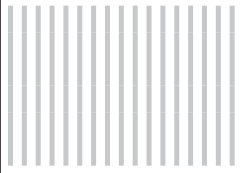


2012 Annual Report

PULMONARY FIBROSIS FOUNDATION



ENGAGING  
OUR GLOBAL  
COMMUNITY.

INCREASING  
OUR **IMPACT.**

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**The past year was one of amazing growth and expansion for the Foundation. We expanded our international presence by introducing new support group initiatives and by making our educational materials more readily accessible to individuals throughout the world. With new strategic partnerships, commitment to funding important research, and working to develop a Pulmonary Fibrosis Foundation Patient Registry and Care Center Network, we have continued to make a positive and lasting impact on our global community.**



## DEAR FRIENDS,

An essential component of helping us achieve two of our important goals — developing effective therapies and improving the quality of life for pulmonary

fibrosis patients — is the creation of a Pulmonary Fibrosis Foundation Patient Registry and Care Center Network. (In the Spring 2013 edition of our *Breathe Bulletin* we provided an in-depth discussion of this topic.) This is something that we have seriously explored and researched and plan to implement in early 2014.

There are many benefits to a registry and a care center network. Some of these include: facilitating an early diagnosis; standardization of care; acquiring important clinical information; assessing efficacy of therapies; performing multi-institutional research; expediting enrollment in clinical trials; and enhancing support services.

The Cystic Fibrosis (CF) Foundation initiated their Patient Registry and Care Center Network over 30 years ago. Through the information and knowledge they acquired, they were able to significantly improve patient care, help develop effective medications, and eventually cure some patients with a specific genetic variant. Through these efforts the expected life span of a CF patient has increased by about 20 years. This is a true testament to the real and achievable benefits of a well-executed registry and care center network.

Clearly this is a large undertaking for the Foundation, requiring significant resources both human and financial. In order for us to attain financial viability for this endeavor, we will need to acquire funding from multiple sources both public and private.

Last year was an exciting time for the PF community and the Foundation and we look forward to continuing successes in 2013. We are developing international programs, expanding our fundraising capacity, and enhancing our educational materials. Additionally, we have partnered with some pharmaceutical companies to help fund and expand our research activities. The planning for the *PF Summit* in December in La Jolla is going well; we have an excellent program for both health care professionals and the patient community. Finally, some medications that may be of benefit for PF patients are working their way through the approval process (clinical trials) and may become available in the near future.

In conclusion, we have grown and progressed dramatically during our 12 years of existence. We still have much work to do. With all of our new programs and with the development of the Registry, we will need the support of the PF community more than ever. All of you have been extremely generous in the past, and I am certain that we can count on your magnanimous support in the future.

Sincerely,

**Daniel M. Rose, MD**

CHIEF EXECUTIVE OFFICER AND  
CHAIRMAN OF THE BOARD OF DIRECTORS



## TO OUR COMMUNITY,

The diagnosis of any life-threatening illness is difficult, presenting new decisions and challenges. For patients diagnosed with pulmonary fibrosis (PF), they must also learn

about a disease they probably have never heard of, its symptoms, and potential treatments. But they are not alone. They enter a large community of support that provides assistance on many levels and connects people who face similar experiences.

At the Pulmonary Fibrosis Foundation (PFF), support for patients, their families, and their caregivers is one of the four pillars of our mission. Support groups provide a warm, non-judgmental environment where members receive emotional support and practical information. Often joined by medical practitioners and representatives of support services, people share personal experiences, learn coping strategies, and receive answers to their questions.

We're pleased that 2012 saw the introduction of new support initiatives, along with the continuation of our ongoing programs for the PF community. Foremost was our commitment to the international community by expanding our Support Group Network to the European Union (EU). In September 2012, the Foundation hosted a Support Group Leader Workshop in Modena, Italy, just prior to the start of the International Colloquium on Lung and Airway Fibrosis (ICLAF). Joined by representatives from all over Europe, our goal was to better engage European patients and family members, along with the distribution of our *Support Group Leader Guide*, translated into six languages.

For patients and caregivers who were unable to attend support groups in person, we were pleased to have partnered with the Inspire<sup>SM</sup> online support group community. Inspire only partners with the most respected patient advocacy organizations and provides secure and moderated online support groups. Patients and caregivers connect by creating personal profiles, participating in discussions, and blogging.

The Foundation also continued our Leanne Storch Support Group Fund, initiated in 2011, and named for the PFF's former Executive Director who was diagnosed with pulmonary fibrosis in 2003. Groups apply for annual awards that can be used towards meeting programming, educational materials, or location requirements.

The Foundation offers support to many people in many different forms. Support may be one-on-one, in a group setting, or an online community. You'll find it across many locations and languages. But regardless of where it is or the format it takes, the benefit to PF patients and those who care about them is unparalleled. The Foundation's dedication to finding new avenues of support for those in need and continued expansion of our current resources is unwavering. We invite you to learn more about the work we are doing and join us.

Sincerely,

**Patti Tuomey, EdD**

PRESIDENT AND CHIEF OPERATING OFFICER

# ABOUT THE DISEASE

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

Pulmonary fibrosis (PF) describes a condition in which the lung tissue becomes thickened, stiff, and scarred.<sup>1</sup> The medical terminology used to describe this scar tissue is fibrosis. The alveoli (air sacs) and the blood vessels within the lungs are responsible for delivering oxygen to the body. All of the body's functions depend upon delivery of an adequate supply of oxygen. As lung tissue becomes scarred and thicker, it is more difficult for the lungs to transfer oxygen into the bloodstream. As a result, the brain, heart, and other organs do not get the oxygen they need to function properly.<sup>1</sup>

Pulmonary fibrosis can result from a number of causes: certain environmental agents (dust, silica), medications (antibiotics, antiarrhythmics), radiation, autoimmune diseases (scleroderma, rheumatoid arthritis), or a genetic predisposition. However, in most situations the etiology (cause) is unknown. If there is no known cause, and specific radiographic or pathologic criteria are met, the disease is called idiopathic pulmonary fibrosis (IPF).

There are more than 200 related diseases that affect the lung with inflammation and scarring, these are known as interstitial lung diseases (ILD). Idiopathic pulmonary fibrosis is the most serious and common form of ILD. IPF is a progressive, fatal lung disease, for which there is no known cause or cure. There is no FDA-approved treatment for IPF in the United States; pirfenidone (Esbriet®, Pirespa®, Pirfenex®) is approved for treatment of mild-to-moderate IPF in the European Union, Canada, and Asia.

## WHAT DOES THE DISEASE LOOK LIKE?

IPF affects between 132,000 and 200,000 individuals in the United States with an estimated annual mortality of 40,000. In the European Union, IPF affects between 37,000 and 40,000 people.

In the United Kingdom alone, more than 5,000 new cases of IPF are diagnosed each year. As a result of the difficulty in making a diagnosis and lack of a patient registry, the accrual of accurate data has been problematic. For these reasons, it has also been difficult to obtain adequate data regarding the incidence of those affected by pulmonary fibrosis from all causes. IPF has no strong demographic profile although it appears to affect more men than women. PF can strike at any age, but usually occurs between the ages of 50 and 70. The median survival is just two to three years following diagnosis and more than two-thirds of patients will die within five years.

Symptoms of pulmonary fibrosis include: shortness of breath (dyspnea), chronic cough, fatigue and weakness, discomfort in the chest, loss of appetite, and weight loss.

Treatment includes supplemental oxygen, pulmonary rehabilitation, medications to manage symptoms, maintaining a healthy lifestyle (optimizing weight and exercise), and lung transplantation for those who qualify.

Pulmonary fibrosis is a devastating disease. It is our goal to help find effective treatments and ultimately a cure. Until that time we aspire to increase disease awareness; provide educational materials and events for patients and health care professionals; advocate for the PF community; and offer support to patients, family members, and caregivers.

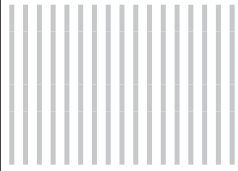
1. National Heart Lung and Blood Institute. "What is idiopathic pulmonary fibrosis?" Available at [www.nhlbi.nih.gov/health/health-topics/topics/ipf](http://www.nhlbi.nih.gov/health/health-topics/topics/ipf). Accessed June 29, 2012.



**One of the important initiatives of the Pulmonary Fibrosis Foundation is to improve patients' and caregivers' access to support groups. With limited options for treatment and no cure for pulmonary fibrosis, support groups provide the crucial information and emotional support that patients and caregivers need in order to improve their lives.**

# SUPPORTING PATIENTS AND CAREGIVERS

## INTERNATIONAL SUPPORT GROUP INITIATIVE



In the United States, people affected by pulmonary fibrosis (PF) have received tremendous benefits from attending support groups where patients and caregivers regularly gather to discuss how PF affects their lives. Often joined by medical professionals and other health care providers, participants learn about the disease, available treatments, and how to improve their quality of life.

Recognizing the value of these groups, the Pulmonary Fibrosis Foundation (PFF) made a commitment in 2012 to expand our Support Group Network into the European Union (EU). Funded by Boehringer Ingelheim, InterMune, and the Culliton-Metzger Family, we held our first international "Support Group Leader Workshop" in the EU.

In partnership with Luca Richeldi, MD, PhD, PFF Medical Advisory Board Member and Director and Founder of the Center for Rare Lung Diseases at the University of Modena and Reggio Emilia, the Workshop was held in Modena, Italy, on September 29, 2012, just prior to the start of

the International Colloquium on Lung and Airway Fibrosis (ICLAF). Representatives from over 90 EU interstitial lung disease centers and 12 patient advocacy groups were invited to attend the event. The goal of the Workshop was to develop new relationships with the European PF community and to learn how to better engage European patients and family members. The agenda included presentations and discussions on support group guidance, best practice models, and relevant cultural and geographic issues. Key to the success of the Workshop was the distribution of the Foundation's *Support Group Leader Guide*, which had been translated into six languages.

Support groups have proven to be a valuable benefit for PF patients and caregivers. The Foundation's international Workshop helped bring this important resource to the global PF community.



*Kathleen O. Lindell, PhD, RN and Luca Richeldi, MD, PhD, (above) at the Support Group Leader Workshop where physicians attended presentations on support group guidance (right).*



*Patients participating in support groups (above).*

## INSPIRING SUPPORT

In the Spring of 2012, the Pulmonary Fibrosis Foundation proudly partnered with the Inspire<sup>SM</sup> online support group community. Inspire provides secure and moderated online support groups that allow patients and caregivers to connect by creating personal profiles, participating in discussions, and blogging. Members may also access relevant health and wellness forums and also obtain information about participation in clinical trials. Inspire partners with only the most respected patient advocacy organizations and currently has over 300,000 members.

Dolly Kervitsky, RCP, CCRC, the Foundation's Vice President of Patient Relations and Medical Affairs, views the partnership as a lasting investment with a far-reaching purpose: "Through well-run support groups, both online and in person, the knowledge gained by the participants helps empower them to become their own advocates and will also allow them to educate others."

For more information, visit [www.inspire.com/partners/pulmonary-fibrosis-foundation](http://www.inspire.com/partners/pulmonary-fibrosis-foundation).



**Pulmonary fibrosis impacts the lives of individuals throughout the world. The Foundation's goal to increase international disease awareness is important to improving their future. In 2012, we maximized the impact of educational initiatives in Europe**

**and the United States by making them available to audiences everywhere via webcasts.**

# CONNECTING THE GLOBAL COMMUNITY

## GLOBAL PULMONARY FIBROSIS AWARENESS DAY

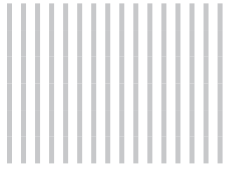


The Foundation continuously pursues opportunities to expand awareness of pulmonary fibrosis (PF).

The potential benefits of increased disease awareness are clear and can lead to earlier diagnosis, improved standards of care, and increased support from government agencies. Expanding awareness can also stimulate support for new research, resulting in new and better treatments.

In 2012, the Foundation took a major step toward increasing disease awareness by conducting the first Global Pulmonary Fibrosis Awareness Day. Funded by Boehringer Ingelheim, InterMune, and the Culliton-Metzger Family, the day was part of a month-long awareness initiative. Held on September 29, Global Pulmonary Fibrosis Awareness Day featured two separate webcasts titled "Living Better with Pulmonary Fibrosis." The educational events were conducted and webcast from the University of Modena and Reggio Emilia in Modena, Italy, and from National Jewish Health in Denver, Colorado. Topics discussed during the webcast included "What is Pulmonary Fibrosis?" along with "The Role of Support Groups"





global  
**PULMONARY FIBROSIS**  
AWARENESS DAY

and “Tools for Living Better with Pulmonary Fibrosis.” Patients, caregivers, and family members were able to view the webcasts at home as well as in groups facilitated by medical professionals at interstitial lung disease centers in Europe and the United States. Attendees and viewers were also provided with the opportunity to ask questions either in person or online.

Central to the success of any global initiative is accessibility to materials in multiple languages. The Modena webcast was translated live into six languages. Additionally, translated copies of the *Pulmonary Fibrosis Patient Information Guide* and *Support Group Leader Guide* (see International Support Group Initiative, page 4) were available.

**MAB UPDATE**

**Medical Advisory Board (MAB)  
Welcomes New Members**

The Foundation is pleased to announce the addition of two new members of the international community to our Medical Advisory Board. Dr. Luca Richeldi from Modena, Italy, and Dr. Andreas Günther from Geissen, Germany — both highly respected investigators — bring valuable international perspective to the MAB.

Special events create unique opportunities to raise funds to support research and programs. These events also foster relationships and promote awareness of the disease. In 2012, the Foundation involved members of the PF community both in the US and abroad through the *Breathe Benefit* annual dinner and *Team PFF*.

# EXTENDING BENEFITS OF SPECIAL EVENTS

## BREATHE BENEFIT 2012: COMMUNITY INSPIRING A CURE



*Kathy Petrak, a dedicated pulmonary fibrosis advocate, and Chuck Lawless, Senior Managing Director and Head of Lawless Advisory Group at Mesiraw Financial, co-chaired the Chicago Dinner.*

Last year, the Foundation extended an invitation to anyone in the world who was unable to attend the *Breathe Benefit* in Chicago to participate by hosting a satellite “Global Dinner.” The concept was introduced to foster a greater sense of unity among members of the pulmonary fibrosis (PF) community.

Held concurrently with the *Breathe Benefit* Chicago Dinner, over 20 Global Dinners were hosted and attended by over 200 guests and took place in locations as diverse as Mobile, Alabama, and Oslo, Sweden.

Guests at the Chicago Dinner included patients, caregivers, family members, medical professionals, and other valued supporters of the Foundation. Mary Ann Ahern, from Chicago’s *NBC5 News*, emceed the evening. She and her husband, Tom Ahern, also served as honorary chairs. Special guests were Broadway actress, Julie Halston, and her husband, broadcaster, Ralph Howard.

*The Young Investigator Awards were presented by Kevin K. Brown, MD, Chairman of the PFF's Medical Advisory Board, and a member of PFF's Board of Directors.*



*Foundation co-founder, I.M. Rosenzweig, PhD. The Young Investigator Awards were re-named in his honor.*



*Former Executive Director of the Foundation, Leanne Storch and husband, Mike. During the awards presentation, the Foundation announced the six recipients of the 2012 Leanne Storch Support Group Fund. Mrs. Storch was diagnosed with PF in 2003 and the Fund honors her deep passion for supporting those affected by the disease.*

Foundation co-founder, I.M. Rosenzweig, PhD, who lost his courageous battle with idiopathic pulmonary fibrosis (IPF) in June 2012, was honored with a photographic tribute as well as some warm remembrances delivered by his daughter, Dr. Karen Schwartz. Dr. Rosenzweig and his brother, Albert Rose, started the foundation in 2000. Both of them had been diagnosed with IPF, and they had previously lost their sister to the disease. Dr. Rosenzweig led the Foundation until he retired in 2009 due to the progression of his illness. In recognition of Dr. Rosenzweig's dedication to research, the Young Investigator Awards were renamed in his honor.

In total, the *Breathe Benefit* Chicago Dinner and Global Dinners raised over \$175,000. These funds will help support important research and many of the Foundation's patient activities.

Like many family members and friends of patients whose lives have been suddenly changed by pulmonary fibrosis, Broadway actress and comedienne, Julie Halston, was shocked when two significant people in her life were diagnosed with the disease. As the host of what has become one of our signature events,

Ms. Halston has made the Foundation's mission her own — to spread awareness about pulmonary fibrosis and support research.

# REACHING FOR THE STARS

## SECOND ANNUAL BROADWAY BELTS FOR PFF!



Julie Halston with the evening's surprise guest, the famed Joel Grey (*Anything Goes*). Mr. Grey performed an impromptu rendition of "Wilkommen" from his Tony Award and Oscar Award winning role in *Cabaret*.

On February 27, 2012, some of Broadway's best performers gathered at New York City's famed Birdland Jazz Club to honor the memory of Associated Press theater critic and reporter, Michael Kuchwara, who passed away from complications due to pulmonary fibrosis (PF) in 2010.

*Broadway Belts for PFF!* was first held in 2011 when Ms. Halston and a group of friends decided to remember Mr. Kuchwara with an evening of his favorite Broadway tunes. Earlier the same year, Ms. Halston's husband, *Howard 100 News* broadcaster Ralph Howard, had a lung transplant for PF, adding even greater meaning to the event.

Sirius Satellite Radio's Seth Rudetsky opened the event with an amusing monologue about "belting." Broadway stars then showcased their talents under the musical direction of Jesse Kissel and returning director Carl Address. The all-star cast included: Tony nominees Adam Pascal (*Memphis*) and Andrew Rannells (*The Book of Mormon*), Robert Creighton (*Anything Goes*), Lindsay



Theater critic, Adam Feldman, gave a heartfelt tribute to friend and colleague, Michael Kuchwara.



The entire cast took the stage to sing “Da Doo Ron Ron” for the evening’s finale.



PHOTOS BY CHRIS OWYOUNG

Pop icon and Broadway regular, Darlene Love, delighted the audience with “Today I Met the Man I’m Going to Marry.”

Mendez (*Godspell*), Betsy Wolfe (*Encores! Merrily We Roll Along*), Heidi Blickenstaff (*Now. Here. This.*, [title of show]), and Julia Murney (*Queen of the Mist*, *Wicked*).

The event raised over \$50,000. All proceeds went toward the Foundation’s Michael Kuchwara Fund for Idiopathic Pulmonary Fibrosis Research, Education, and Advocacy.

The Foundation sincerely thanks Julie Halston, Ralph Howard, D. Michael Dvorchak, Ed Windels, Sue Frost, and Charlie Siedenburg for their profound dedication and generous contributions to the PF community.



**I.M. Rosenzweig, PhD, one of the co-founders of the Pulmonary Fibrosis Foundation who lost his battle with idiopathic pulmonary fibrosis in 2012, believed strongly in the importance of funding research. The Foundation carries on**

**his legacy by strategically funding innovative research and establishing important partnerships.**

# EXPANDING RESEARCH BOUNDARIES

## FUNDING RESEARCH FOR SUCCESSFUL THERAPIES

An important part of the Pulmonary Fibrosis Foundation’s goal to fund research that will ultimately lead to the development of successful therapies for pulmonary fibrosis (PF), is to support early phase research that is often underfunded. One successful example of this approach is demonstrated by the development of a lysophosphatidic acid (LPA) antagonist.

A few years ago the Foundation provided a research grant to Andrew Tager, MD, of Massachusetts General Hospital.



*Andrew Tager, MD*

Through this “seed” grant, Dr. Tager was able to identify a potential target (the LPA pathway) that is key in the development of lung fibrosis. As a result of this initial research, Dr. Tager secured a larger grant from the National Institutes of Health to continue this research.

Dr. Tager subsequently partnered with a small biotech company, Amira Pharmaceuticals, which helped develop an LPA antagonist (a drug called AM152) to block this pathway. This compound was shown to inhibit the development of lung fibrosis in an experimental model. In a Phase 1 trial the drug was shown to be safe in humans. Bristol Myers Squibb subsequently purchased Amira and is now recruiting for a Phase 2 trial.

The Foundation has funded numerous other early stage projects, which we are hopeful will eventually lead to successful therapies. For a complete list, please visit [www.pulmonaryfibrosis.org/research](http://www.pulmonaryfibrosis.org/research).





## EXPANDING THE UNDERSTANDING OF FIBROSIS

Along with top scientists from around the world, the Pulmonary Fibrosis Foundation (PFF) participated in the “Fibrosis Across Organs Symposium.” The conference, held on March 11–12, 2012, in Denver, discussed fibrotic diseases that exist in different organs including the lung, liver, kidney, heart, and skin. Advancing the understanding of fibrotic disease in these organs may ultimately lead to better treatments for fibrotic diseases of the lung.

The American Thoracic Society (ATS) sponsored the Symposium. Organizers included Kevin K. Brown, MD, Chairman of the PFF Medical Advisory Board; Gregory P. Cosgrove, MD, PFF Medical Advisory Board Member; and Dolly Kervitsky, RCP, CCRC, Vice President of Patient Relations and Medical Affairs for the PFF.

The goal of the conference was to take a multidisciplinary approach to defining scientific priorities for future research, assess the relevance of currently available experimental models, and to identify potential therapies.

Organizers of the Symposium are currently in the process of developing a “Fibrosis Roadmap” for multidisciplinary and inter-institutional investigations that will soon be published.

### ICLAF

#### Leading the Way for Advocacy at the International Colloquium on Lung and Airway Fibrosis

The Pulmonary Fibrosis Foundation (PFF) was honored to be a partner, as well as the first advocacy organization invited to present, at the International Colloquium on Lung and Airway Fibrosis (ICLAF) that took place in Modena, Italy.

The 17th biennial conference was organized by the Center for Rare Lung Diseases at the University of Modena and Reggio Emilia and was attended by over 250 leading investigators in lung fibrosis.

Daniel M. Rose, MD, Chief Executive Officer and Chairman of the Board of Directors of the PFF, gave a presentation on “The New Paradigm of Patient Advocacy Organizations.”



The creation of a Pulmonary Fibrosis Foundation Patient Registry and Care Center Network is essential for assessing effective therapies and improving patient care. In 2012, we began establishing partnerships with clinicians, researchers, government agencies, and biopharmaceutical organizations to make a Patient

Registry and Care Center Network a reality.

# RAISING THE BAR FOR HIGHER STANDARDS OF CARE

## PLANNING THE PFF PATIENT REGISTRY AND CARE CENTER NETWORK

The most common form of pulmonary fibrosis (PF), idiopathic pulmonary fibrosis (IPF), affects between 132,000 and 200,00 people in the US.<sup>1</sup> As such, many institutions do not have a sufficient number of patients to conduct meaningful clinical research.

Developing a pulmonary fibrosis patient registry would make standardized data available to all clinicians and researchers. This information would include demographic data, patient history and physical findings, drug therapies utilized, high-resolution computed tomography (HRCT) findings, laboratory data, and results from other diagnostic procedures. This information can be extremely helpful in the development of new and effective treatments. With a Pulmonary Fibrosis Foundation Patient Registry and Care Center Network there is the potential to acquire significant funding from the National Institutes of Health and industry for collaborative studies that will facilitate much needed research of the disease.

As an important adjunct to a Registry, the Foundation also began plans to create a Care Center Network that will afford a standardized and comprehensive, multi-disciplinary approach to patient care. This integrative method of treatment is crucial to providing quality patient care.

The PFF Patient Registry and Care Center Network initiative will provide data that is necessary to improve and extend the lives of patients with PF.



1. Raghu G, Weycker D, Edelsberg J, Bradford WZ, Oster G. "Incidence and prevalence of idiopathic pulmonary fibrosis." *Am J Respir Crit Care Med* 2006;174:810–816.

# PFF RESEARCH PROGRAM

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

## 2012 PFF Research Fund Awards

### GENERAL RESEARCH GRANTS

- Dr. Erica Herzog of Yale University – “Prospective Evaluation of IPF Biomarkers” (Year 2)
- Dr. Aldo T. Iacono of University of Maryland – “Open Label Use of Inhaled Cyclosporine in Lung Transplant Recipients” (Year 3)
- Dr. Daniel J. Kass and Dr. Naftali Kaminski of University of Pittsburgh – “Targeting the Relaxin Pathway in Pulmonary Fibrosis” (Year 2)
- Dr. David J. Lederer of Columbia University – “Subclinical Interstitial Lung Disease in MESA: The MESA Lung Fibrosis Study”
- Dr. Imre Noth of University of Chicago – “miRNA Expression in Patients with Rapidly Progressive IPF Versus Stable IPF” (Year 2)
- Dr. Patricia J. Sime of University of Rochester – “Translational Studies of New Therapeutic Targets & Biomarkers in PF” (Year 2) FUNDED IN PART BY THE GREG CHANDLER AND GUY F. SOLIMANO MEMORIAL GOLF TOURNAMENT
- Dr. Andrew Tager of Massachusetts General Hospital – “Profibrotic Mechanisms of the LPA Pathway” (Year 1) FUNDED IN PART BY THE TIGHE FAMILY TRUST AND THE ROUINE RUN, INC.

### I.M. ROSENZWEIG YOUNG INVESTIGATOR AWARDS

- Dr. Haitao (Mark) Ji of University of Utah – “Design and Synthesis of Selective Beta-catenin/T-Cell Factor Inhibitors for the Treatment of Idiopathic Pulmonary Fibrosis” (Year 1) FUNDED BY A GRANT FROM INTERMUNE, INC.
- Dr. Rebecca Keith of University of Colorado, Denver – “Therapeutic Targeting of PTPN-13 in Idiopathic Pulmonary Fibrosis” (Year 1)

### ALBERT ROSE ESTABLISHED INVESTIGATOR AWARDS

- Dr. James S. Hagood of University of California, San Diego – “Extracellular Vesicles Alter Cell Phenotype in Pulmonary Fibrosis” (Year 1)
- Dr. Glenn D. Rosen of Stanford University – “Analysis of Novel Functions of Human Telomerase RNA in IPF” (Year 1)

### ATS/PFF INTERNATIONAL PARTNERSHIP GRANTS

- Dr. Anthony Shum of University of California, San Francisco – “Defining the Molecular Basis of Interstitial Lung Disease in Rheumatoid Arthritis” (Year 1)
- Dr. Anne Holland of La Trobe University, Australia – “Where Does Pulmonary Rehabilitation Fit in the Management of Pulmonary Fibrosis?” (Year 2)

### ATS/PFF/CPF YOUNG INVESTIGATOR

#### PARTNERSHIP GRANTS

- Dr. Jia Guo of University of Rochester – “Fibrocyte Differentiation is Regulated by Yin Yang 1 in Pulmonary Fibrosis” (Year 2)
- Dr. Yan Sanders of University of Alabama at Birmingham – “Epigenetic Regulation of Caveolin-1 by TGF-beta Mediated Signal Pathway in Lung Fibroblasts” (Year 2)

## 2012 Partnerships

- 17th International Colloquium on Lung and Airway Fibrosis (ICLAF)

## 2012 Sponsorships

- American Thoracic Society – Fibrosis Across Organ Systems Symposium
- National Jewish Health – Familial Pulmonary Fibrosis Genetic Counseling Program
- Pittsburgh International Lung Conference
- University of California, San Francisco – “Update in Interstitial Lung Disease: Diagnosis and Management” CME Course
- University of Maryland – Hales Lung Conference
- University of Minnesota – Annual PF Educational Symposium
- Yale University – Sixth Annual Yale Fibrosis Symposium

## PFF RESEARCH FUND

### Young Investigator and Established Investigator Awards

To learn more, visit [www.pulmonaryfibrosis.org/research/PFFgrants](http://www.pulmonaryfibrosis.org/research/PFFgrants).

# THANK YOU TO ALL OUR DONORS



## TEAM PFF

Over the years, the Foundation has benefited from the efforts of the many volunteers who have dedicated their seemingly endless energy to help support the mission of the Pulmonary Fibrosis Foundation. These dedicated individuals have organized many diverse fundraising events. In 2012, the Foundation launched *Team PFF* to provide them with the guidance and tools they need to host successful events, and to create a stronger network of advocates.

The Foundation wishes to thank *Team PFF* members for their generous support. You will find their names throughout these donor recognition pages. Read more about two *Team PFF* members who are making a difference on pages 37 and 38.

To learn more about *Team PFF* and how to host your own event, visit [www.pulmonaryfibrosis.org/teampff](http://www.pulmonaryfibrosis.org/teampff).

## 2012 SUPPORTERS

### \$100,000+

Boehringer Ingelheim  
The Cowlin Family Fund  
Tom & Alice Hales  
InterMune, Inc.  
Charles & Monica McQuaid  
Steve & Joan Wald

### \$10,000–\$99,999

Ritu S. Baral  
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Doris Reynolds-Johnson  
Daniel M. Rose, MD  
RS Family Trust, DTD  
SCDF Family Partnership, LLLP  
Culliton-Metzger Family Gunterberg Foundation

### \$5,000–\$9,999

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Angelina Caldwell  
Broadway Cares/Equity Fights Aids  
Jeffrey & Pam Choney  
Phyllis N. Demont  
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**\$2,500–\$4,999**

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10th Annual Mossman Spirit Triathlon  
 1st Annual Alice Beal Memorial Walk for Pulmonary Fibrosis  
 1st Annual Jim Hodge 5K/10K Run for Pulmonary Fibrosis  
 1st Annual Teddy Bear Open for PFF  
 2012 ILD Strolls  
 2nd Annual Dave L. Smith Golf Tournament for IPF  
 2nd Annual George Lujan Memorial Softball Tournament  
 2nd Annual John F. Tighe Walk for Pulmonary Fibrosis  
 2nd Annual Octoberfest Half Marathon  
 2nd Annual Pete DeVito Memorial Golf Outing  
 2nd Annual Ready. Set. Breathe!  
 2nd Annual Richard G. Hall Memorial Golf Tournament  
 2nd Annual Team Dan Walk-A-Thon  
 3rd Annual Christine C. Hack Walkathon  
 3rd Annual Rouine Run for Pulmonary Fibrosis  
 3rd Annual Willacker Family Pulmonary Fibrosis Golf Outing  
 4th Annual Garden State 5K Run/Walk  
 4th Annual Joseph S. Lore Memorial Golf  
 5th Annual Greg Chandler & Guy F. Solimano Memorial Golf Tournament  
 5th Annual Joanne's Ride  
 5th Annual SAL-ABRATIION  
 7th Annual Barbara A. Fiorillo Memorial Bike Run/Picnic  
 A Night with Family and Friends at the Old Ballpark  
 ACTS of LOVE  
 Amherst Middle School Adirondack Chair Project  
 Avon American Legion Post #145 Fish Fry Dinner  
 Barbara Lynch Fundraiser  
 Boogie for Breath  
 BROADWAY BELTS for PFF!  
 California Pizza Kitchen FUNdraising Event  
 Carolyn Connor Fundraiser  
 Choral Stones of Stonecrest Concert  
 Cocktails for a Cause  
 Colors for a Cause  
 Cruisin' Toward a Cure for PF... Because Breathing Matters!  
 Donna Schwartz Memorial Walk for Pulmonary Fibrosis  
 Draper and Kramer Jeans Day  
 Eat, Drink & Be Greek!  
 Elaine Grant Fundraiser  
 Felice Santoro Pulmonary Fibrosis Foundation  
 Three on Three Basketball Tournament  
 Gale Davidson Memorial Shoot  
 Go! St. Louis Half Marathon  
 HOCR Directors Challenge Mixed 2x Honoring John Wilson  
 Hodgson Russ – Dress Down Day  
 John F. Adams Birthday Party  
 Joie de breathe 2012  
 Joseph DeGrazia Memorial Golf Outing  
 Josh Ohlinger: Running for My Dad  
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 Manchester Marathon  
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 Octoberfest Half Marathon and 10K  
 Orange Runners Club: Jingle Jog 2012  
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 PFF Jean's Team  
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 PFF Team M&M  
 PFF Walk with Pat  
 Pilot for a Cure  
 Reflections and Improvisations Recital  
 Roy Fuhr Golf Outing  
 Rugalech – David Leavitt

Saturday Sports for the PFF  
 Scott Stiglitz and Pam Visser's Bowling Party  
 Tastefully Simple Fundraiser  
 Team Breathe On Runs  
 the Rock 'n Roll Half Marathon  
 Team PFF: Hike for Lung Health  
 Team Mossman Event  
 The Bernice F. Dunlop Memorial Golf Tournament  
 The Willacker Action Committee  
 Presents: Comedy for a Cause  
 Ultimate Frisbee (NY)  
 Sunday Team – Jeff Don't Want No Subs  
 Woodlawn Run for a Cause  
 Zumbathon



*Pictured left to right are Pete's children and wife, Daniel, Nicholas, Susan, and Peter.*

## CELEBRATING THE LIFE OF PETE DEVITO

The Pete DeVito Memorial Foundation and annual Golf Outing & Dinner was established to celebrate the life of Pete DeVito, who passed away from idiopathic pulmonary fibrosis on December 10, 2010, while also raising awareness and funds to support research for idiopathic pulmonary fibrosis.

*"Pete, my father, was a vibrant man that had such a great impact on the lives of each and every person he met both personally and professionally. His diagnosis with IPF and rapid deterioration made us learn all about this life altering disease and adapt quickly. With the Pete DeVito Memorial Foundation having the same goal as the PFF, it became evident that we have to work together to help find a treatment and hopefully one day a cure for this devastating disease."*

The Foundation wishes to thank the DeVito Family for their generous support. For more information, please visit [www.petedevitofoundation.org](http://www.petedevitofoundation.org).



## 2012 IN-KIND SUPPORTERS

Amy Slate's Amora Dive Resort  
 An Apple A Day Catering  
 Arthur Murray Dance Center  
 August Hill Winery  
 Balena Chicago  
 Belle Vie Bridal Couture  
 Berryville Vineyards  
 Best Buy  
 Bliss Salon of Winnetka  
 Blue Sky Vineyard  
 Camp Tosebo  
 Chateau Chantal  
 Chicago Blackhawks  
 Chicago Chocolate Tours  
 Chicago Cosmetic Surgery and Dermatology  
 Chicago Cubs Baseball Club, LLC  
 Chicago River Canoe and Kayak  
 Chicago Sky  
 Chicago White Sox  
 Chicago Wolves  
 Clearwater Marine Aquarium  
 Cooper's Hawk Winery & Restaurant  
 Dolphins Plus, Inc.  
 Douglas Valley Winery  
 Elizabeth Arden Red Door Spa  
 Ellen's on Elm  
 Fair Oaks Farms  
 Freedom Woods  
 Galena Cellars Vineyard & Winery  
 Gray's Travel Management  
 Green Bay Cycles

Hampton Inn & Suites Islamorada  
 Hotel Baker  
 Hub 51  
 J. Hilburn  
 Jam Productions, Ltd.  
 Jim Swon  
 Kane County Cougars  
 Kathy & Chris Petrak  
 Kevin Brown, MD  
 Key Largo Conch House  
 Kickapoo Creek Winery, Inc.  
 Kiehl's  
 Krista K Boutique  
 Kryssage Wellness  
 La Madia  
 Lenswork Studios  
 Lifeline Theatre  
 Lynfred Winery  
 Marriott Theatre-Lincolnshire  
 Melrose Park Indoor Grand Prix  
 Microsoft  
 NBC Universal Media, LLC  
 Ocean Divers, Inc.  
 O'Hare Midway Limousine Service  
 Outback Steakhouse  
 Pandora Jewelry Water Tower Place  
 Panera Bread  
 Paris Club  
 Port Edward Restaurant  
 Pro Football Hall of Fame  
 Randoons

Renaissance Meadowlands Hotel  
 Rosebud Restaurants  
 Roundabout Theatre Company  
 Rovia  
 ROX City Grill  
 RPM Italian  
 Sam's Club  
 Schaumburg Boomers  
 Shawnee Winery  
 Shedd Aquarium  
 Sheraton Chicago Hotel & Towers  
 Sherrill Bodine  
 Spirit Knob Winery  
 Sprinkles Cupcakes  
 Suzy Halpin Photography  
 The Book Stall at Chestnut Court  
 The Comix Gallery  
 The Hockadoo Company, LP  
 The Late Late Show with Craig Ferguson  
 The Signature Room at the 95th  
 Tom Panoplos  
 Tracy & Anne-Marie Lee  
 Tyler & Sara Turnquist  
 US 99.5 / WUSN-FM  
 Vera Bradley  
 Village Toy Shop  
 Windy City Thunderbolts  
 Winnetka Golf Club  
 Woodhouse Day Spa  
 WXRT-FM  
 Zazu Salon and Day Spa

## WALKING FOR JOHN F. TIGHE

"My father, John F. Tighe, passed away from IPF on December 21, 2010.

My father was a man of great kindness and always wanted to help others. We decided that the best way to honor our father/husband was to 'do as he would do' and that is to somehow help others that are suffering from this disease. My family has embarked on a mission to raise awareness and funds to help find a cure for this disease!

We found the Pulmonary Fibrosis Foundation (PFF) after my father's passing and with the help and support of the PFF we have been able to make our mission possible!

We are currently planning our 3rd Annual John F. Tighe Walk for Pulmonary Fibrosis and we are hoping each year we will help make a difference!"

– Lisa Tighe, Team PFF



*The Tighe Family at the 2nd Annual John F. Tighe Walk for Pulmonary Fibrosis.*

# FINANCIAL SUMMARY

## STATEMENT OF FINANCIAL POSITION

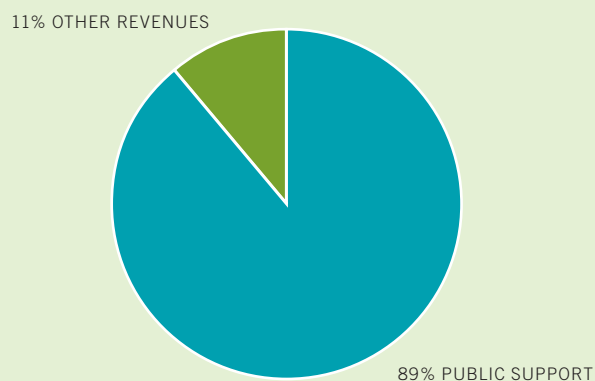
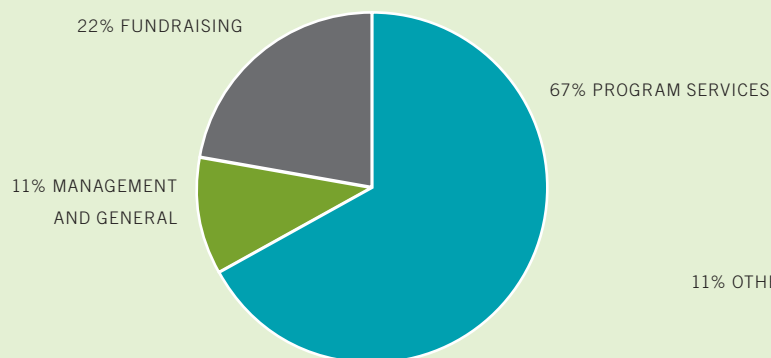
AUDITED NUMBERS

	2012	2011
Total Assets	3,724,437	3,489,197
Total Liabilities	63,632	152,316
Total Net Assets	3,660,805	3,336,881

## STATEMENT OF ACTIVITIES

AUDITED NUMBERS

Total Revenue	2012	2011
Unrestricted	2,256,757	2,135,741
Temporarily Restricted	398,144	97,274
	2,654,901	2,233,015
Total Expenses	2,330,977	2,425,673
Loss on Disposal of Property and Equipment	–	(2,645)
Change in Net Assets	323,924	(195,303)



## ALLOCATION OF 2012 EXPENSES

AUDITED NUMBERS

### Program Services by Category

Advocacy	84,938	
Physician and Patient Education	491,207	
Research	501,331	
Patient Outreach	277,328	
Registry	154,280	
Summit	39,452	
Shop PFF	24,961	
Program Services Total	1,573,497	67%
Management and General	247,047	11%
Fundraising	510,435	22%
Total 2012 Expenses	2,330,979	100%

## SOURCES OF 2012 REVENUE

Public Support	2,352,135	89%
Other Revenues	302,766	11%
Total 2012 Revenue	2,654,901	100%

## BOARD MEMBERS

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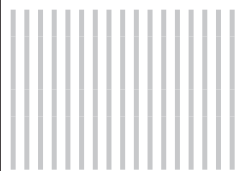
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**The mission of the Pulmonary Fibrosis Foundation is to help find a cure for idiopathic pulmonary fibrosis, advocate for the pulmonary fibrosis community, promote disease awareness, and provide a compassionate environment for patients and their families.**



# Pulmonary Fibrosis

**FOUNDATION**

230 EAST OHIO STREET SUITE 304 CHICAGO, ILLINOIS 60611-3201 [www.pulmonaryfibrosis.org](http://www.pulmonaryfibrosis.org)