

Pulmonary Fibrosis  
FOUNDATION

2014 ANNUAL REPORT

leading  
the way  
to better  
living

**THE MISSION** of the Pulmonary Fibrosis Foundation (PFF) is to serve as the trusted resource for the pulmonary fibrosis (PF) community by raising awareness, providing disease education, and funding research.

# dear friends,

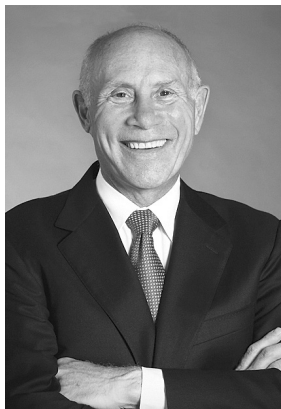
**2014 was an exceptional year for the Pulmonary Fibrosis Foundation (PFF), with key advancements in the Foundation's efforts.**

The approval of two new therapies (nintedanib and pirfenidone) by the US Food and Drug Administration (FDA) is a true milestone in pulmonary fibrosis (PF) treatment, and the result of a tremendous joint effort by the PFF, patients, physician researchers, the FDA, and industry.

In 2014 we set the stage for expansion of the PFF Care Center Network (CCN) to 21 centers throughout the US, which will have a direct impact on the quality of patient care, research, and education. The CCN will work in tandem with the planned PFF Patient Registry, the first source of large-scale, anonymized data on patients living with PF. With continued collaboration in the PF community, the CCN and PFF Patient Registry will help identify additional therapies and thus benefit more people living with pulmonary fibrosis.

Matching the Foundation's expanding influence, the PFF's medical team leadership has grown in the past year. Gregory P. Cosgrove, MD, Chief Medical Officer; Kevin R. Flaherty, MD, MS, Steering Committee Chair, PFF Care Center Network and PFF Patient Registry; David J. Lederer, MD, MS, Senior Medical Advisor, Education and Awareness; and Harold R. Collard,

MD, Senior Medical Advisor, Research Advisory Forum Chair, *PFF Summit 2015* Chair are outstanding leaders in the PF community and bring their vision and expertise to furthering the Foundation's efforts.



It's been a year of momentum for the Foundation, and another transition is underway. I've been honored to serve as the PFF's Chief Executive Officer during its early years of development and growth — and proud to have made a tangible difference in the lives of PF patients and their families through our team's efforts in awareness-building, education, and research. We started as a small, family foundation, and have become the most trusted source of information, education, and referrals for the PF community.

As I continue to serve on the PFF Board of Directors and transition to a senior advisory role for the Foundation, I'll be passing this legacy to Patti Tuomey, EdD, who will succeed me as CEO. Patti has been the PFF's President and Chief Operating Officer for the past five years and is a natural choice to lead the Foundation into its next stage of growth. Her experience, expertise, and energy are well known to our community's patients, caregivers, health care professionals, researchers, and educators, and I look forward to seeing the Foundation's future unfold under her capable leadership.

**I'm grateful for the engagement and participation you've shown the Foundation** during my time as CEO — and for the ongoing support of individual contributors, volunteers, foundation grants, and corporate donors. Your continued commitment moves us ever closer to ending PF. Once again, thank you for all you do for the PF community.

Sincerely,

A handwritten signature in black ink that reads "Daniel M. Rose". The signature is written in a cursive, flowing style.

**DANIEL M. ROSE, MD**

MEMBER, BOARD OF DIRECTORS  
SENIOR ADVISOR

# to our community,

**Exceptional programming — for patients, caregivers, and health care professionals seeking**

a greater understanding of pulmonary fibrosis (PF) and support while living with the disease — is the backbone of the Pulmonary Fibrosis Foundation (PFF). The Foundation has taken giant steps forward in the past few years, and 2014 was the most notable year yet for programs that educate, connect, and support the PF community.

One of our biggest achievements last year was the establishment of the PFF Patient Communication Center (PCC), a one-stop shop for the most accurate and up-to-date information about PF, medical care and support options, and programs and initiatives of the Foundation.

No one can tell the PF story like the people who live it every day. The PFF Ambassador Program, also launched in 2014, empowers PF patients and caregivers and health care professionals to speak at support groups and other public gatherings. Patients and caregivers share their personal PF stories, while health care providers impart current information about the disease. It's a personal and engaging way to spread the word about PF and help other PF families feel supported.

Our new PFF Disease Education Webinar Series is a popular monthly tool for support groups,



families, and individuals who want to learn more about the disease. Delving into a variety of topics on aspects of PF, the series is also archived for those who can't attend in real time, and even offers an "Ask a Doc" quarterly webinar through which patients and their caregivers questions are answered by PF experts.

Support groups, both in person and online, are a critical means of improving the quality of life for both patients and caregivers alike. Growing since its 2012 debut, the PFF Support Group Leader Network arms members of the PF community with the patient education materials, funding, and other resources they need to start a support group — or keep an existing group plugged in and passionate.

While our exceptional programming continues to flourish, I take pause to reflect on how the vision of our leadership has allowed us to find new ways to even better serve the PF community. As Daniel Rose, MD, prepares to make the transition to a senior advisory role and continues his involvement as a member of the Board of Directors, I'm honored to accept the role of PFF Chief Executive Officer. Dr. Rose's contributions to the PF community are immeasurable, and I'm grateful for the solid platform he created for our future work at the Foundation. It's a privilege to carry on our shared goal of eradicating this deadly disease.

**We're deeply grateful to all the PFF sponsors and donors who, through your support of and participation in our quality programming, improve the lives of PF families everywhere.** With your involvement, we continue to inspire hope, open new doors, and change the way families meet the PF challenge.

Sincerely,

*Patti Tuomey*  
**PATTI TUOMEY, EdD**  
PRESIDENT AND CHIEF EXECUTIVE OFFICER

# PILLARS of the Foundation's mission

The formula for a world without pulmonary fibrosis (PF) is a mixture of awareness, education, and research. Here's how the Pulmonary Fibrosis Foundation (PFF) spread the word, shared vital information, and made scientific inroads in 2014.

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## AWARENESS

**Raising awareness of a rare disease is challenging.** It takes time, perseverance, and community involvement to let the world know about pulmonary fibrosis (PF), but these awareness-building efforts yield significant payoffs. The Pulmonary Fibrosis Foundation (PFF) engages in multipronged efforts to heighten awareness that extend beyond the patient and caregiver community, also reaching health care providers, researchers, legislators, and the public. Awareness efforts can be local, like fundraising events shared with family and friends or wearing PFF Breathe Bracelets that spark conversation about the disease.

Awareness can be nationally targeted activities, such as presentations about PF to the US Food and Drug Administration, Congressional leaders, and other policymakers. During September's Global Pulmonary Fibrosis Awareness Month events, awareness efforts even go worldwide. Every mention of PF brings us closer to finding a cure.

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## EDUCATION

**The more patients and caregivers know about PF, the better the quality of life.** The one-stop PFF Patient Communication Center, PFF Disease Education Webinar Series, and other PFF education materials provide practical information about PF symptoms, diagnostic tests, treatment, monitoring, lifestyle changes, and palliative and hospice care.

PFF events including the biennial *PFF Summit*, *Team PFF* fundraisers, social gatherings, and presentations by PFF Ambassadors help attendees learn how to live with the disease and get involved with the PF community. Support groups and social media networks help patients and caregivers connect and share information with other PF families. At a community level, the PFF Support Group Leader Network institutes best practices and shares resources among leaders who guide support group meetings across the country.

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## RESEARCH

**Increased research is key to developing more effective treatments and a cure for PF patients.**

The PFF funds research, promotes advocacy efforts, encourages collaboration between industry and academic researchers, and develops solutions to bridge gaps in PF research. At PFF Care Center Network sites, patient care goes hand in hand with a comprehensive treatment approach — ultimately collaborating with critical research strengthened by data in the national PFF Patient Registry, once fully realized.

The Foundation's I.M. Rosenzweig Junior Investigator Awards and Albert Rose Established Investigator Awards support projects with a high likelihood of widening PF knowledge in the areas of basic science, translational research, clinical medicine/research, and social science/quality of life. The PFF also partners with other professional organizations and foundations to support research that empowers the PF community today — and brings a brighter tomorrow.

# about

## WHAT IS PULMONARY FIBROSIS AND WHAT ARE THE CAUSES?

Pulmonary fibrosis (PF) is a condition in which the walls of the air sacs of the lungs become thickened and stiff due to a build up of scar tissue. This scar tissue makes it more difficult for your lungs to transfer oxygen into your bloodstream.

Pulmonary fibrosis can result from a number of causes: certain environmental agents (molds, birds, fibers, dusts), medications (antibiotics, chemotherapy), radiation therapy, autoimmune diseases (scleroderma, rheumatoid arthritis), or a genetic predisposition.

However, in most situations the cause is unknown. There are many types of PF for which we don't know the cause. One specific type of PF of unknown cause is called "idiopathic pulmonary fibrosis" or IPF. IPF is diagnosed when either a CAT scan or a lung biopsy show certain findings in the absence of an identifiable cause. IPF is a progressive, fatal lung disease, for which there is no known cure.

## WHAT DOES THE DISEASE LOOK LIKE?

There are no reliable data to determine how many people are affected by PF, possibly due to the large number of conditions under which it can arise. However, one recent study estimates IPF affects 1 out of 200 adults over the age of 65 in the United States. Approximately 50,000 new cases are diagnosed each year and as many as 40,000 Americans die from IPF each year. The current estimate of the incidence of IPF in the EU is between 37,000 and 40,000 people. It is anticipated that the number of individuals diagnosed with IPF will continue to increase as a result of people living longer, an improved clinical understanding of IPF, and earlier and more accurate diagnosis.

PF can strike at any age, affects both men and women, and is found among all racial and ethnic groups. IPF is more common among older adults and is rare in adults under the age of 50. About half of people diagnosed with IPF will live longer than three or four years, but the other half will pass away within three or four years.

**Symptoms include:** breathlessness upon exertion, dry cough, and fatigue.

**Treatments include:** supplemental oxygen, pulmonary rehabilitation, optimizing weight and exercise, lung transplantation for those who qualify, and medications to manage symptoms. Some patients may benefit from disease-specific therapy for IPF:

**NINTEDANIB:** Nintedanib is an anti-fibrotic drug that has been approved to treat IPF in the US and the European Union (EU). Nintedanib slows the progression of IPF.

**PIRFENIDONE:** Pirfenidone is an anti-fibrotic drug approved to treat IPF in the US, EU, Canada, and Asia. Pirfenidone slows the progression of IPF.

**PREDNISONE:** Prednisone is an anti-inflammatory therapy that can help some people with inflammation in the lungs.

Pulmonary fibrosis is a devastating disease. It is the Foundation's goal to help find effective treatments and ultimately a cure. As we strive to accomplish that goal, the Foundation is committed to increase disease awareness; provide educational materials and events for patients and health care professionals; advocate for the PF community; and offer support to patients, family members, and caregivers.

## MEDICAL TEAM grows, expanding expertise

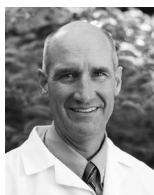
To maximize its expertise and impact, the Pulmonary Fibrosis Foundation (PFF) expanded its medical team during the past year. These outstanding individuals and important thought leaders share the Foundation's vision to improve the lives of PF patients. They are helping to make vital contributions that will lead to better therapies and hopefully one day a cure.



**GREGORY P. COSGROVE, MD**

**Chief Medical Officer**

Dr. Cosgrove oversees medical affairs and serves as the primary medical consultant for the PFF. He advises in defining priorities, creating new initiatives, and enhancing existing Foundation programs. From 2010 to 2014 he served on the Medical Advisory Board, the Scientific Advisory Committee (formerly known as the Research Advisory Committee), and was Co-Chair of the *PFF Summit 2013*. Dr. Cosgrove is Associate Professor of Medicine in the Division of Pulmonary and Critical Care Medicine at the University of Colorado School of Medicine. Dr. Cosgrove sees patients in the Interstitial Lung Disease Clinic at National Jewish Health in Denver, Colorado.



**KEVIN R. FLAHERTY, MD, MS**

**Steering Committee Chair, PFF Care Center Network and PFF Patient Registry**

Dr. Flaherty, who has a background in biostatistics and clinical studies, oversees the development and implementation of two important PFF initiatives that work synergistically: the PFF Care Center Network (CCN) and the PFF Patient Registry. The CCN is a consortium of academic medical centers and community-based clinics with proven, multidisciplinary expertise in the care of patients with fibrotic lung disease. The Registry comprises a collection of patient information for use by qualified investigators to better understand fibrotic lung diseases and assist in the development of more effective therapies. Dr. Flaherty is Professor of Medicine in the Division of Pulmonary and Critical Care Medicine, Department of Internal Medicine, at the University of Michigan Health System in Ann Arbor, Michigan.



**DAVID J. LEDERER, MD, MS**

**Senior Medical Advisor, Education and Awareness**

Dr. Lederer communicates with the PF community to help make complex and sometimes confusing information less difficult to understand. Working with Patient Relations and Medical Affairs, he produces and reviews content for PFF educational materials and responds to medical inquiries submitted to the PFF Patient Communication Center. Dr. Lederer is Associate Professor of Medicine and Epidemiology in the Division of Pulmonary, Allergy, and Critical Care Medicine at Columbia University Medical Center in New York City, New York. He is Co-Director of the Interstitial Lung Disease Program at Columbia and is the principal investigator of the National Institutes of Health-funded MESA Lung Fibrosis Study.



**HAROLD R. COLLARD, MD**

**Senior Medical Advisor, Research Advisory Forum Chair, PFF Summit 2015 Chair**

Dr. Collard provides strategic guidance and oversight to the PFF, with particular attention to the development of the PFF Research Advisory Forum. Additionally, Dr. Collard is Chair of the *PFF Summit 2015*, where he is responsible for organizing the clinical, scientific, and educational content of the conference. Dr. Collard is Associate Professor of Medicine, Division of Pulmonary and Critical Care Medicine, and Director of the Interstitial Lung Disease Program at the University of California, San Francisco (UCSF) School of Medicine.

**HIGHLIGHTS** In dedication to its mission of serving as the trusted resource for the pulmonary fibrosis (PF) community by raising awareness, providing disease education, and funding research, the Pulmonary Fibrosis Foundation (PFF) launched new programs and participated in a variety of events across the country and globe in 2014.





# 2014

- 2.26** THE 4TH ANNUAL **BROADWAY BELTS FOR PFF!** RAISED NEARLY \$110,000 TO BENEFIT THE MISSION OF THE PFF
- 3.27** INTRODUCED THE FIRST CENTRALIZED CALL CENTER FOR THE PF COMMUNITY — THE **PFF PATIENT COMMUNICATION CENTER**
- 5.14** LAUNCHED THE **PFF DISEASE EDUCATION WEBINAR SERIES** AND THE REDESIGNED PFF WEBSITE — **WWW.PULMONARYFIBROSIS.ORG**
- EXHIBITED AT **ATS 2014 INTERNATIONAL CONFERENCE** **5.16–21**
- 7.23** LAUNCHED NATIONAL **PFF AMBASSADOR PROGRAM**
- EXHIBITED AT **SCLERODERMA FOUNDATION 2014 NATIONAL** **7.25–27**  
**PATIENT EDUCATION CONFERENCE**
- 9.1–30** **BLUE-IT-UP FUNDRAISING/AWARENESS CAMPAIGN** INSPIRED RECORD-BREAKING PARTICIPATION FROM MEMBERS OF PF COMMUNITY INCLUDING CCN SITES
- EXHIBITED AT **ERS ANNUAL CONGRESS 2014** **9.6–10**
- 9.18** PARTICIPATED IN THE **RALLY FOR MEDICAL RESEARCH CAPITOL HILL DAY**
- ATTENDED **2014 ICLAF** **9.20–24**
- 9.26** REPORTED INTERIM FINDINGS FROM THE **PFF PATIENT AND CAREGIVER SURVEY** TO THE FDA AS PART OF THE **PATIENT-FOCUSED DRUG DEVELOPMENT MEETING**
- 10.16** APPLAUDED THE FDA FOR ITS PROMPT DECISION TO APPROVE **NINTEDANIB AND PIRFENIDONE** FOR IPF
- 10.23** CITED AS **NUMBER ONE THIRD PARTY SOURCE** FOR INFORMATION ABOUT THE FDA'S APPROVAL OF TWO NEW DRUGS TO TREAT PULMONARY FIBROSIS
- EXHIBITED AT **CHEST 2014** **10.25–30**

**PHILANTHROPY** is the power behind the Pulmonary Fibrosis Foundation's (PFF) growing accomplishments. Every dollar given to the PFF increases awareness of pulmonary fibrosis (PF), provides resources and support to those living with the disease, and expands the research that improves outcomes for tomorrow. In the following pages, meet several committed Foundation donors whose generosity is bringing us ever closer to finding new treatments and ultimately—a cure for PF.



**Julie Willis O'Connor** and her family have been dedicated champions of the PF community for many years. Willis O'Connor served on the PFF Board of Directors from 2007–2013 and continues to fight for those living with PF.



**Myrna Taylor** is a multifaceted PF advocate and mentor who has capitalized on her leadership skills to spearhead numerous efforts in support of the mission of the PFF.



Married couple **Colleen and Martin Attwell** found a common bond in an unfortunate coincidence: both lost their fathers to pulmonary fibrosis (PF). Today they are fervent supporters of the Foundation and PF research.

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# Julie Willis O'Connor

## DONOR / BENEFACTOR

Julie Willis O'Connor and her brother, Dave Willis, are the second generation of devoted pulmonary fibrosis (PF) advocates in their family. After their father, Bo Willis, was diagnosed in 2002, Willis O'Connor summited all 46 mountain peaks in the Adirondack Park in New York in his honor. Friends and family showed their support by making pledges by the mile. In 2014, she honored her late mother, another strong Pulmonary Fibrosis Foundation (PFF) supporter, by hiking around Mont Blanc on the border between France and Italy.

### TELL US ABOUT YOUR EUROPEAN HIKING ADVENTURE.

I have a friend I hike with in the Adirondacks. She called me up and asked whether I wanted to climb Kilimanjaro with her. We looked into it, but decided to go to Mont Blanc instead. I'm glad we did, because wherever you are on Mont Blanc, the view you're seeing is spectacular. There's a reward every step! I thought of my parents a lot; this was a nice way to honor them. We did 100 miles through France, Italy, and Switzerland and raised over \$130,000. Through the generosity of our friends, family, and members of our community we've raised a total of nearly \$260,000 for PFF in support of the pulmonary fibrosis community since 2007.

### WHAT'S NEXT ON YOUR CLIMBING SCHEDULE?

I spent summer 2015 in the Adirondacks again, and am just eight mountains short of becoming a Forty-Sixer for the second time. I may do another PFF fundraiser to celebrate that milestone!

### DID YOU LEARN ABOUT THE PFF ONLINE?

Yes. You're just playing a waiting game once you find out the diagnosis. I wanted our dad to know how much we all cared and wanted to support him. I chose to fundraise for the PFF because it was impressive how much funding went to research. They were in the trenches making a difference.

### WHAT DO YOU FIND MOST REWARDING ABOUT RAISING MONEY TO SUPPORT THE PFF'S MISSION?

What's really exciting is to see the PFF staff's determination, the growth of their outreach, and the support they're able to provide. Since I first got in touch with them, their dedicated staff and volunteers have worked to make the Foundation a force to be reckoned with.

### WHAT'S MOST IMPORTANT IN THE FIGHT AGAINST PF?

Raising awareness. Once the public realizes how many people the disease impacts, and that they know people affected by it in their community, they'll say, "I can't believe we don't have a cure for this."

### WHAT DO YOU WISH PEOPLE OUTSIDE THE PF COMMUNITY KNEW ABOUT PF?

How many people it affects. Because PF is not as well known as some other diseases, it can be more difficult to get people to take action. I'd like to hear people say, "Yes! I'll participate in an event for pulmonary fibrosis. Not that I've ever had it, but plenty of people do."

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# Myrna Taylor

## PF ADVOCATE / MENTOR

Myrna Taylor says her extensive engagement with the Pulmonary Fibrosis Foundation (PFF) “just evolved” after she lost her husband, Lee, to pulmonary fibrosis (PF) in 2010. “I thought, I know more about PF than most people at this point, and maybe I can help other spouses and families get through,” she says. Now Taylor is involved in multiple PFF efforts: she and fellow PF advocate Grace Jacobson started the Eastern Idaho PF Support Group; Taylor is also a member of the Support Group Leader Network and a PFF Ambassador; she’s spearheaded several fundraising efforts; and she’s even mentored a teenager who lost her father to PF.

### **TELL US ABOUT THE YOUNG PF ADVOCATE YOU MENTORED.**

Nerissa Thompson’s late father, Robert, had come to some of our support group meetings. In Idaho, every high-school student has to do a senior project, and Nerissa’s mother called to ask if I could help her daughter do one focused on PF.

Even though there’s a 60-year difference in our ages, Nerissa and I became friends. She did a wonderful job and went far beyond the project’s requirements. She conducted a survey that compares our regional PF statistics to the national average and collected memorial contributions to support the PFF that totaled nearly \$700. The main part of her project was a PowerPoint presentation she gave to our support group — they all loved it and wanted to contact her teacher to make sure Nerissa got an A!

### **WHY IS IT IMPORTANT FOR YOUNG PEOPLE TO LEARN ABOUT THE VALUE OF PHILANTHROPY AND GIVING BACK AT A YOUNG AGE?**

I don’t think the kids in my family had any idea of what’s involved in putting on a fundraising event, but they all love being involved in planning our support group’s “TAKE A BREATH for Someone Who Can’t” golf tournament and dinner, which we held for the third time in September 2015. It was hard for them to lose their grandfather to PF, but I think this participation will set them on a lifelong path of service.

### **WHAT’S YOUR ADVICE FOR SOMEONE THINKING OF STARTING A FUNDRAISING AND PF AWARENESS INITIATIVE?**

Whatever you’ve got an interest in — make that your starting point. My husband was well known and loved in the golfing community here, so a golf tournament was a logical choice for me. Find something you love that you’re knowledgeable about and turn it into an event.

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# Colleen and Martin Attwell

## PF ADVOCATES / TEAM PFF EVENT LEADERS

The Attwells are enthusiastic volunteers for the Pulmonary Fibrosis Foundation (PFF), most recently hosting a successful dance party that raised almost \$13,000 for PF research. The couple's fundraising has been a road to further involvement with the Foundation: both recently joined PFF committees that focus on development, strategic planning, and IT.

### PLEASE DESCRIBE YOUR FAMILIES' EXPERIENCE WITH PF.

**Martin:** My father died before Colleen and I met. I'm from the United Kingdom and came to the United States in 1993. My father became ill a few years after that and died in 1999 at age 61.

**Colleen:** My father had already been diagnosed with PF when Martin and I were married in 2012. He passed away in 2013. I hadn't realized exactly what Martin's dad died from; PF is not widely known and I didn't put it together until my dad had it.

### WHY IS FUNDRAISING TO SUPPORT THE FOUNDATION'S MISSION IMPORTANT TO YOU?

**Martin:** PF is something to which we both have a connection and commitment. We've been able to put our energy into something that helps make a difference.

**Colleen:** Anybody who's been through this knows the helplessness you feel. There was nothing we could do to save our fathers, but this is something we can do.

### WHAT MADE YOU CHOOSE A DANCE PARTY FOR YOUR 2014 FUNDRAISER? WHAT WAS THE EVENT LIKE?

**Colleen:** Martin and I had been taking dance lessons at the Arthur Murray Dance Studio in Oakbrook Terrace, Illinois. We had the idea of renting out the studio and offering group dance lessons. Arthur Murray donated the space and refreshments. We wanted a fun, private party for friends, family, and coworkers.

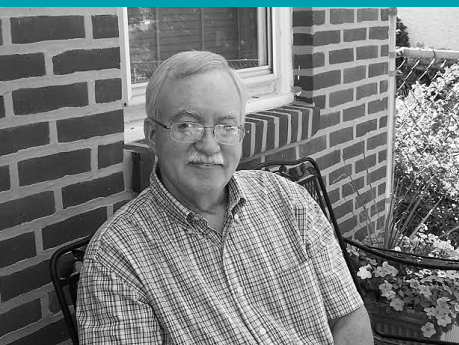
**Martin:** It was a great event that let us bring together people we know from different settings to share something unique and fun that was also a tribute to our fathers. Both our mothers were there — mine came all the way from England.

### HOW CAN OTHERS FOLLOW YOUR LEAD IN GETTING INVOLVED?

**Colleen:** Without money for PF research, there's never going to be any change. So we really encourage others to get involved. But you don't have to raise \$13,000 or host a complicated event. Anyone can put on an event — you just have to have a few basic components in place plus a group of supporters.

**Martin:** Set a goal and a date, allow yourself enough time to plan, line up your core supporters, and take the plunge!

**TEAM PFF** is a dedicated group of advocates who make a difference in the lives of those with pulmonary fibrosis by leading fundraising events to support disease awareness and research. In 2014, Team PFF hosted events in 38 states and seven countries outside of the US.



\$6,000+

\$15,000+

## Sean O'Dell

### **NJ5K FOR PF — JAMES LYNAM MEMORIAL 5K RUN/1 MILE WALK**

After James Lynam passed away from idiopathic pulmonary fibrosis (IPF) in 2011, nephew Sean O'Dell wanted to do something to honor his uncle's fight. "My wife and I like to run and do a lot of 5K events, so we felt confident hosting one," O'Dell says. The 2014 NJ5K for PF, held in Washington Lake Park in Sewell, New Jersey raised over \$6,000. The event, now celebrating its second year, includes a one-mile walk popular with participants who have pulmonary fibrosis (PF). "I have as many walkers as runners at this point," O'Dell says. "Hopefully, it's going to be bigger each year — that's my goal."

## Gary Leibovitz

### **NO KEEPING HIM FROM THE FINISH LINE**

Gary Leibovitz literally ran into trouble 12 miles into his first Chicago Marathon in 2014. But he was running in memory of his mother, Myrna, an idiopathic pulmonary fibrosis (IPF) patient who died in 2008, so there was no giving in to an injury. "I limp-walked through the last 14 miles and finished about a minute under six hours, the required time for getting a medal," remembers Leibovitz, who later buried the medal at his mother's grave. Leibovitz set a fundraising goal of \$10,000 but brought in well over \$15,000. "My mother always told me there's no greater gift than the gift of helping others," he says. "I try to live my life in her honor every day."

# volunteers raised nearly \$500,000



\$30,000

## Jenni Hudson

### KARL G. HUDSON, JR. GOLF TOURNAMENT

Jenni Hudson's grandfather lost his battle with idiopathic pulmonary fibrosis in 2006, but is remembered as a family man and Raleigh business leader who played golf every chance he got. Hudson started the Karl G. Hudson, Jr. Golf Tournament in Cary, North Carolina in 2014 and in the first year the event raised an impressive \$30,000 in support of the Pulmonary Fibrosis Foundation. Planning an event to spread pulmonary fibrosis awareness may seem daunting at first, but Hudson's advice is to "Just start doing it! The best way to ensure a successful event is to establish what you hope to accomplish, determine a location, and gauge community interest in participating." Hudson anticipates selling-out the 2nd annual tournament this year.



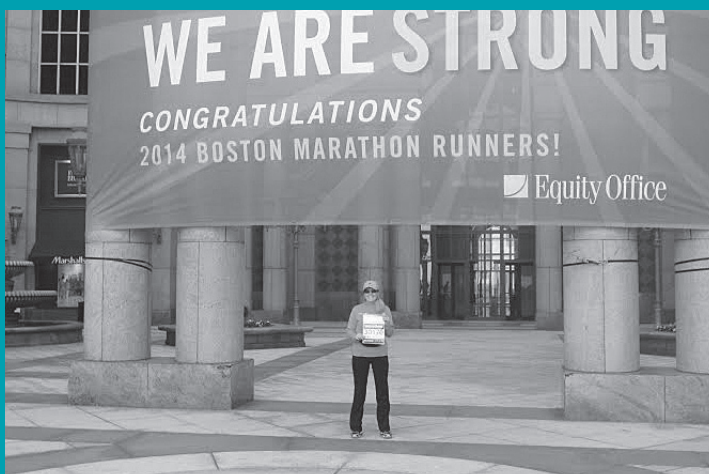
\$13,000+

## Sara Dykstra

### GEARIN' UP FOR GRADY

"Ever since my dad was a kid, cars were his passion," says Sara Dykstra about her father, Grady Usrey, who passed away from pulmonary fibrosis in 2014. When Dykstra decided to raise funds in honor of her ailing father, "Gearin' Up for Grady," a car show was a natural choice. With the support of her community, Dykstra put together a 115-car show with many local merchants providing raffle prizes. The event, which took place a month after Usrey passed away, raised over \$13,000 for the PFF. "Organizing a fundraiser was a good distraction for me and our family when my dad was sick," Dykstra says. "It was a real positive in a negative situation, and I honestly think it kept my dad with us longer."

## RUNNING MY FIRST BOSTON MARATHON IN MEMORY OF MY MUM



\$9,000+

### Sarah Manning

#### RUNNING 26.2 MILES IN A PF PATIENT'S SHOES

When Mary Burke Holian passed away in 2013, the cause was lung cancer, but PF, which had taken two of her five siblings, was also present. Holian's daughter, Sarah Manning, ran the Boston Marathon in 2014 "in honor of my mother and for strong, healthy lungs." Manning says that because lung cancer is widely known and funded she chose the Pulmonary Fibrosis Foundation to receive the more than \$9,000 she raised. A brutally cold training winter and scorching marathon day made for a grueling experience, "but not being able to catch my breath just reminded me of the battle PF patients go through every day," Manning says. "I want to do what I can to help future patients have the full life we runners have."



\$12,000+

### Walgreens CT / Hyman Glick

#### A "ONE-TIME" EVENT THAT KEEPS GOING

Walgreens pharmacist Greg Walsh and store manager Hyman Glick had been colleagues and close friends for decades, even traveling together with their families. Walsh passed away from pulmonary fibrosis (PF) in 2012. In 2014, Glick and his staff decided proceeds from the Connecticut Walgreens annual fundraising golf outing — which benefits a different cause every year — would go to PF research in Walsh's memory. "It's a wonderful way to remember Greg," says Glick, who was recently honored by Walgreens for his community engagement. The 2014 event raised over \$12,000. Although the Walgreens sponsorship was a one-time event, Glick and Walsh's two sons, Matt and Ryan, decided to continue to organize an annual fundraiser in memory of Walsh. They raised over \$8,000 in 2015. "We're going to keep this going and growing it every year," Glick declares.



**SOCIAL MEDIA** inspires hope in those affected by pulmonary fibrosis (PF) — and helps the Foundation raise pulmonary fibrosis (PF) awareness and the necessary funds to support critical programs and initiatives. In 2014 the PFF's #Giving Tuesday campaign generated \$20,000 in a single day.



# 20,636

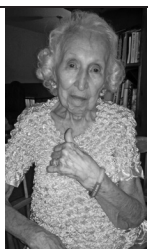
gained 7,190 Facebook followers

saw an increase of 877% Facebook post reach during Global Pulmonary Fibrosis Awareness Month

#BlueUp4PF yielded 300% of its original goal

named Top 10 Influencer for #ERS2014 #ATS2014 #CHEST2014

our highest-liked photo was of a 100-year-old PF advocate with 973 likes



**FACEBOOK**  
20,636 followers in 2014  
52% increase from 2013

**TWITTER**  
2,601 followers in 2014  
31% increase from 2013

**INSTAGRAM**  
812 followers in 2014  
67% increase from 2013

OVER 1,700 PEOPLE  
**WATCHED** a PFF webinar  
either through **live broadcasts**  
or online views



“THE FOUNDATION’S WEBINARS PROVIDE A UNIQUE AND VALUABLE OPPORTUNITY TO DISCUSS KEY TOPICS AND ISSUES ACROSS A BROAD AND DIVERSE AUDIENCE. THIS FORMAT ALSO LETS US REACH INDIVIDUALS WHO MAY BE TOO ILL TO TRAVEL OR MAY NOT BE ASSOCIATED WITH A MEDICAL CENTER THAT HAS THE RESOURCES TO PROVIDE THIS INFORMATION TO PEOPLE WITH PF.”

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

## PFF DISEASE EDUCATION WEBINAR SERIES

The online series is a free resource available to anyone who wants to learn about pulmonary fibrosis (PF).

With topics ranging from supplemental oxygen to lung transplantation, monthly webinars address the diverse needs of the PF community. Quarterly “Ask a Doc” webinars offer opportunities to pose questions to PF experts. Webinars are archived and accessible 24/7.

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### Michele Peters

#### CAREGIVER

PFF Ambassador (see page 21) Michele Peters shared her perspective during the Foundation’s first “Caregiving 101” webinar.

“It’s very hard work, but so rewarding helping your loved one through their journey,” says Michele Peters of the care she provided her husband, Jeffery, from the time he was diagnosed with pulmonary fibrosis (PF) in 2010 until he passed away in May 2015.

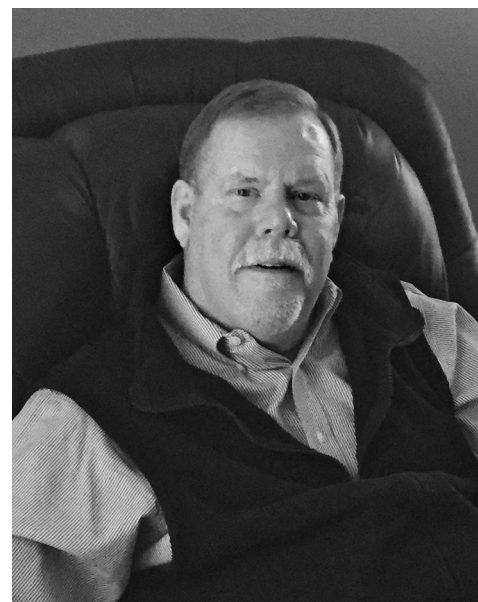
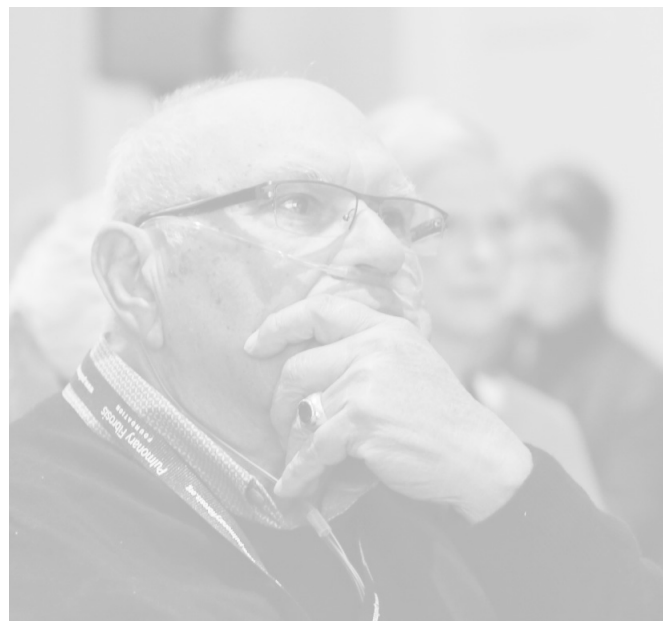
In the caregiving webinar, Peters talked about her experiences caring for Jeffery and the intensifying job caregivers have as PF progresses. “You’re not alone in this,” she says. “Caregiving can be isolating at times. We were lucky to have a wonderful network of family and friends, but for those without that network, the PFF offers a lot of support. There are support groups throughout the country and online where you can take a big breath, relate your story, and get encouragement from others.”

Peters adds that she learned some things from fellow webinar presenter Ginny Maril, PhD, who discussed the need for caregivers to also attend to their own physical and emotional requirements. “I thought I’d been handling my situation well, but when I heard the signs of stress caregivers need to look out for, I realized I needed to take better care of myself so I could be there for Jeffery,” Peters says.

Besides participating in the caregiving webinar and serving as a PFF Ambassador, Michele and her family have sponsored several fundraisers to benefit PF research. She plans to carry on her work with the PFF.

“My involvement didn’t end when my husband passed away,” she says. “My resolve is ever stronger.”

**13 NEW support groups** were added in 2014  
for a total of **75 SUPPORT GROUPS** in the  
**United States** and **internationally**



**“OUR SUPPORT GROUP IS A VITAL PART OF THE CARE WE RECEIVE.”**

**“I WAS BAFLED BY WHAT WAS HAPPENING TO ME. ONLINE INFORMATION WAS DIRE.  
BEING WITH FOLKS IN THE SAME BOAT IS VERY USEFUL.”**

**SUPPORT GROUP  
MEMBERS**

**SUPPORT GROUP LEADER NETWORK** Support groups are a valuable quality-of-life resource for pulmonary fibrosis (PF) patients and their caregivers. The PFF Support Group Leader Network, launched in 2012, offers quarterly teleconferences, eNewsletters, patient education materials, and grants through the Leanne Storch Support Group Fund to help group leaders make meetings more informative and engaging.

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## John Myers

### SUPPORT GROUP LEADER

When John Myers, a resident of Greensboro, North Carolina was diagnosed with idiopathic pulmonary fibrosis (IPF) in 2011, “there wasn’t a single support group in North Carolina,” he noted. Myers connected with the Pulmonary Fibrosis Foundation (PFF) to learn about the disease. When he discovered the PF support groups on the Foundation’s website, he decided to take action and form North Carolina’s first group, the PFF Piedmont Triad Support Group.

“I couldn’t just sit here in my recliner. I felt I needed to be useful in the community,” he says. With support from the Foundation, including educational resources and a grant from the Storch Fund, Myers recruited other PF patients he met through pulmonary rehabilitation and his physical therapist.

At the PFF Piedmont Triad Support Group’s first meeting, “we had 50 people show up,” Myers noted. “I was shocked at the amount of interest out there.”

For caregivers who attend, support group meetings can help shine a brighter light on patients’ experiences. “At our first meeting, a patient told me that her husband hadn’t understood how difficult it was for her to clean the house,” Myers recalled. She said this was a real eye opener for him.

For patients, support groups help them realize they’re not alone. Myers also stated, “Unless you have PF, you don’t understand what it’s like to be out of breath, how much you have to plan ahead just to leave the house. When you’re in a support group, you’re with other people who know what you’re going through.”

**Special thanks** to Boehringer Ingelheim.

PFF AMBASSADORS have  
**SHARED** their stories and **SPREAD** PF awareness  
to over **700 people** at 25 different events



“ANY TIME YOU’RE IN THE TRENCHES WITH THE PATIENTS AND HEARING WHAT THEY’RE EXPERIENCING, YOU’RE LEARNING AS MUCH FROM PATIENTS AS THEY DO FROM US. IT MAKES US MORE COGNIZANT OF PATIENTS’ NEEDS.”

**JANET TALBERT**  
CERTIFIED GENETIC COUNSELOR,  
PFF AMBASSADOR

**PFF AMBASSADOR PROGRAM** This national program enables patients, caregivers, and health care professionals to provide information and lend support to the PF community. Patients and caregivers share their personal stories at support group gatherings, meetings with health care organizations, and fundraisers, while health care professionals provide current disease information at these events.

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## Doug Jones

### PATIENT / PFF AMBASSADOR

“This is one small way of paying back everything that the PFF has done for me following my transplant,” says Doug Jones, who brings a patient’s perspective through his work as a PFF Ambassador.

In the last year, Jones has traveled every couple of months — to Indiana, Illinois, Kansas, and New York, among other locations — to speak at a variety of events. Last February in Washington, DC, Jones spoke to a packed Congressional briefing on Rare Disease Day. Jones helped legislators and their staffs better understand the scope and impact of pulmonary fibrosis on those living with the disease and also the challenges of funding PF research.

“It’s gratifying because I’m doing something,” Jones says. “I’m out there actually walking the pavement and knocking on doors to drum up support for the patients and the Pulmonary Fibrosis Foundation.”

Feedback from event attendees is very positive. After Jones’s first public appearance in Evansville, Indiana, he was approached that evening in a local restaurant. “One of the people who’d been at the presentation came over to say he was so impressed by my talk that he and his wife were going to become organ donors,” Jones recalls. “That was really gratifying.”

“I encourage people to take their meds, do the rehab, and see their doctors — my main message is one of hope,” says Jones, who celebrated the fifth anniversary of his double lung transplant in August.

over **1,400 INQUIRIES** were made through **email and phone calls** from **33 states** and **12 countries** during the **PCC's first year**



“THE PCC IS VERY WILLING TO HELP IN WHATEVER WAY POSSIBLE. WHEN THE PFF SUMMIT OCCURRED IN 2013 I COULDN'T ATTEND, BUT SOMEONE MADE SURE I GOT A PACKAGE OF INFORMATION FOLLOWING THE EVENT. IT'S NICE TO KNOW THAT SOMEONE CARES AND IS THERE TO HELP A PATIENT LIKE ME.”

**EDWARD LEVINE, NEW YORK**  
LIVING WITH PF



## PFF PATIENT COMMUNICATION CENTER (PCC)

The Pulmonary Fibrosis Foundation's (PFF) mission took a major step forward by establishing the first-ever comprehensive information center for the entire PF community. PCC staff is available to listen and lend support by personally answering every call and email and offering educational resources to patients, caregivers, and health care providers.

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### David J. Lederer, MD, MS

#### SENIOR MEDICAL ADVISOR

"Patients with PF and their caregivers need two things from us: information and support," says David J. Lederer, MD, MS, Senior Medical Advisor, Education and Awareness.

Dr. Lederer continued, "People find a lot of information online and some of it may be helpful. But a lot of information may be misleading or frightening and needs to be put into context. Reliable information about the disease, its expected course, available therapies, and local resources are critical to managing this disease."

The PCC helps callers find in-person and online support groups where they can reach out to other people with this condition. Dr. Lederer also notes, "When you call the PCC, you can expect to talk to someone who's knowledgeable not only about the Foundation and the resources we offer but is also well informed about the disease itself."

Callers can also learn about the PFF Care Center Network (CCN), a growing group of medical centers with multidisciplinary expertise in treating patients with PF. According to Dr. Lederer, the most common question the PCC receives concerns how callers can find a doctor or health care team that specializes in PF.

"We refer callers to our 21 CCN sites and other health care programs around the country and that information is also available on the PFF website," says Dr. Lederer. "The PCC facilitates the connections within the PF community that are necessary for patients and caregivers to consistently receive the best treatment and care."

The PFF Patient Communication Center is staffed Monday through Friday, 9:00 a.m.–5:00 p.m. CT. Contact the PCC at 844.TalkPFF (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

## BY THE NUMBERS

70+

**EVENTS** were held in support of Global Pulmonary Fibrosis Awareness Month

600+

**PEOPLE** at 12 events spanning 10 states heard **PFF Ambassadors** share their stories and spread awareness

21

**EDUCATIONAL EVENTS**, including luncheons, information tables, medical grand rounds, and symposia, were held by the PFF Support Group Leader Network, PFF Care Center Network sites, and other **PATIENT ADVOCACY** organizations

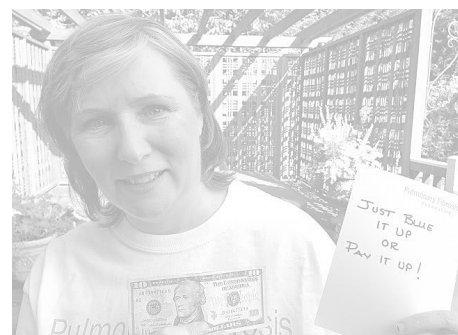


43

**TEAM PFF** fundraising events took place, an increase of **105%** from 2013

\$7,000+

was raised by **generous people** who participated in the “**Blue-It-Up or Pay-It-Up**” PF awareness campaign, started by the late **PFF AMBASSADOR Diane Reichert**



SEE PAGE 36 TO LEARN MORE ABOUT LISA TIGHE'S FUNDRAISING EFFORTS.

“I WANTED TO DO SOMETHING TO HELP RAISE AWARENESS. MY DAD WAS SUCH A CARING PERSON, VERY COMMITTED TO CHARITABLE GIVING. SO THIS WAS SOMETHING HE WOULD HAVE BEEN PROUD OF.”

**LISA TIGHE**  
PFF ADVOCATE

# GLOBAL PULMONARY FIBROSIS AWARENESS MONTH

The Pulmonary Fibrosis Foundation (PFF) encouraged the entire community to mobilize in September by joining in awareness, fundraising, and education events around the globe. Participants included the PFF's Support Group Leader Network, the PFF Care Center Network, Interstitial Lung Disease (ILD) centers, Team PFF, and other patient advocacy organizations.

## PF Awareness

### LET THE WORLD KNOW

#### Spotlight on social media

- PFF shared over 250 photos from the “Blue-It-Up or Pay-It-Up” campaign.
- Selfies of individuals from 42 states and six countries wearing PFF Breathe Bracelets were posted in support of PF awareness.
- PFF Facebook page received 2,500 new LIKES in five weeks during Global Pulmonary Fibrosis Awareness Month.
- On Twitter an estimated two million impressions were made with notable retweets in support of pulmonary fibrosis awareness, including: Rosie O'Donnell, Broadway star Robert Creighton, actress Kristen Johnston, comedian Judy Gold, and staff members of the Howard Stern Show.
- Plague Inc. displayed an “in-game message” for Global Pulmonary Fibrosis Awareness Month, viewed over 20 million times.

#### More visibility for PF

- Mayor Rahm Emanuel of Chicago officially designated September Global Pulmonary Fibrosis Awareness Month in Chicago.
- Lamar Advertising promoted Global Pulmonary Fibrosis Awareness Month on more than 68 outdoor advertising boards in 17 cities across 14 states.
- Jon Leiberman of “Leiberman Live” on Sirius XM Radio, with 26.3 million subscribers, gave on-air recognition to Global Pulmonary Fibrosis Awareness Month and the Pulmonary Fibrosis Foundation.

Although September comes just once a year, the Foundation and PF community keep the momentum going by providing PF awareness and education every day.

## WORKING TOGETHER to improve patient outcomes

Living with pulmonary fibrosis (PF) is hard. The Pulmonary Fibrosis Foundation (PFF) has been working for over a decade to improve the lives of people living with PF. Two new endeavors — the PFF Care Center Network (CCN) and the PFF Patient Registry — have the potential to change the face of PF now and for years to come.

### CCN SITES PROVIDE EXPERT MEDICAL CARE TO PEOPLE LIVING WITH PF

Launched in 2013, the CCN initially included nine medical centers with specific expertise in treating PF, a family of diseases that are often difficult to diagnose and manage. Since then, additional funding has allowed the CCN to expand to 21 sites throughout 20 states, with new sites scheduled to join the Network before the end of 2015.

Medical centers in the Network use a multidisciplinary approach to deliver comprehensive care. These specialized care teams include health care providers with expertise in pulmonary medicine, rheumatology, radiology, pathology, gastroenterology, and thoracic surgery. Only medical centers that combine teaching, research, education, and community engagement are selected to be part of the CCN through an objective review process. This multipronged, collaborative approach is critical to managing these complex diseases and ensuring that each person with PF receives an accurate diagnosis, obtains quality clinical care, and has access to important support services.



### PATIENT REGISTRY TO OPEN NEW DOORS IN UNDERSTANDING PF

In the near future, the CCN sites will begin enrolling patients in the PFF Patient Registry, which will collect medical data about patients in order to facilitate biomedical research and clinical trials.

The Registry will be an electronic database of de-identified patient medical information collected during routine clinical visits. Patients will also have the opportunity to donate blood and other biological samples to a bio-repository linked to the Registry. These biological samples are critical tools that scientists will use to identify new causes and mechanisms of PF that may one day lead to new treatments and a cure for the disease.

The CCN and Registry efforts are intuitively linked — and, once the Registry is fully operational, it will assist researchers and health care providers to be able to more fully understand the disease and treatment patterns and improve outcomes for patients. Ongoing funding for the Registry is critical to the project's success: the scope and depth of the Registry — and the project's power to positively transform the way patients and their caregivers experience PF — is limited only by the funds it receives.

**Special thanks** to Genentech, Inc., the Rattner Family Foundation, the Cowlin Family Fund, Biogen, Inc., the Charles and Monica McQuaid Family Foundation, Fred Krauss and Virginia Dirks, and the Shillington Family Foundation.

## VITAL PATIENT INSIGHTS presented by the PFF

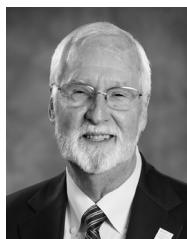
When the US Food and Drug Administration (FDA) held its public meeting on Idiopathic Pulmonary Fibrosis (IPF) Patient-Focused Drug Development in Silver Spring, Maryland, last fall, the Pulmonary Fibrosis Foundation (PFF) helped inform FDA representatives about the experience and needs of IPF patients.

Following the PF community's efforts, including the PFF sharing initial findings from a patient and caregiver survey conducted earlier in 2014, the FDA approved two new treatments for IPF, nintedanib (Ofev®) and pirfenidone (Esbriet®) less than one month later.

This landmark meeting was part of a new FDA initiative to consider the patient point of view during evaluation for new drug approval. The FDA wanted to obtain a better understanding of how IPF patients and caregivers cope with symptoms, learn about the impact of the disease on their daily lives, and find out their views on current treatment approaches. The meeting was simultaneously webcast for those who couldn't attend.

Michael C. Henderson, PFF Board Chair, and PFF Ambassadors Taleena Koch and the late Diane Reichert (pictured above, left to right), along with other IPF patients, caregivers, and advocates, participated in a panel discussion and provided input to the FDA.

In August 2014, the PFF launched an independent patient and caregiver survey to collect meaningful insights about living with the disease. Initial survey results from the more than 1,100 respondents were presented during the open discussion portion of the meeting by Gregory P. Cosgrove, MD, PFF Chief Medical Officer. David J. Lederer, MD, MS, PFF Senior Medical Advisor for Patient Communications and Dolly Kervitsky, CRT, CCRC, former PFF Vice President of Patient Relations, also spoke about the serious impact of the disease on patients and the urgent need to develop new treatments.



Interim survey findings presented to the FDA included the following information:

- 65% of respondents reported shortness of breath as the one symptom having the most impact on their lives
- 25% of patients reported no improvement in their condition based on their current treatment regimen
- On their worst days, respondents reported that they were unable to talk or speak with others (47%); could not walk across the room (40%); and were not able to prepare meals (38%)

A few days prior to the meeting, the PFF also participated in the Rally for Medical Research Capitol Hill Day, where PFF staff, PFF Ambassadors, and dedicated volunteers urged Congressional representatives and their staffs to make medical research funding a top legislative priority. PFF Ambassador Doug Jones (also see page 21) traveled to Capitol Hill to spread the word on behalf of the pulmonary fibrosis community.

The PF community achieved several significant gains as a result of the PFF's participation in the FDA meeting and its efforts on Capitol Hill: the FDA now has a better understanding of the impact IPF has on patients and caregivers; IPF patient input will be part of the drug evaluation process; and there is increased public visibility and general awareness of the disease.

## 2014 PFF RESEARCH FUND AWARDS

The Pulmonary Fibrosis Foundation places enormous importance on funding new research, developing solutions to bridge existing gaps in pulmonary fibrosis research, and encouraging collaborative relations between industry and academic researchers that will ultimately lead to successful therapies for pulmonary fibrosis.

### GENERAL RESEARCH GRANT

**PATRICIA J. SIME, MD** – UNIVERSITY OF ROCHESTER (Year 1)

“Metabolic Derangement in Pulmonary Fibrosis”

### I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARDS

**JUNG-WHAN (JAY) KIM, DVM, PHD** – UNIVERSITY OF TEXAS AT DALLAS

“Evaluation of Hypoxia-inducible Factor-1 (HIF-1) Signaling as Anti-fibrosis Therapy”

**CHIKO SHIMBORI, PHD** – MCMASTER UNIVERSITY

“The Role of Mast Cells in Pathophysiology of Pulmonary Fibrosis”

FUNDED BY INTERMUNE, INC.

### ALBERT ROSE ESTABLISHED INVESTIGATOR AWARDS

**STIJN DE LANGHE, PHD** – NATIONAL JEWISH HEALTH

“Role of Wnt and FGF Signaling in Alveolar Epithelial Regeneration After Bleomycin Injury”

**BRIAN ZABEL, PHD** – PALO ALTO INSTITUTE FOR RESEARCH AND EDUCATION, INC.

“Role of Chemerin and its Receptors in TGF-beta-induced Experimental Pulmonary Fibrosis”

FUNDED BY BOEHRINGER INGELHEIM

### ATS FOUNDATION/PFF/CPF PARTNERSHIP GRANTS

**NATHAN SANDBO, MD** – UNIVERSITY OF WISCONSIN (Year 1)

“Mechanisms Facilitating Enhanced Fibronectin Assembly by Myofibroblasts”

**CHI HUNG, MD** – UNIVERSITY OF WASHINGTON, SEATTLE (Year 2)

“Role of Collagen I-Derived Cells in Pulmonary Fibrosis”

### 2014 SPONSORSHIPS

Federation of American Societies for Experimental Biology – Science Research Conferences (FASEB SRC): The Lung Epithelium in Health & Disease

Fibrosis Across Species: A Workshop on Comparative Pathology of Fibrosing Lung Disorders

International Colloquium on Lung and Airway Fibrosis (ICLAF)

Wendi Mason, NP – Patient Education Seminar

University of California, San Francisco (UCSF) – Interstitial Lung Disease: Advances in Diagnosis and Management

### PROGRAM GRANT

National Jewish Health – Familial Pulmonary Fibrosis Genetic Counseling Program (Year 3)

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# thank you to our Team PFF volunteers

## Lisa Tighe

### WALKING TO RAISE AWARENESS — AND INSPIRE OTHER FUNDRAISERS

Lisa Tighe's father passed away in 2010, just three months after being diagnosed with pulmonary fibrosis (PF). "It was very sudden. We'd never heard of PF, so we had no idea what we were dealing with," Tighe says. After her father was gone, "I wanted to do something to help raise awareness," she recalls — so she took the lead in an all-family effort to organize the Annual John F. Tighe Walk. "My dad was such a caring person, very committed to charitable giving. So this was something he would have been proud of," Tighe adds.

The walk raised \$35,000 in its fourth and final year, held during Global Pulmonary Fibrosis Awareness Month 2014. In a unique twist, the Tighes annually invited other PF families to share photos of loved ones they've lost to the disease. Posters featuring those individuals' names and photos were showcased at the walk. The successful event has even had a ripple effect: a family that came to the first few events has now started its own walk, the Jim Cormier Memorial Canal Walk.



Having succeeded in building a successful annual walk, the Tighes are planning new fundraising events to help spread awareness in honor of their dad. "We love the PFF and definitely want to stay involved," Lisa Tighe says.

## 2014 TEAM PFF

10K Run in Memory of Medardo de Jesus Martell\*  
1st Annual Greg Walsh Memorial Golf Tournament  
20th Annual Father's Day Road Race  
2nd Annual Caroline M. Fell 5K Memorial Walk/Run  
2nd Annual Janet Hovey Memorial Fundraiser  
2nd Annual Team Jeffery Trivia Night  
2nd Annual Tom Rutledge Memorial Ready, Set, Breathe, Fun Run & 5K  
3rd Annual Jim Hodge Memorial Run  
3rd Annual Pilot for a Cure Yard Sale  
4th Annual John F. Tighe Walk for Pulmonary Fibrosis\*  
4th Annual Oktoberfest 10K & Half Marathon  
4th Annual Pete DeVito Memorial Golf Outing  
4th Annual Ready, Set, Breathe!  
6th Annual Garden State 5K Run/Walk for Pulmonary Fibrosis\*  
7th Annual Alamance Force Volleyball Camp  
7th Annual Greg Chandler & Guy F. Solimano Memorial Golf Tournament  
A Musical Tribute to Ravi Ravindranath  
A Wine Tasting to Support the Pulmonary Fibrosis Foundation\*  
AMP Jeans Week for PFF  
Andrew & Alyssa Willits's Wedding  
Art for PF\*  
Avon American Legion Legion Post 145 Fish Fry Dinner for PFF  
Avon Online Event  
Baheti & Vora Happy Hour  
Bake Sale & Raffle in memory of Ed Roberts\*  
Battle for Breath, Zumba for a Cure  
"Battle Out Pulmonary Fibrosis" Fight, Give, Win!\*  
Bob Logan Memorial Golf Tournament at 49er's Country Club  
Bowling for PF Awareness\*  
Bravelets for PFF  
Breathe for Duffy (Rhode Island Public Defenders Fundraiser)  
Breathe Love\*  
Brianna Broderick Helps Pulmmel Pulmonary Fibrosis\*  
Calgary Farmers Market for Global PF Awareness\*  
Candlelight Vigil  
Central Valley Pulmonary Fibrosis Support Group Meeting  
for Global PF Awareness\*  
Cheryl Runyon's Bumper Sticker Fundraiser  
Chesterfield Support Group Meeting for Global PF Awareness\*  
Chicago Marathon in Memory of Myrna Leibovitz  
Chip Away Pulmonary Fibrosis\*  
CJ Bornstein's 1st Birthday  
Coins for PFF  
Comedy for a Cause  
Community Health & Wellness Expo for Global PF Awareness\*  
Cruisin' Towards a Cure for PF—Because Breathing Matters!  
Dallas/Fort Worth PF Support Group Meeting for Global PF Awareness\*  
Daniel & Joan Beren IPF Registry, Awareness & Advocacy Event  
David & Rachel Daniels's Wedding  
Dellinger Yard Sale for PFF  
Donna Schwartz Memorial Walk\*  
Doug & Ellen Run the Chicago Marathon  
Dress to Donate at ABC Bank\*  
Eat Wings Raise Funds for Pulmonary Fibrosis!\*  
Fairfax Pulmonary Fibrosis Patient Education Day  
Fashion Project  
Field Day at Canton Middle School  
First Midwest Bank's Jean Day for PFF  
First National Bank of Omaha (First National Operations  
Divisions) Jeans Day  
Fish Fry Fundraiser benefiting the PFF  
Free Throws for Fibrosis  
Fundraiser For PFF & Glenn Eul  
Gearin' Up for Gravdy & a Cure for Pulmonary Fibrosis  
Gift of Life & Love ~ Celebrating Dave Rude in Color  
Govoni Family Reunion  
Grade 3 Craft Fair  
Grand Rounds at Stony Brook University Hospital for  
Global PF Awareness\*  
Greater Kansas City Support Group Fundraisers  
H.O.T.T. MOMMEE FITNESS BOOTCAMP\*  
Hands Up—the Pose  
Healthy Lung Month for Global PF Awareness\*  
Healthy Lungs for Life for Global PF Awareness\*  
Hike for Lung Health—Breathe 2014—Cure PF\*  
Hike for Lung Health—Debbie's Lungs\*  
Hike for Lung Health—Huffin' & Puffin' for PaPa\*  
Hike for Lung Health—In Memory of Chris Ferrell\*  
Hike for Lung Health—In Memory of Glenn Eul\*  
Hike for Lung Health—Jack's Team\*  
Hike for Lung Health—Josie's Angels\*  
Hike for Lung Health—Kuhn Family & Friends\*  
Hike for Lung Health—Mar's S.O.B. Squad\*  
Hike for Lung Health—Muskie Mania\*  
Hike for Lung Health—PFF Team\*  
Hike for Lung Health—Team Breathe On\*  
Hike for Lung Health—Team M&M\*  
Hike for Lung Health—Team Renstrom\*  
Hike for Lung Health—Team Wilson Family & Friends\*  
Hike for Lung Health—Walk With Pat\*  
Hike for pulmonary fibrosis in honor of Jose L. Suarez\*  
Ilga Bokalders's Birthday  
Jamberry Nails for Pulmonary Fibrosis\*  
James & Frances Kushner's Wedding  
Jefferson Parish Clerk of Court Employees  
Joseph DeGrazia Memorial Golf Outing  
Julie O'Connor's Hike Around Mont Blanc\*  
Just Blue It!\*  
Katie Hart Runs the Lilac Bloomsday Run  
Kickin It Full Throttle—Benefit Classic Car Show  
Kyle & Nicolle Krause's Wedding

\*OCCURRED DURING GLOBAL AWARENESS MONTH

## 2014 TEAM PFF (continued)

LBX Dig Deep 5K  
Lily Diana Abram's Bat Mitzvah  
Linda Zion's 70th Birthday  
Marine Corps Marathon  
Martha Virginia Dupree Memorial Golf Challenge  
Martin & Colleen Attwell's Dance Party Fundraiser  
Massage for PF Awareness\*  
Master Brand Denim Day  
Matt & Mary Clare Babel's Wedding  
Miguel & Kerri Buzio's Wedding  
Mowery Clinic Jeans Day for PFF  
Naperville Marathon & Half-Marathon  
National Beauty Counter sales for PFF\*  
National Mary Kay Fundraiser for Pulmonary Fibrosis  
New Jersey Women's Flag Football Tournament  
Night at the Old Ball Park Benefiting the PFF  
NJ5K for PF James Lynam Memorial 5K Run/Walk  
Oak Creek Back Sale for Global PF Awareness\*  
Order of the Eastern Star of Utah—Grand Chapter Fundraiser  
Origami Owl Jewelry Bar\*  
Pacific High School Charity Art Auction  
Panfilo Pely Ferrer Memorial Fundraiser  
Phil Allard Memorial Fishing Tournament  
Pie In The Face for PF\*  
Polychronopoulos Online Fundraiser benefiting the PFF\*  
Providence Elementary School Fundraiser for Global PF Awareness\*  
Pulmonary Fibrosis—Coachella Valley  
Raise Awareness for Pulmonary Fibrosis—Breath by Breath\*  
Rally for Medical Research for Global PF Awareness\*  
Rally for Ronnie for Global PF Awareness\*  
Recycle for Research  
Rene Carrillo Memorial Fundraiser  
Rock Run 8K  
Rockin' PF Out! A concert for awareness & a cure  
of Pulmonary Fibrosis  
Roger & Marilynne Wilander's Wedding  
Roger Wallace: John Deere Golf Classic  
Rosner Family Trivia Night  
Run/Walk For Those Who Can't\*  
Ryan Shen's Bake Sale  
San Diego Half Marathon  
Sarah Manning Runs for Pulmonary Fibrosis  
Sean & Lianne Dugan's Wedding  
Shop Till You Drop for Global PF Awareness\*  
South Miami Hospital PF Awareness Education Event\*  
Summer Festival  
Swings for Steve

T.A.B. Scramble for Global PF Awareness Month\*  
Tastefully Simple for PFF\*  
Team Breathe On  
Team Joyce Challenge\*  
Temple University Lung Center IPF Seminar for  
Global PF Awareness\*  
The Jane Blair Project 5K Fun Run  
The Seidensticker Cup Golf Scramble  
Traverse City IPF Support Group Meeting for  
Global PF Awareness\*  
Trivia Night for the Pulmonary Fibrosis Foundation  
Vickie Dastillung's Retirement  
Virgil Englishbee's Birthday  
Walk With Purpose & You'll Never Walk Alone  
West's Insurance Agency Fundraisers  
Wineglass Marathon Weekend  
Winthrop University Hospital PF Support Group Meeting  
for Global PF Awareness \*  
Yoga for Global PF Awareness\*  
Younique Online Fundraiser for PFF

**DONORS RECOGNIZED IN THIS LIST ARE FOR GIFTS  
RECEIVED BETWEEN JANUARY 1 AND DECEMBER 31, 2014.  
THE PFF THANKS EVERYONE FOR THEIR GENEROUS  
CONTRIBUTIONS.**



**The Pulmonary Fibrosis Foundation  
has a four-star rating from Charity Navigator  
and is a Better Business Bureau  
accredited charity.**

\*OCCURRED DURING GLOBAL AWARENESS MONTH



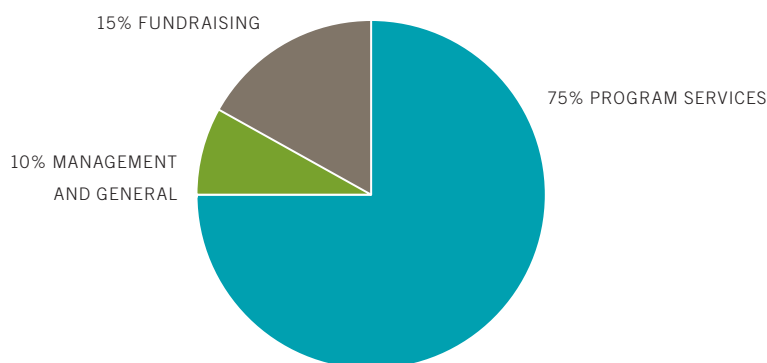
# FINANCIAL SUMMARY

## STATEMENT OF FINANCIAL POSITION

AUDITED NUMBERS	2014	2013 RESTATED
Total Assets	\$5,200,307	\$3,962,848
Total Liabilities	601,747	478,330
Total Net Assets	\$4,598,560	\$3,484,518

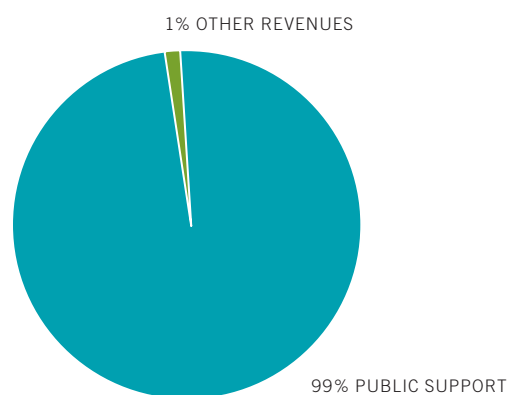
## STATEMENT OF ACTIVITIES

AUDITED NUMBERS	2014	2013 RESTATED
Total Revenue		
Unrestricted	\$4,408,580	\$3,534,035
Temporarily Restricted	1,018,247	162,354
	\$5,426,827	\$3,696,389
Total Expenses	4,312,785	3,872,676
Change in Net Assets	\$ 1,114,042	\$ (176,287)



## ALLOCATION OF 2014 EXPENSES

AUDITED NUMBERS		
Program Services by Category		
Patient Registry	\$ 711,911	
Care Center Network	574,614	
Research	435,175	
Outreach and Awareness	345,822	
Program Support	327,334	
Patient Communication Center	290,013	
Physician and Patient Education	187,414	
PFF Summit	189,568	
Support Groups	97,934	
Advocacy	79,617	
Program Services Total	\$3,239,402	75%
Management and General	441,555	10%
Fundraising	631,828	15%
Total 2014 Expenses	\$4,312,785	100%



## SOURCES OF 2014 REVENUE

Public Support	\$5,375,355	99%
Other Revenues	51,472	1%
Total 2014 Revenue	\$5,426,827	100%

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