

PULMONARY FIBROSIS FOUNDATION

# Breathe

## BULLETIN

VOLUME 17 | ISSUE 01

SPRING 2017



# in this issue

BREATHE BULLETIN VOLUME 17 | ISSUE 01 SPRING 2017



## SPECIAL INTEREST

### MOVING FORWARD

- 04 Ways to Give and Get Involved with the PFF
- 05 Join Us for PFF Summit 2017
- 06 PFF Summit 2017 Program
- 09 Increased Focus on Loved Ones and Transplant Recipients
- 10 Poster Presentation
- 11 PFF Patient Registry Reaches Milestone

**PFFSUMMIT2017**

## REGULAR FEATURES

### COMMUNITY ENGAGEMENT

- 12 Chicago Bear Jordan Howard Brings his Fight to PF
- 14 September is Global Pulmonary Fibrosis Awareness Month
- 16 Taking on the Seattle Marathon with an Oxygen Tank
- 17 Inaugural PFF Walk Unites Community
- 18 Spotlight on Team PFF Event Leaders on the Front Lines
- 20 New Members Join the PFF Board of Directors

### ADVOCACY / RESEARCH

- 24 PFF Daughters Advocate and Raise Funds
- 26 PFF Research Awardees Further the Fight against PF

### PFF NEWS

- 28 Broadway Belts for PFF! —A Night of Stars, Music, and Hope
- 30 2017 Calendar

*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 INTERIM CHIEF EXECUTIVE OFFICER AND OUR CHIEF MEDICAL OFFICER



## DEAR FRIENDS,

**The Pulmonary Fibrosis Foundation (PFF) has many achievements to celebrate and important changes to welcome in 2017.** We are excited to share them with you in this issue of the *Breathe Bulletin*.

One of the most valuable tools the PFF developed in the past year is the *Pulmonary Fibrosis Foundation Strategic Plan: PFF2020*, a five-year plan that takes a forward-thinking approach to our vision for growth and how our role should impact the needs of the entire PF community. Your support is crucial as we work to achieve the ambitious goals laid out in the plan. This issue of the *Breathe Bulletin* contains an exciting update about one of the milestones we recently reached. We are nearing 1,000 enrollees in the PFF Patient Registry.

You will also read about two important upcoming events. During Global Pulmonary Fibrosis Awareness Month in September, we will launch the inaugural PFF Walk in Chicago's Lincoln Park. In November, our fourth biennial *PFF Summit* will take place in Nashville, Tennessee. We look forward to seeing you at both events!

**Thank you, as always, for your commitment to the Foundation and its mission.**

**SCOTT STASZAK**  
INTERIM CHIEF EXECUTIVE OFFICER

**GREGORY P. COSGROVE, MD, FCCP**  
CHIEF MEDICAL OFFICER







Your actions have the power to make an impact and create hope for pulmonary fibrosis (PF) patients everywhere. There are many opportunities to get involved with the Pulmonary Fibrosis Foundation (PFF), and every action helps us make progress.

# WAYS TO GIVE AND GET INVOLVED

## Volunteer and Fundraise for Team PFF

Have an idea for a fundraiser? *Team PFF* is your opportunity to turn your vision into reality. By joining *Team PFF*, you can host a fundraising event that is meaningful to you. Some successful *Team PFF* events have included car shows, 5K runs, and walks.

## Give a Monthly Gift

Make an ongoing impact by providing year-round support to those living with PF! Setting up monthly donations takes less than a minute and allows us to plan ahead and use your gift strategically. For additional giving options, including ways to get your workplace involved, visit [pulmonaryfibrosis.org/ways-to-give](http://pulmonaryfibrosis.org/ways-to-give).

## Shop at the PFF Store

Visit our online store today to join others and help spread awareness with our Breathe Bracelets, T-shirts, travel mugs, tote bags, and much more! Go to [ShopPFF.com](http://ShopPFF.com) to get started.

## Attend or Support an Event

Attending or supporting an event is a great way to get involved and learn more about the Foundation's programs and work, educate yourself and others about PF, or connect with other PF advocates. If you cannot attend an event in person but still wish to contribute, you can often provide donations or sponsorships. You can view a full list of upcoming events at [pulmonaryfibrosis.org/get-involved/attend-an-event](http://pulmonaryfibrosis.org/get-involved/attend-an-event).

Read about **two important upcoming events** in this issue:

- the inaugural PFF Walk (see page 17)
- the *PFF Summit 2017* (see pages 5–10)



## Contact Your Legislator

Make your voice heard at the federal, state, or local level. Your advocacy can spotlight the disease and let policymakers know we need research funding and improved access to care.

## Nominate Yourself or Someone Else for the PFF Board of Directors

We are looking for qualified candidates to join our board of directors. The PFF's directors lay the groundwork for the Foundation's strategic vision and contribute significantly to resource development. A central focus of the board is fundraising. The PFF welcomes inquiries from seasoned professionals, including retired individuals, who are motivated to contribute to the Foundation's efforts to fulfill on its ambitious strategic plan. For more information, please contact Zoë Bubany at [zbubany@pulmonaryfibrosis.org](mailto:zbubany@pulmonaryfibrosis.org).



# PFFSUMMIT2017

## IMPORTANT DATES

### Call for abstracts

June 15–August 1, 2017

### Exhibitor deadline

September 15, 2017

Hurry—space is limited!

### Hotel group rates deadline

October 8, 2017

## INFORMATION

### Sponsorships

For sponsorship information, please contact Heather Kundert at 312.224.9832 or [hkundert@pulmonaryfibrosis.org](mailto:hkundert@pulmonaryfibrosis.org)

### Registration

To register for the *Summit*, visit [pffsummit.org/register.html](http://pffsummit.org/register.html)

### Information

For any additional information, visit [pffsummit.org](http://pffsummit.org) or email [summit@pulmonaryfibrosis.org](mailto:summit@pulmonaryfibrosis.org)



join  
us

## PROGRAM AT A GLANCE

### THURSDAY, NOVEMBER 9

#### Arrivals and registration

7:30 a.m.–8:00 p.m.

#### Session for pulmonologists and ILD fellows

10:00 a.m.–4:00 p.m.

#### Session for patients and caregivers

1:00 p.m.–4:00 p.m.

#### Welcome reception and poster presentation

5:00 p.m.–8:00 p.m.

### FRIDAY, NOVEMBER 10

#### Registration and continental breakfast

7:00 a.m.–8:00 a.m.

#### Plenary session

8:00 a.m.–10:00 a.m.

#### Sessions for professionals

10:30 a.m.–4:50 p.m.

#### Sessions for patients, caregivers, those who have lost a loved one, and transplant recipients

10:30 a.m.–4:50 p.m.

#### Cocktail hour / networking dinner

5:30 p.m.–9:00 p.m.

### SATURDAY, NOVEMBER 11

#### Registration and continental breakfast

7:00 a.m.–8:00 a.m.

#### Plenary session

8:00 a.m.–10:00 a.m.

#### Sessions for professionals

10:30 a.m.–4:50 p.m.

#### Sessions for patients, caregivers, those who have lost a loved one, and transplant recipients

10:30 a.m.–4:30 p.m.

NASHVILLE, TN  
NOVEMBER 9–11



PRESENTED BY

Pulmonary Fibrosis  
FOUNDATION

## CONFERENCE VENUE AND HOTEL ACCOMMODATIONS

### Hotel reservations

To book your room, please visit <http://bit.ly/pffnashville>

#### Omni Nashville Hotel

250 5th Avenue South  
Nashville, Tennessee 37203  
Phone: 615.782.5300

### Guest room block rates

\$264 per room night (single and double)

### Deadline for group rates

October 8, 2017

### Travel

To book travel, please visit <http://bit.ly/pffconcur>

## THE PFF THANKS THE PFF SUMMIT 2017 EVEREST SPONSORS



Boehringer  
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# program



## plenary sessions

The Friday and Saturday sessions are open to all attendees, providing interactive discussions about these important topics.

### FRIDAY

#### PROMISE OF GENETICS AND PERSONALIZED MEDICINE IN PF

The keynote address will discuss support for personalized therapy in lung disease. Further talks in this session will focus on genetic and environmental influences in interstitial lung disease (ILD), the current status of clinical genetic testing in ILD, and a genetic counselor's perspective on the impact of genetic information for patients and families. This session will be concluded with a panel discussion that includes experts and people affected by pulmonary fibrosis (PF).

### SATURDAY

#### MAXIMIZING THE IMPACT OF AVAILABLE THERAPIES IN IPF

The keynote address will focus on evaluating effectiveness of therapies in the real world. The Pulmonary Fibrosis Foundation (PFF) will provide updates on the PFF Care Center Network and Patient Registry and a physician will provide a physician/family member perspective on how best to improve care for PF patients and how best to adhere to treatment plans. This session will be concluded with a panel discussion on opportunities and obstacles to providing optimal care for PF in 2017. The panel will include experts and people affected by PF.



### SUMMIT EDUCATION / ORGANIZING COMMITTEE

#### PFF SUMMIT COMMITTEE CO-CHAIRS

TIMOTHY BLACKWELL, MD and  
LISA LANCASTER, MD

LISA BOYD  
ZOË D. BUBANY  
HAROLD R. COLLARD, MD  
GREGORY P. COSGROVE, MD  
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ANDREW LIMPER, MD  
JESSE ROMAN, MD  
LAURA SADLER  
DAVID SHERRY  
JERI WEBB

The PFF is currently finalizing faculty assignments. A complete list will be provided at [pffsummit.org](http://pffsummit.org)

## REGISTER TODAY

visit [pffsummit.org/register.html](http://pffsummit.org/register.html)

# professional sessions

## THURSDAY

The *Summit* will begin with a full day of programming for pulmonologists and interstitial lung disease (ILD) fellows, who often are the first point of contact for patients and caregivers. Topics covered will include accurate diagnosis of ILD; how to effectively read an HRCT; options for lung biopsy; approved therapies, their safety, and management; and evaluation for lung transplant. There will be opportunities to ask questions of our expert faculty members throughout the day.

## FRIDAY

Friday's sessions for professionals and healthcare providers will examine genetics, environmental influences, and disease mechanisms for ILD.

### GENETICS OF ILD

A winner from the academic poster presentation will begin this session with a brief synopsis of his/her research project. In addition, sessions will cover the spectrum of telomere-related ILD, progression and outcome of telomere-related ILD, new genes associated with familial ILD, and results of whole genome sequencing in sporadic idiopathic pulmonary fibrosis (IPF).

### ENVIRONMENTAL INFLUENCES

A winner from the academic poster presentation will begin this session with a brief synopsis of his/her research project. In addition, sessions will cover the microbiome, GERD and sleep apnea in ILD, and autoimmune mechanisms of PF.

### DISEASE MECHANISMS I

A winner from the academic poster presentation will begin this session with a brief synopsis of his/her research project. Sessions will also cover preclinical modeling of telomerase deficiency, lessons from other rare genetic diseases (e.g. Hermansky-Pudlak Syndrome), the lung's response to injury with the epithelium as the lung guardian, and the impact on ILD found in the mechanism of alveolar epithelial cell renewal.

## SATURDAY

Saturday's sessions for professionals and health care providers will examine advances in IPF diagnosis, therapeutics, and disease mechanisms for ILD.

### IPF DIAGNOSIS

A winner from the academic poster presentation will begin this session with a brief synopsis of his/her research project. Sessions will also cover advances in HRCT imaging/quantitative HRCT imaging in IPF trials and clinical care. New approaches to diagnosis and the potential role for cryobiopsy will be discussed. Experts will also examine preclinical ILD and lessons from at-risk cohorts.

### THERAPEUTICS

A winner from the academic poster presentation will begin this session with a brief synopsis of his/her research project. Several questions to be considered in these sessions are: What is on the horizon with drug development in IPF? Are stem cell therapies a real possibility for ILD? What are the benefits of personalized medicine and integrating genetics in clinical trials? What is the role of biomarkers in diagnosis and treatment? Experts will address these questions.

### DISEASE MECHANISMS II

Experts will cover the role of aging and senescence in IPF, research advances with mechanoregulation of matrix deposition and fibrosis progression, epithelial-fibroblast interaction in lung fibrosis and immune/inflammatory cells in IPF.



## CME/CE INFORMATION

Continuing Medical Education (CME) / Continuing Education (CE) details will be provided at [pffsummit.org](http://pffsummit.org).



# program

## patient and caregiver sessions

New to 2017 is separate programming for those who are newly diagnosed and their family members, those who have been living with PF and already understand the basics, and those who have lost a loved one or who have received a lung transplant. Attendees are welcome to attend any session that meets their individual interest level.

### THURSDAY

#### **INTRODUCTION TO THE PULMONARY FIBROSIS FOUNDATION AND UNDERSTANDING THE BASICS OF RESEARCH**

Learn about the latest updates at the PFF and take a Research 101 course that will give you a basic understanding of the research process, terminology, definitions, and drug trial steps. This session will introduce you to the PFF Care Center Network and the people involved with keeping the network thriving. The PFF team will share ideas on how to effectively fundraise, volunteer, and use social media to tell your story and promote PFF awareness. Plenty of time is allocated for Q&A as well as rotating in small-group discussion for both patients and caregivers.



## REGISTER TODAY

visit [pffsummit.org/register.html](https://pffsummit.org/register.html)

### FRIDAY

Because we are in Nashville, what better way to start the day than with a song! All are encouraged to attend an interactive session by Kidbilly Music, whose award-winning songwriters will gather input from the participants to create a song that incorporates various and unique perspectives about your journey. Be part of this collaboration and help us to make it “go viral” on social media.

#### **UNDERSTANDING INTERSTITIAL LUNG DISEASE (ILD) AND IDIOPATHIC PULMONARY FIBROSIS (IPF)**

Are you newly diagnosed with lung disease or the caregiver of someone just learning to manage the disease? This session will offer an overview with a Q&A session. Learn how to better understand your test results, receive tips on living with oxygen therapy, and learn symptom management for cough, dyspnea and fatigue. Also find out if pulmonary rehab can help you manage your symptoms.

#### **QUALITY OF LIFE AND NEXT-STEP DECISIONS AND AN OVERVIEW OF CLINICAL TRIALS AND THERAPEUTICS IN THE PIPELINE**

This session is designed for people who have an advanced understanding of life with an ILD and want more information on disease management. Evaluation for lung transplantation will be covered. Alternative medicine options such as using mindfulness, acupuncture, and nutrition will be discussed by professionals from integrative medicine professionals at Vanderbilt University. There will also be an overview about how the clinical trial process works and a presentation on the current drug pipeline and future therapeutics.

#### **CALL TO ACTION**

This session is designed for those who may have lost a loved one to the disease or have moved to a new journey as a transplant recipient. The transitions and experiences will be shared in an interactive environment and a panel of experts will give you ideas to take back to your home region.





## SATURDAY

### BASICS OF GENETICS AND STEM CELL THERAPY

This session is provided to all patients, transplant recipients, caregivers, and people who have lost a loved one. The session will provide an overview of the role of genetics in IPF. Experts will address concerns and provide updated information about stem cell therapies, biotourism, stem cell centers in the community, and clinical trials with stem cells for ILD.

### DIAGNOSIS AND TREATMENT OF COMORBIDITIES AND APPROVED THERAPIES FOR IPF

Learn about the two approved IPF drug therapies, adherence to treatment plans, safety, and management of side effects. The session will include breakout discussions for those with comorbidities such as obstructive sleep apnea (OSA) and gastroesophageal reflux disease (GERD) and others.

### ROUNDTABLE DISCUSSIONS—SHARE YOUR EXPERTISE

Roundtable discussions will be available in this peer-supported environment on financial topics (e.g. insurance, reduced payment plans for IPF drugs, Medicare/Medicaid, estate planning, etc.), caregiver burnout, coping with depression and/or anxiety, how to prepare for an effective visit with your doctor, how to participate in legislative advocacy, and issues surrounding palliative and hospice care.

### OFF-SITE ACTIVITY

For those who have lost a loved one or who have received a lung transplant, we will provide an off-site activity that will allow you to explore Nashville all while putting what you've learned about awareness and advocacy into action.

## Increased Focus on Loved Ones and Transplant Recipients

The *PFF Summit 2017* will provide expanded programming for members of the pulmonary fibrosis (PF) community who are not current patients or caregivers, but still have a strong connection to the community, such as people who have received a lung transplant or have lost a friend or family member to the disease.

“Those who have watched a loved one struggle to breathe and unfortunately decline can make a big impact in the community. Sometimes, this group of people feels that since their loved one passed, there is nothing more they can do. It's crucial to incorporate their perspective into the *PFF Summit* and to educate them on all the ways they can support the PFF's mission,” says Nick DeVito, whose father was diagnosed with idiopathic pulmonary fibrosis in 2009 and passed away the following year. The Pete DeVito Memorial Foundation, created in memory of Nick's father, generously sponsored the *PFF Summit 2015* Poster Presentation. DeVito now serves on the *PFF Summit 2017* Education/Organizing Committee, and has helped guide the development of the new sessions, which cover a number of topics including volunteering, fundraising, and advocacy.

“There is no better advocate for pulmonary fibrosis awareness than a person who has lost someone to this horrific disease,” DeVito says.

“Those who have watched a loved one struggle to breathe and unfortunately decline can make a big impact in the community.”

NICK DEVITO / PFF SUMMIT 2017 EDUCATION/ORGANIZING COMMITTEE MEMBER

# poster presentation

PFFSUMMIT2017

## CALL FOR ABSTRACTS

The Pulmonary Fibrosis Foundation (PFF) invites academic and industry researchers to submit abstracts of their scientific research for poster presentation at the *PFF Summit 2017*. **All applicants must be registered to attend the *PFF Summit 2017* in order to be considered for presentation.** The call for abstracts will open on June 15, 2017 and close on August 1, 2017.

Subject matter deemed appropriate for poster presentation at the *PFF Summit 2017* include original ideas that will help improve the understanding of pulmonary fibrosis in the following areas:

- Basic Research
- Translational Research
- Clinical Research
- Social Science/Quality of Life Research

A panel from the PFF's Scientific Advisory Committee (SAC) will review all academic abstracts. Notification of the Committee's decision will be completed by September 2017.

Industry posters are not subject to peer review.

Space can be reserved by submitting an abstract,

and acceptance is based on a first-come, first-served basis. Space allotted will be confirmed by September 2017.



## PRESENTATION AND RECOGNITION

The Poster Presentation will take place on Thursday, November 9 from 5 p.m. to 8 p.m. in conjunction with the Welcome Reception. Presenting authors are expected to be present at their posters between 5 p.m. and 7 p.m. Academic posters will be evaluated by the SAC selection panel and the top five poster presenters will be recognized at the Networking Dinner on Friday, November 10. The top five poster presenters will also be asked to briefly present their research during sessions on Friday, November 10 or Saturday, November 11.

In addition to a cash prize, travel awards will be granted to the top five presenting authors, which will include reimbursement for airfare up to \$500 for domestic travel or \$1,000 for international travel, two nights lodging at the Omni Nashville Hotel, and up to \$100 for ground transportation. Note: Industry posters are exempt from scoring and will not be considered for awards.

- First place: \$1,500 and travel award
- Second place: \$1,000 and travel award
- Third place: \$500 and travel award
- Honorable mentions (2): travel award

**Learn more about the call for abstracts and poster presentation at [pffsummit.org/posters.html](http://pffsummit.org/posters.html).**

## REGISTER TODAY

visit [pffsummit.org/register.html](http://pffsummit.org/register.html)

# PFF PATIENT REGISTRY REACHES MILESTONE



In early December 2016, the Pulmonary Fibrosis Foundation (PFF) enrolled the 500th person in the PFF Patient Registry. We are now nearing almost 1,000 enrollees. This brings us close to the halfway mark of one of the major goals of the PFF's five-year strategic plan, *PFF2020*: to enroll 2,000 patients by the end of 2017.

The Registry is a valuable collection of information from patients with pulmonary fibrosis (PF). The information collected includes demographics, details on diagnoses and how they were made, medical test results, medications taken, and medical outcomes. Participants may also choose to contribute blood samples to the PFF's biorepository for use in future research. When combined with the information in the Registry, these 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 disease progression, and help discover new treatments.

"Research is the pathway to a cure," says Kevin Flaherty, MD, MS, the chair of the PFF Care Center Network and PFF Patient Registry Steering Committee. "This combination of data will increase our understanding of the disease and enable better diagnostics and treatments."

Patient enrollment in the PFF Patient Registry takes place at participating sites in the PFF Care Center Network, a national network of more than 40 sites in 27 states across the country. Launched in 2013, the network is comprised of medical centers that use a multidisciplinary, collaborative approach to deliver comprehensive care to people living with PF. Each site also offers access to important support services for patients and their families.

"The Registry database is something the PF community has needed for a long time," says Terence Hales, who sits on the PFF Board of Directors, and whose family has been affected by PF. "You hear all the stories, but now we'll have the data collected in a standardized way for accurate and meaningful analyses. That will make recruitment for clinical trials easier, help develop effective therapies and provide researchers with valuable data."

## "Research is the pathway to a cure."

KEVIN FLAHERTY, MD, MS / CHAIR OF THE PFF CARE CENTER NETWORK AND PFF PATIENT REGISTRY STEERING COMMITTEE

### What we can study:

Investigate the causes and progression of disease

Develop, test, and validate biomarkers (measurable indicators of the presence or status of a disease)

Assess effectiveness of all treatments and understand variations in outcomes

### How this will impact patients:

Support research and encourage targeted investment in drug development

Enable faster diagnosis of PF patients and identify those most likely to progress and require early treatment

Develop evidence-based care guidelines to enable higher quality care of PF patients



# #24 Chicago Bear Brings His Fight to Pulmonary Fibrosis

**Jordan Howard, 22-year-old Chicago Bears running back, has joined the Pulmonary Fibrosis Foundation (PFF) in the fight against pulmonary fibrosis (PF). Howard announced his commitment to the PF community at the PFF Volunteer Meeting on November 9, 2016. A number of major news outlets were present to cover Howard's speech.**



Howard delivers a speech declaring his commitment to the PF community at the PFF Volunteer Meeting.



Howard's connection to pulmonary fibrosis is a very personal one. When he was only 12 years old, he lost his father, Dr. Reginald B. "Doc" Howard, to the disease.

"My father was an active, athletic man in the prime of his life when he was diagnosed with pulmonary fibrosis," says Howard. "The diagnosis did not stop him from being a loving father and did not prevent him from helping prepare me for life and the game of football. I believe his diagnosis inspired him to enjoy life and his family even more."

Upon being drafted by the Chicago Bears, Howard, an Alabama native, was inspired to help raise awareness and funds for the PFF, which is headquartered in the heart of his new home, Chicago.

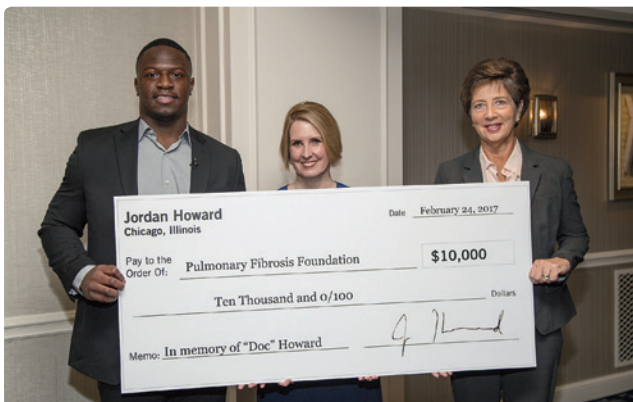
One of Howard's first fundraising initiatives for the PFF was his participation in the NFL's inaugural *My Cause, My Cleats* campaign. During week 13, *My Cause, My Cleats* participants were allowed to wear personalized cleats for a charitable cause for the first time in NFL history. They then auctioned them off with 100 percent of the proceeds benefiting the player's chosen charity. Howard chose the PFF. His cleats showcased the Foundation's signature blue and green colors, and were embroidered with the name "Doc."

Adorned with his custom cleats and a PFF Breathe Bracelet, Howard scored an astounding three touchdowns in the December 4 game during the *My Cause, My Cleats* campaign. Howard's cleats raised \$1,421 for the PFF.

Jordan Howard as a child with his father, Dr. Reginald B. "Doc" Howard.



Howard holding the custom PFF cleats that were auctioned off as a part of My Cause, My Cleats.



Jordan Howard pictured with Patti Tuomey (center) and Marge Hamm (right).

From December through the end of February, Howard was featured in a super-sized ad campaign in the middle of New York City's bustling Times Square. In the 15-second ad, he shared the story of his father's passing, and encouraged viewers to donate and learn about pulmonary fibrosis by visiting his personalized web page at TeamPFF.org. The ad ran three times per hour for 20 hours each day. On New Year's Eve, up to three million people were estimated to have seen the ad.

Following the ad, Howard launched another heart-felt campaign to benefit the PFF.

January 31, 2007 was the day Doc passed away from pulmonary fibrosis. In January, to honor the 10th anniversary of his father's passing, Howard launched a campaign in which people were asked to donate \$10 and then recruit 10 people to do the same. The campaign goal was to raise \$10,000, which Howard pledged to personally match.

"My dad was my best friend and I miss him every day," says Howard. "10 years is like yesterday to me. I want everyone affected by pulmonary fibrosis to keep fighting, keep having hope and keep believing there will be a cure."

Before the end of the month, the campaign met, and exceeded, the goal of \$10,000!

As promised, the campaign goal was matched with an additional \$10,000 gift from Howard. On February 24, alongside Patti Tuomey, EdD, then the president and CEO of the PFF, and Marge Hamm, Bears Care director, Howard publicly presented a jumbo-size check to the PFF.

"Jordan Howard offers new hope to the community of 200,000 people fighting pulmonary fibrosis," said Patti Tuomey to the news outlets gathered for the announcement. "We share with Jordan an unwavering commitment to find a cure for all who are affected by this disease."

Howard's relationship with the PFF continues. You can stay up to date with news about Howard's involvement by subscribing to the PFF's monthly newsletters, visiting our website, and following us on social media.

**"My dad was my best friend and I miss him every day.... I want everyone affected by pulmonary fibrosis to keep fighting, keep having hope and keep believing there will be a cure."**

# Let the world know.



## This September, join those who have been impacted by pulmonary fibrosis (PF) worldwide and unite for Global Pulmonary Fibrosis Awareness Month (GPFAM)!

As the Pulmonary Fibrosis Foundation (PFF) gears up for GPFAM, we invite you to help spread the message to family, friends, health care professionals, colleagues, neighbors, community leaders, and everyone else in your circle.

Below are just a few of the countless ways you can participate in GPFAM.

### PFF WALK

This year, we are thrilled to host our inaugural PFF Walk during GPFAM. We hope that you will celebrate this special month with us by joining the walk in Chicago on September 9, signing up to be a virtual walker, or by walking with family and friends in your own neighborhood to raise awareness. (See page 17 for details.)

### TOOLKIT

If you're excited about GPFAM but not sure how to start, our online GPFAM toolkit is a great resource. You can download the toolkit online at [bit.ly/PFFGPFAM](http://bit.ly/PFFGPFAM).

Included in the toolkit you'll find:

- Fundraising ideas
- Downloadable materials
- Quick facts to share when you talk to family and friends about PF
- Sample proclamation letters and letters to the editor



Jetta Thompson and her family securing a proclamation in Southlake, Texas.



## global PULMONARY FIBROSIS awarenessmonth SEPTEMBER

### START A TEAM PFF EVENT OR ONLINE FUNDRAISING CAMPAIGN

*Team PFF* is your opportunity to join forces with passionate individuals and families around the globe to raise funds and awareness. Members of *Team PFF* host a variety of fundraising campaigns and events to support the mission of the PFF. Consider your hobbies, interests and talents and create an event around them! It's a great way to share your passion and raise funds at the same time.

Here are a few quick ideas:

- 5K runs/walks or marathons
- Golf tournaments
- Garage sales, art sales, and bake sales
- Bowling parties
- Wine tastings

For more ideas on how you can plan a *Team PFF* event in your community, contact Amy Kozyra at [akozyra@pulmonaryfibrosis.org](mailto:akozyra@pulmonaryfibrosis.org) or 312.878.2351.





WNBA Pro Basketball Player Jeanette Pohlen Mavunga, California (above)

Edgar A. Diaz II, Zhejiang University, Hangzhou, China (right)



Students at Leduc Composite High School, Leduc, Alberta, Canada



Staff at the Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease at UPMC

## #BLUEUP4PF ON SOCIAL MEDIA

Where in the world is PF? You can let us know where you are raising awareness during GPFAM by taking selfies with our downloadable sign. Simply write the name of the city and state you live in on the sign, snap a photo of yourself holding it, and post it on social media with the hashtag #BlueUp4PF. Make sure to “blue it up” by wearing blue and a PFF Breathe Bracelet! (You can purchase a bracelet at [ShopPFF.com](http://ShopPFF.com).)

Want to take the #BlueUp4PF campaign a step further and make a hair-raising conversation starter? Dye your hair blue! Whether you want to add subtle streaks or color your whole mane, #BlueUp4PF is a fun way to show your support during GPFAM. For a quick and temporary #BlueUp4PF activity, you can purchase

blue hair extensions or wigs at your local costume shop or beauty supply store. Don't forget to take selfies of your new do using the hashtag!



Ashley Miller

## LET US HELP!

The PFF can help you bring the following activities to your community:

- Patient and physician education programs
- Awareness events
- *Team PFF* events
- Fundraising events

These are just some of the countless ways you can participate in GPFAM. Whether you are raising awareness by customizing your social media profiles or hosting an educational event in your community, you can make a difference in the fight against PF.

## SPONSOR US!

If you are interested in sponsoring GPFAM 2017, please contact Heather Kundert at 312.224.9832 or [hkundert@pulmonaryfibrosis.org](mailto:hkundert@pulmonaryfibrosis.org).

# Join us to help make GPFAM 2017 a success!

# TAKING ON THE SEATTLE MARATHON WITH AN OXYGEN TANK

**Evans Wilson did not let his diagnosis of pulmonary fibrosis (PF) keep him from reaching the finish line.**

**On November 27, 2016, Wilson took on the challenge of the Seattle Marathon, a 26.2-mile race.** He participated with the goal of raising \$50,000 and PF awareness for the Pulmonary Fibrosis Foundation (PFF).

“I’m really not doing it for fun,” says Wilson. “I’m doing it because PF as a disease is incredibly underfunded.”

Wilson was a competitive runner prior to his diagnosis and could run a mile in under five minutes. When he decided to participate in the marathon in spite of his PF, he began training for the event by walking on his home treadmill with his oxygen tank for 90 minutes a day.

Wilson knew he could not complete the race within the time limit. Throughout the course he was accompanied by his wife and a friend whose father passed away from PF. They both walked beside him to help switch out the oxygen tanks he went through while completing the course. A team of volunteers also assisted him along the way. With his oxygen tank in tow each step of the way, he reached the finish line in a remarkable 10 hours and 55 minutes.



It was Wilson’s first marathon, and seeing the staff waiting for him at the finish line turned his adrenaline into emotion.

“The stadium was empty and all the awards were done, but the Seattle Marathon people were there, and they had my medal waiting for me,” Wilson says.

Several media outlets covered Wilson’s phenomenal story and brought attention to the PFF, including ABC News, CBS News, ESPN, Fox News, and Inside Edition. Seattle’s local KOMO news also followed his story before and after the race.



He participated with the goal of raising PF awareness and \$50,000 for the Pulmonary Fibrosis Foundation.





# JOIN US FOR THE INAUGURAL PFF WALK

September is Global  
Pulmonary Fibrosis  
Awareness month, and  
joining the walk is a great  
way to contribute to  
this initiative.

## You asked, we listened!

The Pulmonary Fibrosis Foundation (PFF) will host its inaugural walk on **September 9 in Chicago** with an additional option to participate virtually. Gather your family and friends, build a team, raise funds and lead the way toward a world without pulmonary fibrosis with us on Chicago's magnificent lakefront in the historic Lincoln Park neighborhood. Those who can't make it to Chicago are welcome to participate by signing up to be virtual walkers. By becoming a virtual walker, you can join or organize a team and fundraise from anywhere in the world, and walk in your own neighborhood on September 9. Be sure to let us know where you're walking!

Join us for this unprecedented opportunity to unite in the fight for a cure. The event promises to engage participants of all ages with entertainment, refreshments, and various festivities throughout the day. September is Global Pulmonary Fibrosis Awareness month, and joining the walk is a great way of contributing to this initiative.

"My family is thrilled to participate in the Foundation's inaugural walk," says Lisa Boyd, chair of the PFF Daughters Steering Committee, a volunteer arm of the Foundation. "We're encouraging participants to do the buddy system so everyone brings one or more people to the event." Lisa, a Chicago native, lost her father after his long battle with pulmonary fibrosis.

Registering for the walk is only the first step. The biggest impact you can make for the PF community is by fundraising with your team from now through September 9 and beyond. You can start planning today by organizing a team, setting a fundraising goal, and spreading the word about the walk.

In 2018, the PFF Walk will go national and could be coming to a city near you. Lead the way toward a world without pulmonary fibrosis and commit to walk with us!

Visit **PFFWalk.org** for news and announcements. Let's get healthy, have fun, and lead the way in fight against PF!



# philanthropy

## SPOTLIGHT ON TEAM PFF

### Event Leaders Raise Funds and Awareness on the Front Lines

**Finding a cure for pulmonary fibrosis (PF) is a team effort.** Families and friends of people affected by PF are taking action and raising funds by hosting a wide range of *Team PFF* events: walks, marathons, golf outings, pancake breakfasts, game nights, and online letter-writing campaigns. Proceeds from *Team PFF* events directly enhance patient services, research, and Pulmonary Fibrosis Foundation (PFF) programs benefiting the PF community.



#### Interested in **ATTENDING** a **TEAM PFF** event?

Visit our website to see what's coming up.  
**[pulmonaryfibrosis.org/get-involved/  
attend-an-event](https://pulmonaryfibrosis.org/get-involved/attend-an-event)**

#### **JIM CORMIER CANAL WALK**

##### **Raising funds at an honoree's favorite strolling spot**

Jim Cormier, who passed away in 2010, loved long morning walks around his neighborhood. His growing difficulties during his favorite pastime was the first sign of pulmonary trouble before his eventual PF diagnosis, says Jim's wife, Mary Beth Cormier.

In Jim's memory, his family began participating in the John F. Tighe Walk for Pulmonary Fibrosis in Woburn, Massachusetts. It wasn't long before the Cormiers decided to start their own event. "There were no *Team PFF* walks on Cape Cod or the South Shore," recalls Mary Beth. "Jim loved to walk along the Cape Cod Canal, so we decided that would be the perfect spot to host a walk honoring him."

Set for September 24, in Buzzards Bay, Massachusetts, the Third Annual Jim Cormier Canal Walk for the Pulmonary Fibrosis Foundation is designed to continue to engage the local community, fundraise for the PFF, and build disease awareness. "Both the first and second years, we were surprised and happy to have just over 100 participants," says Mary Beth. Last year's walk raised more than \$10,000 for the PFF.

The canalside path is paved, "so everyone can attend, with no barriers to their movement," she adds. "We also welcome people who don't want to walk, but still attend to show their support."

Mary Beth's advice to others thinking of starting a *Team PFF* event is to start out simple and make sure you choose an event in line with your strengths and interests.

Staying organized ahead of time has kept event day fun for the Cormiers. "We're really pleased with how the first two walks have gone," Mary Beth says. "We are looking forward to doing it again."



## A MICHIGAN GOLF OUTING WITH A TWIST

### Family aims to broaden recognition of PF

When Frank Spadafore was diagnosed with PF five years ago, none of his family members had ever heard of the disease. The Spadafores own Twisters, a chain of soft-serve ice cream stores in central Michigan. They decided to use their business success to become more involved in the community. “Raising awareness of PF was a natural fit,” says Frank’s son, Nick.

With his brother, Joe, and other family members, Nick put together the Tee It Up with Twisters Golf Outing Benefiting the Pulmonary Fibrosis Foundation. Beating the family’s expectations, the inaugural event in 2016 sold out its 36-team limit, raising \$7,500 for the Foundation.

“We hope we can have that same great turnout this year and raise even more,” says Nick.

The second annual outing, a four-man scramble format followed by dinner, is planned for August 19, at the Hawk Hollow course in Bath, Michigan. The Spadafores, especially Nick’s wife, Melissa, are again working their professional and personal connections in the community to collect sponsorships, raffle items, and prizes for contests.

“We got so much positive feedback last year that we feel like we have a good formula,” Nick says.

The Spadafores are focusing on spreading the word through their *Team PFF* work so that PF becomes more widely known and the average time to diagnosis is shortened. “Besides raising money, our number one goal is building awareness,” Nick says.

## Interested in PLANNING a TEAM PFF event?

The Pulmonary Fibrosis Foundation can make planning an event easy with resources and tools such as examples of fundraising letters, donation forms, and checklists.

Visit [pulmonaryfibrosis.org/get-involved/team-pff](https://pulmonaryfibrosis.org/get-involved/team-pff) or contact Amy Kozyra, Development Manager, at [akozyra@pulmonaryfibrosis.org](mailto:akozyra@pulmonaryfibrosis.org) or 312.878.2351.

## WAYS TO GIVE

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](https://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/team-pff](https://pulmonaryfibrosis.org/team-pff).

### 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.

### 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 for our important programs. To learn more about how you can maximize your impact, visit us at [pulmonaryfibrosis.org/pledgefaqs](https://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](https://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.**

# NEW MEMBERS JOIN THE PFF BOARD OF DIRECTORS

## COLLEEN ATTWELL



“You have to get involved  
and try to make it better for  
someone else.”

Colleen and Martin  
Attwell at Broadway  
Belts for PFF! 2017.



Attwell has been deeply impacted by pulmonary fibrosis: not only her father, but also her father-in-law, passed away from the disease. “I don’t want anyone else to go through what my family did,” Attwell says. “You have to get involved and try to make it better for someone else.”

Attwell’s background in the nonprofit sector is an asset to the board and the PFF committees she serves on. She is currently the chair of the Development Committee, sits on the Nominating and Governance Committee, and the task force that is leading the search for a new PFF president and CEO. “My entire career, more than 24 years, has been with nonprofit organizations. So getting involved with the PFF feels very natural to me. I’m a big proponent of medical research.”

Her husband, Martin Attwell, is also actively involved with the PFF, most recently as a member of the committee that guided the creation of the Foundation’s strategic plan, *PFF2020*.

Colleen Attwell’s experience working in the nonprofit sector began with the American Medical Association and City of Hope.

She subsequently worked as the State Director of Development for the March of Dimes Illinois Chapter, National Director of Development for Prevent Blindness America, and Senior Director of Development for the Creating IT Futures Foundation. Her experience includes fundraising, event planning, volunteer and board management, and program development. In addition, she has volunteered and freelanced in the Chicago sports industry for many years, including work with the Chicago Bears, Chicago Blackhawks, Chicago Fire, and Comcast SportsNet Sports Awards. She holds a BA in Communications from Michigan State University and a graduate certificate in nonprofit management from North Park University. She is a member of the Association of Fundraising Professionals.



The Pulmonary Fibrosis Foundation (PFF) is proud to have a committed board of directors to help guide the activities that support our important mission. Members of the board are actively involved in the PFF's activities and participate in fundraising, promoting awareness, and advocating for the pulmonary fibrosis (PF) community. Highlighted here are the four newest members, who further enhance the board's wide range of expertise and experience.

#### LAURIE CHANDLER



**“I’ve been very fortunate, but I don’t want anyone else to have to wait so long to be diagnosed.”**

A 2014 bilateral lung transplant recipient, Chandler shares the experience of many PF patients who are initially misdiagnosed. By the time her disease was identified as PF, she had only about 20 percent lung capacity left. That experience is at the heart of why she decided to get involved with the PFF. “I’ve been very fortunate, but I don’t want anyone else to have to wait so long to be diagnosed,” she says.

Chandler is a partner at Vigilant Capital, LLC, where she has served clients as a relationship manager and wealth planner for over 10 years. Prior to joining Vigilant, she was a senior vice president in the private clients group of Fleet Boston Financial for 18 years. She holds an MBA from Southern New Hampshire University, is a Certified Financial Planner™, and a graduate of the Cannon Financial Institute for Trust, Estate, and Financial Planning. She has served as an officer or trustee for several nonprofit organizations.

Before joining the PFF board, Chandler brought her professional and volunteer expertise to the Foundation’s finance and development committees. “Getting involved at the committee level was a great introduction to the Foundation,” she says. “It gave me familiarity with the organization and I felt like I could contribute in a meaningful way. It quickly became clear to me that the PFF is a safe place for people who’ve been impacted by this disease to share information, improve their quality of life, and get access to valuable resources.”

When she was asked to join the board of directors, she was pleased to join a group “with so much energy and a broad array of talent and skill sets,” she says. “I feel very stimulated by the work and the people I’m working alongside.”

**“I feel very stimulated by the work and the people I’m working alongside.”**

# NEW MEMBERS

## JOIN THE PFF BOARD OF DIRECTORS

### TERENCE HALES



Hales previously served on the board of the Coalition for Pulmonary Fibrosis while his father, Thomas Hales, a transplant recipient, was a member of the PFF's board. The two always advocated joining the two organizations, and Terence's familiarity with both groups made for an easy transition and valuable expertise when he joined the Foundation's board after the two organizations merged.

A corporate real estate executive based in New York City, Hales has over 18 years of industry experience and has worked for a number of global Fortune 100 companies including Time Warner, Bear Stearns, Lehman Brothers, CBS Corporation, and Pfizer Inc. He's currently the Director of Global Real Estate for Zoetis Inc., the former Pfizer Animal Health Division. He holds BS and MBA degrees from Fordham University.

**"We've been climbing up this PF hill for the longest time, and now we're getting closer to the top."**

Hales is also the founder of the NYC Run-Walk-Hike for Pulmonary Fibrosis. The event, which marks its 10th anniversary this year, is scheduled for June 24 in Central Park. In its first nine years, the event has raised more than \$500,000 toward PF research and patient services.

Last year, the Run-Walk-Hike raised a record \$100,000-plus, with proceeds supporting, among other initiatives, the I.M. Rosenzweig Junior Investigator Award (also see pages 26–27). This year, Hales hopes to direct event proceeds toward the Junior Investigator Award, plus diagnosis and treatment brochures targeted to community pulmonologists and respiratory therapists.

He calls his experience on the PFF board very positive so far. "It's a great experience to work with a lot of motivated, qualified people who are fully engaged," he says.

"We've made a lot of progress over the last 10 years. It's a different time, with better awareness, dedicated research, and new drugs. We've been climbing up this PF hill for the longest time, and now we're getting closer to the top."

Hales speaking before attendees at the NYC Run-Walk-Hike for Pulmonary Fibrosis.



# “We’re almost at the tipping point now with PF.”

## NAFTALI KAMINSKI, MD



You can visit Dr. Kaminsky’s web page at the Yale School of Medicine at <http://bit.ly/pffkaminsky>, and follow him on Twitter at [@kaminskimed](https://twitter.com/kaminskimed).

Dr. Kaminski is the Boehringer Ingelheim Endowed Professor of Medicine and Chief of Pulmonary, Critical Care, and Sleep Medicine at Yale School of Medicine. Involved with the PFF since its early days, Dr. Kaminski says he’s “very excited about this amazing shift in activity and focus at the Foundation over the past few years. We’re almost at the tipping point now with PF.”

Successfully fighting a disease, he explains, requires four components: solid science, patients’ willingness to participate in research, a workable business model from industry (as in approval for new, effective drugs), and wide public awareness of the disease. “If you’re missing one of those components, you don’t usually get the critical mass that drives effective therapy,” Dr. Kaminski says. “The PF community now has all four pieces that can get us to that tipping point.”

In 2016, Dr. Kaminski was elected a fellow of the European Respiratory Society (ERS) and was awarded the ERS Gold Medal in Interstitial Lung Disease. He received the American Thoracic Society Recognition Award for Scientific Accomplishments and the Helmholtz International Fellow Award in 2013. Before joining Yale, he served as founding director of the Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease at the University of Pittsburgh Medical Center, which he led to national prominence.



Dr. Kaminski speaking at the PFF Summit 2015.

Dr. Kaminski is a strong advocate for breaking barriers between patients, their families, and health care systems and empowering patients to become stakeholders in research, medical management, and health care policy. “Many of the positions we take as physicians and scientists aren’t intuitive to the general population,” he says. “So I believe in interacting with patients on social media—and I set aside time every week to informally answer the patient questions and concerns that can be missed in structured interactions.”

On the other side, “interacting with patients and their families provides inspiration for our work and makes our theoretical academic questions complete,” he adds. “It’s a huge driving force for research.”

# advocacy

## EMPOWERING PEOPLE LIVING WITH PF

### PFF Daughters Advocate and Raise Funds

**No one is more invested in ending pulmonary fibrosis (PF) than individuals and families affected by the disease. An innovative Pulmonary Fibrosis Foundation (PFF) program, PFF Daughters, harnesses that commitment with a network of leaders, volunteers, advocates, and fundraisers dedicated to helping the PFF fulfill its mission.**



PFF Daughters, staff at the PFF, and representatives of numerous rare disease organizations gather outside of Illinois Senator Dick Durbin's office.

**“We’re here to fully support the PFF’s drive and direction through advocacy, awareness, and fundraising.”**

**LISA BOYD / PFF DAUGHTERS STEERING COMMITTEE CHAIR**

The PFF Daughters began at the Coalition for Pulmonary Fibrosis as a project focusing on women and girls whose parents had been diagnosed with PF. Now part of the Pulmonary Fibrosis Foundation’s suite of signature programs, PFF Daughters brings members together to increase awareness about PF, advocate for improved care for people with PF, and raise support for continued research efforts. Membership in the PFF Daughters program is open to anyone affected by pulmonary fibrosis.

“This is a group that’s really passionate about spreading awareness of PF,” says Kate Gates, PFF Director of Programs, noting that nearly 70 people have become members in the program’s first year at the PFF. “From hosting support groups and fundraisers, to talking to legislators about PF, to getting the word out on social media, PFF Daughters work really hard to find creative ways of reaching new segments of the population and engaging them in the fight against PF.”

“We’re here to fully support the PFF’s drive and direction through advocacy, awareness, and fundraising,” says Lisa Boyd, PFF Daughters Steering Committee Chair and a *Team PFF* leader. “All three are absolutely vital aspects of keeping a foundation healthy and strong. We take all our direction from the Foundation and are there to support them.”

Every PFF Daughters member has the following responsibilities:

- Support the PFF by raising \$500 each year, an amount members can contribute or raise from their friends, family, or business associates. The funds raised will be used to improve the lives of the hundreds of thousands of people impacted by PF each year. The Foundation will support members’ efforts with various resources to ensure success.
- Help the PFF raise awareness during Global Pulmonary Fibrosis Awareness Month in September.
- If possible, attend at least one PFF-sponsored event such as a *Team PFF* event, the *PFF Summit*, *Broadway Belts for PFF!*, or a PFF Care Center Network patient education event.





Doug Jones (left) and Senator Roy Blunt (right).

**“This is my way of paying back and paying forward. I’m alive today because of the work done at the NIH, funded in part by Congress. I want the people following me to have access to better treatments and better medications.”**

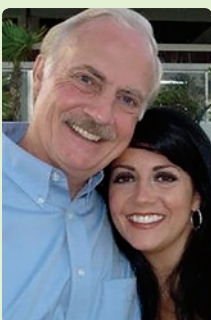
**DOUG JONES / PFF DAUGHTERS VICE CHAIR FOR ADVOCACY**

Doug Jones, the group’s Vice Chair for Advocacy, joined other PFF Daughters members and PFF staff for events in Washington, DC surrounding Rare Disease Day, February 28. The group sponsored an information table at the National Institutes of Health’s (NIH) Rare Disease Day event, participated in a training program on advocating with legislators, and traveled to Capitol Hill to speak about PF to legislative staff from their own Congressional districts. (See social media coverage from the week’s events at [storify.com/pfforg](http://storify.com/pfforg).)

Jones, a transplant patient who has also been active as a PFF Ambassador, says his new PFF Daughters leadership role dovetails with his interest in politics and past experience as an advocate for professional associations.

He adds, “This is my way of paying back and paying forward. I’m alive today because of the work done at the NIH, funded in part by Congress. I want the people following me to have access to better treatments and better medications.”

Like Jones, Courtney Culver Baker is bringing her past experience to the benefit of the PFF Daughters. A Houston-based attorney, Baker is a *Team PFF* leader and has served on the development committee of several area nonprofit groups active in child and family health issues. Now, she’s the Vice Chair for Fundraising for the PFF Daughters.



Courtney Culver Baker  
with her late father, Judge  
Thomas R. Culver, III.

“PFF Daughters pulls people in from all across the nation. It is flexible so that with other work and family commitments, you can pick your path,” says Baker, whose father passed away from PF complications in 2015. “It’s a really good jumping-off point if you want to get involved with the Foundation’s work.”

Boyd, who lost her father to PF in 2012, says, “All of us in the Daughters have been touched by PF. You go through that experience and you cannot come out the same. The way I have dealt with grief is to be a force for change—and for me, this has been an optimistic, positive way of channeling those emotions. Working alongside so many talented, dedicated people gives me great hope for the future.”

**For more information on joining PFF Daughters, contact Kate Gates at 312.224.9820 or [kgates@pulmonaryfibrosis.org](mailto:kgates@pulmonaryfibrosis.org).**

The PFF Daughters is made possible by the generous support of Boehringer Ingelheim Pharmaceuticals, Inc. and Genentech. Rare Disease Day activities are sponsored by Boehringer Ingelheim Pharmaceuticals, Inc.

**“PFF Daughters pulls people in from all across the nation. It is flexible so that with other work and family commitments, you can pick your path.”**

**COURTNEY CULVER BAKER / PFF DAUGHTERS VICE CHAIR FOR FUNDRAISING**

# research

## PUTTING YOUR DOLLARS TO WORK

### PFF Research Awardees Further the Fight Against PF

The Pulmonary Fibrosis Foundation (PFF) is committed to creating an environment that encourages the development of effective treatments for pulmonary fibrosis (PF). Recognizing the key role that expanded research plays in improving treatments and the patient experience, the Foundation funds research, supports collaborative relations between industry and academic researchers, and advances solutions to bridge existing gaps in PF research.

The PFF's Albert Rose Established Investigator Award and I.M. Rosenzweig Junior Investigator Award fund research projects that offer a high likelihood of improving the understanding of PF in the following areas: basic science, translational research, clinical medicine/research, and social science/quality of life. Each year, the PFF awards two \$50,000 grants in each of the two categories, disbursed over a two-year period.

#### ALBERT ROSE ESTABLISHED INVESTIGATOR AWARD

Created to allow established investigators to explore novel, innovative areas of research, the Albert Rose Established Investigator Award provides critical support to the development of new projects, and enables the investigator to pursue additional funding through the National Institutes of Health or other agencies.

**Guoying Yu, PhD** / RESEARCH SCIENTIST, DEPARTMENT OF INTERNAL MEDICINE, YALE UNIVERSITY

#### "Thyroid hormone as a novel therapeutic agent in lung fibrosis"

A growing body of evidence shows thyroid hormone (TH) plays a significant role in protecting cells from death and injury. Most recently, hypothyroidism has been associated with increased mortality in a large cohort of patients with IPF. Studying the effect of TH on models of PF in mice, Dr. Yu and his colleagues discovered that TH supplementation remarkably weakened experimental fibrosis in hypothyroid mouse lungs. "These observations suggest that TH supplementation is an attractive therapeutic candidate for lung fibrosis considering the cost-effective advantage of an already known safety profile, evidence that significantly reduces hurdles to initiate a clinical trial," says Dr. Yu. "The overall objective of this proposal is to develop a clinical formulation of T3, one of the thyroid hormones, as a novel, long-term and efficient anti-fibrotic or preventive therapeutic intervention."

**DR. YU** earned his BS, MS and PhD in the Henan Normal University, Yunnan University, and The Chinese Academy of Sciences in the Peoples' Republic of China, respectively. He joined the research group of Naftali Kaminski, MD, (also see page 23) in 2006.

**Jerry Yu, MD, PhD** / PROFESSOR OF MEDICINE, UNIVERSITY OF LOUISVILLE RESEARCH FOUNDATION, INC.

#### "The vagus nerve in pulmonary fibrosis"

FUNDED BY A GRANT FROM BOEHRINGER INGELHEIM PHARMACEUTICALS, INC.

Increasing evidence indicates that the neuroendocrine system controls immune and cellular responses, and that alteration of the system influences progression of many pulmonary diseases. Dr. Yu hypothesizes that this neuroendocrine system is essential for lung repair: lung injury activates the system, which then promotes fibrogenic (fiber-forming) cells and molecules to cause PF. "Our preliminary data show that the neuroendocrine system is activated following treatment with bleomycin, a medication for treating cancer, yet removing the vagus nerve decreases fibrogenic factors and weakens fibrosis formation," says Dr. Yu. "Therefore, overactivation of the system would contribute to disease progression." The award will allow Dr. Yu's team to further examine physiology, biochemistry, and histology of the fibrotic lung in a mouse model to assess the neuroendocrine system in relation to the severity of the lung fibrosis.

**DR. YU** received his medical training at Shanghai First Medical College and his PhD degree from the University of California, San Francisco. His research projects have been supported by grants from the National Institutes of Health, the American Lung Association, the American Heart Association, and VA Merit Review.



Albert Rose Established Investigator Award Recipients  
Guoying Yu, PhD (left) and Jerry Yu, MD, PhD (right).



I.M. Rosenzweig Junior Investigator Award Recipients Vinicio de  
Jesus Perez, MD (left) and Koji Sakamoto, MD, PhD (right).

## I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARD

The I.M. Rosenzweig Junior Investigator Award was established to encourage researchers to maintain and enhance their interest in PF research during the early stages of their academic career. Researchers who have completed their formal training within the past five years are eligible for this award. The I.M. Rosenzweig Junior Investigator Award is funded by the NYC Run-Walk-Hike for Pulmonary Fibrosis.

**Vinicio de Jesus Perez, MD / ASSISTANT PROFESSOR**  
OF PULMONARY AND CRITICAL CARE MEDICINE,  
STANFORD UNIVERSITY

### “HH-10: A novel therapeutic for idiopathic pulmonary fibrosis”

Fibrosis in IPF is due to excessive collagen production by fibroblasts (connective tissue cells) following lung injury that triggers an inflammatory response. One potential approach to treat fibrosis is to restore the production of anti-inflammatory cytokines (a type of substance in cells of the immune system) capable of shutting down inflammation and suppressing collagen production in fibroblasts. Among known anti-inflammatory cytokines, interleukin (IL) 10 is an attractive therapeutic candidate as it has both anti-inflammatory and anti-fibrotic properties. “We have developed a novel inhaled IL 10-based compound, HH-10, capable of both preventing and reversing lung fibrosis in mice, leading us to propose a possible therapeutic role in IPF,” says Dr. de Jesus Perez. “Our ultimate goal is to demonstrate that HH-10 can both prevent and treat lung fibrosis in IPF prior to pursuing clinical studies in patients afflicted with the disease.”

**DR. DE JESUS PEREZ** received his MD from the University of Puerto Rico Medical School. As a medical professional belonging to a minority group, he is involved in academic endeavors that improve access of care for patients with disadvantaged ethnic backgrounds and promote diversity in medicine.

**Koji Sakamoto, MD, PhD / DESIGNATED ASSISTANT**  
PROFESSOR, DEPARTMENT OF RESPIRATORY MEDICINE,  
NAGOYA UNIVERSITY GRADUATE SCHOOL OF MEDICINE

### “The role of LincRNA FENDRR as a novel regulator of myofibroblast differentiation in idiopathic pulmonary fibrosis”

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

IPF represents a disease paradigm in which gene-environment interactions, often regulated by epigenetics (nongenetic influences on gene expression), significantly determine the susceptibility of patients to developing this progressive disease. Ribonucleic acids, or RNAs, are essential to the coding, decoding, regulation, and expression of genes. Long intergenic non-coding ribonucleic acids (lincRNAs) are an understudied class of RNAs whose critical role as epigenetic regulators has recently received increased attention. “We discovered that FENDRR—Fetal-lethal non-coding developmental regulatory RNA—a lincRNA highly involved in lung development, was the most decreased lincRNA in lungs of IPF patients,” says Dr. Sakamoto. The award will support further exploration of his team’s hypothesis that decreased FENDRR in IPF lungs renders them susceptible to disease development, and that restoring its levels within the fibrotic lung may exert a therapeutic role.

**DR. SAKAMOTO** obtained his MD and PhD degrees at Nagoya University in Japan. As a physician-scientist motivated by his clinical experience, Dr. Sakamoto enjoys opportunities to participate in patient support group events and disease awareness events.

# A NIGHT OF STARS, MUSIC, AND HOPE

On February 27, stars from Broadway hits including *Hamilton* and *Legally Blonde* performed at the Edison Ballroom in New York City to support *Broadway Belts for PFF!*, an annual fundraiser that benefits the Pulmonary Fibrosis Foundation's (PFF) mission. This year's event was the biggest yet, and raised nearly a quarter of a million dollars for the Foundation's programs—a record.



Julie Halston

The event was hosted, as always, by award-winning actress and comedian Julie Halston, and featured Grammy and Tony Award winners throughout the evening. *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). When Halston's husband, broadcaster Ralph Howard, was diagnosed with IPF soon after Kuchwara's passing, Halston became a leading spokesperson for the PFF. Following the diagnosis, Howard underwent a lung transplant.

"To say the show was a smash is an understatement," said Halston. "Our performers were so incredibly gracious and everyone brought the house down. Ralph and I are grateful for the opportunity to promote awareness of the Pulmonary Fibrosis Foundation's important work in helping patients and funding research for a cure."

This year's performers included Grammy-winner Stephanie Mills (*The Wiz*), Mandy Gonzalez (*Hamilton*, *In The Heights*), Orfeh (Tony-nominee for *Legally Blonde*), Lucas Steele (*Natasha, Pierre & The Great Comet of 1812*), James Snyder (*If/Then*, *Cry-Baby*), NBC's Gus Rosendale ("Weekend Today in New York"), Stephanie J. Block (*Falsettos*, and Tony-nominee for *The Mystery of Edwin Drood*), Mario Cantone ("The View"), Robert Creighton (*Cagney*), and Tony-winner Randy Graff (*City of Angels*, *The Babylon Line*).

"Enhanced awareness and expanded research are vital to support those affected by pulmonary fibrosis and to continue to identify effective therapies," said Gregory Cosgrove, Chief Medical Officer at the Pulmonary Fibrosis Foundation. "We thank everyone involved in supporting our efforts and helping to make *Broadway Belts For PFF!* the success it has become."



Stephanie Mills



Bobby Creighton and T. Oliver Reid



Mandy Gonzalez





The performers of *Broadway Belts for PFF! 2017*



James Snyder

“Our performers were so incredibly gracious and everyone brought the house down. Ralph and I are grateful for the opportunity to promote awareness of the Pulmonary Fibrosis Foundation’s important work in helping patients and funding research for a cure.”

**JULIE HALSTON** / AWARD-WINNING ACTRESS AND COMEDIAN + HOST OF *BROADWAY BELTS FOR PFF! 2017*

## The Foundation thanks the 2017 Broadway Belts for PFF! Sponsors



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**The 2018 date will be announced soon!**

Look for updates in the monthly PFF eNewsletter.

# 2017 CALENDAR

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

**MAY 13 • University of Minnesota Patient Education Day**  
MINNEAPOLIS, MINNESOTA

**MAY 19–24 • PFF @ ATS Conference**  
WASHINGTON, DC

**MAY 20 • 6th Annual Vic Vittorino Walk for Your Next Breath 5K**  
DELANCO, NEW JERSEY

**MAY 20 • Skate for Stephen**  
MAPLE PLAIN, MINNESOTA

**JUNE 16 • Pete DeVito Memorial Foundation 7th Annual Golf Outing**  
MT. SINAI, NEW YORK

**JUNE 17 • Vanderbilt Patient Education Event**  
BRENTWOOD, TENNESSEE

**JUNE 24 • 10th Annual NYC Run-Walk-Hike**  
NEW YORK CITY, NEW YORK

**JULY 21–23 • PFF @ Scleroderma Conference**  
CHANDLER, ARIZONA

**JULY 29 • Twisters Ice Cream Golf Outing for PF**  
BATH, MICHIGAN

**AUGUST 14 • Drive Fore Breathing Inaugural Golf Outing**  
STOW, MASSACHUSETTS

**SEPTEMBER • Global Pulmonary Fibrosis Awareness Month**  
WORLDWIDE

**SEPTEMBER 9 • PFF Walk**  
CHICAGO, ILLINOIS and ONLINE

**SEPTEMBER 16 • Garden State 5K**  
NEW YORK CITY, NEW YORK

**SEPTEMBER 23 • Third Annual Bourbon & Barbecue PF Education Day**  
LOUISVILLE, KENTUCKY

**SEPTEMBER 24 • Jim Cormier Canal Walk**  
BUZZARDS BAY, MASSACHUSETTS

**OCTOBER 4–7 • PFF @ AARC Meeting**  
INDIANAPOLIS, INDIANA

**OCTOBER 28–NOVEMBER 1 • PFF @ CHEST Meeting**  
TORONTO, ONTARIO, CANADA

**NOVEMBER 9–11 • PFF Summit 2017**  
NASHVILLE, TENNESSEE

**PFFSUMMIT2017**

global  
PULMONARY FIBROSIS  
awareness<sub>month</sub>  
SEPTEMBER

The Pulmonary Fibrosis Foundation expresses its sincere gratitude and appreciation to the CHEST Foundation and Feldman family for their partnership and fundraising efforts this spring. Together we have raised over \$160,000 toward helping patients and families fight pulmonary fibrosis.

Thank you!

# Pulmonary Fibrosis

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# Pulmonary Fibrosis FOUNDATION

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# register now!

## PFFSUMMIT2017

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

NASHVILLE, TN  
NOVEMBER 9-11



# INAUGURAL 09.09 PFF WALK

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awareness month  
[bit.ly/PFFGPFAM](http://bit.ly/PFFGPFAM) **SEPTEMBER**

# VISIT US THIS FALL AT CHEST

10.28-11.01 TORONTO, CANADA  
PFF BOOTH #2105

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