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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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DEAR FRIENDS,

I would like to update you on some of the important events that have recently taken place. The Foundation conducted its second biennial health care conference, PFF Summit 2013: From Bench to Bedside in December 2013 in La Jolla, California. This was a unique opportunity for patients, family members, health care providers, health care professionals, and leading researchers from around the world to all come together and exchange information.

There were compelling educational sessions for the patient community, health care professionals, and researchers. Presentations were delivered by many world-renowned experts. The interaction and exchange of new information made the Summit a resounding success.

An important highlight for the Foundation was our recent announcement to launch the PFF Care Center Network (CCN) and the PFF Patient Registry. These initiatives will improve the health and quality of life of patients suffering from pulmonary fibrosis (PF). They will also help provide insights that can enable the medical community to develop new and more effective therapies. You can read more about the CCN and Registry on pages 4–7.

This promises to be a landmark year as the Foundation moves forward with a number of new programs that will provide significant benefits for the PF community.

This spring we introduced the first centralized call center for the PF community. The PFF Patient Communication Center (PCC) is designed to enable two-way communication by providing educational information along with access to our database of support services. The PCC will also assist in referral information for treatments and clinical trials. As our services expand, we envision tremendous growth of the PCC over the next several years.

Our PFF Ambassador program is the first of its kind for the PF community. Designed to enhance disease awareness, education, and motivation, PFF Ambassadors are a group of patients, caregivers, and health care professionals that will be professionally trained to speak about PF on behalf of the Foundation. An additional element of the program will be a group of Ambassadors that will also conduct educational sessions. The PFF Ambassador program will be a key element in future CCN educational events.

Additionally, Ambassadors will be available to support groups and other programs throughout the country. You can contact the PCC to schedule an Ambassador to come to your program or event.

Expanding our team is critical to providing quality services to the PF community, and we are pleased to announce Gregory P. Cosgrove, MD, Kevin R. Flaherty, MD, MS, and David J. Lederer, MD, as new additions to the Foundation. Dr. Cosgrove serves as Chief Medical Officer for the Foundation, Dr. Flaherty chairs the Steering Committee of the PFF Care Center Network and the PFF Patient Registry, and Dr. Lederer assists with our patient communication efforts. They are recognized leaders in the PF community and their expertise will guide the Foundation to best serve the PF community.

In addition to reading our Breathe Bulletin, we hope you’ll take advantage of another Foundation resource, our website. Recently redesigned with improved access and valuable resources, we hope it makes it easier for everyone in our community to learn more about the Foundation and pulmonary fibrosis.

Finally, we would like to thank all of you who have generously contributed to the continuing success of the Foundation by making donations and volunteering your time. Our growth is only possible through your continued assistance. We greatly appreciate your continued support now and in the future.

Sincerely,

Daniel M. Rose, MD
Chief Executive Officer and Chairman of the Board
Kevin R. Flaherty, MD, MS, was recently appointed Chairman of the Steering Committee of the PFF Care Center Network (CCN) and the PFF Patient Registry. He will help guide these important initiatives. The goals for the CCN and Registry are to improve the general health and quality of life of patients suffering from pulmonary fibrosis (PF) and to additionally provide insights important for developing more effective therapies.

What is your educational background?
I completed medical school and residency at Indiana University. I began my Pulmonary Fellowship at the University of Michigan in 1997, and joined the faculty following completion of my fellowship training. While at the University of Michigan I obtained a Master’s Degree in Biostatistics and Clinical Study Design.

What interested you in pulmonary medicine, and specifically pulmonary fibrosis and interstitial lung diseases?
The variety of medical conditions and the ability to establish close patient relationships drew me to specialize in internal medicine. From there I sub-specialized in pulmonary and critical care medicine. At the time of my fellowship, the University of Michigan was one of several centers that specialized in IPF research, and I was able to begin caring for these patients. I was also provided a great deal of opportunity to become involved with clinical research studies and interact with and learn from key opinion leaders in the field.

Do you have a specific focus in the area of pulmonary fibrosis?
In addition to clinical care of patients, my research has focused on diagnosis of interstitial lung diseases, determinants of prognosis, imaging, and clinical trial design.
You see patients in your clinic several times a week. What makes a personal impact on you and your approach?

What strikes me about pulmonary fibrosis is how many people it affects and our lack of definitive therapies. Pulmonary fibrosis impacts broad groups of patients—the young, the middle aged, and the elderly. Yet we don’t have a great understanding of the most important risk factors. I certainly have heartfelt stories of very young patients who have succumbed to this disease as well as very vibrant and active people in their 60s, 70s, and 80s. These patients may be in the prime of life with young children, or getting ready to enter the golden years of retirement, and they find out that the cough they’ve had for six or 12 months is actually the first symptom of what turns out to be a debilitating and eventually fatal disease.

What do you tell your patients about how to care for themselves? What are your general health tips for people?

We currently lack approved therapies in the United States for pulmonary fibrosis. Fortunately there are many clinical trials going on so hopefully, in the very near future, that statement will no longer be true.

Right now, without a specific medical therapy that targets pulmonary fibrosis, we really focus on treating the rest of the patient, keeping him or her as healthy as possible. We aggressively treat comorbidities, try to improve exercise capacity, and help maintain mental health.

How would you describe the PFF Care Center Network (CCN) to a patient?

The CCN is a group of centers that are working together to provide a standardized and comprehensive, multidisciplinary approach to the care of patients with fibrotic lung disease. Although each of the pilot sites has individual expertise in the care of patients with interstitial lung diseases, a strength of the CCN is in the ability of these sites to collaborate to advance research and help determine best practice patterns.

“Our goal is to create a broad, representative, well-thought-out PFF Care Center Network and PFF Patient Registry. From there we can work to study, improve the care, and eventually find cures for patients with pulmonary fibrosis.”

What is the difference between the PFF Care Center Network and other networks like the IPFnet, for example?

IPFnet was an extremely successful National Institutes of Health initiative with the primary charge of performing clinical trials. Although research is a component of the PFF Care Center Network, it’s not the only task. There’s also a focus on education and the determination of best practices. Another key difference, which I think will be a huge strength, both in terms of the research and what we’re going to be able to learn, is the inclusion of a more diverse group of patients with pulmonary fibrosis—not just IPF.

How do you foresee the PFF Care Center Network growing or expanding, and how will this impact patient care and research?

My hope is that this Network will expand and reach across not only the United States but all around the world. Accomplishing this will take time. Our goal is to work out much of the infrastructure with the pilot sites and then begin to expand the Network.

If we’re learning the best ways to do things, sharing educational resources, practice models, and casting a broader net to more readily enroll patients in clinical trials across all areas of the globe, then we’re going to be able to impact many more patients in terms of the care and study of pulmonary fibrosis.

continued on next page >
What is a patient registry and why is it important for those affected by the disease, both patients and caregivers?

At the simplest level a registry is a tool to systematically collect information on a large group of patients that can be used to better understand and study the disease(s). A registry is not a clinical trial—nothing is specifically being done to patients as part of a registry. This is a potential strength as it allows the collection of information that is part of “usual care” and not determined by a study protocol. Evaluating this type of information can help us understand the distribution of disease types, how diseases behave across a wide demographic and geographic background, and aid in the determination of “best practice” patterns. Registries can also be tools that allow for facile communication with patients to make them aware of recent advances or the potential to participate in research.

What do you think the patient reaction will be to the PFF Patient Registry?

I think patients will enthusiastically partner with their physicians to make the Registry a success.

There are other registries currently enrolling patients. What is unique about the PFF Patient Registry? If a patient already participates in one, why should they also participate in the PFF Patient Registry?

A key difference of the PFF Patient Registry is inclusion of patients from across the country, and hopefully internationally in the future. Although participation in local registries and research projects is extremely important, a strength of the Registry is the opportunity to pool and examine information from a larger and potentially more diverse group of patients and caregivers.

Because the Registry is being organized and funded by the Pulmonary Fibrosis Foundation, there is hope that there will be broad intellectual investment as well as broad utilization by different stakeholders—patients, academics, physicians, and the medical industry. We will move away from work that is fragmented; the research and care discoveries will be completed by working together as a global team. This will hasten the milestones we achieve, to eventually cure this disease.

What other information will the PFF Patient Registry collect?

Although this is not yet quite finalized, we will collect information on demographics, pulmonary function testing, laboratory results, radiographic and pathologic appearances, and outcomes. One of the key aspects of the PFF Patient Registry will be a focus on collecting quality of life outcomes or patient-reported outcomes and health care utilization costs. So in addition to capturing data points that a patient’s doctor collects as part of their usual care, like a lab value or a pulmonary function study, patients will also be contacted by the specialized Registry site for an interview that will focus on quality of life, patient-reported outcomes, and health care utilization. That’s another real strength and unique aspect of the Registry. Of course, all the data will be anonymous.

Will the PFF Patient Registry include a bio-repository?

Yes, there is a goal to provide patients the option to provide blood samples to be banked for future research. These samples could be used to understand the pathobiology of fibrotic diseases, define markers of prognosis, or the likelihood of responding to specific therapies.

What is your role as Chairman of the PFF Care Center Network and the PFF Patient Registry Steering Committee?

I am blessed to be part of a team of extremely talented individuals. My role is to encourage input, focus the ideas, and help move these projects forward efficiently. Our goal is to create a broad, representative, well-thought-out PFF Care Center Network and PFF Patient Registry. From there we can work to study, improve the care, and eventually find cures for patients with pulmonary fibrosis.

Before accepting your new position, what was your involvement with the Foundation?

Although I wasn’t actively involved in terms of the day-to-day workings or initiatives, I was an outside admirer and used the educational materials and the website for my patients and myself. It’s really exciting for me to be able to take on this new responsibility and help move the PFF Care Center Network and the PFF Patient Registry forward.
How do you view the role of the Foundation in these initiatives?

It’s critical. In my mind the Foundation is the “honest broker” among the many PF constituents. The Foundation reaches out to all of the different groups who have an interest in developing cures for patients with pulmonary fibrosis—the pharmaceutical industry, which may have to answer to their stakeholders and investors; academic physicians who need grants and publications; government agencies; and most important—the patients and caregivers themselves. All these entities share a common goal, yet sometimes because of how their roles differ, they can’t dance as well together as we may like.

As the “honest broker,” the Pulmonary Fibrosis Foundation can bring everyone together, allowing us to pool our resources and come up with something that ultimately benefits the entire PF community. Individually we might not be able to accomplish this goal, but by working together we can make it happen.

The application process to become a PFF Care Center Network site will open May 15, 2014. Centers will be able to complete an online application. Visit www.pulmonaryfibrosis.org often for the latest information on the application process.

About Kevin R. Flaherty, MD, MS

Dr. Kevin R. Flaherty is a 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. Dr. Flaherty received his medical degree and completed a residency in Internal Medicine at Indiana University School of Medicine in Indianapolis, Indiana. He completed a fellowship in pulmonary and critical care medicine at the University of Michigan where he also received a Master’s Degree in Biostatistics and Clinical Study Design from the School of Public Health.
PFF Patient Communication Center

On March 27, 2014, the Foundation launched the PFF Patient Communication Center (PCC) to serve as the central information hub for the PF patient, caregiver, and health care professional communities. PCC staff:
• Provide educational information to callers about pulmonary fibrosis
• Supply information about how to find support services, available treatments, and clinical trials
• Distribute PFF patient educational materials

Call the PFF Patient Communication Center toll free at 844.TalkPFF (844.825.5733) or email pcc@pulmonaryfibrosis.org.

New Online Program: Disease Education Webinars

In May 2014, the Foundation will launch our Disease Education Webinars program, which allows the PF community to virtually learn from, connect with, and pose questions to leading pulmonary fibrosis specialists. The program includes a community-driven Disease Education Webinars series that enables PF patients, caregivers, and family members to submit their medical-related questions directly to PF physicians. Topics that are important to this community are then covered in the following months’ Webinars.

Our first Disease Education Webinars will feature new members of the PFF team, Dr. Gregory P. Cosgrove, Dr. Kevin R. Flaherty, and Dr. David J. Lederer. They will speak about their new roles with the PFF and answer questions about the PFF Care Center Network and the PFF Patient Registry, and patient education programs. In addition, they will answer medical questions from the patient and caregiver community. The following webinars in 2014 will feature: Dr. David Lederer, Co-Director of the Interstitial Lung Disease Program at New York Presbyterian Hospital/Columbia and author of the blog, “Pulmonary Fibrosis: Clearing the Air,” and Dr. Jeffrey Swigris, Associate Professor of Medicine at the University of Colorado, member of the PFF Medical Advisory Board, and author of National Jewish Health’s “Participation Program for Pulmonary Fibrosis” blog. The PFF wishes to thank our generous sponsor, InterMune, for making the Disease Education Webinars possible.

To submit questions, visit our website at www.pulmonaryfibrosis.org and register.
Announcing the New PFF Website

This month the Pulmonary Fibrosis Foundation’s newly redesigned website went live. The site was redesigned to better serve PF patients, caregivers, and medical professionals. Visitors to the site will easily find information on living with the disease, stay up to date on the latest research and clinical trials, and make connections with others in the PF community. Improvements include a search feature that will make it simple to find medical care and support services in your area.

Visit www.pulmonaryfibrosis.org often for the latest information and news.

Two New Online IPF Informational Resources

KNOWIPFNOW.COM

Debuting this month, KnowIPFnow.com is a comprehensive resource specifically for patients and caregivers affected by idiopathic pulmonary fibrosis (IPF). The InterMune-sponsored website provides clear and easy-to-read information about IPF, explanations about common tests used for diagnosis and monitoring symptoms, and tips about ways to help maintain one’s lifestyle. In addition, KnowIPFnow.com offers a helpful directory of online resources for patient support and additional information.

To learn more, and to download the Know IPF Now Patient Brochure, visit KnowIPFnow.com.

LUNGSANDYOU.COM/IPF

Boehringer Ingelheim Pharmaceuticals, Inc. is excited to introduce a new website focused on idiopathic pulmonary fibrosis (IPF)—lungsandyou.com/ipf.

Uniquely designed for people living with idiopathic pulmonary fibrosis (IPF) and their caregivers, LungsandYou™ includes easy-to-understand information on the condition, suggestions for managing its symptoms, and access to other useful resources.

Visit lungsandyou.com/ipf today and sign up to stay up to date with the latest information.
The PFF Inspire.com support group community of over 4,000 members will celebrate two years of connecting on May 15, 2014. Some of the topics that have been discussed include:

- Living with pulmonary fibrosis
- Meeting new friends who share similar experiences and challenges
- Learning strategies to better cope with PF
- Inspiring hope
- Opinions
- Questions

**PF Support Group Grants**

The Pulmonary Fibrosis Foundation is dedicated to assisting PF support groups. Additionally, the Foundation is committed to the establishment of new in-person and online PF support groups both in the US and abroad. We recognize that individuals often lack the necessary resources to develop new groups, support established groups, or hold educational events for members and their families. To address this need, the Leanne Storch Support Group Fund, named after the Foundation’s former Executive Director, was established in 2012 to provide financial aid to our Support Group Network.

In its inaugural year, the PFF awarded six $500 grants, and in 2013 the Foundation awarded 11 grants. When the application process opened in April this year, the PFF was proud to expand the program to offer awards to 18 support groups. These grants can be utilized to establish a new support group, or to defray the expenses of running a monthly or quarterly support group. The funds can be used to pay for educational materials, refreshments, location expenses, and/or speaker fees.

The Foundation will continue to accept applications for the Leanne Storch Support Group Fund awards until August 1, 2014. The awardees will be announced during Global Pulmonary Fibrosis Awareness Month in September 2014. To apply, please call the PFF Patient Communication Center toll free at 844.TalkPFF (844.825.5733) or email pcc@pulmonaryfibrosis.org.

**EduCATIoNAL mATERIALS**

Our patient educational materials, including PF disease awareness brochures and Patient Information Guides, physician note pads, and medical posters are now available in English, Dutch, French, German, Italian, Portuguese, and Spanish. Please email pcc@pulmonaryfibrosis.org to order.

**PFF Ambassador Program**

The PFF is pleased to offer a new program to promote awareness of idiopathic pulmonary fibrosis (IPF), offer insight into the experiences of those living with IPF, and provide hope and inspiration to others living with the disease. The PFF Ambassador program will empower patients and IPF medical professionals to become spokespersons (Ambassadors). Individuals participating in the program will undergo formal training to prepare them to speak and advocate on behalf of the PFF and the IPF community. This initiative is made possible through a generous grant from InterMune.

To request an Ambassador at your next event, call the PFF Patient Communication Center toll free at 844.TalkPFF (844.825.5733) or email pcc@pulmonaryfibrosis.org.
The Pulmonary Fibrosis Foundation (PFF) has designated September as Global Pulmonary Fibrosis Awareness Month. As the leading patient advocacy organization, we are requesting that all members of the global PF community join us to increase disease awareness during the month. The Foundation encourages everyone to support this important initiative by participating in some of the following activities:

- Patient and Physician Educational Programs
- Awareness Events
- Fundraising Events

Participants

Global Pulmonary Fibrosis Awareness Month requires action and collaboration among all members of the PF community. Key participants are:

- PF patients
- PF caregivers
- Friends of PF patients
- PFF Board of Directors
- PFF Medical Advisory Board
- PFF staff
- PFF Support Group Leader Network
- Team PFF event leaders
- PFF volunteers
- PFF social media community: Facebook, Twitter, Instagram
- InspireSM – Online PFF Support Community
- PFF Care Center Network
- PF advocacy organizations around the world
- Respiratory and thoracic societies

Website:
www.globalPFawareness.org

All Global Pulmonary Fibrosis Awareness Month activities can be found at www.globalPFawareness.org. Visit the website for:

- Links to information about Physician and Patient Educational Events
- Tools for PF community members to create their own grassroots awareness campaign and fundraising events
- Downloadable educational materials in English, Dutch, French, German, Italian, Portuguese, and Spanish
- Ways for PF community members to share their stories and photos

Visit www.globalPFawareness.org often to learn more about the latest PF community events taking place around the world.

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Team PFF: Fundraising Opportunities

Now is the perfect time to start planning your own Global Pulmonary Fibrosis Awareness Month event through Team PFF. We recently updated our Event Leader Guide to make it even easier to hold an event to increase disease awareness and fundraise. Please contact Jennifer Bulandr, Director of Community Events and Social Media, at jennifer@pulmonaryfibrosis.org to learn more.

FUNDRAISING IDEAS

- Host a Global Pulmonary Fibrosis Awareness Dinner
- Create a FirstGiving page to share your story and hold a virtual fundraiser
- Ask your HR Director to hold “Blue Jeans Day” at work and donate the proceeds
- Set up a lemonade stand with your children
- Plan a bowling night with friends and family and ask them to make a donation
- Ask your office, school, or church if you can sell PFF Breathe Bracelets
- Crafty? Open a shop on Etsy and donate a portion of your sales
- Hold a bake sale and donate the proceeds to the PFF
- Host a direct sales party such as PartyLite® or Avon® and donate a percentage of sales
- Take up a collection in your neighborhood
- Donate to the PFF in lieu of favors at your baby shower, wedding reception, bar mitzvah, etc.
- Wear a PFF T-shirt to your favorite sporting event and send us a photo

To learn more about how Team PFF members are raising funds and awareness, see page 13.
Thank You to Our Volunteers

The Pulmonary Fibrosis Foundation (PFF) is fortunate to benefit from passionate volunteers committed to making a difference. Here are two individuals who have made important contributions.

LAURETTE HARMON
Laurette, a dedicated Team PFF volunteer whose father passed away from PF last year, works to spread Global Pulmonary Fibrosis Awareness every day. An international flight attendant, she takes photos of herself, friends, and family wearing our PFF Breathe Bracelets all around the world, and then shares them through PFF social media.

SEAN GRIFFIN
Sean Griffin had never heard of pulmonary fibrosis until his lifelong friend, Kevin Cochran, spoke about his dad’s diagnosis. Always one to jump in, Sean, who owns Chicago Primal Gym, immediately organized a fitness boot camp fundraising event and donated the proceeds to the Pulmonary Fibrosis Foundation in memory of Steve Cochran, Kevin’s father.

“I saw Steve as he left this life. I want to make sure the fundraising experience was meaningful and the participants walked away with knowledge of this disease,” said Sean.

“Our Swings for Steve event was put together in eight days with the help of the Pulmonary Fibrosis Foundation — they made it incredibly easy! We surpassed our first goal of $1,000, and then hit our next target of $1,500!”

TEAM PFF EVENTS WERE HELD ALL ACROSS THE UNITED STATES IN 2013.
WANT TO HOLD AN EVENT IN YOUR STATE?
Contact Jennifer Bulandr, Director of Community Events and Social Media, at jennifer@pulmonaryfibrosis.org to learn more.

did you know?
The number of Team PFF events increased by 50% from 2012 to 2013.
What are clinical trials and what do we learn from them?

Clinical trials are important for the development of new treatments or for improving the detection of diseases. This might include the use of new drugs or utilizing a new combination of existing drugs, applying new surgical procedures or devices, or looking at different ways to use existing treatments. The goal of clinical trials is to determine if a new test or treatment works and is safe. Individuals volunteer to participate in carefully conducted investigations. Clinical trials can also look at other aspects of care, such as improving the quality of life for people with chronic illnesses.

ARE THERE DIFFERENT TYPES OF CLINICAL TRIALS?

The two general categories of clinical trials are interventional and observational (non-interventional).

For example, a patient registry is a clinical research study that is “observational.” The researcher observes those enrolled and measures their outcomes but does not provide a therapy or other type of intervention that may change the natural history of the disease being studied.

The other category is an “interventional” study; researchers give participants a particular medicine or other intervention. This method enables researchers to compare the results of the effect of a therapy on those individuals who receive the therapy and compare it with those who don’t. In most instances when a medication is involved, the participant (and researcher) do not know if the participant is (or is not) receiving the medication under investigation. This is called a “double-blind” study.

An example of a “blinded” interventional trial or clinical research study was the PANTHER-IPF (Prednisone, Azathioprine, and N-acetylcysteine: A Study that Evaluates Response in Idiopathic Pulmonary Fibrosis). This trial was conducted by the Idiopathic Pulmonary Fibrosis Clinical Research Network, and received funding from the NHLBI. The PANTHER-IPF study was designed to evaluate whether this commonly used triple-therapy regimen could slow disease progression and improve lung function in individuals with moderate IPF.

It was determined during this study that people with IPF receiving the triple therapy of prednisone, azathioprine, and NAC had worse outcomes than those that received a placebo. This combination therapy had been widely used in patients with IPF but its efficacy had not been ever assessed in a rigorous manner.

The results from this study showed that compared to placebo, those individuals receiving triple therapy had greater mortality (11% vs. 1%), more hospitalizations (29% vs. 8%), and more serious adverse events (31% vs. 9%). There was also no difference in lung function changes between the two groups. Participants assigned to triple therapy had a higher drop-out rate than those receiving placebo (22% vs. 2%).

It is recommended that anyone receiving a combination of these medications should consult with their health care provider. It is important to realize that these results definitively apply only to patients with well-defined IPF and not to people taking these drugs for other lung diseases or conditions.

For a complete list of clinical trials currently enrolling participants, visit www.pulmonaryfibrosis.org/clinicaltrials.
ARE THERE DIFFERENT PHASES OF CLINICAL TRIALS?

Clinical trials are conducted in “phases.” Each phase has a different purpose and helps researchers answer different questions.

- **Phase 1 trials:** This initial study investigates an experimental drug or treatment in a small group of people (20–80) to evaluate its safety and identify side effects.
- **Phase 2 trials:** The experimental drug or treatment is administered to a larger group of people (100–300) to determine its effectiveness and to further evaluate its safety.
- **Phase 3 trials:** The experimental drug or treatment is usually administered in a randomized and “blinded” fashion to a larger group (1,000–3,000). This phase will determine the efficacy of a particular therapeutic intervention, monitor side effects, compare it with standard or equivalent treatments, and collect information that will allow the experimental drug or treatment to be used safely.
- **Phase 4 trials:** After a drug is approved by the FDA and made available to the public, the investigators track its safety and gather more information about a drug or treatment’s risks, benefits, and optimal use.

WHAT ARE THE POTENTIAL BENEFITS TO PARTICIPATION IN CLINICAL TRIALS?

Well-designed and well-executed clinical trials provide the best approach for participants to:

- Play an active role in their health care.
- Gain access to new research treatments before they are widely available.
- Receive regular and careful medical attention from a research team that includes doctors and other health professionals.
- Help others by contributing to medical research.

WHAT ARE THE POTENTIAL RISKS TO PARTICIPATION IN CLINICAL TRIALS?

Some of the risks to participants include the following:

- There may be unpleasant, serious, or even life-threatening side-effects as a result of receiving the experimental treatment.
- The study may require more time and attention than standard treatment. This can (but not necessarily) include visits to the study site, more blood tests, more treatments, more hospital stays, or receiving complex dosages of medications.

For more information about clinical trials, please visit:
- NIH CLINICAL RESEARCH TRIALS AND YOU
  www.nih.gov/health/clinicaltrials

For more information about research safety, please visit:
- OFFICE FOR HUMAN RESEARCH PROTECTIONS
  www.hhs.gov/ohrp/
- CHILDREN’S ASSENT TO CLINICAL TRIAL PARTICIPATION
  www.nichd.nih.gov/health/cr/aboutclinicalresearch/aboutclinicalresearch.cfm#3

For more information on participants’ privacy and confidentiality, please visit:
- NATIONAL INSTITUTES OF HEALTH, HIPAA PRIVACY RULE
  privacyruleandresearch.nih.gov

WHO PARTICIPATES IN CLINICAL TRIALS?

Many different types of people participate in clinical trials. All clinical trials have guidelines about who can participate, called inclusion/exclusion criteria. Factors that allow someone to participate in a clinical trial are “inclusion criteria.” Those that exclude or do not allow participation are “exclusion criteria.” These criteria are based on factors such as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. Before joining a clinical trial, a participant must qualify for the study. Some research studies seek participants with illnesses or conditions to be studied in the clinical trial, while others need healthy volunteers. Some studies need both types.

HOW DOES THE OUTCOME OF CLINICAL RESEARCH MAKE A DIFFERENCE?

Only through clinical research can we gain insights and answers about the safety and effectiveness of drugs and therapies. Many groundbreaking scientific advances have been possible only as a result of participation by volunteers—both healthy and those diagnosed with an illness—in clinical trials. As clinical research opens new doors to finding ways to diagnose, prevent, treat, or cure disease, clinical trial participation is essential to help find the answers.


Disclaimer: Please note that any information contained in this article is for informational and/or educational use only and does not constitute an endorsement of any product, person, or services offered. It is not intended to be a substitute for professional medical advice. Always consult your personal physician or health care provider with any questions you have regarding your specific medical conditions, individual needs, or before making any medical decisions.
THE IMPACT OF THE PFF CARE CENTER NETWORK AND PFF PATIENT REGISTRY ON CLINICAL TRIALS

An interview with Gregory P. Cosgrove, MD, Chief Medical Officer

What is your background and how did you become interested in working in pulmonology, and specifically in pulmonary fibrosis?

I went to medical school in Philadelphia, Pennsylvania, at Hahnemann University Hospital and then subsequently was a medical resident at Thomas Jefferson University Hospital. While rotating in the intensive care unit, I cared for a number of patients with interstitial lung disease. Unfortunately, many of these patients did poorly. My inability to help them drove my interest to better understand this complex set of diseases. My interest in interstitial lung disease and pulmonary fibrosis led me to a pulmonary fellowship at the University of Colorado and National Jewish Health, where I began working in the Interstitial Lung Disease (ILD) Clinic in 2000.

As part of my training, I began a basic science research fellowship in the lab of Dr. G. Scott Worth. At the same time I also began caring for patients in the Interstitial Lung Disease Clinic at National Jewish Health under the direction of Dr. Kevin Brown. After I completed my training I joined the faculty at the University of Colorado and National Jewish Health in 2002. I have been fortunate to be able to work in the ILD program for the past 12 years. In addition to the basic and translational research projects, I’ve also participated in the IPFnet (a network of centers performing clinical trials that was funded by the National Institute of Health—NIH), as well as various other pharmaceutical industry-sponsored and other NIH-sponsored clinical research studies.

My clinical and research emphasis in the field of pulmonary fibrosis led me to become involved in advocating for patients with the disease, during which time I began to work with the Pulmonary Fibrosis Foundation (PFF).

Through interactions with the members and the staff of the PFF, I began to assist in developing educational seminars, patient discussion sessions, and also participated in the inaugural IPF Summit in 2011. Subsequently, I was invited to Co-Chair the PFF Summit 2013 with Drs. Martin Kolb and Patricia Sime this past December.

You recently joined the PFF as Chief Medical Officer (CMO). How do you see your role as the Foundation’s CMO?

I am fortunate to have the opportunity to take on the role of CMO at the Foundation. This position not only enables me to help organize national and international meetings and symposia, but to also help shape and guide the course of the Foundation as it relates to medical operations and patient advocacy. I am hopeful that the PF research community will be successful in identifying treatment(s), and eventually a cure. Until we find better therapies and a cure, improving the quality of life and extending the patients’ lives needs to be our focus. Serving as the CMO for the PFF is a wonderful opportunity. I’m very passionate about our ability to have a regional, national, and international impact on PF.

I feel very fortunate to be able to join a team of dedicated experts at the Foundation as well as the devoted individuals that volunteer their time and effort to advancing the mission of the PFF.

The opportunity to serve as Chief Medical Officer really is a unique chance to make a valuable contribution to this field and improve the lives of many individuals.
As the CMO, how do you envision the PFF Care Center Network and the PFF Patient Registry impacting patients with pulmonary fibrosis?

The PFF Clinical Care Network (CCN) and the PFF Patient Registry will allow us to create a uniform approach to the care of PF patients and begin to establish mechanisms to evaluate any intervention for the treatment of the disease. These include new pharmacologic therapeutic agents (medications) and non-pharmacologic interventions such as pulmonary rehabilitation. In addition to interventions, we will gain a better understanding about how to ensure the best outcomes for our patients.

Single center studies are fundamentally important, but a coordinated network allows us to more broadly answer questions, and most likely in a more efficient and complete manner. Through a network we will be able to more rapidly and efficiently enroll patients in research studies, and this will allow us to have more opportunities to try to help our patients.

What is the role of the PFF Care Center Network and the PFF Patient Registry in other types of clinical research and clinical trials?

There are a lot of different venues in which patients can be evaluated. The classic academic or university center is certainly a well-established model, but it’s not a model that may serve all patients across different geographic regions. One of the goals of the PFF Care Center Network and the PFF Patient Registry is to provide access for all patients who would like to participate in research and to be able to do this in a safe, secure environment.

We know that not all patients have access to an advanced lung disease center or an interstitial lung disease center. As the Foundation facilitates the development of the accredited CCN sites that are closer and more accessible to patients, the medical community will be better prepared to provide enhanced care and also a more comprehensive approach to patients with PF.

Consensus statements published by the leading medical associations (such as the ATS/ERS/JRS/ALAT IPF Evidence-Based Guidelines for Diagnosis and Management) have helped to guide the medical community with what are perceived to be the best practice patterns. A consensus opinion based on observational data is an important first step in the absence of controlled studies. Rigorously determining which care is “best” for patients with PF should be pursued by utilizing multiple sites and asking relatively straightforward questions which will address important issues about care, epidemiology of the disease, and who’s at risk. While these questions have been investigated in the past, we anticipate that with a large PFF Care Center Network, the depth and breadth of the answers to those questions will be improved.

Additionally, we hope that the PFF Care Center Network and the PFF Patient Registry will allow us to more thoroughly investigate important new observations that have been identified over the past ten years. Specifically, I am referring to a better understanding of the rate of disease progression and the role and incidence of acute exacerbations. The function of the PFF Care Center Network and the PFF Patient Registry will be to help find answers to novel questions more rapidly and advance our understanding of the disease in real time.

We hear a lot about clinical trial networks for many different diseases. In pulmonary fibrosis we know of one network, the IPFnet. How do the PFF Care Center Network and the PFF Patient Registry compare to a clinical trial network?

There are differences in terms of how the PFF Care Center Network and the PFF Patient Registry are being organized in contrast to a clinical trials network.

In a clinical trial there is a specific intervention being tested on a specific group of patients with well-defined parameters such as their lung function (PFTs), age, and diagnosis. These studies generally address one important question, and that’s the purpose of the clinical trial—to determine if a particular medication or therapy has a positive effect on patients and improves one or more of the measured parameters.

The PFF Care Center Network and the PFF Patient Registry are not limited to investigating one specific therapy or agent; we want to be able to identify effective pharmacologic and non-pharmacologic interventions for patients. This is an expansion of the clinical trials network, and that’s why the names are different—the PFF Care Center Network and the PFF Patient Registry. These initiatives augment and enhance the clinical trial process, allowing us to answer many different questions.

continued on next page
Do clinical trials need to include a placebo arm?

Clinical trials that utilize a placebo arm are very important, especially when we haven’t identified effective therapies for a disease. By utilizing a placebo arm or an arm in which patients are not receiving the therapeutic intervention, and the participants receive the medication in a “blind” fashion (the patient does not know if he/she is receiving the drug or not), we can assess the true benefit of a specific treatment.

A placebo arm allows for a comparison of a new intervention versus no intervention (or an accepted intervention) in an unbiased way. If we don’t have clinical trials to answer these very important questions, and we don’t design trials correctly, we can’t answer these questions.

If trials are not performed appropriately, patients could be subjected to treatments that have no benefit or may actually be harmful. One example of an intervention being identified as harmful was demonstrated in the PANTHER-IPF trial conducted by the IPFnet. In this trial, patients volunteered to assess whether or not prednisone, azathioprine, and N-acetylcysteine were truly beneficial. In fact, the combination therapy of all three medications was found to be harmful to IPF patients.

This study is an excellent example of the importance of a well-designed clinical trial, which demonstrated that a well-accepted treatment actually had a deleterious effect. The study had an important impact on patient care.

The advantage of participating in clinical trials for patients is that it potentially gives them access to medical interventions not yet approved, and may also provide access to specialty care that may not otherwise be available. Participants also have an opportunity to give back to the community, which many feel is important. Clinical trials also advance our understanding and have a positive impact on the medical community, patients, and society as a whole.

How do you see the PFF Care Center Network expediting and facilitating clinical trials, and why is it important?

The PFF Care Center Network will create a consortium of accredited academic medical centers and community-based clinics that have experience and expertise in the care of patients with fibrotic lung diseases. This network of interested parties will have the ability to rapidly implement protocols and assess different interventions in an organized and systematic way.

Rather than re-establishing a network for every trial that we want to perform, the PFF Care Center Network will be an existing network with ongoing collaborative studies. This will enable a more efficient initiation of trials, and we can move ahead answering questions in a more expeditious fashion.

For patients, the PFF Care Center Network provides regional, if not local, access to accredited interstitial lung disease centers, and the hope is that we establish the best practice patterns for patients with PF. Additionally, the CCN is designed to enhance education of patients, caregivers, health care providers, and physicians.

Directly and indirectly, we will increase disease awareness and reach out to our community. We no longer want hear the phrase, “I never heard of pulmonary fibrosis before I was diagnosed.”

It is devastating to think of 40,000–50,000 individuals dying each year of PF. We need to address the impact of this disease so that we can help a large number of individuals, not only in the United States, but also throughout the world.

Sources:

To watch Dr. Cosgrove’s “What is Pulmonary Fibrosis?” webinar, visit www.pulmonaryfibrosis.org/webinars.
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. In order to advance the development of effective treatments for PF, the Foundation funds research and also encourages partnerships with industry and academic research centers. In order to help facilitate this, the Pulmonary Fibrosis Foundation launched the PFF Care Center Network and the PFF Patient Registry.

**BENEFITS OF THE PFF CARE CENTER NETWORK AND THE PFF PATIENT REGISTRY INCLUDE:**

- Enabling an earlier diagnosis
- Standardizing care
- Acquiring accurate clinical information
- Assessing efficacy of new therapies
- Establishing best clinical practices
- Conducting multi-institutional research
- Facilitating enrollment in clinical trials

We will begin accepting applications for the PFF Care Center Network on May 15, 2014. Patients will begin to be enrolled in the PFF Patient Registry at pilot sites starting in November 2014.

To read more about the PFF Care Center Network and the PFF Patient Registry, turn to pages 4–7.

To view the video, visit www.pulmonaryfibrosis.org.

For questions, contact the PFF Patient Communication Center toll free at 844.TalkPFF (844.825.5733) or email pcc@pulmonaryfibrosis.org.
Overview

PFF Summit 2013: From Bench to Bedside, was held from December 5–7 in La Jolla, California. The conference brought together PF patients, caregivers, and medical professionals. There were over 500 attendees including individuals from 14 countries in addition to the United States.

The most up-to-date medical information was provided to both the medical professional and patient communities. Some of the conference goals were:

- Increase knowledge and inspire hope
- Improve the health and quality of life of PF patients
- Encourage collaboration that will lead to development of new therapies

The Program

The two-day program featured professional and patient sessions. The Summit began Thursday evening with a welcome reception and poster presentations. New research was presented, which included studies on improving the diagnosis of PF, enhancing clinical care, and research into the causes of pulmonary fibrosis.

On the opening day of the Summit, Dr. Daniel M. Rose, CEO and Chairman of the Board of the Foundation, welcomed the attendees. Robert J. Beall, PhD, President and CEO of the Cystic Fibrosis Foundation (CFF), delivered the keynote address. The CFF has become a model for improving patient care and has provided a roadmap for the development of new and effective therapies. Dr. Beall discussed drug innovations that have dramatically improved the lives of individuals with cystic fibrosis. An inspirational talk was given at the luncheon presentation by John F. Crowley, JD, MBA, who presented his own journey: “When Drug Research is Personal: The Importance of Patient Advocacy in Drug Development and Advocacy.” He shared his story about the diagnosis of his daughter and son with Pompe disease, a rare neuromuscular disorder, that led him to co-found a biotech company developing new innovative treatments for the disease.

During the Networking Dinner on Friday evening, the PFF announced plans to launch the PFF Care Center Network (CCN) and the PFF Patient Registry at nine pilot sites. Goals of the CCN are to improve diagnosis and care for the PF patient. Through standardized data collection, the Registry will track disease progression and provide critical information that will help provide insights important to the development of more effective therapies for PF.
Medical Professionals, Patients, and Caregiver Sessions

Many of the presentations on the first day for health care professionals focused on the basic science of PF. Topics included lung injury and repair, genetics and biomarkers, and drug development. Day two for the professional attendees was dedicated to clinical sessions. Topics presented included making an accurate diagnosis, understanding therapeutic options, current treatment of co-morbidities, and effectively communicating with patients and caregivers. An update on global perspectives and ongoing clinical trials was also featured.

The concurrent program for patients and caregivers addressed awareness and educational needs, as well as, how to live better with PF. Important topics for this audience were definitions of the disease, causes, and treatments. Also included were sessions on research, drug development, and advocacy. Patients and caregivers had an opportunity to directly ask questions of the medical experts.

Continuing Medical Education

The PFF was pleased to partner with National Jewish Health of Denver, Colorado, to provide a continuing medical education (CME) program. National Jewish Health is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

View the PFF Summit 2013 sessions online.

PROFESSIONAL → www.pffsummit.org/professionals.html

PATIENT AND CAREGIVER → www.pffsummit.org/patients.html

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“PFF Summit 2013 brings value to all members of the PF community—as an educational resource, as a catalyst for change, and as a symbol of hope.”

–MARTIN KOLB, MD, PHD, AND SUMMIT CO-CHAIR

PFF Summit 2013 Faculty

GREGORY P. COSGROVE, MD  
Co-Chair  
National Jewish Health  
University of Colorado Denver  
Denver, Colorado  

MARTIN KOLB, MD, PhD*  
Co-Chair  
McMaster University  
Hamilton, Ontario, Canada  

PATRICIA J. SIME, MD*  
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Former US Representative to Congress  
Vancouver, Washington  

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University of California, Los Angeles  
Los Angeles, California  

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National Jewish Health  
Denver, Colorado  

CRAIG HENKE, MD  
University of Minnesota  
Minneapolis, Minnesota  

ERICA L. HERZOG, MD, PhD  
Yale School of Medicine  
New Haven, Connecticut
PFF Educational Materials Available

At PFF Summit 2013, the Foundation distributed our new educational materials including a PF medical poster, physician note pad, and Understanding Pulmonary Fibrosis brochure. To order these materials in English, Dutch, French, German, Italian, Portuguese, or Spanish, contact us at 844.TalkPFF (844.825.5733) or pcc@pulmonaryfibrosis.org.
Congratulations to Our Poster Winners

Fifty-two researchers from academic institutions and the pharmaceutical industry presented findings on their research. The posters from the academic institutions were peer-reviewed by a panel from the PFF’s Research Advisory Committee. Award recipients were announced at the Networking Dinner on Friday and were invited to speak about their research at one of the scientific sessions.

1st place
Andrew Bryant, MD
Vanderbilt University
“Endothelial Specific Inhibition of Hypoxia-Inducible Factor Blocks Development of Pulmonary Hypertension Associated with Lung Fibrosis”

2nd place
Shanna Ashley, MS
The Regents of the University of Michigan
“Periostin Regulation of Mesenchymal Cells in Lung Fibrosis”

3rd place
Robert Kottman, MD
University of Rochester
“The Lactate Dehydrogenase Inhibitor Gossypol Inhibits TGF Induced Myofibroblast Differentiation In Vitro and Bleomycin Induced Pulmonary Fibrosis In Vivo”

Honorable Mention
Orquidea Garcia, PhD
Children’s Hospital Los Angeles
“Targeted Depletion of Type II Alveolar Epithelia Provides a Dynamic Functional Model for Chronic Respiratory Disease”

Ana Mora, MD
University of Pittsburgh
“Advancing Age Reduces PINK1-mediated Mitochondria Quality Control in Alveolar Epithelial Cells and Promotes Lung Fibrosis”
The Pulmonary Fibrosis Foundation’s (PFF) annual dinner, *Breathe Benefit 2013: Community Inspiring a Cure*, was held at The Drake Hotel in Chicago last October. The event raised approximately $200,000 and will fund important support and research for patient initiatives. The PFF is appreciative of many people who helped make the *Breathe Benefit 2013* a success. Co-Chairs for the dinner were Dr. Stephen and Joan Wald, and The Family of Michael P. Savoca.

Over 250 individuals attended *Breathe Benefit 2013*. Dinner guests included patients, caregivers, family members, medical professionals, researchers, and valued supporters of the PFF. The Foundation was honored to have award-winning Broadway actress, comedienne, and devoted PFF advocate Julie Halston and WGN Radio’s Cubs play-by-play announcer Pat Hughes as the emcees. Julie Halston and husband, Ralph Howard, former anchorman for Howard Stern’s *Howard 100 News*, served as Honorary Chairs of the event. Ms. Halston and Mr. Howard spoke of their own experiences with PF as caregiver and patient.

*continued on next page*
One of the evening’s highlights was a tribute to Foundation co-founder Albert Rose. He lost his battle to idiopathic pulmonary fibrosis (IPF) in February 2002. His son, Daniel M. Rose, MD, the PFF’s Chairman of the Board and Chief Executive Officer, provided a moving tribute to his father. Dr. Rose stated, “The PFF Established Investigator Awards have been re-named in my father’s honor in recognition of his dedication and passion. We want to ensure that there will always be a resource to help develop effective therapies for this terrible disease.”

The PFF Research Fund’s 2013 Young Investigator and Established Investigator grant recipients were presented by Jesse Roman, MD. Dr. Roman serves as Chairman of the PFF’s Research Advisory Committee and spoke of the collaboration between academic researchers and industry. The PFF acknowledged the support of Boehringer Ingelheim for funding an Established Investigator Award and InterMune for funding an I.M. Rosenzweig Young Investigator Award. Additionally, the PFF announced 11 recipients of the 2013 Leanne Storch Support Group Fund awards.

The PFF’s Legacy Award, which recognizes an individual or corporation that has made significant contributions to the PF community, was presented to Thomas E. Hales. Mr. Hales has been a long-standing member of the Foundation’s Board of Directors. He has provided the Foundation with critical guidance and support during its continued growth.

The Foundation was pleased to announce the creation of two new volunteer awards, the Young Philanthropist Award and the Team PFF Award. Ten-year-old Brock Powers was presented with the Young Philanthropist Award for his work on behalf of the PF community. The Team PFF Awards were presented to Cindy Chandler and Marilyn Solimano for the “Greg Chandler and Guy F. Solimano Memorial Golf Outing,” Nick DeVito for the “Pete DeVito Memorial Golf Outing,” and Rob Fiorillo for the “Barbara A. Fiorillo Memorial Bike Run and Picnic.”

The evening concluded with Patti Tuomey, EdD, the PFF’s President and Chief Operating Officer, thanking presenting sponsor, Boehringer Ingelheim, for their continued support of the PF community and the PFF.
ALBERT ROSE ESTABLISHED INVESTIGATOR AWARDS

- **Michael Beers, MD**, Director of Fellowship Research Training, The Trustees of the University of Pennsylvania – “Modeling of Epithelial Cell Dysfunction in Pulmonary Fibrosis using SP-C Brichos Mutations” Funded by Boehringer Ingelheim
- **Mauricio Rojas, MD**, Assistant Professor, University of Pittsburgh – “Aging of Stem Cells and Disease Susceptibility”

I.M. ROSENZWEIG YOUNG INVESTIGATOR AWARDS

- **Kusum Pandit, MBBS, PhD**, Research Post Doctoral Associate, University of Pittsburgh – “The Role of microRNA let-7d in Idiopathic Pulmonary Fibrosis” Funded by InterMune
- **Kristen Leeman, MD**, Instructor, Children’s Hospital Boston – “Using Endogenous Lung Stem Cells to Discover Novel Pulmonary Fibrosis Disease Mechanisms”

LEANNE STORCH SUPPORT GROUP FUND AWARDS

- **Russell Glover**
  Breath Matters Support Group of Virginia
  RICHMOND, VIRGINIA
  2014 Support Group Meetings
- **Kirk J. Mathison, RN**
  Calgary Pulmonary Fibrosis Support Group
  CALGARY, ALBERTA, CANADA
  2014 Support Group Meetings
- **Maya Juarez, Oanh Nguyen, and Carolyn King**
  Central Valley Pulmonary Fibrosis Support Group
  SACRAMENTO, CALIFORNIA
  2014 Support Group Meetings
- **John Domínguez**
  IPF Support Group of the Berkshires
  PITTSFIELD, MASSACHUSETTS
  2014 Support Group Meetings
- **Wendi Mason, NP**
  Middle Tennessee Idiopathic Pulmonary Fibrosis Support Group
  NASHVILLE, TENNESSEE
  2014 Support Group Meetings
- **David Naumann**
  Minnesota Pulmonary Fibrosis Support Group
  MINNEAPOLIS, MINNESOTA
  2014 Support Group Meetings
- **Julie Porcelli, BSN, RN**
  New York Presbyterian ILD Support Group
  NEW YORK, NEW YORK
  2014 Support Group Meetings
- **Dionne Blasingame, PhD, RRT, and Marcy Solmson**
  Piedmont Atlanta Hospital’s Pulmonary Fibrosis Support Group
  ATLANTA, GEORGIA
  Global Pulmonary Fibrosis Awareness Day Symposium in 2014
- **Nancy Neil**
  Pulmonary Fibrosis Foundation Support Group
  ELMHURST, ILLINOIS
  2014 Support Group Meetings
- **Kathleen O. Lindell, PhD, RN**
  Simmons Center IPF Support Group
  PITTSBURGH, PENNSYLVANIA
  November 2013 “Dealing with the Impact of IPF & Moving Forward” Meeting
- **Susan S. Jacobs, RN, MS**
  Stanford University Medical Center, Living with Pulmonary Fibrosis Support Group
  STANFORD, CALIFORNIA
  2014 Support Group Meetings

LEGACY AWARD

- **Thomas E. Hales**

TEAM PFF AWARDS

- **Cindy Chandler and Marilyn Solimano**, Greg Chandler and Guy F. Solimano Memorial Golf Outing
- **Nick DeVito**, Pete DeVito Memorial Golf Outing
- **Rob Fiorillo**, Barbara A. Fiorillo Memorial Bike Run and Picnic

YOUNG PHILANTHROPIST AWARD

- **Brock Powers**
Golden Globe and Tony Award winners showcased their talents on February 24, 2014, to raise funds and increase pulmonary fibrosis (PF) disease awareness. The event also honored the memory of Associated Press theater critic and reporter, Michael Kuchwara, who died from PF. Award-winning actress and devoted PF advocate, Julie Halston, hosted Broadway Belts for PFF! at Birdland Jazz Club in New York City for the fourth year in a row. The evening brought together Broadway performers, patrons, and members of the PF community for a night of music and stories. This year the event raised over $110,000 to benefit the Pulmonary Fibrosis Foundation’s Michael Kuchwara Fund for Idiopathic Pulmonary Fibrosis Research, Education, and Advocacy.

Broadway stars performed under the direction of Christopher McGovern and returning director Carl Andress, who has directed all four of the Broadway Belts for PFF! shows. The cast included: Lindsay Mendez (Wicked), Lucas Steele (Natasha, Pierre and the Great Comet of 1812), Tony Yazbeck (Little Me), Liz Callaway (recording artist and Emmy Award-winning actress), Robert Creighton (Little Me), Christina Bianco (Forbidden Broadway), Cady Huffman (The Producers), and Rashidra Scott (Beautiful). Ms. Halston brought her usual wit and great storytelling to the event. She is now co-starring with Charles Busch in The Tribute Artist.

One highlight of the evening was television and stage icon Tony Danza singing “Out of the Sun,” composed by Jason Robert Brown for the Broadway-bound new musical, Honeymoon in Vegas. Based on the hit film, the musical is scheduled to open this fall starring Mr. Danza.
Thank you to this year’s generous sponsors.

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Michelle Harmon-Madsen and Ken Madsen
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in Memory of Mohammadali Mottaghian, MD
Wendy and Neil Scheer

Julie Halston became a leading spokesperson for the PFF after her husband, broadcaster Ralph Howard, received a lung transplant due to idiopathic pulmonary fibrosis. She hopes that the awareness created by Broadway Belts for PFF will help others affected by the disease. “I want to make sure that everyone knows about the Pulmonary Fibrosis Foundation, so that no one with pulmonary fibrosis has to go through this alone,” said Halston. “First my husband was diagnosed and then we lost our friend Michael Kuchwara. We first started this benefit four years ago to remember Michael and raise money to someday cure this terrible disease. I am so thankful to my dear friends who give their time and talent year after year. Their dedication helps us raise awareness to fund research and bring us closer to a cure. We’re already looking forward to next year’s event on February 23, 2015!”

“We are so thankful to Julie Halston, D. Michael Dvorak, Ed Windels, and Sue Frost for their hard work,” said Patti Tuomey, President and Chief Operating Officer of the Foundation. “They produce such an amazing show by bringing this talent together; it has contributed almost $275,000 to our PF community over the last four years.”

PHOTOS BY SETH WALTERS
2014 CALENDAR

PF COMMUNITY EVENTS

MAY 16–21 • PFF @ ATS 2014 International Conference
American Thoracic Society
SAN DIEGO, CALIFORNIA

JUNE 4–7 • Aspen Lung Conference: Rebuilding the Injured Lung
ASPEN, COLORADO

JULY 25–27 • Scleroderma Foundation 2014 National Patient Education Conference
ANAHEIM, CALIFORNIA

AUGUST 8–10 • Children’s Interstitial and Diffuse Lung Disease Foundation (chILD) Annual Conference
AURORA, COLORADO

SEPTEMBER • Global Pulmonary Fibrosis Awareness Month 2014
Pulmonary Fibrosis Foundation WORLDWIDE

SEPTEMBER 6–10 • PFF @ ERS Annual Congress Munich 2014
European Respiratory Society MUNICH, GERMANY

SEPTEMBER 16 • Daniel & Joan Beren PA-IPF Registry: IPF Awareness & Advocacy Event
University of Pittsburgh Simmons Center for ILD PITTSBURGH, PENNSYLVANIA

SEPTEMBER 20–24 • 2014 International Colloquium on Lung and Airway Fibrosis (ICLAF)
MONT-TREMBLANT, QUEBEC, CANADA

OCTOBER 1–31 • Healthy Lung Month
American Lung Association UNITED STATES

OCTOBER 19–25 • National Respiratory Care Week
American Association for Respiratory Care UNITED STATES

OCTOBER 25–30 • PFF @ CHEST 2014
American College of Chest Physicians AUSTIN, TEXAS

TEAM PFF EVENTS

ONGOING • Bravelets for PFF Awareness VIRTUAL

ONGOING • Every Penny Counts: A Year-Long Fundraiser VIRTUAL

ONGOING (ENDS JUNE 15) • Recycle for PF Research SOMERS, NEW YORK

MAY 4 • Bows for Pulmonary Fibrosis CONROE, TEXAS

MAY 4 • Lilac Bloomsday Run SPOKANE, WASHINGTON

MAY 8 • 2nd Annual Zumba For A Cure: Battle For Breath BURLINGTON, MASSACHUSETTS

MAY 17 • Lemonade Day for PFF INDIANAPOLIS, INDIANA

MAY 24 • Team Breathe On Soldier Field 10 Mile Race CHICAGO, ILLINOIS

MAY 31 • Gearin’ Up for Grady and a Cure Car Show CAMBRIDGE, ILLINOIS

MAY 31 • NJ5K for PF James Lynam Memorial 5K Run/Walk SEWELL, NEW JERSEY

JUNE 1 • San Diego Rock ‘n’ Roll Half Marathon SAN DIEGO, CALIFORNIA

JUNE 6 • Fish Fry Fundraiser DAYTON, OHIO

JUNE 8 • 7th Annual Greg Chandler and Guy F. Solimano Memorial Golf Tournament benefiting the PFF WEBSTER, NEW YORK

JUNE 12 • 4th Annual Pete DeVito Memorial Golf Outing benefiting the PFF MT. SINAI, NEW YORK

JUNE 21 • Kickin’ It Full Throttle Benefit Classic Car Show for PFF GRAND PRAIRIE, TEXAS

DONNA SCHWARTZ MEMORIAL WALK FOR PULMONARY FIBROSIS IN CRIWITZ, WISCONSIN.

JUNE 4–6 • 3rd Annual Pilot for a Cure Yard Sale WATER MILL, NEW YORK

JUNE 12 • LBX Dig Deep 5K LEXINGTON, KENTUCKY

JULY 12 • 4th Annual “Night at the Old Ball Park” WAPPINGERS FALLS, NEW YORK

SEPTEMBER 20 • 4th Annual John F. Tighe Walk for Pulmonary Fibrosis WOBURN, MASSACHUSETTS

SEPTEMBER 22 • Karl G. Hudson, Jr. Golf Tournament RALEIGH, NORTH CAROLINA

SEPTEMBER 27 • 6th Annual Garden State PF Support Group 5K Run/Walk for the PFF CRANFORD, NEW JERSEY

OCTOBER 4 • 5th Annual Cruisin’ Toward a Cure for PF... Because Breathing Matters! HOLLAND, INDIANA

Donna Schwartz Memorial Walk for Pulmonary Fibrosis in Crivitz, Wisconsin.

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Sarah Ridder at Hustle Up the Hancock in Chicago, Illinois.
Tighe Family's 2nd Annual Zumba for a Cure: Battle for Breath in Burlington, Massachusetts.

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