

PULMONARY FIBROSIS FOUNDATION

Breathe

BULLETIN

VOLUME 16 | ISSUE 02

FALL 2016

in this issue

BREATHE BULLETIN VOLUME 16 | ISSUE 02 FALL 2016



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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.

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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LETTER FROM OUR PRESIDENT AND CEO



DEAR FRIENDS,

The Pulmonary Fibrosis Foundation (PFF) has marked many milestones the past few years, and I'm thrilled to announce another special one: We've enrolled our 300th individual in the PFF Patient Registry.

Working in tandem, the PFF Care Center Network (CCN) and the PFF Patient Registry are dramatically increasing and improving research, patient care, and our understanding of the disease. The more individuals enroll in the Registry, the more we amass critical data that will lead the way to new treatments, best practices, and eventually, a cure.

We are also pleased with progress we've made this year on several of our ground-breaking programs. The PFF Patient Communication Center, a centralized resource for information about pulmonary fibrosis (PF) and the Foundation, has new educational materials available. The PFF Ambassadors are thriving as they take their personal stories on the road to spread the word about PF. The PFF Support Group Leader Network offers a new toolkit that makes it easier than ever to start or revitalize a support group. On the heels of Global Pulmonary Fibrosis Awareness Month, we provided real-time translations of a fundamental PFF Disease Education Webinar into several languages.

We know health care professionals need more information about diagnosing, treating, and managing pulmonary fibrosis. Our continuing medical education (CME) offerings are expanding to fill the gap with a supplement based on the *PFF Summit 2015: From Bench to Bedside* and two new physician simulations.

You helped make Global Pulmonary Fibrosis Awareness Month a smashing success. Our community sponsored *Team PFF* events, walked Capitol Hill to convince legislators to support research funding, and shared personal stories on social media. With every year's observance in September, we raise more awareness and motivate more people to contribute to programs that significantly improve the lives of PF families.

Please remember the Pulmonary Fibrosis Foundation on Giving Tuesday, November 29. On this day dedicated to giving back, cause-centered people share a common purpose: celebrating and modeling generosity. With your gift, we can finish 2016 strong. **Thank you for your untiring efforts as a #PFWarrior**—you make an extraordinary difference in the PF community.

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

PATTI TUOMEY, EdD
PRESIDENT AND CHIEF EXECUTIVE OFFICER

MAJOR PFF PRIORITIES MAKE HEADWAY

With 300th Patient Enrolled, The PFF Patient Registry is Off to Strong Start

Two major, intertwined priorities of the Pulmonary Fibrosis Foundation (PFF) are the PFF Care Center Network (CCN) and the PFF Patient Registry. Together, they represent one of the most promising steps forward in the diagnosis, treatment, and quality of life for pulmonary fibrosis (PF) patients and their families.

Networking Research and Best Practices

The CCN is a collaboration of clinical sites across the United States that specialize in the diagnosis and treatment of interstitial lung disease (ILD) and PF. Sites have been selected for their expertise in accurate diagnosis of ILDs, excellent patient care, and ongoing involvement in research into the causes and treatments of PF.

A primary CCN goal is improving quality of care. “We’ll compare the various care practices of these sites against how their patients respond to identify those activities that provide the greatest benefit,” says Kevin R. Flaherty, MD, MS, PFF Steering Committee Chair for the CCN and Registry. “What we learn will ultimately be used to develop improved disease management guidelines, not only to improve the care at CCN sites, but also for all health care providers dealing with these devastating diseases.” In fact, even though the CCN currently includes 40 sites, the plan is for the Network to expand its reach by building partnerships with community care providers whose practice and outcomes can benefit from CCN expertise.

A second goal of the CCN is facilitating PF research. Researchers at all CCN sites are performing important studies among their patients. “The Network allows us to expand the scope of this research across multiple sites to speed our understanding of the causes of PF and how different patients will respond to the disease, as well as support the development of new treatments,” Flaherty says.

CCN SITES OBSERVE GLOBAL PULMONARY FIBROSIS AWARENESS MONTH

During Global Pulmonary Fibrosis Awareness Month, several CCN sites hosted educational events for the community and health care providers. Highlights included the Second Annual **Bourbon & Barbeque** event at the University of Louisville, Kentucky; a **Pulmonary Fibrosis Awareness Symposium** at Piedmont Hospital, Atlanta, Georgia; and the Eighth Annual **ILD Patient Appreciation Luncheon** at the University of California, San Francisco.

PFF PATIENT REGISTRY

PFF CARE CENTER NETWORK

Pulmonary Fibrosis
FOUNDATION

HELP THE CCN AND REGISTRY SUCCEED



An Invaluable Patient Database is Born

A primary example of CCN research is the PFF Patient Registry, which is currently enrolling patients to create the largest research database of all-cause PF. Unlike a single-center registry, the PFF Patient Registry includes a broader population base, invites comparisons between variable practice patterns, and enables the study of patients from diverse geographic areas.

The Registry enrolled its first patient in March 2016 and has greatly exceeded early expectations, with more than 300 patients now enrolled. The goal is to enroll 2,000 patients by 2018.

“Right now, 30 CCN sites are participating in the Registry,” says Rex Edwards, Vice President, PFF Care Center Network and PFF Patient Registry. “We hope all 40 sites will eventually participate and also plan to develop partner sites outside the Network.”

A related initiative, a biorepository, lets patients choose to donate blood for future research. So far, participation is close to projected estimates, with nearly 90% of patients enrolled in the Registry choosing to participate in the biorepository.

To keep the momentum going, the CCN and Registry need the participation of donors, patients, and researchers.

SUPPORT → Support from individuals, corporations, and organizations will sustain and expand these critical initiatives, as well as development of a therapeutics network facilitating the development of new drugs to treat and cure PF and other ILDs.

ENROLL → If you’re a patient with a scarring disease of the lung who is not enrolled in the Registry and biorepository, consider participating in this ground-breaking data collection effort—your involvement could help change the lives of future patients.

STUDY → The collected data is not yet mature enough to support specific research, but the PFF is currently collecting information on investigators’ research interests, as well as preparing materials to help researchers determine whether their research can effectively use CCN and Registry resources. The PFF will soon welcome proposals for substudies.

For more information about how you can help the CCN and Registry succeed, call the PFF office at 888.733.6741.



LEARN MORE ABOUT OTHER PFF PROGRAMS

The CCN and Registry are just two of the PFF’s forward-looking programs. In this issue of the *Breathe Bulletin*, read more about—and get involved with—the **PFF Patient Communication Center** (see page 6), **PFF Ambassadors** (page 7), **Support Group Leader Network** (page 7), **PFF Daughters** (page 8), and **PFF Disease Education Webinars** (page 8).

PFF PROGRAMS UPDATE

The PFF Patient Communication Center: Central Hub for Info and Resources

Have questions—general or specific—about pulmonary fibrosis (PF)? Need a hand finding resources and support? The PFF Patient Communication Center (PCC) is the central information resource for patients, families, caregivers, and health care providers. The PCC staff answers questions via phone and email, providing personalized information for each individual. Available services and resources include:



- Accurate, up-to-date information about pulmonary fibrosis
- Help finding PFF Care Center Network sites and other medical centers that treat interstitial lung disease, access in-person and online support groups, and obtain available treatment options
- Information on disease management, supplemental oxygen, and pulmonary rehabilitation
- Guidance on finding financial assistance for IPF medication
- Information on lung transplantation
- Help locating clinical trials and PFF Patient Registry sites (also see page 5)
- Information about caregiving, palliative care, and hospice
- PFF educational materials for patients and health care professionals
- Information about PFF programs
- PFF Disease Education Webinar Series information and archive (also see page 8)

“The PFF Physician Notepad is an excellent tool for keeping track of a patient’s information. I suggest patients write down the questions they have for their doctor ahead of time, and also have their doctor make notes about needed tests, referrals, etc.”

MICHELE PETERS / PFF AMBASSADOR AND SUPPORT GROUP LEADER

New Educational Materials

Updated educational materials now available through the PCC include both English and Spanish versions of the popular PFF Physician Notepad, an updated PF Information Guide (formerly the Patient Information Guide) and a revised PFF Clinic Poster. The recently introduced ILD Physician Pocket Guide is also available in English.

The PFF Patient Communication Center is open Monday through Friday from 9:00 a.m. to 5:00 p.m. (Central time). Contact the PCC with questions or to request materials at **844.TalkPFF** (844.825.5733) or pcc@pulmonaryfibrosis.org.



PFF Ambassadors: Sharing Stories to Build Connections, Awareness

Every member of the pulmonary fibrosis (PF) community has a unique story to tell, and sharing a personal experience is a powerful way to engage and educate. The Pulmonary Fibrosis Foundation's PFF Ambassador program empowers patients, caregivers, and health care professionals to become spokespersons for the PF community. Patient and caregiver Ambassadors focus on their own PF journeys, while Ambassadors who are health care professionals provide disease education and management information.

The PFF welcomes several new members to its cadre of Ambassadors: Dot Delarosa, Heather Kagel, John Mullin, Barbara Murphy, Emily Prin, Alejandro Puebla, and Jim Rock.

Interested in booking a PFF Ambassador for your support group or other event? Contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.825.5733) (844.825.5733) or pcc@pulmonaryfibrosis.org.

Support Group Leader Network: Jump-Start Your Group

It's never been easier to start or revitalize a pulmonary fibrosis (PF) support group. The PFF Support Group Leader Network offers a three-part webinar series on starting and running a support group, plus a retooled Support Group Leader Guide. "These tools are designed for both new and existing support groups—they guide novice and seasoned leaders through creating and sustaining successful groups," says Kate Gates, PFF Manager, Volunteer Programs. In addition, the Leanne Storch Support Group Fund provides grants that help groups create more effective, welcoming meetings.

Cheryl and Pete French took full advantage of the PFF's assistance when starting a support group that meets at the Integris Baptist Medical Center (IBMC) in Oklahoma City, Oklahoma. Active in a Houston-area group since Pete's diagnosis with PF in 2012, the Frenches decided to lead the formation of a much-needed Oklahoma City group when they moved after retirement. The couple joined forces with Lisa Ball, IBMC Outpatient Pulmonary Disease Management Clinic Manager, to make sure area health care centers and providers were aware of the new group. The group has already doubled in size after just four meetings.

Ball and the Frenches plan meetings around a variety of topics. "At our first gathering, we went over how to be prepared for severe weather—common in Oklahoma!—when using oxygen," says Ball. "At another meeting, we went through the PFF website and made attendees aware of all the available resources."

"The Foundation has been marvelously supportive and helpful, directing us to the right resources," says Cheryl. "Just one example: within seven days of our group's formation, they had our contact information up on the PFF website."

Although the PFF welcomes participation everywhere, these states are in particular need of support group leadership:

Alaska	Mississippi	South Dakota
Arkansas	Montana	Vermont
Delaware	Nebraska	West Virginia
Iowa	Nevada	Wisconsin
Kansas	New Hampshire	Wyoming
Maine	Rhode Island	

To learn more about starting a support group, contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.825.5733) (844.825.5733) or pcc@pulmonaryfibrosis.org.

...a way for its members to magnify their own efforts through fundraising and advocacy.

PFF Daughters: Members Draw Strength From Shared Experience

Family members tend to be the strongest advocates for people living with pulmonary fibrosis (PF). Members of PFF Daughters, a network of leaders, volunteers, advocates, and fundraisers dedicated to helping the PFF achieve its mission, are bringing their family PF connections to the larger “family” of the program.

“Everyone in PFF Daughters is either dealing with PF on a daily basis or has lost a loved one to the disease,” says Lisa Boyd, the group’s new steering committee chair. Boyd, who lost her father to PF, sees PFF Daughters as a way for its members to magnify their own efforts through fundraising and advocacy.

“When the opportunity came up to join PFF Daughters, I said, ‘This is the perfect fit for me,’” Boyd recalls. “It’s powerful to have a group of people who’ve had the same experience and come out of it knowing we can collectively work together for better outcomes.”

Recently, PFF Daughters focused its efforts on the Hike for Lung Health. Centered in Chicago, the hike was joined remotely by walkers across the country—including Boyd herself, who hiked with friends while on vacation in Arizona and Utah on the date of the event (also see page 12).

To learn more about how you can get involved, contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.TalkPFF) (844.825.5733) or pcc@pulmonaryfibrosis.org.

PFF Disease Education Webinar Series: Going Multilingual

A favorite tool of the pulmonary fibrosis (PF) community, the PFF Disease Education Webinar Series explores topics that are important to those impacted by the disease. Webinars are broadcast throughout the year with suggested topics from the community and recorded for on-demand viewing.

In honor of Global Pulmonary Fibrosis Awareness Month, the September webinar went “back-to-basics” but expanded its reach with a “What is PF?” presentation translated in real-time to Arabic, Hindi, Mandarin, Polish, Russian, Spanish, Urdu, and Vietnamese. Recordings in each language are available at pulmonaryfibrosis.org/webinars.

Archived webinars are available 24/7. To register, view webinars, and submit questions for the next presentation in the PFF Disease Education Webinar Series, visit pulmonaryfibrosis.org/webinars. Please share this link with others in the PF community who may be interested in participating.

“I truly feel grateful for the webinar on oxygen equipment usage. The webinar answered all my questions. Thank you again for all your hard work!”

PFF DISEASE EDUCATION WEBINAR SERIES PARTICIPANT



PFF VOLUNTEER MEETING FOCUSES ON PFF STRATEGIC PLAN

Building on last year's first volunteer meeting, which brought together members of all Pulmonary Fibrosis Foundation (PFF) active volunteer constituencies for the first time, the Foundation will hold a second all-volunteer meeting in Chicago in November. Participants will include PFF Ambassadors, as well as representatives of the PFF Care Center Network, *Team PFF*, the Support Group Leader Network, the PFF Board of Directors, and PFF Daughters.

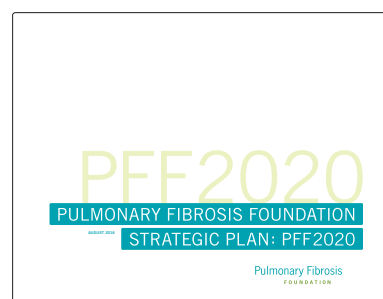
The event is an opportunity for volunteers to network, learn about each other's work, and make a deeper investment in their own involvement. The PFF's newly developed strategic plan will be a cornerstone of the meeting. The first of its kind for the Foundation, Pulmonary Fibrosis Foundation Strategic Plan: PFF2020 "takes a forward-thinking approach at our vision for growth and how our role should drive, support, and impact the growing needs of the entire PF community," says Patti Tuomey, EdD, PFF President and Chief Executive Officer.



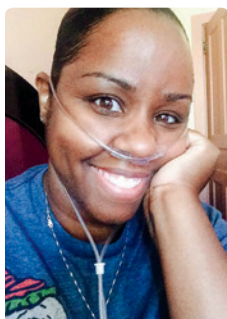
Ready to get involved? Contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.825.5733) (844.825.5733) or pcc@pulmonaryfibrosis.org.

"[PFF2020] takes a forward-thinking approach at our vision for growth and how our role should drive, support, and impact the growing needs of the entire PF community."

PATTI TUOMEY, EDD / PFF PRESIDENT AND CHIEF EXECUTIVE OFFICER



We let the world know.



The pulmonary fibrosis (PF) community spread the word... all around the globe!

From telling their stories on social media, to organizing educational events, to helping the media and legislators better understand the challenges of PF, members of the PF community participated in a wide variety of activities during September's Global Pulmonary Fibrosis Awareness Month—and raised awareness as well as funds for the battle against PF.

global
PULMONARY FIBROSIS
awareness month
SEPTEMBER



Sharing the Message on Social Media

On Facebook, Twitter, and Instagram, #PFWarriors shared their stories (other hashtags: #BlueUp4PF, #GPFAM, #pulmonaryfibrosis).

- **Portraits of PF.** The popular Portraits of PF series on Facebook encourages patients, caregivers, and other members of the PF community to recount their personal PF journeys. During September, the PFF posted a story each day.
- **Downloadable cover and profile photos.** With a downloadable Facebook cover and profile photos, participants spread awareness about PF among their friends and families.
- **30 Facts in 30 Days.** Every day in September at noon, the PFF posted a helpful, surprising, or moving (and shareable!) fact about PF on Facebook, Twitter, and Instagram.
- **#BlueUp4PF.** As part of this social media fundraising and awareness campaign, started by the late PFF Ambassador Diane Reichert, participants wore blue or dyed their hair blue, posted photos on social media, and made contributions to the PFF. New this year: participants posed with downloadable selfie signs and posted their photos on social media.

Thank you to Walgreens Specialty Pharmacy for sponsoring Global Pulmonary Fibrosis Awareness Month Portraits of PF.

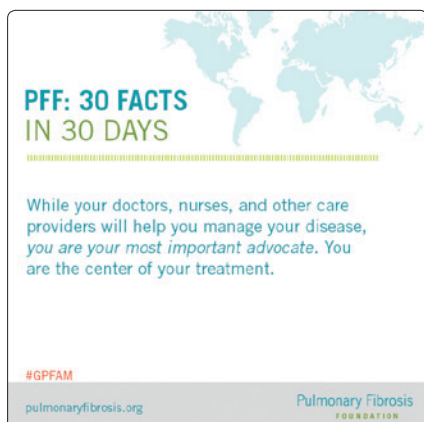
Walgreens Specialty Pharmacy



PFF advocates Cheryl and Larry Runyon participating in #BlueUp4PF.



University of Alabama at Birmingham Pulmonary, Allergy, and Critical Care Medicine faculty pose in blue with selfie signs for #BlueUp4PF.





Staff at the University of Louisville School of Medicine in Louisville, Kentucky



Pete Nelson from Treehouse Masters on Animal Planet (right), with Henry Nelson (left) and Patrick Willse (center)



Staff at East Montgomery Primary Medicine in Montgomery, Alabama



Artwork at Piedmont Healthcare in Atlanta, Georgia



PHOTO: JEFF ALPERIN



Wrigley Building Went Blue

The famed Wrigley Building, a Chicago icon, went PFF blue and green the night of September 2 in honor of Global Pulmonary Fibrosis Awareness Month. Located on Michigan Avenue's "Magnificent Mile" (just blocks away from the PFF Chicago office) the building's lights were visible to countless Chicago residents, tourists, and other visitors from around the world. A sign explaining the significance of the colored lights and meaning of Global Pulmonary Fibrosis Awareness Month greeted all who entered the building through the main lobby.

Thank you to the Wrigley Building for sharing pulmonary fibrosis awareness with Chicago—and the rest of the world!

AMBASSADORS HELP GET THE WORD OUT

In observance of Global Pulmonary Fibrosis Awareness Month, PFF Ambassadors (also see page 13) appeared at a variety of events to share experiences and information:

- **Grand Rapids Pulmonary Fibrosis Support Group Meeting** at Spectrum Health Medical Group / GRAND RAPIDS, MICHIGAN
- **Piedmont Healthcare Pulmonary Fibrosis Awareness Day** (educational symposium) / ATLANTA, GEORGIA
- **University of Texas Southwestern PILOT Regional Conference** / DALLAS, TEXAS
- **University of Utah Salt Lake City PILOT Regional Conference** / SALT LAKE CITY, UTAH
- **Oahu IPF Support Group Meeting** / KAILUA, HAWAII
- **IPF Transitions of Care Pathway Meeting** / WASHINGTON, DC
- **California Institute for Regenerative Medicine Scientific Workshop** / LOS ANGELES, CALIFORNIA

global PULMONARY FIBROSIS awarenessmonth SEPTEMBER

PFF President and
CEO Patti Tuomey, EdD,
with Illinois State Senator
Don Harmon.



Proclamations About PF

Official proclamations help raise awareness of PF, and the Foundation provided sample proclamations to get people started. This year, Illinois State Senator Don Harmon sponsored a Senate resolution to recognize Global Pulmonary Fibrosis Awareness Month, and the team at the Yale School of Medicine PFF Care Center Network site and PFF Ambassador John Morthanos secured a proclamation from Connecticut Governor Dannel P. Malloy.



Pictured, from left to right, at the Yale School of Medicine PFF Care Center Network site: Robert Homer, MD; Naftali Kaminski, MD; Mridu Gulati, MD; John Morthanos, PFF Ambassador; Erica Herzog, MD; Ami Rubinowitz, MD; and Jose Herazo-Mayo, MD.

Karen Lane with Waterville,
Maine, Mayor Nick Isgro, who
read the city's proclamation
during a September city
council meeting.



PFF Daughters Steering
Committee Chair Lisa Boyd
hiking in Horseshoe Bend,
Arizona, as a virtual
participant in the Hike for
Lung Health (left).

One of the Hike for Lung
Health teams walked to honor
the memory of PFF supporter
Liliana Aguirre (below).



Hike for Lung Health

Members of the PF community laced up their real and virtual boots for the Hike for Lung Health, held September 25 in Chicago's Lincoln Park. This year's event brought together 39 teams and over 250 walkers. The fundraising event included a one- and three-mile walk plus lakefront activities including a show by the Jesse White Tumblers, face painting, bouncy houses, and giveaways.

Participants who were unable to make it to the Chicago event were invited to participate and raise funds virtually. Individuals who couldn't travel to Chicago became "virtual walkers," participating in locations of their choice across the country. Lisa Boyd, PFF Daughters Steering Committee Chair, completed her hike during a tour of western national and state parks.

As of September 29, the Hike for Lung Health participants had raised over \$35,000.



PFF Ambassador
Charolette Saunders
holding the proclamation
she helped secure.

PFF Medical Advisory Board Chair, Jesse Roman, MD, at the opening of the Center for Pulmonary Fibrosis at the Mayaguez Medical Center.



Puerto Rico Educational Outreach and Awareness Activities

On the heels of Global Pulmonary Fibrosis Awareness Month and IPF World Week, PFF Medical Advisory Board Chair Jesse Roman, MD, participated in several activities to educate and spread awareness about pulmonary fibrosis in Puerto Rico. Efforts included:

- **Center for Pulmonary Fibrosis opened** at the Mayaguez Medical Center. Dr. Roman assisted in training residents and fellows on pulmonary fibrosis during two clinics.
- **5th Puerto Rico Respiratory Congress** was sponsored by the Coalition of Asthma and Other Chronic Respiratory Conditions of Puerto Rico, Inc. Dr. Roman delivered a lecture on IPF to physicians in attendance.
- **Veterans Affairs Caribbean Healthcare System** hosted a lecture on PF that was delivered by Dr. Roman to approximately 65 physicians and trainees.
- **Secretary of Health of Puerto Rico** proclaimed August 26–September 2 Puerto Rico Pulmonary Fibrosis Awareness Week.

This year, more than
25,000 viewers from 19
countries visited our website
during Global Pulmonary
Fibrosis Awareness Month!

RALLY FOR MEDICAL RESEARCH

Face-to-face conversations are among the most effective ways of raising awareness and shifting opinion. **On September 21 and 22, a group of dedicated PFF volunteers and staff members visited Washington, DC, for the Rally for Medical Research.** The annual event includes representatives of nearly 300 national organizations calling on our nation's policymakers to make funding for the National Institutes of Health (NIH) research a national priority.

Attendees received training on September 21, gathered for an evening reception the same day, then dispersed on Capitol Hill the following day to visit their representatives and senators. PF advocates from all around the US included:

Jennifer Bulandr / PFF Director, Social Media and Community Engagement / CHICAGO, ILLINOIS

Cindy Chandler / PFF Daughters Advocacy Working Group Member / ROCHESTER, NEW YORK

Paul Fogelberg / Director, Pulmonary Fibrosis Advocates / MINNEAPOLIS, ST. PAUL

Kate Gates / PFF Manager, Volunteer Programs / CHICAGO, ILLINOIS

Lisa Hall / PFF Daughters Advocacy Working Group Member / DALLAS, TEXAS

Doug Jones / PFF Daughters Vice Chair for Advocacy and PFF Ambassador / ST. LOUIS, MISSOURI

John Morthanos / PFF Daughters Advocacy Working Group Member, PFF Ambassador, and support group leader / STRATFORD, CONNECTICUT



Clockwise, from far left: "Cruisin' Towards a Cure"; Buzzards Bay Cormier Walk; and Jamie Malam.



TEAM PFF

During Global Pulmonary Fibrosis Awareness Month, *Team PFF* event leaders spread awareness about the disease and raised funds on behalf of the Pulmonary Fibrosis Foundation (PFF) with events that reflected their passions and interests.

THE CORMIER FAMILY hosted the second annual **Jim Cormier Canal Walk for Pulmonary Fibrosis** on Cape Cod, Massachusetts. Jim Cormier loved long morning walks around his neighborhood, and his family could think of no better way to honor him than inviting relatives, friends, and community members to join a 5K run/walk in his memory. The Cormiers reached their goal of raising \$10,000 for the PFF and brought together families from all over the Northeast.

THE DOUGLAS R. PARTENHEIMER FOUNDATION's annual event is a tribute to the life of Doug Partenheimer, a classic car enthusiast. For the past eight years, the Partenheimer family has hosted "**Cruisin' Towards A Cure**" during Global Pulmonary Fibrosis Awareness Month. With over \$33,500 raised, this event is designed to appeal to the entire community, and includes a 5K run/walk in the morning and a car show in the afternoon.

Bike Tour of California

Biking enthusiast Jamie Malam recently completed a 516 mile ride from San Francisco, California to Huntington Beach, California to raise funds and awareness in honor of his dad.

Jeans Day at Assurant

Get your company involved with a #BlueUp4PF jeans day! It's an easy way to fundraise and raise awareness. For Global Pulmonary Fibrosis Awareness Month, Karen Killburn from Assurant took the lead within her company and raised over \$2,500!

Online Letter-Writing Campaign

Amanda Pohlen asked her friends and family for support through an easy online letter-writing campaign. She also donated a percentage of sales during the entire month of September from her LuLaRoe store.

Events like these are a great way to have fun and raise funds for the Pulmonary Fibrosis Foundation any time of the year. Contact Amy Kozyra, Development Manager, at akozyra@pulmonaryfibrosis.org to learn how to get started today.

SOCIAL MEDIA: AN ONLINE COMMUNITY OF SUPPORT



When Jennifer Bulandr, Pulmonary Fibrosis Foundation (PFF) Director, Social Media and Community Engagement, updates the PFF's social media presence, she sees strong relationships in the making. **"I love watching connections being formed and patients reaching out to other patients,"** she says. "We all have stories to share about this little-known disease with others who understand the journey."

Check out what the PFF has to offer on social media:

- **FACEBOOK** — PFFORG
- **TWITTER** — @PFFORG
- **INSTAGRAM** — PFFORG



Bulandr especially encourages the PF community to visit the PFF's Storify (storify.com/PFFORG) for a digest of upcoming events, tweets, photos, and much more. "It's a great way to find a lot of useful PFF information in one place," she says.



join us

TURN YOUR PASSION

You can turn your desire to find a cure for pulmonary fibrosis (PF) into positive action —

and the Pulmonary Fibrosis Foundation (PFF) will help you every step of the way. Volunteer *Team PFF* Event Leaders host a wide variety of events: marathons and mountain treks, golf outings, bake sales, car shows, and online letter-writing campaigns.

Proceeds from the events directly enhance patient services, research, and PFF signature programs benefiting the PF community. The Foundation provides resources and tools, including a comprehensive *Team PFF* Event Leader Guide and Welcome Kit, to make planning and hosting your third-party event easy and fun.

For details and assistance visit pulmonaryfibrosis.org/get-involved/team-pff, or contact Amy Kozyra, Development Manager, at akozyra@pulmonaryfibrosis.org or 312.878.2351.

IN YOUR CORNER

With help from the PFF, new team leader succeeds

Paula Belanger lost her husband, Allen, to pulmonary fibrosis in 2015 and immediately wanted to do something to honor his memory. She'd never produced an event, fundraised, or even participated in a walk, but when Belanger learned of a charity day in her town, she reached out to the PFF to help her plan a third-party

fundraising event. "From sending me educational materials to writing my event announcements, I felt like the Foundation staff's arms were around me every step of the way," she says, "and they put their hearts into it, too."

Belanger continued her fundraising efforts post-walk with a workplace "jeans day"

and an online fundraising page for Global Pulmonary Fibrosis Awareness Month. To date, Belanger has raised \$4,220.

"Seeing my grandsons walk and having my family surround me is why I will walk again next year," Belanger says. "I want those affected by this disease to feel there's someone out there working hard in their corner."



EMPOWERED TO FIGHT BACK AGAINST PF

Country music evening exceeds expectations

Lauren Bruning, Secretary, PFF Board of Directors, first heard the words "idiopathic pulmonary fibrosis" (IPF) in 2015 when her mom, Peggy Wherley, was diagnosed. "I was upset for five minutes and then I thought, 'Now, let's do something,'" says Bruning. "Let's raise awareness, fundraise, and help find a cure."

When she couldn't find an event in her hometown of St. Louis, Missouri, Bruning contacted the Pulmonary Fibrosis Foundation (PFF) and began planning. She started with a conservative goal of \$2,500, quickly surpassed it, and decided to "dream big" with a larger event. In its inaugural year, "Nashville's Next Big Stars" welcomed more than 100 guests, featured country music recording artist Renee Blair, and raised a tremendous \$20,000.

"Throwing this event gave me the feeling of taking back control over something that previously made me feel helpless," Bruning says. "I felt empowered to fight back against this terrible disease. I can't wait for next year."



INTO ACTION

BY JOINING TEAM PFF

SKATING TOWARD THE GOAL

Hockey fan gets an event planning assist from the PFF

Joe McBride, a pulmonary fibrosis (PF) patient, uses his love of hockey to raise funds and increase awareness for the Pulmonary Fibrosis Foundation (PFF). This fall, McBride will host his second annual PF fundraiser and awareness night with the Philadelphia Flyers.

A Flyers representative whose own family had been touched by PF was especially receptive to McBride's initial request, and the awareness night took off. "We get a great section of seats and have a table to share our PF materials with the entire community," McBride says.

McBride says he's found the PFF's help invaluable in planning the events. "Their assistance with donation request letters has helped me reach out to potential company sponsors," he says, "and the network of *Team PFF* event leaders throughout the region has helped me to spread the word of my event across Philadelphia and New Jersey."

INVESTED IN SUCCESS

For best results, pick an event with personal meaning

Katie McKeehan Hart started fundraising 10 months after her dad passed away from idiopathic pulmonary fibrosis in 2012. She began by participating in the Bloomsday Run—an event that had been important to her dad—in Spokane, Washington.

"Your event has to be something you're invested in and want to succeed," she advises. "Find an event that's meaningful to you and not too complicated."

McKeehan Hart expanded her *Team PFF* event efforts with multiple marathons and 10Ks, bake sales, and a \$1 dress-as-you-wish day at her workplace. Her events have spread awareness to her community while raising \$6,500.

"I've had a lot of support from the Pulmonary Fibrosis Foundation," she says. "They helped me set up my fundraising pages and even met with me this summer when I was in Chicago. They're very accessible and friendly."



HALES HITS HALF-MILLION

Terence Hales, a Pulmonary Fibrosis Foundation (PFF) board member along with his father, transplant recipient Tom Hales, has reached the half-million dollar mark in funds raised to reduce the impact of pulmonary fibrosis. Terence Hales hosts an annual event, The Run-Walk-Hike for Pulmonary Fibrosis, in New York City's Central Park.

"Congratulations to Terence and his team for their extraordinary efforts," says Patti Tuomey, PFF President and Chief Executive Officer. "Their perseverance and determination to improve the lives of families living with pulmonary fibrosis is an inspiration to our entire community."

2017 TEAM PFF EVENTS

Team PFF members are already planning their 2017 events. A few highlights:

- **MAY 14 – 6th Annual Vic Vittorino Walk for Your Next Breath** – Delanco, New Jersey
- **MAY 25 – 2nd Annual Rocking Out for Pulmonary Fibrosis** – St. Louis, Missouri
- **JUNE 4 – 10th Annual Greg Chandler & Guy F. Solimano Golf Tournament** – Rochester, New York
- **JUNE 24 – 10th Annual NYC Run-Walk-Hike** – Central Park, New York

Visit pulmonaryfibrosis.org/get-involved for details of these events and to begin planning your own event in 2017. We are here to support you every step of the way.

philanthropy

SPOTLIGHT ON WAYS TO GIVE

Gifts to the Pulmonary Fibrosis Foundation (PFF) bring the Foundation closer to realizing its vision of a world without pulmonary fibrosis.

Boost Your Gift's Impact with Employer Matching

You can double or even triple the impact of your gift to the Pulmonary Fibrosis Foundation (PFF)! Many employers will match charitable contributions made by their employees. “It’s an easy way to maximize your contribution to fighting pulmonary fibrosis—at no extra cost to you,” says Patti Tuomey, PFF President and Chief Executive Officer. Find out whether your employer matches gifts by visiting pulmonaryfibrosis.org/employermatch.

There are several other ways for you to get your company to support your fundraising and awareness efforts:

- Setting up a recurring gift through payroll deduction.
- Asking your employer to partner with reputable nonprofit federations such as United Way or Community Health Charities, or to join forces with state and city giving campaigns.
- Hosting a “lunch-and-learn” to educate your colleagues or staff on what pulmonary fibrosis is and how the PFF helps those affected by PF.
- Asking the PFF to participate in your company’s wellness program.
- Checking to see whether your company offers grants for the hours your volunteer for the PFF.

Corporate Partnerships: Businesses and Organizations Help Lead the Fight Against PF

Winning the battle against pulmonary fibrosis (PF) requires having businesses, organizations, and community partners joining our ranks. Corporate sponsorships provide an opportunity to get involved in the Pulmonary Fibrosis Foundation’s (PFF) work and to help change the future of people affected by PF.

“The Foundation is a very broad-based organization that works with every single sector of the PF community—patients, caregivers, physicians, other health care professionals, researchers, and other advocates,” says Patti Tuomey, PFF President and Chief Executive Officer. “Becoming a foundation wide sponsor increases and customizes your visibility, touchpoints, and communication with those audiences, whether it’s the whole PF community or specific sectors within it.”

The PFF offers a range of sponsorship opportunities at several different levels, benefiting a variety of programs and initiatives including:

- *Team PFF*
- *PFF Summit: From Bench to Bedside*
- *Broadway Belts for PFF!*
- PFF Care Center Network
- PFF Volunteer Meeting
- PFF Support Group Leader Network
- PFF Ambassadors
- PFF Breathe Benefit
- Educational programs and materials

Sponsorship packages including the program you would like to impact can also be tailored to meet organizations’ individual goals. Please contact Heather Kundert at hkundert@pulmonaryfibrosis.org or 312.224.9832 for more information.

Madelyn Brafford, whose daughter Anne honors her memory by requesting gifts be made to the PFF.



More Lasting Than Flowers: Tribute Pages Make a Long-Term Impact

Tribute gifts supporting the important work of the Pulmonary Fibrosis Foundation (PFF) provide a meaningful way to remember loved ones who have passed away, honor those living with pulmonary fibrosis (PF), or celebrate milestones such as successful lung transplants.

When Anne Brafford's mother, Madelyn, passed away in June, a friend set up a tribute page on the PFF website to honor Madelyn's memory. Anne and her family requested gifts be made to the Foundation in Madelyn's obituary, on the funeral home's website and donation cards, and on social media, resulting in a tremendous \$5,625 given in Madelyn's name.

"Flowers are lovely, but they don't last," Anne says. "My mother would have appreciated the contribution we're making in asking for donations instead."

Todd Tullis has been an important supporter and friend of the PF community since his late mother, Kathy Owens Tullis, was diagnosed in 2007. Before she passed away, Todd told his mother that his fight to help find a cure would not end with her life. He designated

his birthday as an annual occasion to honor his mom. "I tell my friends, 'I don't want gifts; contribute to the PFF instead!'" he says.

Creating or donating to a tribute page is simple: visit pulmonaryfibrosis.org/ways-to-give/honor-a-loved-one.



Todd Tullis with his mother, Kathy Owens Tullis.

research

PUTTING YOUR DOLLARS TO WORK

Promising Pulmonary Fibrosis Research

Research developments are key to improving the diagnosis and treatment of pulmonary fibrosis (PF)—and, eventually, for finding a cure. Two prominent researchers associated with the Pulmonary Fibrosis Foundation (PFF) have recently made important advances.



INEXPENSIVE DRUG MAY HELP ONE IN FOUR IPF PATIENTS

Imre Noth, MD, a pulmonologist and PF researcher at the University of Chicago, has discovered a potentially significant impact of genetics on the effectiveness of a drug to treat idiopathic pulmonary fibrosis (IPF).

Dr. Noth began by studying hundreds of thousands of genes in more than 1,500 patients. He identified a number of genes, including one called *TOLLIP*, that seemed to increase the risk of developing interstitial lung disease (ILD).

European researchers had found that N-acetyl cysteine (NAC), an inexpensive drug usually prescribed for liver disease, helped some IPF patients. But a study called PANTHER-IPF, which was conducted by the Idiopathic Pulmonary Fibrosis Clinical Research Network and received funding from the NHLBI, found little or no help and even the potential for harm in using the drug. Using samples from PANTHER-IPF and his own genetic findings, Dr. Noth discovered that people with IPF who were using NAC seemed to have better outcomes if they had one of three particular variations in the *TOLLIP* gene.

“About 25 percent would do worse with NAC, about half would see no difference, and 25 percent would benefit,” explains Dr. Noth, who confirmed the result in two other groups of IPF patients.

Dr. Noth is hopeful that these findings will hold up when studied in more rigorous clinical trials that include randomization to NAC or a placebo. Because NAC costs only about \$30 per month, the possibilities of reducing adverse events in many IPF patients are promising. Dr. Noth and other researchers are currently organizing a clinical trial. If the results replicate his earlier findings, he says, the use of NAC in treating IPF could be “a poster child for what we call precision medicine.”

About Dr. Noth

Imre Noth, MD, Professor of Medicine and Director of the Interstitial Lung Disease Program at the University of Chicago, sees a wide variety of pulmonary patients. Over the last half decade, he has concentrated his efforts on interstitial lung diseases with a special emphasis on idiopathic pulmonary fibrosis (IPF).

Noth has been the principal investigator in numerous clinical trials that focus predominantly on IPF but also on severe asthma and chronic obstructive pulmonary disease (COPD). Noth is also a member of the National Institutes of Health-sponsored Idiopathic Pulmonary Fibrosis Clinical Research Network. In addition to

authoring several book chapters on critical care medicine, he is a reviewer for the *American Journal of Respiratory and Critical Care Medicine* and the *Journal of Respiratory Diseases*. He also sits on the editorial board for American College of Chest Physicians (CHEST).

LINKING GENE MUTATIONS TO FAMILIAL PF

Since 2003, Christine Kim Garcia, MD, PhD, Associate Professor of Internal Medicine at the University of Texas (UT) Southwestern and member of the Pulmonary Fibrosis Foundation Medical Advisory Board, has been collecting DNA samples from families in which more than two people are diagnosed with pulmonary fibrosis (PF).

“That’s quite unusual, so we’ve used genetic tools to try to explain why PF might occur in multiple individuals in one family,” Dr. Garcia says.

Dr. Garcia and her team have made significant progress in studying the genetic pathways for PF, identifying mutations in five genes that cause familial PF. The team’s earlier research discovered mutations in three genes. One, *SFTPA2*, affects a protein expressed only in the fluid that bathes the lung’s epithelial cells.

Two others, *TERT* and *TERC*, affect the length of telomeres, repetitive sequences of DNA that protect the ends of chromosomes from deteriorating (sometimes compared to the plastic ends of shoelaces).

In Dr. Garcia’s more recent work, she and her team identified mutations in two other genes, *PARN* and *RTEL1*, which can also lead to shortened telomeres, in people with familial PF. Altogether, the five gene discoveries account for about 25 percent of all cases of familial PF.

“Our ultimate goal is to gain a full understanding of what causes the genetic form of this disease so that effective medications can be developed,” says Dr. Garcia, whose most recent study was supported by the National Institutes of Health’s National Center for Advancing Translational Sciences and the Howard Hughes Medical Institute.



Late last year, UT Southwestern was selected to join the PFF Care Center Network (also see page 6). Dr. Garcia, who holds the Kern and Marnie Wildenthal President’s Research Council Professorship in Medical Science, believes the connection will be a valuable connector among researchers, commenting, “We anticipate that the network will provide opportunities to participate in research studies across the country.”

About Dr. Garcia

Christine Kim Garcia, MD, PhD, received both her medical and graduate degrees from the University of Texas Southwestern Medical Center, and is currently an Associate Professor of Internal Medicine and a member of the Division of Pulmonary and Critical Care Medicine at UT Southwestern. She cares for patients seen in the UT Southwestern Advanced Lung Disease Clinic, Clements University Hospital, and Parkland Memorial Hospital.

She is also a member of the Eugene McDermott Center for Human Growth and Development. She directs a research laboratory that focuses on defining the genetic underpinnings of adult-onset lung disease. Dr. Garcia is a member of the American Society for Clinical Investigation and has authored several scholarly articles and book chapters.

“...we’ve used genetic tools to try to explain why PF might occur in multiple individuals in one family.”

research

PFF RESEARCH FUND

The Pulmonary Fibrosis Foundation (PFF) is pleased to announce the recipients of the 2016 Established Investigator and Junior Investigator Awards.

A key part of the PFF's mission is to fund research that will enhance pulmonary fibrosis (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 improve the understanding of PF.

The Research Fund to Cure Pulmonary Fibrosis supports two funds that are awarded each year: the Albert Rose Established Investigator Award and the I.M. Rosenzweig Junior Investigator Award. Launched in 2012, these awards support projects that work toward a better understanding of PF and encourage collaboration between industry and academic researchers. Each grant underwent a peer review process that was administered by the PFF's Scientific Advisory Committee. Each award recipient will receive a \$50,000 grant that is distributed over two years. These awards are made possible by private gifts to the PFF and through the generous support of Boehringer Ingelheim.

Sponsorships

The PFF recently reactivated its sponsorship program, which provides funding to sponsor educational activities across the country based on available funds. For complete details about the program and application guidelines, please visit: pulmonaryfibrosis.org/medical-community/sponsorship-opportunities.

2015 Partnership Grant

ATS Foundation / Pulmonary Fibrosis Foundation

- **David Lagares, PhD**
MASSACHUSETTS GENERAL HOSPITAL
"Role of α TAT-1 in Mediating Fibroblast Durotoxis and Pulmonary Fibrosis"

ALBERT ROSE ESTABLISHED INVESTIGATOR AWARD

The Albert Rose Established Investigator Award is named for PFF co-founder Albert Rose and provides support to established investigators to develop new projects that explore innovative areas of research. This year's award recipients and titles of their research proposals are:

- **Jerry Yu, MD, PhD**
UNIVERSITY OF LOUISVILLE RESEARCH FOUNDATION, INC.
"The vagus nerve in pulmonary fibrosis"
FUNDED BY BOEHRINGER INGELHEIM
- **Hans-Willem Snoeck, MD, PhD**
COLUMBIA UNIVERSITY MEDICAL CENTER
"Modeling of IPF Using Induced Pluripotent Stem Cells"

I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARD

The I.M. Rosenzweig Junior Investigator Award is named for PFF co-founder Mike Rosenzweig and provides support to researchers in the early stages of their academic careers that may maintain and enhance their interest in PF. This year's award recipients and titles of their research proposals are:

- **Koji Sakamoto, MD, PhD**
YALE UNIVERSITY
"The role of LincRNA FENDRR as a novel regulator of myofibroblast differentiation in idiopathic pulmonary fibrosis"
- **Vinicio de Jesus Perez, MD**
STANFORD UNIVERSITY
"HH-10: A novel therapeutic for idiopathic pulmonary fibrosis"

2017 GRANT CYCLE

The call for letters of intent (LOI) for the 2017 grant cycle opens in October 2016. The LOI review process will take place in December and notifications of acceptance to submit a full application will occur in January 2017. Full grant proposals from investigators will be due in February/March 2017. The Scientific Advisory Committee will then peer review all applications and make final determination of awardees in May 2017. Award recipients will be notified in June 2017 and will be acknowledged in the Fall 2017 *Breathe Bulletin*, on the PFF website, and on all other pertinent materials.



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pulmonaryfibrosis.org/ways-to-give/broadway-belts-for-pff

Survey on Patient Diagnostic Experience Gets National Attention

Last year, in partnership with Veracyte, Inc., a pioneer in the field of molecular cytology, the Pulmonary Fibrosis Foundation (PFF) developed a US patient survey that will advance our understanding of patients' diagnostic experiences with interstitial lung diseases (ILDs).

Survey results are now generating national attention among health care and research audiences. Gregory P. Cosgrove, MD, PFF Chief Medical Officer, presented "The Interstitial Lung Disease Patient Journey (INTENSITY) Survey" at the American Thoracic Society's 2016 International Conference in San Francisco, California, in May 2016. The presentation was accepted as a late-breaking abstract, a category typically reserved for breakthrough announcements. In October 2016,



Dr. Cosgrove presented the survey results at the American College of Chest Physicians (CHEST) Annual Meeting in Los Angeles, California, in a session entitled "Care of the Patient with IPF." CHEST recognized the survey for original investigation.

Foundation Debuts New Continuing Medical Education Options

With the successful launch of the PFF Care Center Network (CCN) and the PFF Patient Registry (also see page 6), the Pulmonary Fibrosis Foundation is taking a greater role in educating health care professionals about pulmonary fibrosis (PF). Previously, the Foundation only offered continuing medical education (CME) at the biennial *PFF Summit: From Bench to Bedside*. Now, the Foundation is working with CME providers to identify health care providers' knowledge gaps and provide them with educational materials that improve their ability to recognize, diagnose, and treat PF.

Current CME offerings include a supplement, "PFF Summit 2015: Key Takeaways in IPF Disease Management and Effective Clinician-Patient Partnering," and a pair of CME-approved simulations, one centering on PF misdiagnosis aimed at general pulmonologists, and a second focusing on disease management for interstitial lung specialists. "As participants move through these simulations, we'll be able to identify knowledge gaps and continuously improve," says Jennifer Mefford, PFF Director of Strategic Partnerships.

As funding for this initiative grows, CME offerings will expand. "In keeping with a two-pronged approach to inform doctors and patients, the PFF will create patient education materials that complement its CME offerings," Mefford says.

...the Foundation is working with CME providers to identify health care providers' knowledge gaps and provide them with educational materials that improve their ability to recognize, diagnose, and treat PF.



PFF Medical Advisory Board Member Honored for ILD Research

Pulmonary Fibrosis Foundation (PFF) Medical Advisory Board member Naftali Kaminski, MD, was honored with the European Respiratory Society's (ERS) first Gold Medal in Interstitial Lung Disease at the ERS International Congress in London in September 2016.

"In receiving the Gold Medal, I represented not only my own scientific and medical career, but also all of the amazing, courageous #PFWarriors that I've gotten to know over the years, and the whole pulmonary fibrosis (PF) community," says Kaminski.

Kaminski is the Boehringer Ingelheim Professor of Internal Medicine and Chief of Pulmonary, Critical Care, and Sleep Medicine at Yale University. A pioneer in precision medicine approaches to PF, he has led his section at Yale through an unprecedented period of growth, including the creation of the Center for Pulmonary Precision Medicine, the Center for Pulmonary Infection Research and Treatment, and the Yale Center of Excellence for Interstitial Lung Disease (Yale-ILD).

PFF Chief Medical Officer Blogs at PatientsLikeMe

Earlier this year, the PFF announced its partnership with PatientsLikeMe (patientslikeme.com), a website where patients can share their experiences and learn from real-world, outcome-based health data. Gregory P. Cosgrove, MD, PFF Chief Medical Officer, is contributing to the PatientsLikeMe blog (blog.patientslikeme.com). Learn more at bit.ly/PFFPatientsLikeMe.

"Through this partnership, the PFF is able to offer the unique tools that PatientsLikeMe provides to the PF community through its website. The Foundation is looking forward to providing even greater patient engagement and improved outcomes thanks to this collaboration," says Dr. Cosgrove.

patientslikeme®

"The Foundation is looking forward to providing even greater patient engagement and improved outcomes thanks to this collaboration."

GREGORY P. COSGROVE, MD / PFF CHIEF MEDICAL OFFICER

Popular Radio Program Spotlights IPF

Marilyn K. Glassberg, MD, Director, Interstitial Lung Disease Program, University of Miami, was featured on Sirius XM's *Doctor Radio* program on August 16. Glassberg discussed risk factors, symptoms, and accurate diagnosis of idiopathic pulmonary fibrosis. The University of Miami Miller School of Medicine was selected last year as a member of the Pulmonary Fibrosis Foundation Care Center Network (also see page 6). Listen to the interview at viddler.com/v/af0293b8.

2016 CALENDAR

View a current list of events at
pulmonaryfibrosis.org/get-involved/attend-an-event

**OCTOBER 12 • St. Luke's Hospital PF
Support Group Meeting**

EASTON, PENNSYLVANIA

OCTOBER 14–18 • PFF @ AARC Congress

American Association for Respiratory Care
SAN ANTONIO, TEXAS

**OCTOBER 19 • NYP ILD Patient and Family
Support Group Meeting**

NEW YORK CITY, NEW YORK

**OCTOBER 21 • Portland Pulmonary Fibrosis
Support Group Meeting**

PORTLAND, OREGON

OCTOBER 22–26 • PFF @ CHEST 2016

American College of Chest Physicians
LOS ANGELES, CALIFORNIA

OCTOBER 24 • Hershey's IPF Support Group

HERSHEY, PENNSYLVANIA

**OCTOBER 29 • Breakfast Club Support Group
at Elmhurst Hospital Meeting**

ELMHURST, ILLINOIS

**NOVEMBER 1 • Oklahoma City Idiopathic
Pulmonary Fibrosis Support Group**

OKLAHOMA CITY, OKLAHOMA

**NOVEMBER 5 • PILOT Pulmonary Fibrosis
Education Program**

NEW YORK CITY, NEW YORK

**NOVEMBER 7 • Simmons Center IPF
Support Group Meeting**

PITTSBURGH, PENNSYLVANIA

**NOVEMBER 8 • Hemet Pulmonary Fibrosis
Support Group Meeting**

HEMET, CALIFORNIA

**NOVEMBER 8 • Winthrop Eager Breathers
Support Group Meeting**

GARDEN CITY, NEW YORK

**NOVEMBER 8 • Joe Walsh Memorial
Pulmonary Fibrosis Support Group**

DENVER, COLORADO

**NOVEMBER 9 • St. Luke's Hospital PF
Support Group Meeting**

EASTON, PENNSYLVANIA

**NOVEMBER 14 • Vanderbilt IPF Support
Group Meeting**

NASHVILLE, TENNESSEE

**NOVEMBER 16 • NYP ILD Patient and Family
Support Group Meeting**

NEW YORK CITY, NEW YORK

**NOVEMBER 18 • Portland Pulmonary Fibrosis
Support Group Meeting**

PORTLAND, OREGON

**NOVEMBER 19 • Pulmonary Fibrosis
Patient Education Day**

PHOENIX, ARIZONA

**NOVEMBER 19 • PHA on the Road
Education Event**

Pulmonary Hypertension Association
TAMPLA, FLORIDA

**NOVEMBER 27 • Seattle Marathon and
Half Marathon**

SEATTLE, WASHINGTON

NOVEMBER 29 • #GivingTuesday

ONLINE

**DECEMBER 5 • Simmons Center IPF
Support Group Meeting**

PITTSBURGH, PENNSYLVANIA

**DECEMBER 6 • Oklahoma City Idiopathic
Pulmonary Fibrosis Support Group**

OKLAHOMA CITY, OKLAHOMA

**DECEMBER 13 • Hemet Pulmonary Fibrosis
Support Group Meeting**

HEMET, CALIFORNIA

**DECEMBER 14 • St. Luke's Hospital PF
Support Group Meeting**

EASTON, PENNSYLVANIA

**DECEMBER 15 • Portland Pulmonary Fibrosis
Support Group Meeting**

PORTLAND, OREGON

**DECEMBER 21 • NYP ILD Patient and Family
Support Group Meeting**

NEW YORK CITY, NEW YORK

FDA ASKS FOR INPUT ON STEM CELL THERAPIES

The US Food and Drug Administration (FDA) held a September hearing at the National Institutes of Health (NIH) campus in Bethesda, Maryland to solicit public input on the use of stem cell and related therapies. The FDA will consider feedback from the hearing when developing its four draft guidance documents on the use of human cells, tissues, and cellular and tissue-based products.

“The Pulmonary Fibrosis Foundation hopes the FDA’s hearing will help raise awareness of the need for stem cell research and the regulatory process,” says David Lederer, MD, PFF Senior Medical Advisor, Education and Awareness, noting that no evidence currently exists that stem cells are effective to treat pulmonary fibrosis. “Scientists are only beginning to understand how stem cells of different types might affect the lung,” he says.



Pulmonary Fibrosis

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