now **within two hours** of a PFF Care Center Network site.

To support the PFF Care Center Network and the PFF Patient Registry, visit [pulmonaryfibrosis.org/donate](https://pulmonaryfibrosis.org/donate) or contact the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

# FIND A PFF CARE CENTER NETWORK SITE IN YOUR AREA.

Visit [pulmonaryfibrosis.org/life-with-pf/find-medical-care](https://pulmonaryfibrosis.org/life-with-pf/find-medical-care) or contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733).

## ALABAMA

**University of Alabama at Birmingham**  
BIRMINGHAM, AL

## ARIZONA

**Dignity Health St. Joseph's Hospital & Medical Center**  
PHOENIX, AZ

**University of Arizona Interstitial Lung Disease Program at the University of Arizona Medical Center – University Campus in Tucson**  
TUCSON, AZ

## CALIFORNIA

**UCLA Health Interstitial Lung Disease Program**  
LOS ANGELES, CA

**UCSF Interstitial Lung Disease Clinic**  
SAN FRANCISCO, CA

**Stanford Health Center**  
STANFORD, CA

## COLORADO

**National Jewish Health**  
DENVER, CO

## CONNECTICUT

**Yale School of Medicine**  
NEW HAVEN, CT

## FLORIDA

**University of Miami Miller School of Medicine**  
MIAMI, FL

## GEORGIA

**Piedmont Healthcare**  
ATLANTA, GA

## ILLINOIS

**University of Chicago Pulmonary Clinic**  
CHICAGO, IL

**Northwestern Memorial Hospital**  
CHICAGO, IL

## KANSAS

**The University of Kansas Hospital**  
KANSAS CITY, KS

## KENTUCKY

**University of Louisville School of Medicine**  
LOUISVILLE, KY

## LOUISIANA

**Tulane University School of Medicine**  
NEW ORLEANS, LA

## MARYLAND

**The Johns Hopkins Hospital and University of Maryland Medical Center**  
BALTIMORE, MD

## MASSACHUSETTS

**Beth Israel-Deaconess Medical Center\*\***  
BOSTON, MA

**Massachusetts General Hospital\*\***  
BOSTON, MA

**St. Elizabeth's Medical Center\*\***  
BOSTON, MA

## MICHIGAN

**University of Michigan Health System**  
ANN ARBOR, MI

## MINNESOTA

**University of Minnesota Medical Center**  
MINNEAPOLIS, MN

**Mayo Clinic in Rochester, Minn.**  
ROCHESTER, MN

## MISSOURI

**Washington University School of Medicine in St. Louis**  
ST. LOUIS, MO

## NEW YORK

**New York – Presbyterian / Columbia University Medical Center and New York – Presbyterian / Weill Cornell Medical Center\***  
NEW YORK, NY

**University of Rochester Medical Center**  
ROCHESTER, NY

**Stony Brook University Hospital**  
STONY BROOK, NY

## NORTH CAROLINA

**Duke University Medical Center**  
DURHAM, NC

## OHIO

**University of Cincinnati Medical Center**  
CINCINNATI, OH

**The Ohio State University Wexner Medical Center**  
COLUMBUS, OH

## PENNSYLVANIA

**Penn State Milton S. Hershey Medical Center**  
HERSHEY, PA

**University of Pennsylvania**  
PHILADELPHIA, PA

**Temple University Hospital**  
PHILADELPHIA, PA

**University of Pittsburgh Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease at UPMC**  
PITTSBURGH, PA

## RHODE ISLAND

**Rhode Island Hospital\*\***  
PROVIDENCE, RI

## SOUTH CAROLINA

**Medical University of South Carolina**  
CHARLESTON, SC

## TENNESSEE

**Vanderbilt University Medical Center**  
NASHVILLE, TN

## TEXAS

**University of Texas Southwestern Medical Center**  
DALLAS, TX

**The University of Texas Health Science Center at Houston (UT Health)**  
HOUSTON, TX

**The University of Texas Health Science Center at San Antonio**  
SAN ANTONIO, TX

## UTAH

**University of Utah Health Care**  
SALT LAKE CITY, UT

## VIRGINIA

**UVA Health Systems Charlottesville, VA**  
**Inova Fairfax Medical Campus**  
FALLS CHURCH, VA

## WASHINGTON

**Interstitial Lung Disease Clinic at University of Washington Medical Center**  
SEATTLE, WA

\*Please note there are two locations for this PFF Care Center Network site.

\*\*Please note these four locations are operating as one PFF Care Center Network site (Boston-Providence Pulmonary Fibrosis Care Centers).

# programs

## PFF PROGRAMS UPDATE

## PFF PATIENT COMMUNICATION CENTER

### One-Stop Shop for Info

Pulmonary fibrosis (PF) patients and the people who care for them need accurate, up-to-date information about the disease and support resources to improve the quality of their lives.

The Pulmonary Fibrosis Foundation's (PFF) Patient Communication Center (PCC) is a central information hub that provides the latest medical information, details on support services, and directions to other essential resources for anyone who has questions about how to navigate through this disease, including patients, caregivers, and health care professionals. The most common PCC requests are for PF disease education materials, locations of PFF Care Center Network sites (also see pages 6–7) and other medical centers with expertise in treating PF, tips on joining or starting a support group, and information on clinical trials. The PCC also fields more general questions, such as helping people who are interested in volunteering for the PFF, providing information about fundraising through *Team PFF*, and directing people to more information about how to get involved with Global Pulmonary Fibrosis Awareness Month in September.

The PFF recently updated a popular educational piece—the PFF Physician Notepad—and introduced a new tool—the PFF Physician Pocket Guide—for health care professionals, both of which are available through the PCC:

- The **PFF PHYSICIAN NOTEPAD** allows patients to take home doctor's notes from a consultation. Designed as an easy-to-understand checklist, the notepad is a handy way to help patients keep track of tests ordered, medications prescribed, recommendations on how to improve quality of life, and other doctor's instructions.
- The new **PFF PHYSICIAN POCKET GUIDE** geared toward physicians, including community pulmonologists and general practitioners, is a handy reference to help diagnose and manage the disease, as well as link patients with essential support resources.

Additional educational materials, including the PFF Disease Awareness Poster and Disease Awareness Brochure, are also available to the PF community.

**pulmonary fibrosis**  
**physician notepad**  
A DISEASE MANAGEMENT WORKSHEET FOR DOCTORS AND PATIENTS

DATE (month/year) / /

**today's discussion**  
We discussed the following today:

**recommendations**  
Things you can do:  
☐ Quit smoking  
☐ Achieve a healthy weight  
☐ Use a pulse oximeter to monitor oxygen levels immediately after exertion  
☐ Monitor oxygen levels over 90% 24 hours per day  
☐ Attend a support group (pulmonaryfibrosis.org/life-with-pf/support-groups)  
☐ Get lifestyle changes  
☐ Learn about PF at pulmonaryfibrosis.org  
☐ Send me prior CT scans on a disk  
☐ Send me biopsy slides from "pathology" office in your hospital

Things I am going to arrange:  
(if you don't hear from me in  weeks, call me)  
☐ Start pulmonary rehabilitation  
☐ Sleep study  
☐ Structural anatomy  
☐ Lung transplant evaluation  
☐ Rheumatology consultation  
☐ Cardiology consultation  
☐ Thoracic surgery consultation  
☐ Nutrition evaluation  
☐ Present your case at our ILD conference

Your return visit is in  weeks / months

These tests should be done prior to or at your next visit:  
☐ High-resolution CT scans (inspiratory & expiratory)  
☐ Pulmonary function tests  
☐ Oxygen titration study  
☐ Six-minute walk test  
☐ Echocardiogram  
☐ Esophagram  
☐ Bloodwork

Treatments we discussed today:

(leave space on back)

Pulmonary Fibrosis  
FOUNDATION

**ILD POCKET GUIDE**  
Interstitial lung disease (ILD) is the presence of fibrosis and/or inflammation of the lung parenchyma not due to infection or malignancy.

**STEP 1: RECOGNIZE ILD**

**TYPICAL PRESENTATION**

- Subacute or chronic cough
- Exertional dyspnea (breathlessness)

**While performing an HRA:**

- Listen carefully for crackles
- Look for evidence of autoimmune disease on the skin and joints
- Walk your patient internally in the hallway to assess for desaturation (< 95% drop)

**Order initial testing based on your HRA. Consider:**

- Spirometry (normal or low FVC, often with a normal FEV1/FVC ratio in ILD)
- Lung volumes (normal or low TLC)
- DLCO (frequently reduced in ILD)
- Chest x-ray (normal or persistent interstitial)

**If you suspect ILD, perform a high-resolution CT scan of the chest. HRCT includes the following:**

- Inspiratory and expiratory apnea imaging
- High spatial frequency algorithm reconstruction at 0.50 to 0.75 mm thickness
- No IV contrast required
- Consider prone imaging when mild dependent ground glass attenuation is present

To request educational materials, have your PF questions answered, or learn more about how you can get involved with the Pulmonary Fibrosis Foundation, contact the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).



# PFF AMBASSADOR PROGRAM

## Strong Advocates for the Pulmonary Fibrosis Community

Telling a personal story is one of the most effective ways to capture listeners' interest on an important topic. The Pulmonary Fibrosis Foundation's PFF Ambassador program empowers patients and health care professionals to become spokespersons for their community. Patient and caregiver Ambassadors focus on their own pulmonary fibrosis (PF) journey, while Ambassadors who are health care professionals provide disease education and management information.



**“You were interesting and informative—you could tell by the types and amount of questions that people were very interested in what you had to say. Thank you so much for making a difference for so many people.”**

**REGINA M. DONOFRIO, MED, RRT**  
PULMONARY REHABILITATION COORDINATOR  
ST. PETER'S HOSPITAL

“By speaking about their individual experiences with pulmonary fibrosis, PFF Ambassadors promote disease awareness, share up-to-date information, and provide hope and inspiration to the PF community,” says Courtney Firak, PFF Director of Programs. “Individuals participating in the program have been trained to speak and advocate on behalf of the PFF and the pulmonary fibrosis community.”

“Patients with PF and their caregivers want to know what information and support are available to them. The slide deck and other materials the PFF provides to its Ambassadors are great tools, and I always encourage audiences to visit the PFF website and use the wonderful resources there,” says Chris Schumann, Program Manager for Cardiopulmonary Rehabilitation at the University of Alabama at Birmingham, which is also part of the PFF Care Center Network.

A health care professional Ambassador since the program's 2014 launch, Schumann says he's impressed by the advancements made in PF awareness and treatment during his 20 years in the pulmonary rehabilitation profession.

“PFF Ambassadors help people learn how to manage and thrive with their disease,” he says. “I feel like I'm doing something that really benefits others.”

PFF Ambassador and lung transplant recipient John Morthanos (pictured left) was recently named to a Rare Disease Task Force, established by the Connecticut legislature. Morthanos represents rare disease survivors on the committee, which also includes representatives of the physician, nursing, research, hospital administration, biopharmaceutical, and caregiving communities. Most recently, John appeared at the Albany Lung Meeting in New York where he shared details about his personal experience with pulmonary fibrosis.

**Looking for a dynamic speaker for your support group or another event marking Global Pulmonary Fibrosis Awareness Month in September?**

To book a PFF Ambassador, contact the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

# SUPPORT GROUP LEADER NETWORK

## New Resources Debut, Storch Fund Awardees Announced

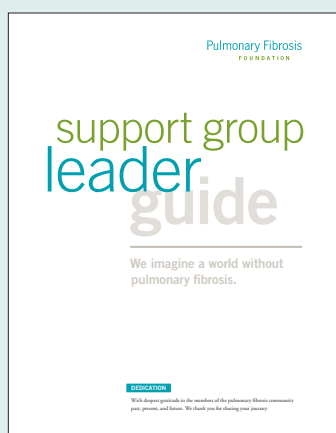
The Pulmonary Fibrosis Foundation (PFF) Support Group Leader Network (SGLN) provides a forum for support group leaders to connect, exchange ideas, learn from one another, and discuss best practices for use at their meetings.

Thanks to a generous grant from Boehringer Ingelheim and the dedicated labors of the SGLN Steering Committee, the SGLN recently debuted valuable new tools for support group leaders and announced the latest Leanne Storch Support Group Fund awardees.

The Training Webinars working group has rolled out a three-part series on starting and running a support group. The first webinar discusses available resources for starting a group: resources for curriculum, funding, group dynamics, leading a discussion, choosing topics and speakers, and more. The second installment covers running a group, including troubleshooting logistics like choosing a setting and arranging for oxygen. The third webinar focuses on helping support group leaders keep their groups lively and growing. All three webinars are now available online.

A second working group updated the PFF Support Group Leader Guide. Based on feedback from experienced support group leaders across the country, the comprehensive guide covers basic guidelines and best

practices, helpful information for new leaders on how to get started, and tips for maintaining and evolving a group over time. Types of meetings, a list of suggested topics/curriculum with leader discussion points, and direction to supplemental resources are also included. The new guide is an invaluable resource for PF support group leaders.



View the Support Group Leader Network Training Webinars and download a copy of the new Support Group Leader Guide at [bit.ly/PFFSGLN](http://bit.ly/PFFSGLN).

“Both the Webinar Series and Leader Guide are designed for new and experienced support group leaders,” says Courtney Firak, PFF Director of Programs. “If you’re far from a major medical center with no local support group, we hope you’ll consider starting your own—these resources will guide and support you through the process. And for existing support groups, these materials provide lots of new ideas to keep things fresh.”

The Leanne Storch Support Group Fund Review Working Group has created a consistent review process for applications for grants. The process’s more specific requirements will improve support groups across the country: awardees now report how they used the money, and that data will create “best practices” guidelines for other groups. The PFF congratulates the recently announced 2015 awardees (see list at [bit.ly/StorchAwardees2015](http://bit.ly/StorchAwardees2015)).

According to Firak, support groups use their grants for a variety of purposes, from the most basic needs to more comprehensive, all of which are important when running such meetings. “Many awardees use the funds for refreshments at meetings. Others purchase projectors or TVs, pay for printing and mailing of newsletters, or buy gift cards with which to thank presenters. Whatever the purchase, our leaders use the funds to create more effective, welcoming meetings.”

## APPLY FOR A STORCH FUND GRANT!

The 2016 Leanne Storch Support Group Fund grant cycle is now open. To apply, visit [bit.ly/StorchAwardees2015](http://bit.ly/StorchAwardees2015). If you have any questions or would like to inquire about starting a new PF support group, please contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.825.5733) (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

# PFF DAUGHTERS

## Unique Program Offers Opportunities to Families

**Support groups, a mainstay of the pulmonary fibrosis (PF) community, provide connections and camaraderie to people living with a serious disease, both patients and family members alike.**

Now, through the acquisition of the PFF Daughters program, the Pulmonary Fibrosis Foundation (PFF) offers a volunteer program that gives people a chance to get involved.

PFF Daughters began with the Coalition for Pulmonary Fibrosis (CPF) as a project that focused on women and girls whose parent was diagnosed with PF. The PFF Daughters became part of the Foundation and is evolving into a program that provides volunteer opportunities for the entire family. PFF Daughters offers an opportunity to increase awareness about PF, advocate for improved care for people with PF, and raise support for continued research efforts, regardless of their gender or familial connection.

“The PFF is here for all affected by PF—including those who have lost their loved one. PFF Daughters offers a way for family members to continue to receive support as well as participate with the PF community,” says Kate Gates, PFF Manager of Volunteer Programs.

“People living with pulmonary fibrosis rely on the support of their family, typically a spouse or child, for their day-to-day advocacy,” Gates says. “And these individuals also need support and a network to become more actively involved. Through PFF Daughters, the Foundation aims to provide a network of members working together as leaders, volunteers, advocates and fundraisers to help the PFF fulfill its mission.”

Though the program is new to the PFF, work is underway to form a steering committee and survey individuals who were members of the CPF Daughters of PF program. “We’re asking how else people think the program should evolve, and what tools and resources would be most valuable to them,” she says.

**Please join us and share your feedback**—contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.TalkPFF) (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

**“With the expanded resources available to patients diagnosed with pulmonary fibrosis, their caregivers, and loved ones, I feel their needs are now finally being met. The PFF has wonderful new resources available to start new support groups, including training webinars and an expanded Support Group Leader Guide. It’s necessary in this fight for a cure, to help others and to raise awareness for this disease.”**

**CAROL BAIR, RCP** / CLINICAL COORDINATOR ILD PROGRAM AT NATIONAL JEWISH HEALTH AND SUPPORT GROUP LEADER  
FOR THE JOE WALSH MEMORIAL PF SUPPORT GROUP IN DENVER, COLORADO

# 24/7

## PFF DISEASE EDUCATION WEBINAR SERIES

### Makes Info Available 24/7

**Traveling can often be tough for pulmonary fibrosis (PF) patients and their caregivers.**

**“As a newly diagnosed patient with tons of information to learn, I like the presentation and content. Great job! You have answered questions I have never thought to ask.”**

PFF DISEASE EDUCATION  
WEBINAR SERIES PARTICIPANT

**“You are all so wonderful to provide these webinars, maintain the webinar library and answer the questions we send in. Thank you for taking the time to provide this valuable information in such a caring manner.”**

PFF DISEASE EDUCATION  
WEBINAR SERIES PARTICIPANT

The Pulmonary Fibrosis Foundation (PFF) Disease Education Webinar Series keeps widespread members of the PF community up to date with vital information about managing the disease, while allowing PF experts from across the country to participate as well. Guided by leading PF specialists on the PFF medical team, the Foundation’s webinars are also a great tool for support group meetings and other PF events.

Archived webinars are available 24/7 at [pulmonaryfibrosis.org/webinars](http://pulmonaryfibrosis.org/webinars). Recent topics include lung transplantation, occupational and environmental PF, pulmonary hypertension and PF, palliative care, PF advocacy, familial PF, and understanding pulmonary function tests. Once each quarter, the series includes an “Ask a Doc” session in which members of the PFF medical team take questions from participants.

To register and submit questions for the next presentation in the PFF Disease Education Webinar Series, visit [pulmonaryfibrosis.org/webinars](http://pulmonaryfibrosis.org/webinars). Please share this link with others in the PF community who may be interested in participating.

**In 2015, 712 people participated in the 10 presentations in the PFF Disease Education Webinar Series.**

**Since May 2014, webinars in the PFF Disease Education Webinar Series Archive were viewed over 1,500 times.**

**Do you have a great idea for a future webinar topic?**

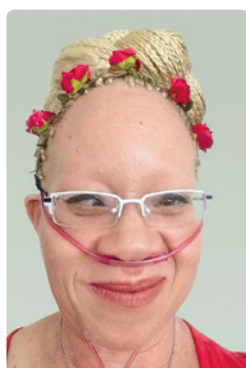
Share your suggestions with the the PFF Patient Communication Center at [844.TalkPFF](tel:844.825.5733) (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).



TONY NISWONGER / JADE PHOTOGRAPHY



# “PORTRAITS OF PF” PUT A FACE ON PF



**Have you visited the Pulmonary Fibrosis Foundation’s (PFF) Facebook page lately?** In addition to sharing the latest on all things PF, including support group meetings, new resources, and heartfelt inspiration, the PFF is proud to feature members of the PF community in a new way, through our weekly series, “Portraits of PF”.

“We have lots of unique stories in our community, from the perspective of patients, caregivers, people who’ve lost a loved one, adult children, and more,” says Jennifer Bulandr, PFF Director of Social Media and Community Engagement. “‘Portraits of PF’ is an inclusive series that tells these stories and has been well received with lots of enthusiasm. Each portrait we post inspires more people to tell their own stories.”

“Portraits of PF” is posted weekly on Monday afternoons. In addition to keeping up with the PFF on Facebook—and sharing your own PF story—check out the Foundation’s presence on other social media: LinkedIn, @PFFORG on Twitter, Instagram, and Storify.

Join the almost  
36,000 followers  
on Facebook!



# TEAM PFF EVENTS

Turn your passion into action! Team PFF members across the country are hosting fundraising events that transform the challenges of pulmonary fibrosis (PF) into new hope for the future. Read what these Team PFF leaders are doing — and draw inspiration for a fundraising initiative of your own.

## A TOWN TAKES STEPS TO HONOR ITS LATE MAYOR

### Annual Vic Vittorino's Walk for Your Next Breath

Like many families, the Vittorinos knew nothing about pulmonary fibrosis (PF) before Vic Vittorino was diagnosed in 2007. Vic, longtime mayor of Delanco, New Jersey, passed away in 2011. In his father's memory, Mike and his family host Vic Vittorino's Walk for Your Next Breath every spring in Delanco.

Mike got the idea for his family's event when he heard a radio broadcaster promoting another walk event to support the cure for pulmonary fibrosis. "I reached out to [PFF Director of Social Media and Community Engagement] Jennifer Bulandr on social media," he recalls. "I still have my original white PFF BREATHE bracelet; it's been on my wrist since 2010."

From there, plans for the walk to honor his father took off. "I got my mom, Pauline, and other family members on board, and asked a graphic designer to make us a logo," Mike explains. "My father, former mayor of Delanco, where he also grew up, meant he had a great bunch of friends. They came with their own shirts that said, 'We walk for Vic.'"

Now, the walk averages 70–100 participants each year and has raised over \$30,000 for pulmonary fibrosis. "It gets better every year," Mike says.



During his dad's illness, the Vittorino family learned a lot about caregiving. "Get support and talk to other PF families," Mike advises. "It can be hard sometimes to know how to truly care for someone. You want to do everything for them, but you need to talk to health care professionals and people who've been through this so they can help you understand how to do what's best for your loved one."

## Learn more and attend an event!

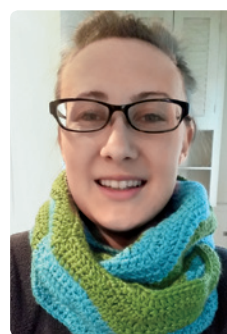
For a complete list of events in your area, visit [pulmonaryfibrosis.org/get-involved/attend-an-event](http://pulmonaryfibrosis.org/get-involved/attend-an-event).

## STITCHING TOGETHER SUPPORT FOR PF

### Crochet. Life. And Passions, Tealspin.com

Sharon Cirrilli was a prolific crocheter and an accomplished seamstress. When she passed away from pulmonary fibrosis (PF) in July 2015, she left behind a room full of handbags, dresses, pillowcases, aprons, and other beautifully detailed products of her talents.

Sharon had long donated her pieces to charities including Little Dresses for Africa, St. Jude's Children's Medical



Center, and Warm-Up America, and her daughter, Ashley M., and daughter-in-law, Ashley E. (the family uses middle initials to distinguish between its identically named members) decided to continue Sharon's philanthropic focus in her memory.

Ashley E., a needlework enthusiast herself, continues to sell Sharon's and her own work at craft shows, with proceeds benefiting the Pulmonary Fibrosis Foundation (PFF). Working together, the two Ashleys also started a "Show Out for Sharon" campaign in which they mailed hundreds of PFF bracelets, asking friends and family to take photos while wearing the bracelets and post the shots to social media.

"We ended up getting 250 photos," Ashley M. says. "For each one, the Cirilli Family donated \$5 and my company, Disney, matched the contributions. It was a great way to keep Mom's memory going and raise awareness for PF."

With this initiative, craft show sales, and a fundraising website the two women set up, the Ashleys have contributed more than \$12,000 to the PFF. That success has created momentum: Ashley E. has set a 2016 goal for herself of raising another \$4,000. "Even if it's only \$25 at a time, we know we're helping someone else and remembering an amazing person," she says.

"Fundraising is more authentic when you're sharing your own story," Ashley M. adds. "We know that awareness and fundraising are the two biggest things that will have a positive impact on PF. That motivates us and moves us forward."

# \$2,000

## TAKING A MIX OF FUNDRAISING APPROACHES

### In-Person and Online Events, Matching Gifts, and Sponsorships

Karen Lane and her husband, Kevin, find particular meaning in a quote from author Maya Angelou: “When you do nothing, you feel overwhelmed and powerless. But when you get involved, you feel the sense of hope and accomplishment that comes from knowing you are working to make things better.”

The Lanes have taken that philosophy to heart since Kevin’s 2013 pulmonary fibrosis (PF) diagnosis. They’re involved in multiple, diverse initiatives to raise money for the Pulmonary Fibrosis Foundation (PFF). First, they hosted an Art for PF painting class led by an artist friend. With other friends and family members, they followed up with a Thirty-One party online ([thirtyonegifts.com/host/](http://thirtyonegifts.com/host/)) and people then colored and shaded tote bags in PFF identity colors. With Karen’s company, Elsevier Inc., matching their donation, the Lanes were able to double their contributions to the PFF to \$2,000 at no additional cost to themselves.

“Check with your human resources department to see whether they offer matches; it’s an important way to broaden your support,” Karen says. “You can take a small gift and make it bigger—or make a big gift even bigger.”

This year, the Lanes also decided to celebrate their late-winter birthdays by becoming sponsors for *Broadway Belts for PFF!*, a gala evening of song featuring stars of Broadway musicals (also see page 24). Karen’s company will also match this sponsorship contribution. In a separate 2016 initiative, they’ll also be raffling a quilt handmade by Karen’s mother.

During each of their fundraising forays, the Lanes find themselves connecting with others whose families have been touched by the disease. “We keep meeting people who know someone with PF,” says Kevin, who’s been listed for lung transplantation and continues to work while he waits for a potential match. “At our painting party, we met three people we didn’t know at all; they were all connected to someone with PF,” Kevin says.

“There are a lot of us out here, and there will be many more. That’s the most important reason to keep fundraising.” Karen is excited and looking forward to her events in 2016. The biggest excitement looking

ahead is how friends and family have not only surrounded them but are now becoming involved in their own events to raise support and awareness.



## TIPS FOR A TIP-TOP EVENT

Take it from experienced event planners—some best practices can really streamline planning a fundraising event. Here’s useful advice from *Team PFF* event leaders Karen Lane, Mike Vittorino, and Ashley E. Cirrilli:

- **Pick an activity with personal meaning.** “Think about things that your loved one likes or liked—or things that you like—and go from there,” Lane says.
- **Start early** to give yourself plenty of time to address unexpected issues. Vittorino begins planning for his annual walk at least four months ahead.
- **Don’t be afraid to turn to other people for help.** “We involve my whole family. And your friends, coworkers, and neighbors will understand why this issue is important to you,” Vittorino notes.
- **Ask lots of companies and organizations for support.** “The more businesses that donate prizes or services, the more money you can save and donate toward PF,” Vittorino says. One company offered us a Porta-Potty, which we didn’t even realize we’d need the first year!”
- **Remember that no prize donation is too small.** “If someone gives us a bottle of wine and someone else gives us pasta, we’ve started a gift basket,” Vittorino says. “Don’t turn away donations; get creative with them.”
- **Leverage social media.** “It’s an easy and free way to get the word out,” Vittorino says.
- **Just do it!** “It feels a little scary the first time you plan a fundraiser, but sharing our story helped us heal in a way,” Cirrilli says. “Making connections with others going through the same thing has been cathartic.”

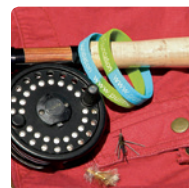
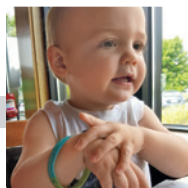
## Ready to learn more or host your own event?

Contact Mary Linder, Development, Team PFF, at [mlinder@pulmonaryfibrosis.org](mailto:mlinder@pulmonaryfibrosis.org).



# join us!

## global PULMONARY FIBROSIS awareness month SEPTEMBER



**The path to a cure for pulmonary fibrosis (PF) winds across the globe. It will take a shared commitment to reach our universal goal of a world without PF.** As the Pulmonary Fibrosis Foundation (PFF) gears up for Global Pulmonary Fibrosis Awareness Month this September, we invite you to recognize your irreplaceable spot in the worldwide PF community, and ask you to think about ways you can spread the message to family, friends, health care professionals, colleagues, neighbors, community leaders, and everyone else in your circle. The goal is global—but the steps toward it are local.

### ALL TOGETHER NOW

Global Pulmonary Fibrosis Awareness Month is a prime time for action and collaboration among all members of the PF community and beyond.

Key participants:

- PF patients, caregivers, and their families and friends
- Family and friends of patients who have passed away
- Physicians, researchers and allied health professionals
- General public
- PFF donors and volunteers
- PFF Support Group Leader Network
- PFF Ambassadors
- PFF Daughters
- Team PFF event leaders
- PFF Care Center Network
- PFF social media community: Facebook, LinkedIn, Twitter, Instagram, Storify
- PFF Board of Directors, Medical Advisory Board, Scientific Advisory Committee, Research Advisory Forum, and staff
- Industry partners
- PF advocacy organizations around the world
- Respiratory and thoracic societies
- News and media outlets



Laury Feldman spreading PF awareness in Cozumel, Mexico. The Feldman family recently held the Third Annual Irv Feldman Texas Hold'Em Tournament and raised over \$180,000 to support the mission of the Pulmonary Fibrosis Foundation.

### MAKE AN IMPACT — IN THREE EASY STEPS

**LEARN:** Increase your knowledge of PF by attending educational events, reading educational materials at [pulmonaryfibrosis.org](http://pulmonaryfibrosis.org) or viewing presentations in the PFF Disease Education Webinar Series at [pulmonaryfibrosis.org/webinars](http://pulmonaryfibrosis.org/webinars).

**SHARE:** Pass along what you've learned so others can understand the challenge and opportunity. Start a conversation by creating your own awareness campaign. Follow the PFF on social media and share Global Pulmonary Fibrosis Awareness Day stories.

**FUNDRAISE:** Host your own event and donate the proceeds to support the mission of the Pulmonary Fibrosis Foundation.

To purchase PFF lapel pins, PFF Breathe Bracelets, and other items to help raise awareness, please visit [bit.ly/shoppff](http://bit.ly/shoppff).



Georgia Lung Associates Support Group, Austell, Georgia



# global

**adjective**

1. of or relating to the whole world; worldwide
2. relating to or embracing the whole of something, or of a group of things

## synonyms and related words

across the board, blanket, overall, universal, all-embracing, broad, comprehensive, extensive, inclusionary, overarching, sweeping, ubiquitous, widespread, collective, complete, full, planetary



## JUMP IN WITH TEAM PFF

Start planning your own Global Pulmonary Fibrosis Awareness event now through *Team PFF*. The *Team PFF* Event Leader Guide makes it even easier to hold an event to increase disease awareness and fundraise. Get inspired from the activities of other *Team PFF* advocates, who share their stories on pages 14–15.

To learn more, please contact Mary Linder, Development, *Team PFF*, at [mlinder@pulmonaryfibrosis.org](mailto:mlinder@pulmonaryfibrosis.org) and visit [pulmonaryfibrosis.org/TeamPFF](http://pulmonaryfibrosis.org/TeamPFF).

## WAYS TO GET INVOLVED

- Host a breakfast, luncheon, coffee gathering, or dinner
- Create a FirstGiving page to share your story and hold a virtual fundraiser
- Donate to the PFF in lieu of favors at your baby shower, wedding reception, bar mitzvah, etc. —or ask friends and family to remember your birthday with a gift to the PFF
- Ask your HR/talent director to hold a “Blue Jeans Day” fundraiser at work and donate the proceeds. If you’re in school, ask your principal if you can sponsor a “Pajama Day” or other themed clothing day as a fundraiser for PFF
- Hold a car wash in your community
- Set up a lemonade stand with your children
- Ask your workplace, school, or church to hold a charity/PF awareness day
- Take up a collection in your neighborhood
- Hold a bake sale and donate the proceeds to the PFF
- Plan a bowling, baseball, or other sports night with friends and family and ask them to make a donation
- Host a direct sales party such as PartyLite, or Avon, and donate a percentage of sales

## ONLINE TOOLBOX

All Global Pulmonary Fibrosis Awareness Month tools and activities can be found at [bit.ly/PFFGPFAM](http://bit.ly/PFFGPFAM). Visit the website for:

- Links to information about physician and patient educational events
- Tools for PF community members to create their own grassroots awareness campaigns and fundraising events
- Downloadable educational materials

## GET INVOLVED ON SOCIAL MEDIA

Follow the Pulmonary Fibrosis Foundation on social media to learn how to get involved. From “BlueUp4PF” to our new “Portraits of PF” series on Facebook, there are tons of fun ways to participate on social media. Remember to use hashtags so that we can stay engaged with your amazing efforts:



#GlobalPFAwareness  
#pulmonaryfibrosis  
#GPFAM2016  
#MakeEveryBreathCount  
#BlueUp4PF  
#PFWarrior

# philanthropy

## SPOTLIGHT ON PHILANTHROPY

### Family's Great Outcome Inspires Them to Help Others

A longtime activist in the pulmonary fibrosis (PF) community, Terence Hales recently joined the Pulmonary Fibrosis Foundation (PFF) board of directors and is a former board member for the Coalition for Pulmonary Fibrosis. His father, transplant recipient Tom Hales, also serves on the PFF board. In honor of his dad, Terence hosts an annual event in New York City's Central Park to raise funds supporting PF research.

#### Tell us about your family's experience with idiopathic pulmonary fibrosis.

My father was diagnosed with PF and had a successful double lung transplant in 2007. It's a great story. At the time he was 70, and the general rule was that they didn't do transplants for patients over age 55 or 60. Several lung transplant centers would not agree to do the surgery and turned him down, but the University of Maryland in Baltimore agreed to do it. In his interview, the transplant team told him, "We'll do it; we'll get you through the surgery, but you have to be diligent with your follow-up care and do everything we tell you." He did and he's been very lucky, with relatively few issues.

#### Why is philanthropic giving and disease awareness so important to you and your family?

My family and I had a great outcome and we know that this is unusual for most families dealing with PF. We also wondered if anyone else in our family might get PF—we wanted to get involved to help raise awareness and try to improve outcomes for others, and maybe even

for someone else in our own family.



Terence Hales (far right) with (from left to right) his father Tom Hales, sister Lianne Hales-Dugan, and mother Alice Marie Hales.

#### What made you decide to host a walk/run/hike versus another type of event? Talk us through the history and growth of your event.

I started the event in 2008, wanting to do something to raise awareness and help make a difference. I'm a runner, and thought a run in Central Park could help spread the word. We designed it as a run-walk-hike to make it accessible for everyone. We had 20 or 25 people the first year, and I remember the participants sitting around in a circle, sharing stories. The inaugural group, most of whom are still part of the event, insisted we make it an annual event. Since that first year, we have grown to 150 or 200 people. From the \$7,500 we raised our first year, our fundraising grew to \$70,000 last year, exceeding \$400,000 over 8 years. People look forward to it and come back each year, sharing stories, experiences and looking for updates on research funding and more recently, available treatments.

We don't care if participants are running, walking, or hiking. The event has been called a combined party and support group, which is a good way to describe it. We do a raffle and silent auction, make announcements about developments in the PF community, and even have guest speakers. We've added a memory wall so people can honor their loved ones who are dealing with the disease or have passed away. And we always make a big push for people to talk to their representatives in Congress and tell them how to do that.

We share stories—the happy kind and the other ones, too. One of our biggest supporters attended several years in a row; then the next year, his family was there and he wasn't. But the work goes on as we raise funds and awareness.



### Which PFF programs and or initiatives are you most excited about working on as a PFF board member?

I'm just getting up to speed, but initially the PFF Care Center Network and the PFF Patient Registry are probably of most interest to me. The Registry database alone is something the community has needed for a long time. You hear all the stories, but now we'll have the data collected in a standardized way for accurate and meaningful analysis. That will make recruitment for clinical trials easier, help develop effective therapies, and provide researchers with valuable data.

### What's your hope for the future?

Ultimately, we'd all love to find a cure. But more immediately, I hope we'll improve upon recent drug breakthroughs to slow the progression of the disease, improve the patients' quality of life, and extend survival rates. In the medium term, there are several other drugs in the pipeline, and I'd love to see them come to market.



The Hales family (from left to right): Jennifer Hales, Tommy Hales III, Donald Gheen, Billy Hales, Tom Hales Jr., Althea Gheen (little girl in front), Terence Hales, Teagan Hales, Lianne Hales-Dugan, Ryan Grady, Allison (Hales) Gheen

# June 25, 2016

## Save the date for the NYC Run-Walk-Hike for Pulmonary Fibrosis.

Visit [bit.ly/nyc-run-walk-hike](http://bit.ly/nyc-run-walk-hike) for more information.

## GIVING OPTIONS

Donations to the PFF are critical for us to maintain our momentum in serving the PF community. Your donations enhance patient support services, increase research funding, and broaden disease education outreach. Please consider supporting the mission of the PFF.

### MAKE A DONATION

**Online** Visit [pulmonaryfibrosis.org/donate](http://pulmonaryfibrosis.org/donate)

**By Mail** Use the donation envelope in this issue

**By Phone** Call us at 888.733.6741

### PLAN A TEAM PFF FUNDRAISING EVENT

*Team PFF* Event Leaders are individuals who have created fundraising events to honor a friend or a loved one. To learn more about *Team PFF*, visit [pulmonaryfibrosis.org/teampff](http://pulmonaryfibrosis.org/teampff).

### PLANNED GIVING

Please think about including the Pulmonary Fibrosis Foundation in your estate plan and leave a legacy that will live on in the PF community. To get started, contact your financial advisor or the PFF's Chief Development Officer, Joel Massel, at 888.733.6741.

### PLEDGE PFF!

Pledge PFF! is our monthly giving program, and an important source of revenue for the Foundation. Our generous monthly donors provide stability and support to our important programs. To learn more about how you can maximize your impact, visit us at [pulmonaryfibrosis.org/pledgefaqs](http://pulmonaryfibrosis.org/pledgefaqs).

### EMPLOYER MATCHING GIFTS

Please consider maximizing your donation through an employer matching gift program. To find out whether your employer will match your gifts, visit [pulmonaryfibrosis.org/employermatch](http://pulmonaryfibrosis.org/employermatch).

**Your contribution today will have a positive and lasting impact on the PF community.**

**The Pulmonary Fibrosis Foundation thanks you for your generosity and support.**



# advocacy

## EMPOWERING PEOPLE LIVING WITH PF

### Keeping Rare Diseases in the Public Eye

In conjunction with Rare Disease Day, February 29, advocates for a variety of rare diseases join forces to spread awareness all around the world. In observation of the day, the Pulmonary Fibrosis Foundation (PFF) participated in several special activities throughout the month of February:

- Staff members from the PFF met with Illinois Senate President John Cullerton and Senator Don Harmon to speak with them about the importance of spreading PF awareness and to ask for their support for Rare Disease Day as well as Global Pulmonary Fibrosis Awareness Month taking place this September.
- The PFF's top social media post during Rare Disease Day week with more than 750 shares, comments and reactions—and a reach of nearly 30,000—was the **USA Today story about PFF Ambassador John Morthanos**, chronicling his personal experience with pulmonary fibrosis for a piece that was distributed online and printed in select markets on Rare Disease Day. Read the full article at [bit.ly/USATodayMorthanos](http://bit.ly/USATodayMorthanos).
- During the sixth annual **Broadway Belts for PFF!** on February 29, cast members, special guests, and PFF staff lent their support and posed for photos with signs sharing information about the day. Photos were shared on social media. *Broadway Belts for PFF!* is an annual event that brings together stars of Broadway theater to raise funds for the Foundation; also see page 24.
- PFF staff participated in the **National Organization for Rare Disorders (NORD) Rare Disease Day initiative** on February 29. The PFF partnered with NORD, along with a distinguished group of nonprofit rare disease advocacy organizations around the world, by posing for a photo with a sign promoting the day. NORD, the US sponsor and host of the international awareness-raising initiative, shared the Foundation's photo on its Facebook page, with more than 33,000 followers. The Foundation also encouraged PFF followers on Facebook to snap a photo with the sign and post the photos online.



Illinois State Senator Don Harmon and Senate President John Cullerton lend their support for Rare Disease Day. Both Senator Harmon and Senate President Cullerton have lost family members to pulmonary fibrosis.

**PFF Rare Disease Day  
engagement on Twitter,  
Facebook, and Instagram  
reached 5.6M!**

To learn more about how you can help increase pulmonary fibrosis awareness, contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.825.5733) (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).



# Foundation Partners with Diagnostics Company on Major Patient Survey

The Pulmonary Fibrosis Foundation (PFF) and Veracyte, Inc., partnered last summer to develop a US patient survey to advance our understanding of patients' diagnostic experiences with interstitial lung diseases (ILDs), including idiopathic pulmonary fibrosis (IPF).

**60%**  
number of respondents  
that reported the Foundation  
as one of their most valuable  
sources of information during  
their diagnostic journey

Veracyte is a company pioneering the field of molecular cytology, which promises to identify new ways to diagnose complex diseases. The Interstitial Lung Disease Patient Journey (INTENSITY) survey assessed the steps and time required for patients to receive a diagnosis, specific obstacles hindering timely diagnosis, and the physical and emotional impact of patients' diagnostic journeys.

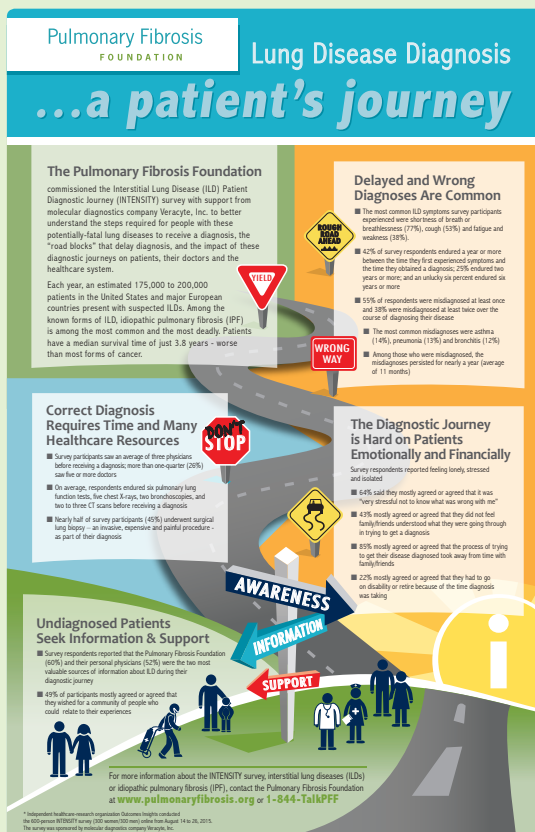
"IPF and other ILDs are notoriously difficult to diagnose, leading to treatment delays, added health care costs, and significant emotional impact for patients and caregivers," says Gregory P. Cosgrove, MD, Chief Medical Officer of the PFF. "Results from the INTENSITY survey have helped us more fully understand patients' diagnostic experiences so that we can further our efforts to improve timely diagnosis and treatment of this disease."

Dr. Cosgrove, with David J. Lederer, MD, MS, PFF Senior Medical Advisor, Education and Awareness, led development of the INTENSITY survey, which was conducted online by independent health care research organization Outcomes Insights, with funding support from Veracyte.

## Key findings include:

- Survey participants saw an average of three physicians before receiving a diagnosis; more than one-quarter (**26%**) saw five or more doctors
- **64%** said they mostly agreed or agreed that it was "very stressful not to know what was wrong with me"
- Nearly half of survey participants (**45%**) underwent surgical lung biopsy—an invasive, expensive and sometimes painful procedure—as part of their diagnosis
- Survey respondents reported that the Pulmonary Fibrosis Foundation (**60%**) and their personal physicians (**52%**) were the two most valuable sources of information about ILD during their diagnostic journey

To download the infographic with the full survey results (shown left), go to [bit.ly/PFFVeracyteSurvey](http://bit.ly/PFFVeracyteSurvey).



# research

## PUTTING YOUR DOLLARS TO WORK

### NIH Supports Studies Which Resulted from PFF-Funded Preliminary Research

The Pulmonary Fibrosis Foundation (PFF) directly funds research, promotes advocacy and fundraising efforts, and assists in developing collaboration between industry and academic researchers. Two researchers are currently engaged in National Institutes of Health (NIH)-supported projects that began as smaller initiatives funded by the PFF.



#### THE ROLE OF AGING IN POST-INJURY LUNG REPAIR

The incidence of idiopathic pulmonary fibrosis (IPF) increases with age, but little is known about why aging increases the risk for lung disease. Research examining the relationship between aging and the inability of the lung to repair itself after injury, as occurs in IPF, could lead to new ways to prevent lung scarring.

Research led by the University of Pittsburgh's Mauricio Rojas, MD has shown that aging increases the susceptibility of the lung to chronic injury in mice. Additionally, the Rojas team has found that a special kind of cell, called a bone marrow-derived mesenchymal stem cells (MSCs), loses its ability to turn into other cells as mice get older. This research was recently funded by a \$2.5 million grant from the NIH.

"The biological consequences of aged MSCs and why they exhibit a functional impairment is not well known," Dr. Rojas says. "Our preliminary data, mostly generated with support from the PFF, was used to generate the novel hypothesis that defective lung repair in aging is associated with dysfunctional activation, proliferation, and mobilization of MSCs."

"We are confident this will help us to understand the pathogenesis of IPF and provide insights for the development of novel strategies for tissue repair," Dr. Rojas says.

Dr. Rojas' NIH support sprang from a preliminary research study, "Aging of Stem Cells and Disease Susceptibility," supported by the PFF's Albert Rose Established Investigator Award.

#### About Mauricio Rojas, MD

Dr. Rojas completed his undergraduate and medical education at the National University of Colombia in 1987, and continued his education in Immunology at the National Institute of Immunology in Colombia from 1987 to 1991. He was a Research Associate at the same institution and became the Scientific Director of the Vaccine Clinical Trials in 1992. Dr. Rojas joined the Department of Microbiology and Immunology at Vanderbilt University in 1994. He was a visiting scientist and a post-doctoral fellow when he developed a novel system to cell permeabilize proteins denominated MTS (membrane translocating sequence) that was patented worldwide by Vanderbilt University.

In 2002, Dr. Rojas served as a junior faculty member at the Center for Translational Research in the Lung Division of Pulmonary and Critical Care at Emory University. While there he developed an independent scientific career by studying the role of bone marrow derived mesenchymal stem cells in lung injury and repair. His work resulted in seminal contributions in understanding the immunomodulatory

mechanisms used by the mesenchymal stem cells. His work has been internationally recognized and supported by several grant awards from the National Institutes of Health, the American Federation of Aging, and other institutional grants.

In 2010 Dr. Rojas was recruited to the University of Pittsburgh where he is an Associate Professor at The Dorothy P. and Richard P. Simmons Center for

Interstitial Lung Disease at the Division of Pulmonary, Allergy and Critical Care Medicine, Department of Medicine, University of Pittsburgh; a Faculty Member at the McGowan Institute of Regenerative Medicine, University of Pittsburgh; and a faculty member of the Regenerative Medicine and Stem Cell Research Center at The University of Pittsburgh.

## THE EFFECT OF LACTATE ON LUNG SCARRING

People who receive radiation therapy for cancer in the chest, including lung and breast cancer, can suffer from injury and inflammation of the lungs. These side effects can lead to serious medical problems, including pulmonary fibrosis.

The NIH recently funded a research grant, “Lactate Promotes Scarring after Irradiation,” which will help a research team at the University of Rochester led by Patricia J. Sime, MD; Jackie Williams, PhD; Richard P. Phipps, PhD; and R. Matt Kottmann, MD, to perform important new research to better understand mechanisms involved in driving radiation-induced pulmonary fibrosis. The NIH provided over \$1.5 million to support this important research.

Previously these researchers made a key discovery that people living with pulmonary fibrosis have high amounts of the lactic acid (also known as lactate) in their lungs. Lactic acid is produced by cells in the body when there isn't enough oxygen available. These researchers found that the lactic acid produced in the lungs activates special scar-forming cells, called myofibroblasts.

“The research newly funded by the NIH grant will examine the mechanisms by which radiation therapy causes the lung to produce lactic acid, and importantly whether blocking lactic acid production can prevent lung fibrosis,” Dr. Sime says. She and her team are hopeful these studies will help identify new therapies for patients with radiation-induced and other types of pulmonary fibrosis.



The support of the PFF from 2011–13 was essential in generating key research findings in tissue and cells from lung biopsies to help support the concept that abnormal lactate levels occur in patients with lung scarring. Funding for the PFF grant was provided by proceeds from the annual Greg Chandler and Guy F. Solimano Memorial Golf Tournament in Rochester, New York. “The team is very grateful for this support, as it served as a catalyst to propel this new and exciting research plan forward,” Dr. Sime says.

### About Patricia J. Sime, MD, FRCP

Dr. Patricia J. Sime received her MD training at the University of Edinburgh, Scotland where she graduated with honors. She went on to do her Residency and Fellowship training in pulmonary medicine in Edinburgh. After being awarded the Medical Research Council and Parker B. Francis Fellowships she went to McMaster University, Ontario, Canada to train in fibroblast biology and the mechanisms of lung inflammation and repair. In 1999, she joined the faculty of the University of Rochester as a physician scientist.

Dr. Sime is the C. Jane Davis & C. Robert Davis Distinguished Professor in Pulmonary Medicine, and is currently Professor of Medicine, Chief of the Pulmonary and Critical Care Division and Co-Director of the Mary Parkes Center for Asthma, Allergy and Pulmonary Care at University of Rochester Medical Center. She is director of the Interstitial Lung Disease Clinic at the University of Rochester and co-directs the PFF Care Center Network site there. She is also Associate Chair for Research in the Department of Medicine.

Dr. Sime specializes in the treatment of patients with lung inflammatory and fibrotic diseases and the discovery of the critical pathways that drive lung inflammation and fibrosis (scarring). Her laboratory studies are focused in identifying novel therapies for those diseases with fibrosis as their hallmark. She is the principal investigator on a number of NIH awards to fund translational studies and has authored numerous publications in the area of lung scarring, inflammation and COPD. Dr. Sime and her team are excited to bring these new discoveries to the care of patients with these lung diseases that currently have few effective, long-term treatments.

To learn more about the PFF Research Fund or to apply for a grant, visit [pulmonaryfibrosis.org/research/PFFgrants](http://pulmonaryfibrosis.org/research/PFFgrants).

# BROADWAY BELTS FOR PFF!

## Melodies of Broadway In Tune With Finding a Pulmonary Fibrosis Cure

**Music does more than soothe the soul—it's a tool for positive change, too.** For the sixth consecutive year, Broadway's finest joined forces in New York City February 29 to raise funds to battle pulmonary fibrosis (PF). In efforts to fund research toward a cure, award-winning actress

and dedicated Pulmonary Fibrosis Foundation (PFF) advocate Julie Halston hosted *Broadway Belts for PFF!* Uniting some of Broadway's best vocal talent, patrons, and key members of the PF community, the event—held for the first time this year at the historic Edison Ballroom—was a night of spectacular entertainment and raised \$180,000 to benefit the PFF.

Halston hosted the program for the sixth time with her irrepressible wit and skillful narration. She most recently appeared in the hit Broadway show *You Can't Take it With You*. Under the musical direction of Christopher McGovern and returning director Carl Address, who has directed all six of the *Broadway Belts for PFF!* performances, this year's cast of stars included Tony Award winners Randy Graff (*City of Angels*), Cady Huffman (*The Producers*), Judy Kaye (*Phantom of the Opera*, *Nice Work If You Can Get It*), Grammy Award winner Daveed Diggs (*Hamilton*), Telly Leung (*Allegiance*), Robert Creighton (*The Mystery of Edwin Drood*), Lisa Howard (*It Should Have Been You*), Margo Seibert (*Rocky*), Hunter Ryan Herdlicka (*Once Upon a Mattress*) and Zakiya Young (*Disgraced*, *Orange is the New Black*).

This year's energetic cabaret-style show included a commanding performance from Daveed Diggs of this year's Grammy award-winning *Hamilton*, who debuted his original rap, "Breathe." Written specifically for the event and inspired by the evening's theme, Diggs' song detailed the difficulties of living with this debilitating disease, declaring "at times it feels dangerous to use my voice," alluding to the very real need to conserve one's breath.

*Broadway Belts for PFF!* began in 2011 as an evening to honor beloved Associated Press theater critic and reporter Michael Kuchwara. In May 2010, Kuchwara passed away from complications due to idiopathic pulmonary fibrosis (IPF). Halston, a friend of Kuchwara, became a leading spokesperson for the PFF after her husband, broadcaster Ralph Howard, received a lung transplant due to IPF shortly after Kuchwara's passing.



Daveed Diggs and Julie Halston

## stay tuned...

### Broadway Belts 2017 to be announced!



Telly Leung



Cady Huffman, Randy Graff, and Judy Kaye



Lisa Howard

## Thank you to our performers!





Cast members belted "Give My Regards to Broadway" for the finale.



Zakiya Young

"We are incredibly grateful to our dear friends and producers Julie Halston, D. Michael Dvorchak, Ed Windels, Sue Frost, and Carl Andress for the magic they weave into making this extraordinary event come alive. Broadway Belts for PFF! always features people with such amazing talent who care deeply about helping others, which means a great deal to the pulmonary fibrosis community."

PATTI TUOMEY, EDD / PFF PRESIDENT AND CEO

## The Foundation thanks the 2016 Broadway Belts for PFF! Sponsors

### PRODUCER'S GUILD

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*A Member of the Roche Group*

### PRESENTING SPONSOR

Doug & Gay Lane Charitable Foundation

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at Yale School of Medicine  
(PFF Care Center Network site)

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Robert Ezykovich

The France Foundation

Jennifer Galvin

Mike & Donna Henderson

InspiRx

Kevin & Karen Lane

Joseph & Kathleen Masterson

Robert & Patricia Ross on behalf of FARE

Bruce T. Sloane

Steve & Joan Wald

Special thanks to Sam Rudy

Broadway Belts for PFF! has raised almost **\$700,000** for the Michael Kuchwara Fund for Idiopathic Pulmonary Fibrosis Research, Education, and Advocacy.

Visit [pulmonaryfibrosis.org/broadwaybelts](http://pulmonaryfibrosis.org/broadwaybelts) for more information.



# PFF SUMMIT FROM BENCH TO BEDSIDE 2015

**A record number of more than 700 researchers, health care professionals, pulmonary fibrosis (PF) patients, caregivers, and industry leaders gathered in Washington, DC, November 12–14**

for the Pulmonary Fibrosis Foundation's third biennial *PFF Summit: From Bench to Bedside*. The event provides a collaborative environment aimed at improving education and awareness of PF and identifying new approaches to treat, manage, and ultimately cure the disease.

Pat Furlong



The *PFF Summit 2015* featured new plenary sessions for the entire PF community and two keynote addresses. “The Future of Drug Development in Pulmonary Fibrosis—A Regulatory Perspective” was delivered by Janet Woodcock, MD, Director, Center for Drug Evaluation and Research at the Food and Drug Administration on November 13 and “Collaborative Networks as Tools for Improving Clinical Care” was presented by Pat Furlong, president and chief executive officer, Parent Project Muscular Dystrophy, on November 14.

During the *Summit's* Networking Dinner, the PFF announced the commitment of an unrestricted \$1 million bequest, which was made by Daniel M. Rose, MD, PFF board member and immediate past CEO, his wife, Ellen M. Pinson, and family.

“Dr. Rose has and continues to be an exceptional advocate for the PF community. We're deeply grateful for this bequest, which will support Foundation programs and research initiatives,” says Patti Tuomey, EdD, PFF President and CEO.

“He's created a fitting legacy through his tireless commitment, creative vision and generous giving.”

On the following pages are a few more *PFF Summit* highlights.



David J. Lederer, MD



Harold R. Collard, MD

# highlights



Gregory P. Cosgrove, MD

## EMPOWERING PF COMMUNITY MEMBERS TO BECOME ADVOCATES

Practicing advocacy—seeking to influence public policy for a specific purpose—can be intimidating to newbies. In “Making Your Voice Heard: Effective Advocacy for Pulmonary Fibrosis,” a *PFF Summit* session presented by psychologist, communications consultant, and former Congressman Brian Baird, attendees learned why PF patients, families, researchers, and health care professionals are the best possible advocates for PF. Baird simplified and demystified the advocacy process with tips on how PF advocates can effectively carry their personal stories to elected and appointed officials.

“Dr. Baird explains in bite-sized bits how to approach politicians, get their attention, and get your point across,” says Jennifer Bulandr, PFF Director of Social Media and Community Engagement. “Everyone left the meeting with an easy-to-follow plan, and the encouragement and knowledge to follow through.” To learn more about becoming a PF advocate, contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).



## FOCUS GROUPS OFFER KEY FEEDBACK ON PATIENT ED MATERIALS

A service- and support-oriented organization is most successful when it checks in regularly with its key audiences. A series of *PFF Summit* focus groups explored how several constituencies use PFF patient education materials and asked for ways these can be improved.

“We hosted focus groups for patients, caregivers, and health care professionals,” explains Laura Sadler, PFF Chief Program and Business Development Officer. “Some of the feedback we received suggested we incorporate shorter webinars; others asked for more disease awareness materials to help spread the word about PF and what it involves. Those materials are already in motion, and we’re glad to see our thinking as an organization is in sync with what our focus groups are requesting.”

The PFF is building regular feedback mechanisms into its calendar: Similar focus groups will take place at other *PFF Summits* and volunteer meetings.

## SUPPORT GROUP LEADERS HEAR GOOD NEWS

Attendees at a *PFF Summit* meeting for support group leaders and participants learned about recent increases in Support Group Leader Network (SGLN) resources and funding. Participants received an update on the large expansion of PF support groups—there are now 84 in the US, spread among 32 states—as well as news about increased grants for support group activities. Chairs of the three SGLN steering committee work groups shared overviews of their recent work on a revised leader guide, training webinars, and grant review process. (See page 10 for details on Support Group Leader Network expansions.)

## Summit webinars now available online

Missed the PFF Summit? Attended but want to delve a little deeper?

Summit webinars are now viewable online at [pffsummit.org](http://pffsummit.org)



## POSTER PRESENTATION SPOTLIGHTS NOTABLE RESEARCH

The *PFF Summit* accepted a record number of abstracts for its poster presentation. Generously sponsored by the Pete DeVito Memorial Foundation, the poster presentation recognizes original ideas that will help improve the understanding of pulmonary fibrosis in the areas of basic research, translational research, clinical research, and social science/quality of life research.

Winners received monetary awards and presented their research during the *PFF Summit*. Of the 64 posters eligible for awards, the top five winners were: Robert Guzy, Washington University School of Medicine; Justin Oldham, University of Chicago; Rachel Scheraga, Cleveland Clinic Foundation; Louise Hecker, University of Arizona; and Renea Jabolonski, Northwestern University Feinberg School of Medicine.

## RESEARCH ADVISORY FORUM HOLDS FIRST MEETING

The newly formed Research Advisory Forum (RAF) held its first in-person meeting at the *PFF Summit*. Designed to promote PF research and scientific discovery, the RAF, chaired by PFF Senior Medical Advisor Harold R. Collard, MD, includes a diverse group of stakeholders, including clinicians, researchers, patients, and industry representatives, with input from appropriate regulatory agencies.

The committee identified several priorities for its first year:

- Promote research into diagnosis and management barriers in pulmonary fibrosis
- Promote stakeholder collaboration in pre-clinical drug development
- Develop tools for increased efficiency in proof of concept clinical development (e.g., biomarkers, measures of disease activity)
- Promote a clinical trial network to streamline trial administration and improve recruitment efficiency



At the American Thoracic Society meeting this spring, the RAF is meeting again to set specific actions in key priority areas.



## ROUNDTABLE DISCUSSION TAPS VOLUNTEER INSIGHTS

As the Foundation implements a long-term strategic plan for its next phase of growth through 2020, volunteers will be a key part of that outreach. A special roundtable discussion at the *PFF Summit* brought together support group leaders, PFF Ambassadors, *Team PFF* event leaders, and other volunteers to discuss future directions.

“Participants included planners of large and small *Team PFF* events, patients, caregivers, nurses, and former caregivers who want to stay involved although their loved ones have passed away,” says Angela Perillo, PFF Director of Development.

“We asked them, ‘Where do you see your involvement with the Foundation in 2020? How should we and can we evolve, and what would you like your role to be as your loved ones or patients pass through the stages of the disease?’ It was a great discussion with valuable feedback for our organization,” Perillo adds. At another meeting for volunteers planned for November 9–11, volunteers will be recognized for their efforts to support the PFF and the PF community.

## share your feedback

### The PFF is listening and wants to hear from you!

Contact the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org) to share your ideas about how the Foundation can best serve the PF community.

## Offers Unique Opportunity to Pulmonary Fibrosis Community

The Pulmonary Fibrosis Foundation (PFF) announces its partnership with PatientsLikeMe, a website where patients can share their experiences and learn from real-world, outcome-based health data. Through the website, people can:

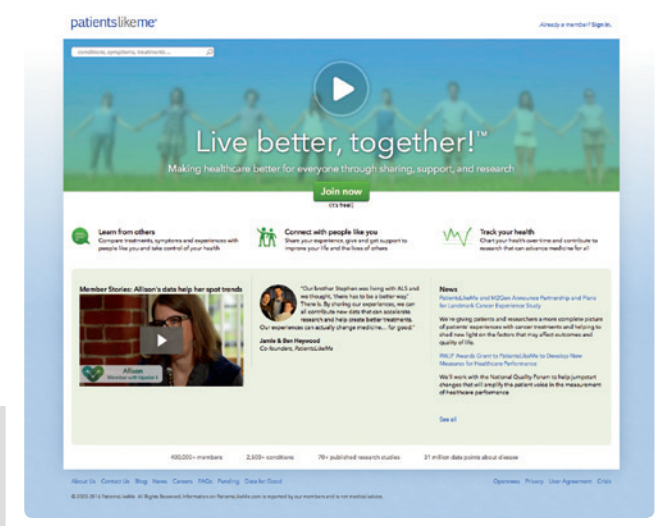
- Compare treatments, symptoms, and experiences
- Give and get support from to other patients who share similar experiences
- Track their health over time and contribute to research that may one day advance medicine for all

“This partnership marks the first time the PFF is able to offer the unique tools PatientsLikeMe provides through its website to the PF community,” says Patti Tuomey, EdD, PFF President and CEO. “The Foundation is looking forward to providing even greater patient engagement and improved outcomes thanks to this engagement.”

PatientsLikeMe was founded in 2004 by three MIT engineers: brothers Benjamin and James Heywood and longtime friend Jeff Cole. Their brother and friend Stephen Heywood was diagnosed with ALS (Lou Gehrig’s disease) at the age of 29. The Heywood family began searching for ideas that would extend and improve Stephen’s life. Inspired by Stephen’s experiences, the

founders and team conceptualized and built a health data-sharing website they hope will transform the way patients manage their own conditions as well as positively change research and patient care.

To learn more about PatientsLikeMe, visit [pulmonaryfibrosis.org/life-with-pf/support-groups/online-support-communities](http://pulmonaryfibrosis.org/life-with-pf/support-groups/online-support-communities).



## The work of the Pulmonary Fibrosis Foundation (PFF) has received notable media coverage in the past few months:

### THE PFF'S DAVID LEDERER MAKES A SPLASH ON SIRIUS

PFF Senior Medical Advisor David J. Lederer, MD, MS, discussed pulmonary fibrosis (PF) on the December 29, 2015 *Doctor Radio* show on the 29 million subscriber-strong SiriusXM Radio. Jennifer Buland, PFF Director of Social Media and Community Engagement, live-tweeted the energetic segment, which resulted in a flurry of Twitter activity on the topic of PF. See the unfolding story on Storify: [bit.ly/dr-lederer-docradio](http://bit.ly/dr-lederer-docradio)

### PFF SUMMIT RECEIVES COVERAGE IN LANCET

Bryant Furlow covered *PFF Summit 2015: From Bench to Bedside* for the News section of *The Lancet Respiratory Medicine*. One of the most prestigious medical journals in the world, *The Lancet* is an independent, international weekly general medical journal founded in 1823. The *Lancet Respiratory Medicine* launched in 2013 and is the fourth largest Lancet specialty journal. [bit.ly/pffsummit-lancet](http://bit.ly/pffsummit-lancet) (subscription only)

### FROM A PATIENT'S PERSPECTIVE

Reporter Christine Blank interviewed PFF Ambassador Pete Mulliner (also see page 9), a speaker during the *PFF Summit 2015* session, “Patient Perspective: Living Well with Pulmonary Fibrosis”. The result: a thoughtful December 18, 2015 piece on how physicians can help idiopathic pulmonary fibrosis (IPF) patients, published in the online publication *Formulary Watch*. [bit.ly/mulliner-formularyjournal](http://bit.ly/mulliner-formularyjournal)



# 2016 CALENDAR

View a current list of events at  
[pulmonaryfibrosis.org/get-involved/attend-an-event](http://pulmonaryfibrosis.org/get-involved/attend-an-event)

## PF COMMUNITY EVENTS

### MAY 13–18 • PFF @ ATS 2016 International Conference

American Thoracic Society  
SAN FRANCISCO, CALIFORNIA

### JUNE 8–11 • The Aspen Lung Conference 2016: “Lung Transplantation: Opportunities for Repair and Regeneration”

ASPEN, COLORADO

### JUNE 17–19 • Pulmonary Hypertension Association International Conference 2016

Pulmonary Hypertension Association  
DALLAS, TEXAS

### JULY 29–31 • PFF @ Scleroderma Foundation 2016 National Patient Education Conference

Scleroderma Foundation  
NEW ORLEANS, LOUISIANA

### SEPTEMBER • Global Pulmonary Fibrosis Awareness Month 2016

Pulmonary Fibrosis Foundation  
WORLDWIDE

### SEPTEMBER 7–10 • American Association of Cardiovascular and Pulmonary Rehabilitation Annual Meeting

American Association of Cardiovascular and Pulmonary Rehabilitation  
NEW ORLEANS, LOUISIANA

### SEPTEMBER 17–25 • IPF World Week

AMA Fuori dal Buio  
WORLDWIDE

### OCTOBER 15–18 • American Association for Respiratory Care Congress 2016

American Association for Respiratory Care  
SAN ANTONIO, TEXAS

### OCTOBER 22–26 • PFF @ CHEST 2016

American College of Chest Physicians  
LOS ANGELES, CALIFORNIA

### OCTOBER 27–29 • PFF @ 30th Annual North American Cystic Fibrosis Conference

Cystic Fibrosis Foundation  
ORLANDO, FLORIDA

### NOVEMBER 9–11 • PFF Volunteer Meeting

Pulmonary Fibrosis Foundation  
CHICAGO, ILLINOIS

## TEAM PFF EVENTS

### MAY 22 • Charity Trail Day

SOUTH WINDSOR, CONNECTICUT

### MAY 25 • Country Spotlight for PFF!

ST. LOUIS, MISSOURI

### JUNE 4 • 6th Annual Pete DeVito Memorial Foundation Golf Outing

MT. SINAI, NEW YORK

### JUNE 4 • 2016 Newport Oregon Marathon in Honor of Robert Lager

NEWPORT, OREGON

### JUNE 11 • 2016 Timberline Marathon

TIMOTHY LAKE, OREGON

### JUNE 12 • 9th Annual Greg Chandler & Guy F. Solimano Golf Tournament

WEBSTER, NEW YORK

### JUNE 18 • Rock N Roll Marathon for PF

SEATTLE, WASHINGTON

### JUNE 25 • NYC Run-Walk-Hike for Pulmonary Fibrosis

NEW YORK, NEW YORK

### AUGUST 6 • Tee It Up with Twisters Inaugural Golf Outing Benefitting Pulmonary Fibrosis

BATH, MICHIGAN

### SEPTEMBER 17 • 8th Annual Garden State Support Group 5K Run/Walk

CRANFORD, NEW JERSEY

### SEPTEMBER 18 • 2nd Annual Jim Cormier Canal Walk for Pulmonary Fibrosis Foundation

BUZZARDS BAY, MASSACHUSETTS



## IN THE NEWS

### AP SHARES THE PF STORY

The Associated Press (AP) wrote and distributed a story on the 2016 *Broadway Belts for PFF!* gala fundraiser at the Edison Ballroom in Manhattan, hosted by longtime PFF advocate and Broadway star Julie Halston. News coverage by the AP is some of the broadest, most extensive reporting available today. The AP is a multinational nonprofit news agency owned by its contributing newspapers and radio and television stations. News collected by the AP is published and republished by as many as 1,400 newspapers and thousands of radio and TV broadcasters. [bit.ly/broadwaybelts-apnews](http://bit.ly/broadwaybelts-apnews)

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## PFFSUMMIT2017

Visit [pffsummit.org](http://pffsummit.org) for updates on dates and location!



## CHEST 2016 | LOS ANGELES

OCTOBER 22-26, 2016

## VISIT THE PFF BOOTH



## PFF VOLUNTEER MEETING

NOVEMBER 9-11, 2016

## save the date!

[pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)