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

The 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.

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LETTER FROM OUR CEO

DEAR FRIENDS,

As I write this message the landscape for patients with pulmonary fibrosis (PF) is changing in very positive ways. I am pleased to report that for the first time in the United States we have two FDA approved treatments for idiopathic pulmonary fibrosis. This remarkable development renews hope for everyone affected by the disease.

The recently approved therapies, nintedanib (Ofev®) and pirfenidone (Esbriet®), had previously received “Fast Track” and “Breakthrough Therapy” designations by the FDA. We applaud the FDA’s decision to expedite the review process for the two drugs and commend the many patients who participated in the clinical trials that eventually led to this achievement. Until a cure is found, we hope that all patients will continue to participate in clinical trials to help researchers develop a better understanding of, and treatments for, pulmonary fibrosis—it’s the best pathway to eventually identifying a cure.

This is significant news for patients and for those who love and care for them, and it’s just one of many achievements for the PF community and the Pulmonary Fibrosis Foundation (PFF) this year. We’re celebrating the results of a very successful Global Pulmonary Fibrosis Awareness Month, which occurred in September. Many individuals attended educational events, hosted Team PFF fundraising affairs, and participated in our webinars. Our September social media campaign sparked a tremendous increase in activity on our Facebook page. “Blue It Up or Pay It Up,” a campaign in which participants added blue streaks to their hair to promote awareness of PF and fundraise in support the PFF’s programs, garnered many new participants and dramatically exceeded expectations.

Please keep the progress of Global Pulmonary Fibrosis Awareness Month going by remembering the PFF on #GivingTuesday. This day will be celebrated on December 2. We invite you to spread the word and join charities, families, businesses, community centers, and students around the world as they come together for one common purpose: to celebrate and engage in generosity. To learn more about how to become involved, visit our Facebook page.

Another major achievement was the PFF Patient and Caregiver Survey. This effort yielded valuable information and will inform our activities and influence the future course of our organization. Some of the survey’s interim findings were presented at the FDA Patient-Focused Drug Development Meeting in September. This meeting is a new initiative focused on giving the FDA a better understanding of the impact of IPF on patients, while providing input on patients’ expectations for current and future therapeutic treatments.

As the holidays approach, we’re especially grateful for your continued support and generosity. Please watch your mailbox. You’ll be hearing about how your donations make a measurable impact on the lives of patients and bring new hope for the future.

Your enthusiasm, energy, and engagement have helped make it possible for the PFF to make major strides in 2014. Thank you for your continuing support and partnership on this important journey.

Sincerely,

DANIEL M. ROSE, MD
Chief Executive Officer
PFF PROGRAMS

The PFF Patient Communication Center—Serving Our Community

The PFF Patient Communication Center (PCC) serves as the central information hub for pulmonary fibrosis (PF) patients, caregivers, and health care professionals. The PCC staff answers questions and provides information that is tailored to individuals’ needs. Resources available to callers include:

• Information about pulmonary fibrosis
• How to find medical care, access support services, obtain available treatments, and enroll in clinical trials
• PFF patient education and advocacy materials
• PFF programs and services

PFF Disease Education Webinar Series

The PFF Disease Education Webinar Series provides a unique gateway for the pulmonary fibrosis community to learn from, interact with, and submit questions to leading pulmonary fibrosis specialists. Since May, the PFF has conducted seven informative webinars for patients, caregivers, and health care professionals. Webinars include:

• What is Pulmonary Fibrosis?
• Ask-A-Doc: Clinical Trial Update
• Making an Accurate Diagnosis: How to Use IPF Consensus Guidelines
• Tools for Living Better with PF: Pulmonary Rehabilitation and Support Groups
• Caregiving 101: Supporting Others While Supporting Yourself
• Tools for Living Better with PF: Supplemental Oxygen
• Talking with PF Patients: Truth-Telling While Maintaining Hope

PFF PROGRAMS UPDATE

did you know?

The PCC is the best way to acquire disease education information and to arrange for a PFF Ambassador to speak at your program or event. PFF Ambassadors have been asked to share their stories at venues ranging from medical centers to support group meetings to Team PFF events. Contact the PCC to schedule a PFF Ambassador today!

Pulmonary Fibrosis Foundation

CALL TOLL FREE OR EMAIL US!
844.TalkPFF (844.825.5733)
pcc@pulmonaryfibrosis.org

“The PCC has done an impressive job in keeping people aware of all kinds of things happening in the world of ‘PF.’”

— SHELLY RASMUSSEN / CAREGIVER

WWW.PULMONARYFIBROSIS.ORG
“It meant so much to me to hear Kathy share the story about her mother-in-law’s struggle with IPF. My mother had IPF and so much of what Kathy shared was familiar to my own journey with my mother. She just thought that her age and weight had made her out of breath.”
— CARRIE ELLIOTT / CAREGIVER

Schedule a PFF Ambassador for Your Next Event

Last July the Pulmonary Fibrosis Foundation (PFF) officially launched the PFF Ambassador program—a group of caregivers, patients and health care professionals who share their stories and provide the latest disease information to audiences across the country. PFF Ambassador Kathy Biggs “kicked-off” the program at the Medical University of South Carolina’s “Idiopathic Pulmonary Fibrosis Education Day.” Biggs was a caregiver to her mother-in-law and best friend, Nini, who was diagnosed with IPF in 2007 and passed away in 2009. Biggs’ words of encouragement, including the importance of learning as much as she could about IPF, resonated with all the attendees at the event.

PFF Ambassadors have lived and worked with IPF and know first-hand the challenges that patients and caregivers face, such as acquiring an accurate diagnosis, coping with the impact of the disease on family and work life, and navigating complex treatment options such as clinical trial enrollment and lung transplantation.

PFF Ambassadors play a vital role in increasing the general public’s understanding of the disease while providing hope and inspiration. Disease education and awareness is a cornerstone of the PFF’s mission.

PFF Ambassadors are available to speak at PFF Care Center Network events, PF support groups, fundraising events, and other disease awareness programs. To request a PFF Ambassador for your event, call the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or email pcc@pulmonaryfibrosis.org.

THANK YOU TO OUR SPONSOR

The PFF Ambassador program is made possible through the generous support of InterMune, Inc.

PFF Ambassadors Areas of Experience:
- IPF patients
- Caregivers
- Lung transplant recipients
- Registered nurses
- Physical therapist
- Clinical Research coordinator
- Genetic counselor

All presentations in the PFF Disease Education Webinar Series are available on the PFF website and can easily be accessed. PFF Support Group Leaders are utilizing both the live and archived broadcasts for their support group meetings.

Recommendations from the PF community for future webinar topics are welcome and will be used to inform future programming. Please email your suggestions to the PFF Patient Communication Center at pcc@pulmonaryfibrosis.org.

To register for upcoming webinars, view archived presentations, and to explore the entire PFF Webinar Library—including presentations from PFF Summit 2013—please visit www.pulmonaryfibrosis.org/webinars.

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PFF Ambassadors—patients and caregivers
THE FUTURE OF PATIENT CARE

Expert Medical Care, Emotional Support, and Dedication to Finding a Cure

The CCN is comprised of a highly qualified group of institutions. A thorough review process ensures that centers that apply for membership meet accreditation requirements prior to being invited to join. Each CCN site has a multidisciplinary team of health care professionals that strive to meet the medical and social service needs of PF patients. This approach is designed to define best practices and advance research that will benefit PF patients around the globe.

The PFF CCN provides physicians and other health care professionals with an environment that facilitates collaborative communication, research, and care. This approach can enhance patients’ experience and enable more research. Expedited communication among the sites allows for rapid dissemination of novel ideas; when one team identifies a new treatment or research idea, this information can readily be shared with all sites.

AVAILABLE RESOURCES AT CCN SITES

- Multidisciplinary care team
- Access to pulmonary rehabilitation
- Support groups — in person and online
- Disease-specific educational materials and programs

GOALS OF THE CCN

- Provide the best possible care to pulmonary fibrosis patients
- Identify best practices that are associated with the best outcomes
- Information sharing
- Facilitate PF research

ACCURATE DIAGNOSIS, TREATMENT, AND CONTINUING CARE

Many studies have shown a multidisciplinary approach is essential to establish an accurate diagnosis. CCN sites have multiple medical experts in a variety of specialties including pulmonary medicine, rheumatology, cardiology, radiology, gastroenterology, thoracic surgery, and pathology. These groups work together to review and analyze all available information and provide the multidisciplinary evaluation required to make a correct diagnosis and recommend appropriate therapy.

Patients with PF often have other ailments that can complicate their disease management. Problems with the heart, immune system, gastrointestinal reflux, sleep apnea, and other organ systems can be quite challenging. At CCN sites, multidisciplinary teams will work together to diagnose and coordinate treatment of these difficult and often interrelated problems.
EDUCATIONAL AND SUPPORT SERVICES

At the time of diagnosis many patients and caregivers have never heard of PF. At PFF Care Center Network sites, education is key to providing patients and their families with the resources they need to live better with PF. Often when patients and families first learn about the diagnosis, they are overwhelmed and may not remember many of the details that were shared during their medical appointment. The Foundation provides CCN sites with many educational resources to share with patients including the PFF Pulmonary Fibrosis Patient Information Guide. This booklet provides medical information about PF as well as suggestions on how to live better with PF.

Patients treated at PFF Care Center Network sites also have access to in-person support group meetings, which provide vital emotional support and a connection to other patients and families with PF. Patients benefit from hearing from individuals who are successfully living with the disease. Patients with limited time or who have difficulty traveling can connect through online support groups including the PFF communities on Inspire™ and RareConnect. There are currently two types of support groups available through each of these platforms—one for patients and one for caregivers. Some people find great value participating in both groups.

VALUE OF THE NETWORK—ADVANCING CLINICAL CARE AND RESEARCH FOR PATIENTS WITH PF

While providing high quality, multidisciplinary health care, the PFF Care Center Network sites will also collect data regarding patient care and outcomes related to different treatment plans through their participation in the PFF Patient Registry. This information will be published in collaboration with the CCN Medical Directors. Review of this data will be used to evaluate best practice patterns and will establish standards for optimal care for pulmonary fibrosis patients. This information will be communicated through publication in medical journals and on the PFF website in order to benefit patients beyond those seen at CCN sites.

MULTIDISCIPLINARY TEAM

Evaluation
Experts working together in the following specialties may be necessary to make an accurate diagnosis:
- Pulmonary Medicine
- Pathology
- Radiology
- Rheumatology
- Cardiology
- Gastroenterology
- Thoracic Surgery
- Lung Transplant

Treatment and Continuing Care
From diagnosis to treatment and to continuing care, the multidisciplinary team works together to ensure that patients receive the best, most comprehensive care. Additional health care professionals are brought onto the team depending on the patient’s diagnosis and ongoing care needs.
- Physicians
- Nurses
- Respiratory therapists
- Physical therapists
- Occupational therapists
- Social workers

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- Social workers
The Pulmonary Fibrosis Foundation is grateful for the support of the PF community who joined us by participating in the #BlueUp4PF campaign, attended educational events, hosted Team PFF fundraising events, participated in our webinars, and spread disease awareness through social media. In Chicago, we kicked off the month with Mayor Rahm Emanuel proclaiming September Global Pulmonary Fibrosis Awareness Month!

“BLUE IT UP” EXCEEDS GOAL AND INCREASES AWARENESS

Last year for Global Pulmonary Fibrosis Awareness Day PFF Ambassador Diane Reichert, who is living with IPF and also lost her mother to the disease, decided to add a blue streak to her hair, hoping the eye-catching color would help spread the word about pulmonary fibrosis and inspire people to give.

“BLUE IT UP OR PAY IT UP” 2014

Diane’s “Blue It Up or Pay It Up” awareness campaign greatly expanded this year for Global Pulmonary Fibrosis Awareness Month, with her original $200 fundraising goal eclipsed—in total raising more than $7,000 thanks to the generosity of people nationwide who participated and challenged others to follow suit. Members of the PF community from patients to caregivers to health care professionals colored their hair, clipped in blue hair extensions, and even wore blue wigs, posted photos on social media and opened their wallets to support Diane’s fundraising campaign.

If you would like to show your support by making a gift, please visit bit.ly/blueituporpayitup.

See photos from the “Blue It Up or Pay It Up” campaign on the PFF Facebook page.

Not on Facebook yet?

PFF Facebook page garnered 2,500 new LIKES in six weeks, which included during Global Pulmonary Fibrosis Awareness Month. Join Facebook and “like” us!

Thanks to Diane Reichert and all who participated in “Blue It Up or Pay It Up!” Staff from the Pulmonary, Critical Care, and Sleep Medicine Section at the Yale School of Medicine (a PFF Care Center Network site) “Blue It Up” with PFF Ambassador Diane Reichert.
DeVito Family

MEDICAL GRAND ROUNDS

In collaboration with the PFF the Pete DeVito Memorial Foundation hosted two physician medical grand rounds, one on September 17 at University Medical Center at Stony Brook, located in Stony Brook, New York and one on September 18 at Southampton Hospital, Southampton, New York.

PFF Patient Communications Senior Medical Advisor David J. Lederer, MD spoke during both physician medical grand rounds. The Stony Brook educational seminar addressed lung transplantation for PF and IPF patients, as well as other patients that may qualify for a lung transplantation with end stage respiratory diseases.

Southampton Hospital featured an educational seminar specifically on IPF and PF and in addition to Dr. Lederer, PFF Ambassador and lung transplant recipient John Moranthos spoke about his journey living with IPF and how lung transplantation was an option for his survival.

“The purpose of these events is to raise awareness of IPF/PF for some of the most important people dealing with this horrific disease on the front lines, but that may not have all the knowledge about it: physicians. The Pete DeVito Memorial Foundation has been successful in raising money to support research for IPF, but feels it is now time to start educating the community as well—we need to have more physicians that are aware of this disease and that can make quicker a diagnosis for the benefit of the patient and their family. My father’s diagnosis was very difficult, took longer than it should have, and the physicians were just unsure of how to treat him,” said Nick DeVito.

Tighe Family

4TH ANNUAL JOHN F. TIGHE WALK

We began the John F. Tighe Walk for Pulmonary Fibrosis after our husband/father passed away from IPF on December 21, 2010. As a family we could not think of any better way to honor him than to raise funds and awareness for IPF.

This year will be our 4th annual walk. It started out as family and close friends and has since grown to include many families from around the state. Not only is this walk in memory of John F. Tighe, but also for all the people who have loved ones who are affected by IPF. Each year we invite families to honor their loved ones by making memorial posters, which will be displayed at the event.

The Tighe family feels very blessed to have made new friends along this heartbreaking journey. We thank all of the families who have made the John F. Tighe walk successful and a special thank you to the PFF for all of their help and support. The event raised over $35,000.

Piedmont Hospital PF Support Group

KNOCK DOWN PULMONARY FIBROSIS

Expanding last year’s Piedmont Hospital Pulmonary Fibrosis Support Group Patient Education Symposium for Global Pulmonary Fibrosis Awareness Day, this year the group decided to include families and friends of PF patients and host “Knock Down Pulmonary Fibrosis,” a bowling event supporting the PFF.

“This is a special month because it is a time when people from all around the world are raising awareness for such an important cause. We are so excited to be a part of this,” said Marcy Solmson, who has been leading the Piedmont Hospital Support Group with Amy Case, MD since 2012.

Attendees at the September 27 event at Stars and Strikes Bowling Alley received a t-shirt, pizza, two games of bowling, and information about the disease. The event raised $3,000 and attracted nearly 50 people who have been impacted by pulmonary fibrosis and wanted to demonstrate their support for Global Pulmonary Fibrosis Awareness Month.

did you know?

GPFAM on Twitter estimated two million impressions with notable retweets including: Rosie O’Donnell, Broadway star Bobby Creighton, actress Kristen Johnson, comedian Judy Gold, and multiple Howard Stern staffers in honor of Ralph Howard!

Lamar Advertising posted PFF PSAs on more than 68 outdoor billboards in 17 cities across 14 states during September. Special thanks to Lamar Advertising employee Jeanne-Anne Renshaw!
What is your educational background and how did you become interested in pulmonary medicine, specifically pulmonary fibrosis (PF) and interstitial lung diseases?

I went to medical school in Brooklyn at Downstate Medical Center, and I completed my training in internal medicine, pulmonary medicine, and critical care at New York Presbyterian/Columbia in Manhattan. I suppose I initially became interested in pulmonary fibrosis because it seemed like a bit of a “black box.” Everything else—asthma, COPD, lung cancer, ventilator management—seemed pretty straightforward. But pulmonary fibrosis was something completely different. How could so many people have scarred up lungs for reasons we don’t understand? I guess I was drawn to the mystery of pulmonary fibrosis.

Do you have a specific focus in the area of pulmonary fibrosis?

I am passionate about trying to improve the lives of people living with pulmonary fibrosis. One way I do this is by providing medical care to my patients in the New York Presbyterian Interstitial Lung Disease Program. I also conduct clinical research focused on identifying early pulmonary fibrosis even before symptoms arise. By understanding the earliest biological changes that lead to PF, we might be able to develop novel ways to prevent the development of what we think of today as PF. One day, I hope to see pulmonary fibrosis become a disease of the past, replacing it with a silent and manageable chronic condition that never progresses beyond a small bit of injury and scarring in the lungs. Another way I try to improve people’s lives is through education. I encourage patients, caregivers, and families to visit www.pulmonaryfibrosis.org for the latest information about the disease and to register for the PFF Disease Education Webinar Series in which PF experts give in-depth presentations on topics of interest to the PF community and answer questions from viewers. Last year I also started blogging about PF for patients and their families. In some ways, I think my blog has had a bigger impact on people’s lives than my medical practice or research.

In your own practice, what are the key points when it comes to educating people about PF? What would you tell someone who has never heard of pulmonary fibrosis?

Learning that you have PF is overwhelming. Most people have never heard of PF, and too much of the information on the internet is unnecessarily frightening. One of the key points I try to convey is that everyone has his or her own kind of PF. It’s not a single disease—it’s a family of diseases where the response to therapy and the risk of progression varies from person-to-person. I also focus on the importance of available treatment options, including supplemental oxygen, exercise, and lung transplantation.

What resources are out there for staying up-to-date about living with PF?

The “Life with PF” section of the PFF’s website at www.pulmonaryfibrosis.org is a terrific resource with information about managing the disease, treatment options, clinical trials, support groups, and more. The PFF also now has a webinar series for patients and caregivers with helpful information. These are archived on the PFF’s website. Everyone should take some time to look at the list of “PF Community Resources” on the PFF website for links to helpful resources about oxygen, transplant, clinical trials, etc. I also think the online support groups at Inspire.com can be very helpful for people struggling with PF.
What do you say to people who ask how they can help those living with PF and their families?

On a personal basis, we can all stop stigmatizing oxygen use in public. My patients with PF are reluctant to wear oxygen in public because they feel they are perceived as “sick” or “weak.” This seems completely backwards to me. People with PF are stronger—not weaker—while wearing oxygen. They can do more with their lives when they use oxygen, including exercise and travel. Don’t forget that we all need oxygen (1/5 of the air we breathe is oxygen) and all of us get short of breath when we exert ourselves at altitude. On a more global scale, we desperately need help raising awareness of PF, improving current treatment strategies, and funding research for better treatments and a cure for PF.

Research is a critical component to the Pulmonary Fibrosis Foundation to help find effective therapies, and ultimately a cure. How can raising awareness about PF support research?

Have you heard of breast cancer? How about juvenile diabetes? Of course you have. You’ve heard of them because of disease awareness campaigns by non-profit organizations. It is very hard to convince the general public or funding agencies to support research for a disease that they don’t think is important to the health of the nation. Breast cancer and juvenile diabetes have succeeded because non-profit organizations were able to raise nationwide awareness of these conditions. New treatments and cures require funding for research—and funding for research requires awareness. The PFF is doing a stellar job of raising awareness, but we still have a long way to go. It is critical to maintain the worldwide momentum that was created during Global PF Awareness Month. By continuing to share disease information each and every day, we can become more empowered as a community to understand symptoms and develop more effective treatments and therapies. Any donation—large or small—helps us fund the crucial research necessary to find a cure.

Are there other opportunities people should be aware of to help raise awareness about PF?

Although we had a highly successful Global Pulmonary Fibrosis Awareness Month this past September, we’re not slowing down and the PF community isn’t either. Anyone can help raise awareness, any day of the year, and it isn’t difficult. People continue to post PF stories, words of encouragement and news on Facebook and Twitter. Others hand out PFF educational materials at local events. We continue to see the generosity of donors throughout the year, including this fall with annual fund donations to the PFF. This helps us produce educational materials and to fund research. We’re so appreciative of PF community involvement. Those interested in asking how else they can help or how they can get started can contact us through the PFF Patient Communication Center.

Why was it important for you to join the PFF as the Senior Medical Advisor for Patient Communications? What do you hope to accomplish—and perhaps have already accomplished—in your role at the PFF?

There’s only so much that a doc can do alone. Perhaps I’ve helped hundreds of people with PF as a physician, but with the PFF I can connect with and help hundreds of thousands of people with PF. I joined the PFF team to help improve the lives of people with PF.

In my role at the PFF, I’ve helped craft medical content on our website, participated in our webinar series, serve as a medical consultant to the Foundation staff, and support the PFF Patient Communication Center—in fact, if you call the PCC, I might be the one answering the phone.

For disease education information and to learn more about how you can help increase disease awareness, contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733).

About David J. Lederer, MD

Dr. David J. Lederer is an Associate Professor of Medicine and Epidemiology in the Division of Pulmonary, Allergy, and Critical Care Medicine at Columbia University Medical Center. He attended medical school at the State University of New York Downstate Medical Center and trained in internal medicine, pulmonary medicine, and critical care medicine at New York Presbyterian/Columbia University Medical Center. He received a Master’s of Science in Biostatistics and Patient Oriented Research at Columbia University’s Mailman School of Public Health.

He is an attending pulmonologist at Columbia University Medical Center in New York where he specializes in the care of adults with interstitial lung disease and those who have undergone lung transplantation. Dr. Lederer is the lead principal investigator of the NIH-funded MESA Lung Fibrosis Study and is the Senior Medical Advisor for Patient Communications for the Pulmonary Fibrosis Foundation.
MOBILIZING THE PULMONARY FIBROSIS COMMUNITY

FDA Patient-Focused Drug Development Meeting

On September 26 the US Food and Drug Administration (FDA) held its Public Meeting on Idiopathic Pulmonary Fibrosis (IPF) Patient-Focused Drug Development in Silver Spring, Maryland. The meeting was simultaneously webcast so those who could not be present still had an opportunity to participate. The purpose of the meeting was to obtain a better understanding of how IPF patients and caregivers cope with symptoms, the impact of the disease on their daily lives, and to learn more about their views on current treatment approaches. Michael C. Henderson, PFF Board Chairman, and PFF Ambassadors Diane Reichert and Taleena Koch, along with other IPF patients, caregivers, and advocates, participated in a panel discussion and provided input to the FDA on the following topic questions:

**Topic 1**

**Disease Signs, Symptoms, and Daily Impacts That Matter Most to Patients**

1. Of all the symptoms that you experience because of the condition, which 1–3 symptoms have the most significant impact on your life? (Examples may include shortness of breath, cough, fatigue, etc.)
2. Are there specific activities that are important to you but that you cannot do at all or as fully as you would like because of your condition? (Examples of activities may include household chores, walking up the stairs, etc.)
   - How do your symptoms and their negative impacts affect your daily life on the best days? On the worst days?
3. How has your condition and its symptoms changed over time?

**Topic 2**

**Patient Perspectives on Current Approaches to Treating Idiopathic Pulmonary Fibrosis**

1. What are you currently doing to help treat the condition or its symptoms? (Examples may include prescription medicines, over-the-counter products, and other therapies including non-drug therapies such as diet modification.)
   - How well does your current treatment regimen treat the most significant symptoms of your disease?
2. What are the most significant downsides to your current treatments and how do they affect your daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.)
3. Because there is no complete cure for your condition, what specific things would you look for in an ideal treatment for your condition?

“I am proud to have represented the patient community as a panelist for this landmark meeting. It is exciting and empowering to have a voice in the future of PF care and know that we are helping shape the future of PF research and treatment in the United States. The meeting was moving and emotional.”

– DIANE REICHERT / PFF AMBASSADOR AND IPF PATIENT
“Overall, the survey results paint a very detailed portrait of patient’s experiences living with this devastating disease, while reinforcing the need for new therapies that can help manage their symptoms and provide a better quality of life. We are gratified to receive such strong participation from the PF community and are pleased to be able to provide this information to the FDA.”

– GREGORY P. COSGROVE, MD / PFF CHIEF MEDICAL OFFICER
A Family Tradition of Giving

Julie Willis O’Connor and Dave Willis are devoted PF advocates and the second generation of Pulmonary Fibrosis Foundation supporters in their family. Julie served on the PFF Board of Directors from 2007–2013.

Julie and Dave, your father courageously fought pulmonary fibrosis (PF), and your family has advocated for the PF community for many years. We would like to learn more about what led you to become the dedicated supporters you are today. Let’s start with what drew you into the PF community in the first place—Julie please tell us about your dad, Bo Willis.

JULIE: Well, my dad had a very natural ability to reach out to people of all walks of life. He was loved by many people and saw life as half-full as opposed to half-empty. He had a great sense of humor and was very funny.

DAVE: I think what Dad had in “spades” was a very generous nature. He had a unique ability to put himself in others’ shoes.

When did your dad first start experiencing symptoms of pulmonary fibrosis?

JULIE: In 2002 he had a knee replacement and leading up to the operation I remember he was winded a lot. When he was in the hospital for the surgery, they realized he had pulmonary fibrosis.

What was your family’s reaction when you learned he had pulmonary fibrosis?

JULIE: We didn’t know what it was.

DAVE: We had no clue. We had to go online to figure out what it was.

Did you learn about the Pulmonary Fibrosis Foundation online?

JULIE: Yes. I wanted to do something. It’s so frustrating—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 Pulmonary Fibrosis Foundation because it was impressive how much funding went to research. They were in the trenches making a difference.

I climbed all 46 mountains in the Adirondack Park in honor of my father. Friends and family showed their support by making pledges by the mile.

My dad didn’t like to bring attention to himself, but I’m glad I did it. It meant so much to him to hear from people and see their support.

That was the first gift your family gave to the Pulmonary Fibrosis Foundation?

JULIE: Yes. After that, Dad died in 2008, and we asked people to give to the PFF in his memory.

DAVE: After Dad was gone, Mom became the driving force.

My company gave annually to the Foundation and Julie was on the Board. During our last meeting Mom looked at the amount we had agreed upon in the prior year and said, “I want it bumped up.” Our gift tripled this year due to Mom’s support.

JULIE: She gave other times as well.

DAVE: Yes. She left half of her 401k plan to the Pulmonary Fibrosis Foundation before she passed away this year, and she also requested that donations be made to the PFF in her memory.

JULIE: During Global Pulmonary Fibrosis Awareness Month this year I’m hiking 100 miles around Mont Blanc through three countries in remembrance of Mom. I just created an online page for it on the PFF website. Friends and family are sponsoring a dollar or more per mile.
GIVING OPTIONS

The PFF is dedicated to serving patients and their families by providing high quality educational programs. Please consider supporting these important educational and research programs by making a contribution to the Foundation.

MAKE A DONATION

Online  Visit www.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 becoming a Team PFF Event Leader, visit www.pulmonaryfibrosis.org/teampff.

PLANNED GIVING

Please think about including the Pulmonary Fibrosis Foundation in your estate plan and leave a legacy that will live on in the PF community. To get started, contact your financial advisor or the PFF’s President and COO, Patti Tuomey, at 888.733.6741.

PLEDGE PFF!

Pledge PFF! is our monthly giving program, and an important source of revenue for the Foundation. Our generous monthly donors provide stability and support to our important programs. To learn more about how you can maximize your impact, visit us at www.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 www.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.

Hurrah! Hike Around Mont Blanc raised over $32,000!

What do you find most rewarding about raising money to support the Pulmonary Fibrosis Foundation’s mission?

JULIE: For me, what’s really exciting is to see is the PFF staff’s determination, the growth of their outreach, and the support they are 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.

DAVE: Every gift made to the Pulmonary Fibrosis Foundation is appreciated and used strategically. Your gift goes a lot further than you might think. It’s great to be a part of an organization that really values the money you’re giving and is transparent as to how it supports the PF community.

JULIE: I appreciate the decisions that the Board of Directors have made. The Board is primarily made up of people who have been personally affected in some way by pulmonary fibrosis and they’re very dedicated.

Julie tell us about your decision to join the PFF’s Board of Directors.

JULIE: It was actually my husband who encouraged me to join. He said, Julie, you’re committed to this cause and to raising funds to support the PFF’s mission—you should be on the Board. I was flattered to even be considered.

You both mentioned your mother’s commitment to the cause. What were her views on philanthropy, and what was her primary decision to include the PFF in her estate planning?

JULIE: It was her love for Dad, for sure.

DAVE: Absolutely. I think Mom and Dad had the same philosophy about charitable contributions. They believed they were blessed and fully committed to giving money to those things that meant a lot to them.

continued on next page >
What would you tell someone who is thinking about donating to or volunteering for the PFF?

JULIE: I would say it’s an awesome organization. It’s filled with really good people who have the best interests of the pulmonary fibrosis community in mind.

DAVE: People want to know that their money is being directed properly. I would reiterate and say that your gift to the Pulmonary Fibrosis Foundation is probably one of the most effective gifts you can give.

What should be done in the fight against PF?

JULIE: 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, it’s ridiculous.”

DAVE: Raising awareness about the disease and also about how effective and efficient you are as an organization. People give because of the passion they have for their cause. But I also think it’s important that they know how effective the organization is with raising awareness and fighting for a cure. Letting people know that their money is well spent is critical.

What do you wish that people outside the PF community knew about PF?

JULIE: How many people it affects, and more importantly that it exists. Because pulmonary fibrosis 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”.

What would you like to share with others who have been affected by PF?

JULIE: I think my dad was able to squeak a few extra years out of his life because he had a great attitude. Easy for me to say, have a good attitude, but really, I think he saw the blessings of his life, and I think it worked in his favor.

DAVE: I would say knowledge and early detection is critical in anything. My dad was able to develop a relationship with his grandchildren that he might not have had if we hadn’t discovered early that he had PF.

Giving to an organization that is going to help us understand a disease that we really don’t know much about is important. If you’ve been touched by PF it’s very rewarding to support an organization like the Pulmonary Fibrosis Foundation that is committed to education and spreading awareness.

PULMONARY FIBROSIS FOUNDATION RATES AMONG TOP CHARITIES IN THE US

Earlier this summer the PFF earned the highest distinctions given by both Charity Navigator and the Better Business Bureau.

Charity Navigator is the largest evaluator of charities in the US and uses an objective numeric system to rate organizations. In the areas of financial health and accountability and transparency the PFF earned a four-star rating for exceeding standards and outperforming most other charities.

The Better Business Bureau’s Wise Giving Alliance evaluates charities based on its 20 Standards for Charity Accountability. The PFF meets all 20 of the organization’s accreditation standards.

The PFF is proud to have received these two important distinctions. We hope that you will continue to give with confidence in support of our mission knowing that your gift will be used wisely.

Please visit www.pulmonaryfibrosis.org to learn more about ways to give.
Do Failing Stem Cells Contribute to Pulmonary Fibrosis?

Every donation to the PFF in support of innovative research empowers medical professionals to further their work and address fundamental questions about pulmonary fibrosis: What causes pulmonary fibrosis? Why do some people get it and others don’t? Which new drugs might help slow or reverse fibrosis? Answering these questions will lead to better treatments and hopefully a cure.

Last year, the PFF awarded an I.M. Rosenzweig Junior Investigator Award to Dr. Kristen Leeman, a neonatologist at Harvard Medical School. The grant is supporting her research regarding the role of two types of stem cells that might help people with pulmonary fibrosis.

This is an exciting approach as stem cells are quite different from other types of cells in the body. They don’t contract like a muscle cells, or fight infection like a white blood cells, or help remove toxins and excess fluid like kidney cells. However there is one really important thing that some stem cells do: they can transform themselves into different types of cells and perform multiple functions.

Of the different types of stem cells, some can develop into many different types of cells while others are more limited in their capabilities. For example, stem cells that reside in the lung can only make additional lung cells. Dr. Leeman is particularly interested in these cells because her research group has already shown that lung stem cells can repair damaged lung tissue in mice.

Another type of stem cell that might be able to heal lung tissue is the “mesenchymal” stem cell. These stem cells are different in that they don’t actually make new lung cells. Instead, they appear to help repair injured lung cells (in mice) by supplying appropriate nutrients—like a nurse giving injured cells IV fluids.

Dr. Leeman is currently studying how these two different kinds of stem cells—lung stem cells and mesenchymal stem cells—work together to help heal and even prevent pulmonary fibrosis in mice. She uses cutting-edge 3D cameras to observe what happens when these two types of stem cells encounter damaged lung tissue.

The PFF is thrilled to help support Dr. Leeman’s research and other researchers pursuing groundbreaking work. Her work could lead to similar studies in people with pulmonary fibrosis. One day, her research might even lead to new stem cell-based therapies for pulmonary fibrosis.

About Kristen Leeman, MD
Dr. Kristen Leeman is a neonatologist in the Division of Newborn Medicine at Boston Children’s Hospital and an Instructor of Medicine at Harvard Medical School. She attended University of Virginia Medical School, completed her Pediatrics residency at University of North Carolina at Chapel Hill, and trained in neonatology in the Harvard Neonatal Perinatal Fellowship Program. She served as a Chief Fellow during her last year of training. Dr. Leeman currently conducts her research under the mentorship of Dr. Carla Kim at the Harvard Stem Cell Institute at Boston Children’s Hospital. Her research interests include examining the role of endogenous lung stem cells in lung injury and repair. Specifically, she hypothesizes that altered lung stem cell functions may play an important role in fibrosis.
PFF Research Fund

The Pulmonary Fibrosis Foundation (PFF) is pleased to announce recipients of the 2014 Established Investigator and Junior Investigator Awards. A key part of the PFF’s mission is to fund research that will enhance pulmonary fibrosis (PF) patient care and identify potential treatment for the disease. The Research Fund to Cure Pulmonary Fibrosis was created to fund innovative grants for projects that may improve the understanding of PF. The Research Fund to Cure Pulmonary Fibrosis supports two funds that are awarded each year: the Albert Rose Established Investigator Award and the I.M. Rosenzweig Junior Investigator Award. Launched in 2012, these awards support projects that work toward a better understanding of PF and encourage collaboration between industry and academic researchers. Each grant underwent a peer review process that was administered by the PFF’s Research Advisory Committee. Each award recipient will receive a $50,000 grant that is distributed over two years. These awards are made possible by private gifts to the PFF and generous sponsorships, indicated below.

ALBERT ROSE ESTABLISHED INVESTIGATOR AWARD

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

• 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 Boehinger Ingelheim

I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARD

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

• Jung-Whan (Jay) Kim, DVM, PhD
  UNIVERSITY OF TEXAS AT DALLAS
  “Evaluation of Hypoxia-inducible Factor-1 (HIF-1) Signaling as Anti-fibrosis Therapy”

• Elizabeth Redente, PhD
  NATIONAL JEWISH HEALTH
  “Mechanisms of TNF-alpha Mediated Resolution of Pulmonary Fibrosis” Funded by InterMune, Inc.

• Chiko Shimbori, PhD
  MCMASTER UNIVERSITY
  “The Role of Mast Cells in Pathophysiology of Pulmonary Fibrosis” Funded by InterMune, Inc.
When first diagnosed with pulmonary fibrosis (PF), many people have a difficult time adjusting to the numerous challenges that the disease brings—from coping with using supplemental oxygen, to experiencing difficulty with everyday activities that were once easy, to trying to explain a complex condition to family and friends who have likely never heard of pulmonary fibrosis. Dealing with these life-altering changes can affect an individual’s emotional well-being and may even contribute to symptoms of depression. Support groups offer patients, caregivers, and family members the opportunity to share their struggles in a comfortable and safe environment. Who better understands the difficulty of maneuvering a 50-foot oxygen tube through a home than someone who has had a similar experience and can offer practical advice? Support groups also help members live more productive and fulfilling lives by addressing employment concerns, providing tips for stress management, and identifying helpful community resources.

In addition to offering much-needed emotional support and advice on how to navigate day-to-day challenges, support groups also play a crucial role in disseminating current and accurate disease information. With so much inaccurate information about pulmonary fibrosis, a support group serves as a source of reliable and experience-based information about disease management, forms of treatment, available clinical trials, and current research.

Anyone affected by pulmonary fibrosis can participate in any of the more than 70 PF support groups across the United States, Canada, the United Kingdom, and Europe. The PFF also offers an active patient and caregiver support community on the Inspire™ online platform with a membership of over 5,000. Participating in an online support group is a great option for those who are unable to travel or who may be thinking about participating for the first time and want to learn more about what to expect.

Both in-person and online support groups can be a source of empowerment for people living with pulmonary fibrosis—just knowing someone else understands and is there to help can make all the difference.

For a list of current in-person and online PF support groups, please visit our website: www.pulmonaryfibrosis.org/life-with-pf/support-groups
Leanne Storch Support Group Fund

Created in 2012, the Leanne Storch Support Group Fund helps fund PF support groups in honor of the PFF former executive director for her tireless efforts to help those affected by pulmonary fibrosis. This fund awarded $500 grants to six support groups in 2012 and 11 support groups in 2013. Our volunteer support group leaders used these funds to host educational events, start a new group, or fund other related support group activities.

In 2014, the PFF is proud to offer 18 Leanne Storch Support Group Fund grants. All PFF Support Group Leader Network members volunteer their time to plan and host meaningful support group meetings. The PFF is honored to be able to offer this additional funding to help those donating their time in order to educate and support the community.

To learn more about how to start your own support group, contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733).

2014 LEANNE STORCH SUPPORT GROUP FUND RECIPIENTS

• Magdalena Pacheco
  Inland Empire Pulmonary Fibrosis Support Group
  FONTANA, CALIFORNIA

• Jeffery Peters
  Breakfast Club Pulmonary Fibrosis Support Group
  ELMHURST, ILLINOIS

• Belica Graf, RRT
  The University of Louisville Pulmonary Fibrosis Support Group
  LOUISVILLE, KENTUCKY

• John W. Dominguez
  IPF Support Group of The Berkshires
  PITTSFIELD, MASSACHUSETTS

• Deborah Dahlgren, RN
  Michigan IPF Support Group
  ANN ARBOR, MICHIGAN

• Gary Cunningham
  Pulmonary Fibrosis Support Group
  STERLING HEIGHTS, MICHIGAN

• David Naumann
  Pulmonary Fibrosis Support Group of Minnesota
  MINNEAPOLIS, MINNESOTA

• Dawnie Ellison, CRT and Eugenia Sullivan-Moley, SC
  The Greater Kansas City Pulmonary Fibrosis Support Group
  KANSAS CITY, MISSOURI

• Grace Trimmer, RN, MSN
  Winthrop University Pulmonary Fibrosis Support Group
  MINEOLA, NEW YORK

• Julie Porcelli, BSN, RN
  New York Presbyterian ILD Patient and Family Support Group
  NEW YORK CITY, NEW YORK

• Susan DiFabio, RT
  Phelps Memorial Hospital Center’s Pulmonary Fibrosis Support Group
  SLEEPY HOLLOW, NEW YORK

• Kathleen O. Lindell, PhD, RN
  Simmons Center for ILD IPF Support Group
  PITTSBURGH, PENNSYLVANIA

• Cindi J. Brannum
  Dallas/Fort Worth Breathe Support Group
  DALLAS, TEXAS

• Dot Delarosa and Anoop Nambiar, MD
  San Antonio Pulmonary Fibrosis Support Group
  SAN ANTONIO, TEXAS

• Jane Harrison, LCSW, CCTSW
  IPF Support Group of Greater Washington, D.C.
  FALLS CHURCH, VIRGINIA

• Russell Glover
  Breath Matters Support Group
  RICHMOND, VIRGINIA
“As we approach the milestone of five years, our desire is to spread awareness of PF to a NATIONAL level. We want everyone in America to at least know what PF is and what can be done about it! The more we KNOW, the more we can HELP!”

– JULIE HALSTON / AWARD-WINNING ACTRESS AND DEVOTED PF ADVOCATE

SPONSORSHIPS NOW AVAILABLE.

Contact Amanda Miller at amiller@pulmonaryfibrosis.org for more information.
2014 CALENDAR

PF COMMUNITY EVENTS

NOVEMBER 7 • Navigating the New Era of IPF—Collaborative Patient Care Educational Symposium
WESTPORT, CONNECTICUT

NOVEMBER 8 • UCSF — Update in Interstitial Lung Disease: Diagnosis and Management
SAN FRANCISCO, CALIFORNIA

NOVEMBER 8 • Living with PF — Education Event for Patients and Families
SACRAMENTO, CALIFORNIA

NOVEMBER 14 • Yale Fibrosis Symposium
NEW HAVEN, CONNECTICUT

NOVEMBER 14 • Valparaiso PF Support Group Meeting
VALPARAISO, INDIANA

DECEMBER 2 • #GivingTuesday
VIRTUAL

FEBRUARY 23 • Broadway Belts for PFF! 2015
NEW YORK CITY, NEW YORK

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

TEAM PFF EVENTS

NOVEMBER 1 • Jamberry Pulmonary Fibrosis Foundation Fundraiser
VIRTUAL

NOVEMBER 2 • Rockin’ PF Out!
BEAVERTON, OREGON

NOVEMBER 8 • Free Throws for Fibrosis
TRAVERSE CITY, MICHIGAN

DECEMBER 13 • No Tap Bowling Tournament
FULLERTON, CALIFORNIA

Daniel and Joan Beren PA-IPF Registry:
IPF Awareness and Advocacy Event

Pulmonary experts from the University of Pittsburgh Simmons Center for Interstitial Lung Disease (a PFF Care Center Network site), Geisinger Health System, Penn State Hershey Medical Center, University of Pennsylvania, and Temple Lung Center presented information about idiopathic pulmonary fibrosis, new research findings, and offered advice to patients about how to cope with the disease. The day-long event was held on September 16, 2014 in Pittsburgh, Pennsylvania in support of Global Pulmonary Fibrosis Awareness Month.

Central Valley Pulmonary Fibrosis Support Group

On September 8, the Central Valley Pulmonary Fibrosis (PF) Support Group in Sacramento, California held its meeting in celebration of Global Pulmonary Fibrosis Awareness Month. PFF Ambassadors Sally McLaughlin, RN, MSN, and Taleena Koch spoke at the event. Ms. McLaughlin gave an overview of idiopathic pulmonary fibrosis (IPF) and answered questions while Ms. Koch shared the story of caring for her mother who lost her battle with IPF in 2009.

Facilitators Maya Juarez, CCRP, Carolyn King, CCRP, and Oanh Nguyen, CCRP, have all developed a passion for connecting those living with this disease to others who share a common experience. “Facilitating the support group is really a privilege. We’ve had the pleasure to learn that a simple thing like sitting in a room full of people who know what you and your family are going through can have an enormously positive impact,” says Ms. Juarez who has been facilitating the group for several years.

It was essential to the Central Valley PF Support Group to recognize Global Pulmonary Fibrosis Awareness Month because its members have all seen first-hand how the disease can completely alter the lives of those it touches. Raising PF awareness is important because it not only increases the public’s understanding of the disease but also creates an invaluable opportunity for those living with it every day to support one another and learn all they can about their illness.
Winthrop-University Hospital PF Support Group—Living with Pulmonary Fibrosis

The Winthrop-University Hospital PF Support Group hosted an educational event for Global Pulmonary Fibrosis Awareness Month in Garden City, New York on September 18, 2014. The event featured PFF Ambassador Michele Peters who shared the story of her journey as caregiver for her husband who is living with IPF. “In a world where no one knew what IPF was, the Pulmonary Fibrosis Foundation was a place to find the information we so desperately needed,” said Mrs. Peters.
save the date!

NOVEMBER 12–14, 2015
WASHINGTON DC
SPONSORSHIPS NOW AVAILABLE.
www.pffsummit.org

tis the season for giving!
PLEASE CONSIDER MAKING YOUR YEAR-END GIFT TO THE PFF.
www.pulmonaryfibrosis.org/donate

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