

Pulmonary Fibrosis

FOUNDATION

2019

ANNUAL REPORT

OUR MISSION

The Pulmonary Fibrosis Foundation mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live longer, healthier lives.



DEAR FRIENDS,

At the Pulmonary Fibrosis Foundation (PFF), our efforts to educate the public, patients, and healthcare providers about pulmonary fibrosis (PF) are complemented by our significant support of the important research that leads to improved drug therapies. Your support has helped the Foundation achieve new goals to improve the lives of patients and their families everywhere.

The PFF Patient Registry is a centerpiece of that research support. With the completion of phase I of patient enrollment, the Registry has reached an important developmental milestone—but our work is far from over. A growing body of current research is based on the invaluable data generated by the Registry and its associated biorepository, but much more participation and data are needed, particularly for clinical trials.

In response to aggressive targeting of PF patients, the Foundation’s medical advisory board updated its position statement on stem cell therapies. In the statement, we urge patients to consider stem cell therapies only in an FDA-approved clinical trial setting. Our website is a valuable resource to find myriad ILD-specific clinical trials in safe environments.

In addition, the Foundation enjoyed unprecedented success during Pulmonary Fibrosis Awareness Month. Thanks to the efforts of the PF community nationwide, more than 1.2 million people on social media read a message from the PFF about this disease.

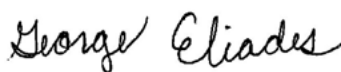
As we work toward improved treatment options for tomorrow, the Foundation is also focused on the quality of life for PF patients today. We know that many of you face challenges in using supplemental oxygen. With heightened legislative advocacy, the PFF is increasing our efforts to improve patients’ understanding of and access to oxygen.

In this report, you’ll learn more about many of our initiatives and find updates on the ways the Foundation is supporting, educating, and advocating for people living with PF. Your support makes this progress possible. You’re a valued member of the PF community—we’re grateful to have you traveling alongside us on our journey to a cure.

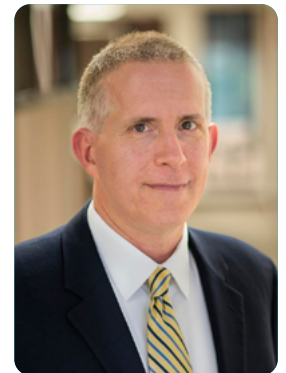
Sincerely,



William T. Schmidt
PFF President and CEO



George Eliades
Chair, Board of Directors



Highlights from the PFF

PROGRAMS



In April, the publication of the “ILD Nursing and Allied Health Guide” provided nurses and allied health professionals with one of the first comprehensive resources for caring for patients with interstitial lung disease (ILD). Examples of topics in the “ILD Nursing and Allied Health Guide” include identifying the disease, disease management, and supporting pulmonary fibrosis patients.

The publication of the Pulmonary Rehabilitation Pocket Guide, also in April, gives respiratory care professionals a quick reference document for working with ILD patients. The guide helps healthcare professionals understand the difference between ILD, cystic fibrosis, and chronic obstructive pulmonary disease (COPD). PFF staff traveled to many healthcare professional conferences to distribute the materials and advise nurses, respiratory therapists, and other allied healthcare providers of the PFF’s available resources.

A new guide for patients, the “Oxygen Basics Booklet,” provides an in-depth overview of supplemental oxygen. Through the guide, patients can see examples of different types of equipment, learn more about traveling with oxygen, and get information on safely using oxygen. The guide complements the introduction in of the Oxygen Information Line at the PFF and a short video on using supplemental oxygen.

A fact sheet series, published in spring 2019, gives patients detailed information about subjects of interest. Topics include causes of pulmonary fibrosis and treatments, such as idiopathic pulmonary fibrosis, rheumatoid arthritis-ILD, and prednisone.

In order to serve a broader audience, the PFF started offering translated versions of five of its resources. All five materials are translated into Spanish, and certain materials are also translated into Brazilian Portuguese, French, Hindi, and Simplified Chinese.

The 2018 Annual Volunteer Meeting took place in Chicago, Illinois from November 7-9. About 90 volunteers from the PFF Ambassador Program, Support Group (Leader) Network, PFF Advocates and Team PFF attended this event. The agenda included training sessions entitled:

- Effective Advocacy for Pulmonary Fibrosis
- Professional Introductions, Networking and Marketing
- 25 Easy Ways to Fundraise for the Pulmonary Fibrosis Foundation
- The Current State of Supplemental Oxygen and Advocacy Efforts
- Supporting Caregivers

The Pulmonary Fibrosis Foundation also premiered the Clinical Trials Innovation Series as the plenary session for this event. To close this meeting, a volunteer recognition ceremony took place.



ADVOCACY

In response to a proposed rule from the Centers for Medicare & Medicaid Services regarding the Medicare Home Oxygen benefit, the PFF joined 13 other organizations in highlighting the needs of patients. The PFF also submitted its own comments on the proposed rule specific to the pulmonary fibrosis community. Both sets of comments emphasized the shortcomings of the current system and the need for better access to oxygen, especially for patients who need high flow oxygen.



In order to better understand the needs of patients who need supplemental oxygen, the PFF started surveying patients regarding their experiences with oxygen in December 2018. The PFF completed a follow up survey in spring 2019. Approximately half of patients reported at least one problem with obtaining supplemental oxygen. Poor service quality and inability to travel with oxygen had the biggest impact on patients' lives in the survey.

DEVELOPMENT



The PFF Walk program, launched in Chicago in 2017, was a great success and led to the program's expansion to two new sites in 2018. On June 23, 2018, we held the first PFF Walk – New York City, and on October 14, the PFF Walk – Washington D.C. In all three locations, nearly 2,000 patients, caregivers, healthcare providers, and friends of the PF community came together to unite in the fight against PF, and collectively raised a robust \$568,000 for patient programs and research.

In the fall of 2018, we launched our first ever planned giving program, the Albert Rose Legacy Society. PFF co-founder, Albert Rose, pledged \$1 million in 2000 to create the PFF. Due to Albert's generosity and foresight, today the PFF is one of the largest funders of PF research and is the leading PF patient education and advocacy organization in the United States.



This year, a total of more than 23,000 donors collectively and generously donated \$4,800,000 to the PFF. It is because of these supporters that we are able to provide patients and families with the necessary educational programs and research that will one-day lead to a cure for this terrible disease.

The ninth annual *Broadway Belts for PFF!* dazzled attendees, sponsors and donors with star-studded performances and raised a record \$400,000 for the pulmonary fibrosis community. The extraordinary event on February 25, 2019, at New York City's Edison Ballroom, showcased the best of Broadway and unveiled a new award to honor a beloved advocate and friend to the Pulmonary Fibrosis Foundation.

Julie Halston, event hostess and co-creator, introduced the Ralph Howard Legacy Award in memory of her husband, Ralph Howard, who passed away in August 2018 due to complications from the disease. The

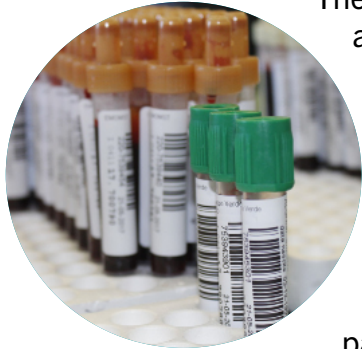


inaugural award was presented to Doug and Gay Lane for their generosity and unwavering support to the pulmonary fibrosis community, and to countless other causes.



The Foundation extends its deepest gratitude to the performers of this year's event. *Broadway Belts for PFF!* is the PFF's largest fundraiser. In addition to raising crucial funds for research and patient programs, the event raises awareness of the debilitating disease.

PFF PATIENT REGISTRY



The PFF reached its initial enrollment goal of 2,000 patients on July 31, 2018, allowing the PFF to open Registry data to researchers. Thus far, 31 research projects, including four biomarker studies, have received approval from a PFF research review panel to use data generated by the Registry.

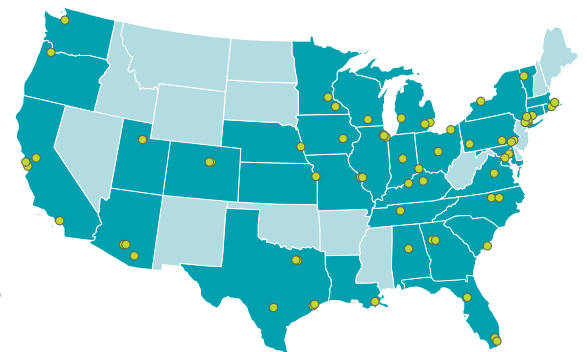
The Registry is an invaluable source of data, which the Foundation share at no cost. Without Registry data, it's estimated that recreating these 31 studies would cost tens of millions of dollars. The Foundation is currently seeking additional funding to expand patient participation and follow already enrolled patients for longer periods of time—developments that are key to meeting the needs of more researchers and additional studies.

CARE CENTER NETWORK

On July 23, 2019, the PFF welcomed eight new sites to the PFF Care Center Network (CCN), bringing its new total to 68 centers nationwide. Indiana, Nebraska, Oregon, and Vermont are among the new states that now include a site.

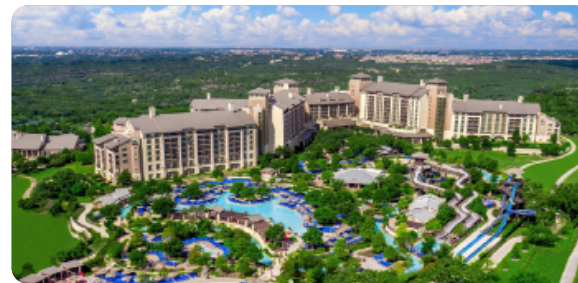
The latest medical centers to receive the Care Center Network designation are:

- Creighton University, Omaha, Neb.
- Emory University Hospital, Atlanta, Ga.
- Indiana University Health, Indianapolis, Ind.
- New York University School of Medicine, New York, N.Y.
- The Oregon Clinic, Portland, Oreg.
- The University of Vermont Medical Center, Burlington, Vt.
- Thomas Jefferson University Hospital, Philadelphia, Pa.
- University of Kentucky Research Foundation, Lexington, Ky.



PFF SUMMIT

The PFF is planning a dynamic program for the PFF Summit in San Antonio, Texas, from November 7-9, 2019. The meeting will take place at the JW Marriott San Antonio Hill Country Resort, surrounded by rolling, oak-covered hills and stunning views.



PFF Summit is the largest international conference on pulmonary fibrosis designed to bring the entire PF community together. The Summit will feature an innovative continuing medical education (CME) program for health care professionals and a continuing education (CE) program for nurses, respiratory therapists, and pharmacists. People living with pulmonary fibrosis, caregivers, transplant recipients, and those who have lost a loved one are encouraged to attend the Summit. Sessions are tailored for everyone in the PF community.

You can view more than 70 full-length Summit sessions on the PFF's YouTube channel. Visit youtube.com/c/pulmonaryfibrosisfoundation to watch today. Don't forget to subscribe so that you can be the first to know when new videos are available.

Our Summit website is bigger and better than ever before. Check out the brand new look at pffsummit.org to learn about the Summit, view the full 2017 program, watch archived videos, and read testimonials.

AWARENESS & MARKETING



Last October, the PFF partnered with Chicago-based L.C. Williams & Associates (LCWA) to launch a new campaign, "Not Everyone Breathes Easy," aimed at increasing awareness about pulmonary fibrosis and the PFF's expertise and resources. The campaign is targeted to individuals who may be at risk for the disease or are undiagnosed, and encourages them to speak with a physician about PF.

To kick off the awareness campaign, LCWA and the PFF created a microsite, AboutPF.org, for visitors to learn about specific symptoms and risk factors. The site includes a Pulmonary Fibrosis Risk List worksheet that individuals can download and bring with them to their next doctor's visit, as well as stories of patients living with the disease. The microsite also directs individuals to pulmonaryfibrosis.org for resources to help them with next steps. Visit the campaign microsite at AboutPF.org and join the conversation on social media with the hashtag, [#NotEveryoneBreathesEasy](https://twitter.com/NotEveryoneBreathesEasy).

PAVING THE WAY

The PFF Medical Advisory Board issued an updated statement on the use of stem cell/cell-based therapies. The statement, first published in 2015, strongly cautions patients with pulmonary fibrosis against using stem cell treatments outside of an approved clinical trial. The statement urges patients to learn about relevant and feasible clinical trials that may be available to them on the PFF website, pulmonaryfibrosis.org. Specific clinical trials evaluating innovative therapies can be located using the online PFF Clinical Trial Finder.



The Foundation reached new heights during September’s Pulmonary Fibrosis Awareness Month (PFAM). Thanks to the dedication of the PF community to raise awareness of this disease, the Foundation made more than 1.2 million impressions on Facebook, Twitter, and Instagram—a groundbreaking new record. Stories from the community, 30 facts in 30 days, and photos of buildings and people nationwide “going blue” took over social media with unprecedented levels of engagement from the community.

RESEARCH AWARDS

A key part of the PFF’s mission is to fund research that will enhance PF patient care and identify potential treatments for the disease. The Research Fund to Cure Pulmonary Fibrosis was created to fund innovative grants for projects that may widen the base of knowledge about PF. The PFF is pleased to announce recipients of two PFF Research Awards: the Albert Rose Established Investigator Award and the I.M. Rosenzweig Junior Investigator Award.

The Foundation is pleased to announce that the next grant cycle in 2020 will launch the PFF Scholars program. The PFF Scholars program will engage emerging researchers in the field of pulmonary fibrosis. With the goal of advancing research that could translate into successful therapies for PF, the PFF Scholars program is designed to support and enable promising researchers to obtain independent funding and continue their cutting- edge research. Scholars will receive up to \$50,000 each over a two-year period.

ALBERT ROSE ESTABLISHED INVESTIGATOR AWARD



Nabeel Hamzeh, MD

University of Iowa

CD4 T-cell Immunophenotype in Hypersensitivity Pneumonitis

Hypersensitivity pneumonitis (HP) is a form of PF caused by inhalation of organic materials, such as mold spores and other particles. Depending on the type of exposure, HP can go by other names including farmer’s lung, pigeon breeder’s lung, and hot tub lung.

HP causes inflammation and scarring (PF) that leads to breathlessness and low oxygen levels. In some cases, HP can be as severe as idiopathic pulmonary fibrosis (IPF). Current therapies for HP are based on clinical experience, not on rigorous clinical trials. “Not fully understanding the type of inflammation seen in HP and the cells involved in this inflammatory response limits our ability to choose drugs to study in HP that can stop the inflammation and limit scar formation,” Hamzeh says.

“By better understanding the type of cells involved in the inflammatory response and what drives them, we can begin to study drugs that can limit the inflammation and subsequent scarring,” he says. In this preliminary study, Hamzeh’s team will recruit patients with HP and, with their consent, perform a scope of the lungs (bronchoscopy) with lung washing to remove inflamed cells from the lungs and further study them in the lab.



I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARDEES



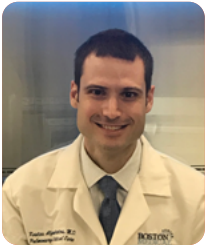
Ayodeji Adegunsoye, MD

University of Chicago

Impact of Race on Genetic Predisposition to Radiologic Honeycombing in Pulmonary Fibrosis

While the cause of PF is frequently unknown, recent studies conducted in non-African-Americans suggest one's genetics contribute to the risk of developing PF. "African-Americans, the largest U.S. minority race with more than 40 million people, have worse survival rates in numerous lung diseases," Adegunsoye says.

"However, the role of genetic markers and their associations with PF in African-Americans is unknown." Adegunsoye's study will use clinical and genetic data collected across diverse races to identify genetic markers associated with the most severe form of PF in African-American and non-African American patients. "By applying this approach to precision medicine, we expect to identify new genes and gene pathways that may one day serve as targets for the treatment of PF across African American and non-African American populations," Adegunsoye says.

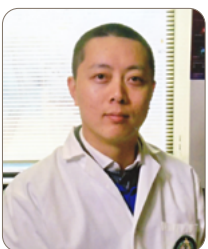


Konstantinos-Dionysios Alysandratos, MD, PhD

Trustees of Boston University, Boston University Medical Campus

Utilizing a Pluripotent Stem Cell Model System to Unravel the Pathogenesis of Pulmonary Fibrosis

The cells that line the inside of the air sacs (called type 2 alveolar epithelial cells) help keep the lung healthy. Changes in the function of these cells are a possible cause of PF. Genes that increase the risk of PF seem to be activated in type 2 alveolar epithelial cells. Capturing these cells for research has been difficult. "We sought to engineer a disease model using induced pluripotent stem cells (iPSCs) from patients with PF," says Alysandratos. iPSCs are made by "reprogramming" blood or skin cells so they can become any cell type in the body – including type 2 alveolar epithelial cells. Alysandratos's team generated iPSCs from patients with PF who carried an abnormal PF gene. By comparing cells with and without the abnormal gene, Alysandratos hopes to learn how this gene leads to PF.



Linlin Gu, PhD

University of Alabama at Birmingham

Metabolic Reprogramming and Mitochondrial Biogenesis Are Regulated by Macrophage MCU in Pulmonary Fibrosis

The lungs contain cells called "macrophages" that are an important part of the body's immune system. Abnormalities in these macrophages, including difficulty making new mitochondria (the "powerhouses" of the cell), may lead to PF. "In this proposal, our team will use innovative strategies to determine if abnormalities in macrophages and mitochondria in the lung might lead to PF," Gu says. "The results may support the notion that metabolism and mitochondria in macrophages are potential therapeutic targets for PF."



**STATEMENT OF FINANCIAL POSITION
AS OF JUNE 30, 2019**

Audited Numbers

Total Assets	\$	10,914,467
Total Liabilities		2,850,718
Total Net Assets	\$	8,063,749

**STATEMENT OF ACTIVITIES
YEAR ENDED JUNE 30, 2019**

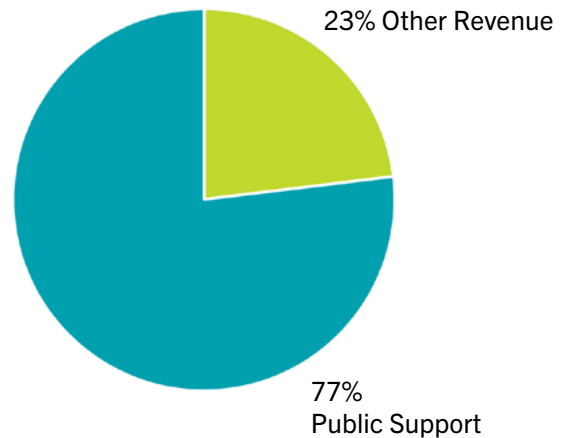
Audited Numbers

Total Revenue		
Without Donor Restrictions	\$	9,588,398
With Donor Restrictions		1,373,779
		10,962,177
Total Expenses		9,005,068
Change in Net Assets	\$	1,957,109

SOURCES OF REVENUE

Public Support	\$	8,494,281	77%
Other Revenue		2,467,896	23%
Total Revenue	\$	10,962,177	100%

SOURCES OF REVENUE

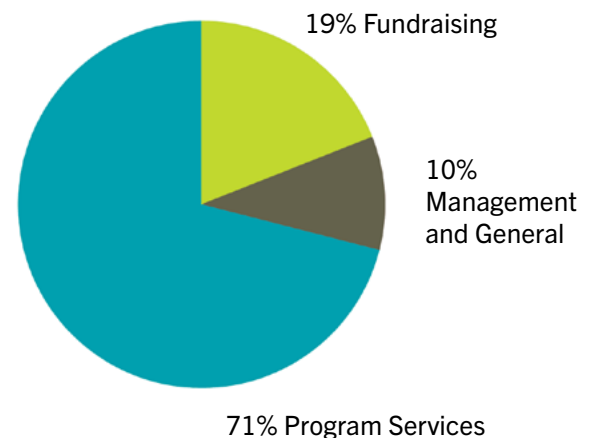


ALLOCATION OF EXPENSES

Audited Numbers

Program Services by Category			
Education	\$	612,475	
Legislative Advocacy		267,031	
Outreach and Awareness		828,930	
Patient Communication Center		91,960	
PFF Care Center Network		770,053	
PFF Patient Registry		2,394,724	
PFF Summit		170,952	
Program Support		543,141	
Research Grants		356,119	
Support Groups		352,817	
Program Services Total		6,388,202	71%
Management and General		907,272	10%
Fundraising		1,709,594	19%
Total Expenses	\$	9,005,068	100%

ALLOCATION OF EXPENSES



The full audited financial statements are available online at pulmonaryfibrosis.org or can be requested by calling 888.733.6741.

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