

2018 ANNUAL REPORT

Pulmonary Fibrosis Foundation
Year Ended: June 30, 2018

Pulmonary Fibrosis FOUNDATION

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.



pulmonaryfibrosis.org | 844.TalkPFF | @pfforg

2018

From the President and CEO, and Board of Directors Chair

Dear Friends,

As we both assumed new leadership roles with the Pulmonary Fibrosis Foundation in 2018, we greatly appreciate your support of the organization and our efforts throughout the year. With your help, we successfully expanded the reach and impact of the PFF while facilitating improved care for patients.

A tremendous achievement for the PF community was reached with the enrollment of the 2,000th patient in the PFF Patient Registry. Now that the initial enrollment goal has been met, researchers can leverage data from the Registry to study the causes of PF and answer key questions about the disease. Our goal to facilitate better care for patients will be realized sooner because of the Registry's ability to help us forward understanding of the disease.

Also, the Registry may speed the path to completion of clinical trials by creating a pool of patients who are interested in participating. Over time and with additional funding, we plan to enroll additional patients and expand the sources of data gathered for the Registry.

In an effort to further stimulate research in the field, we launched a new mentoring program to provide funding to early stage investigators. PFF Scholars will enable promising researchers to obtain independent funding for their cutting-edge research by providing a \$50,000 grant over a two-year period. Scholars engage with the community by attending the PFF Summit and Volunteer Meeting. They receive mentorship by PFF Scholar Advisors who assist with career development opportunities.


This report also highlights the inaugural PFF Walk, record attendance at the PFF Summit 2017 (page 3), the launch of the PFF Clinical Trial Finder (page 4), and the expansion of the PFF Care Center Network to 60 sites (page 5). Our new video series, Life With PF, featuring a collection of 12 patient documentaries and disease education videos, is profiled on page 5.

Thank you again for your continued partnership with the PFF as we lead the way to a world without pulmonary fibrosis.

Sincerely,



William T. Schmidt
PFF President and CEO



George Eliades
Chair, Board of Directors



2018

Highlights from the PFF



INAUGURAL PFF WALK

On September 9, 2017 during Pulmonary Fibrosis Awareness Month, the pulmonary fibrosis community united to lead the way toward a world without PF at the inaugural PFF Walk. This milestone event was held in Chicago's beautiful Lincoln Park on a sunny and breezy morning. More than 850 patients, caregivers, healthcare providers, and friends of the PF community came together to unite in the fight against PF, and collectively raised an astounding \$234,000.

At the PFF Walk, members of the PF community had the opportunity to share their stories and build connections with other individuals and families. The event welcomed special guests Mary Ann Ahern (NBC 5 Chicago), Tom Johnson (Director of Public and Board Relations, Better Business Bureau of Chicago and Northern Illinois), Dr. Sangeeta Borhade (pulmonologist, Northwestern Memorial Hospital), and Heather Kagel (PFF Ambassador, patient) as speakers in the opening ceremony.

The Foundation encouraged those who could not be present in Chicago to register as virtual walkers and to participate by raising funds, building a team, and walking in their own community on September 9, or on a day that worked best for them. More than 200 additional walkers participated in the walk virtually, representing 40 states and four countries, including Belgium, France, Ireland, and Australia.

PFF SUMMIT 2017

This year's PFF Summit 2017, held November 9-11 in Nashville, Tennessee, opened its doors to more than 800 attendees from throughout the United States and internationally—our largest Summit attendance to date!

Beginning in 2011 and held biennially, the PFF Summit welcomes anyone who has been affected by pulmonary fibrosis. At the Summit, patients, caregivers, transplant recipients, and those who lost a loved one are joined with physicians, researchers, allied health professionals, and industry representatives to collaborate, learn, and drive the need to find a cure for PF.

New at PFF Summit 2017, non-industry attendees were categorized into three groups based on their experiences: recently diagnosed patients and their caregivers, those who have been living with PF, and those who are currently transplant recipients or have lost a loved one. Attendees were encouraged to participate in sessions that were tailored to their experiences and interests.

The Summit held a scientific poster presentation, providing a snapshot of 78 current research projects. Academic posters were evaluated by the Foundation's Scientific Advisory Committee selection panel and the top six poster presenters were recognized at the Networking Dinner.

Each year, the Summit provides continuing medical education (CME/CE) for healthcare professionals in accordance with the Essential Areas and policies of the Accreditation Council for Continuing Medical Education (ACCME).





PFF CLINICAL TRIAL FINDER

The PFF Clinical Trial Finder debuted in February and is intended to help raise awareness of and increase participation in clinical trials. This will help accelerate the development of new treatment options for patients with pulmonary fibrosis.

Until now, finding an appropriate PF clinical trial has been daunting for patients. Information on every current and upcoming U.S. trial is listed on the government website ClinicalTrials.gov, but the site offers little ability to tailor a search. The PFF Clinical Trial Finder allows searchers to filter information from ClinicalTrials.gov by zip code, how far they're willing to travel, age, gender, disease status, and type of trial.

"Clinical trial awareness and participation are a great way for individuals to get involved in research to speed the development of new therapies," says Mike Wenger of Clinical Trial Connect, the company that created the PFF Clinical Trial Finder. "The PFF Clinical Trial Finder makes that process easy."

RARE DISEASE DAY

One in 10 people will live with a rare disease at some point—but no cure is available for the majority of rare diseases, and many go undiagnosed. To raise awareness among the public and key decision-makers about the impact of rare diseases on patients' lives, the Pulmonary Fibrosis Foundation once again participated in Rare Disease Day, held annually on the last day of February, and Rare Disease Week, observed the last week in February.

PFF's Rare Disease Day efforts included a pulmonary fibrosis awareness campaign centered on social media. "We recapped what we've accomplished in our PFF programs over the past few years, encouraging patients, caregivers, and others in the PF community to get involved in the Foundation's initiatives," says Kate Gates, PFF Director of Programs.

PFF representatives traveled to Washington, D.C., during Rare Disease Week for a three-day program of advocacy for expanded research. After a day of training hosted by the Rare Disease Legislative Advocates and attended by representatives of many patient advocacy organizations, participants spent a lobby day on Capitol Hill meeting individually or in small groups with members of Congress or their aides. On the final day, Brian Baird, a former U.S. representative and pulmonary fibrosis advocate, moderated a briefing for the Rare Disease Congressional Caucus, hosted by Caucus Co-chair Leonard Lance (R-NJ).



BROADWAY BELTS FOR PFF!

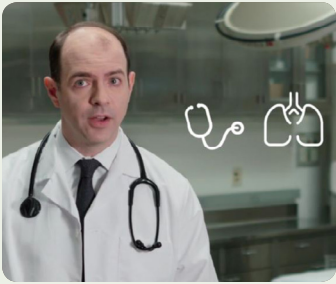
The PFF's annual *Broadway Belts for PFF!* raised a record-breaking \$370,000, bringing its eight-year fundraising total to nearly \$1.2 million. The sold-out event on March 12, 2018 featured a star-studded "Sweet 16" revival of the Tony Award-winning musical *Hairspray*. Original cast members came together to honor Margo Lion, a producer and a longtime supporter of *Broadway Belts for PFF!*

The reunion, helmed by its Tony Award-winning composers Marc Shaiman and Scott Wittman, and featuring stunning performances by Andrew Rannells, Harvey Fierstein, Jackie Hoffman, Chester Gregory, Marissa Jaret Winokur and many original *Hairspray* cast members, drew standing ovations from the crowd.

An annual sold-out event that is an exclusive New York musical theater experience, *Broadway Belts for PFF!* features Broadway stars performing some of their favorite songs and original pieces. The benefit began as a tribute to Michael Kuchwara, Associated Press theater critic, who died suddenly of pulmonary fibrosis in 2010. Julie Halston, a founding partner of the event, is one of PFF's leading advocates nationwide and shines as the evening's witty and dynamic host.

"*Broadway Belts for PFF!* has been a labor of love from the start," said Julie Halston. "And through the enormous generosity of the Broadway community, we have grown bigger every year to provide resources for pulmonary fibrosis patients and their families."





LIFE WITH PULMONARY FIBROSIS VIDEO SERIES

The Foundation's video series, Life With Pulmonary Fibrosis, introduced a wide variety of topics to the PF community in early May. For 12 weeks, a new video was released each week. The videos include individual patient profiles (Portraits of PF), explanations of pulmonary rehab and PF disease progression, a description of palliative care, and much more.

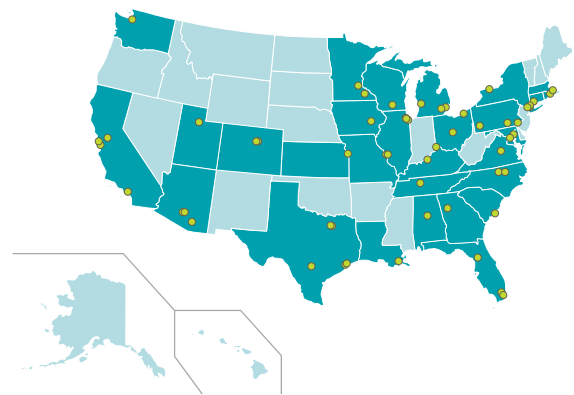
"Our intent with this video series is to offer patients, their caregivers, and loved ones an easy resource to provide a deeper understanding of living with pulmonary fibrosis," said Kate Gates, Director of Programs. "The videos are a tool for patients to learn and share important information and personal stories connected to the disease."

The documentary-style patient profiles feature people living with PF helping others as they continue with their own journeys. In the PF education videos, Dr. David Lederer, the PFF's Senior Medical Advisor for Education and Awareness, describes PF, the progression of the disease, and explains that each person's experience is unique.

PFF CARE CENTER NETWORK

In its first several years, the PFF Care Center Network (CCN) has established a solid framework across the country. Our goal at the Foundation is to have a Care Center located within a two-hour drive for 90 percent of the U.S. population. In June, the PFF reviewed nearly 30 applications from medical centers seeking to become sites in the network, and selected 15 new sites to join the CCN, including:

- Banner University Medical Center (Phoenix, Arizona)
- UC Davis Interstitial Lung Disease Program (Sacramento, California)
- University of Colorado Anschutz Medical Campus (Aurora, Colorado)
- Cleveland Clinic Florida (Weston, Florida)
- University of Florida (Gainesville, Florida)
- Loyola University Medical Center (Maywood, Illinois)
- University of Iowa (Iowa City, Iowa)
- Henry Ford Health System (Detroit, Michigan)
- Spectrum Health System (Grand Rapids, Michigan)
- St. Luke's Hospital (Chesterfield, Missouri)
- LeBauer Health Care at Cone Health (Greensboro, North Carolina)
- Cleveland Clinic (Cleveland, Ohio)
- Baylor University Medical Center (Dallas, Texas)
- Houston Methodist Hospital (Houston, Texas)
- University of Wisconsin (Madison, Wisconsin)



PFF PATIENT REGISTRY

On July 31, 2018, the Pulmonary Fibrosis Foundation announced that it achieved its enrollment goal for the initial phase of the PFF Patient Registry with participation of 2,002 patients. The Registry, launched in 2016, is a collection of comprehensive anonymized data from patients living with pulmonary fibrosis.

"The PFF Patient Registry is a major resource designed to accelerate progress in pulmonary fibrosis research and in understanding the causes of PF," said Dr. Kevin R. Flaherty, Steering Committee Chair of the PFF Patient Registry and PFF Care Center Network. "Since the Registry launched, we've seen a tremendous response from the research community and are eager to assist them in answering key questions about this disease."

The Registry may also speed the path to completion of clinical trials by creating a pool of patients who are interested in participating. Over time and with additional funding, the PFF aims to enroll additional patients and expand the sources of data gathered for the Registry.

In addition to Genentech, a Member of the Roche Group, the first phase of the PFF Patient Registry was funded through the support of corporations, foundations, and individuals who have been impacted by PF.

GRANT RECIPIENTS

The Albert Rose Established Investigator Awards and the I.M. Rosenzweig Junior Investigator Awards support projects that offer a high likelihood of improving the understanding of pulmonary fibrosis in the following areas: basic science, translational research, clinical medicine/research, and social science/quality of life.

THE ALBERT ROSE ESTABLISHED INVESTIGATOR AWARD



Steve M. Albelda, MD / The Trustees of the University of Pennsylvania
Use of T cells Directed to Fibroblast Activation Protein to Treat Pulmonary Fibrosis

Dr. Albelda is the William Maul Measey Professor of Medicine, Associate Director of the Pulmonary Division, Director of the Thoracic Oncology Research Laboratory, and co-director of the Translational Center of Excellence for Lung Cancer at Penn.

Despite the recent approval of perfenidone and nintedanib to slow the progression of idiopathic pulmonary fibrosis (IPF), there is no way to reverse the established scarring (fibrosis). A key factor in IPF is production of excess scar tissue by a cell type known as fibroblasts, which normally function in wound healing. Dr. Albelda's team proposes to use a new technology that they developed for the treatment of cancer that can genetically redirect blood cells (lymphocytes) to attack "scar-producing" activated fibroblasts in the fibrotic lung. The research team will test this approach in three mouse models of lung fibrosis. If successful and safe, this study will pave the way toward clinical trials that could change the treatment paradigm for IPF and potentially reverse lung scarring and improve lung function.

THE I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARD



Samuel Yoffe Ash, MD / Brigham and Women's Hospital
Quantitative Imaging Biomarkers in Early Interstitial Lung Disease: Progression and Susceptibility

Dr. Ash is a clinical/research fellow in Harvard-Brigham and Women's Pulmonary and Critical Care Fellowship Program. His research centers on quantitative analysis of CT imaging in acute lung injury as well as ongoing longitudinal analysis of CT imaging in lung transplant.

Quantitative imaging biomarkers are objective characteristics found in imaging that may indicate whether biologic processes are normal, pathogenic, or responsive to treatment — for instance, a change in tumor size for a patient with cancer or an assessment of brain atrophy for patients with multiple sclerosis. In this project, Dr. Ash will investigate whether the progression of interstitial radiographic features detected using quantitative imaging biomarkers is associated with decline in lung function, and whether those individuals who have both interstitial disease and emphysema are at increased risk of respiratory exacerbation and mortality.

GRANT RECIPIENTS

The Albert Rose Established Investigator Awards and the I.M. Rosenzweig Junior Investigator Awards support projects that offer a high likelihood of improving the understanding of pulmonary fibrosis in the following areas: basic science, translational research, clinical medicine/research, and social science/quality of life.



Robert Guzy, MD, PhD / The University of Chicago

Mechanism of Gremlin-1 in Pulmonary Fibrosis

Dr. Guzy is an assistant professor in the University of Chicago Department of Medicine, Division of Pulmonary/Critical Care. His research focuses on the mechanisms involved in recovery from lung injury, and how aberrant recovery from injury leads to fibroblast (connective cell tissue that plays a critical role in wound healing) activation and the development of pulmonary fibrosis.

“The goal of my research is to understand the mechanisms regulating how lung epithelium, endothelium, and fibroblasts interact following injury to promote repair following lung injury and Acute Respiratory Distress Syndrome (ARDS), as well as pathological fibroblast proliferation resulting in a variety of lung diseases, including PF,” Dr. Guzy explains.

Results from his experiments in this project will be instrumental in establishing the requirement for Gremlin-1 — a protein-coding gene — in the pathogenesis of pulmonary fibrosis. These studies also will establish the role of fibroblast-derived Gremlin-1 in fibrogenesis. This award is funding models, reagents, and preliminary data needed to pursue future independent studies on the mechanisms of Gremlin-1 signaling in PF, and will provide novel mechanistic insights and the potential to develop cell-specific therapeutics, Dr. Guzy says.

COMING SOON: PFF SCHOLARS

This fall, the Pulmonary Fibrosis Foundation will launch a new program, PFF Scholars, to 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 over a two-year period. More announcements on this program will be published on the PFF website, the email newsletter, and social media outlets.

Financial Summary

STATEMENT OF FINANCIAL POSITION AS OF JUNE 30, 2018

Audited Numbers

| | | |
|-------------------------|-----------|------------------|
| Total Assets | \$ | 8,884,514 |
| Total Liabilities | | 2,777,874 |
| Total Net Assets | \$ | 6,106,640 |

STATEMENT OF ACTIVITIES YEAR ENDED JUNE 30, 2018

Audited Numbers

| | | |
|-----------------------------|-----------|------------------|
| Total Revenue | | |
| Unrestricted | \$ | 9,449,726 |
| Temporarily Restricted | | (320,867) |
| Total Expenses | | 8,736,784 |
| Change in Net Assets | \$ | 392,075 |

SOURCES OF REVENUE

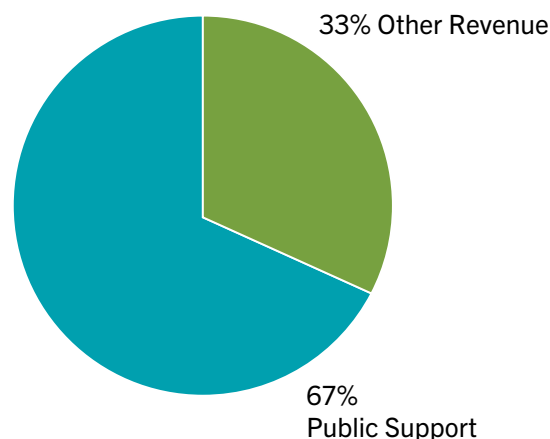
| | | | |
|----------------------|-----------|------------------|-------------|
| Public Support | \$ | 6,045,366 | 67% |
| Other Revenue | | 3,083,493 | 33% |
| Total Revenue | \$ | 9,128,859 | 100% |

ALLOCATION OF EXPENSES

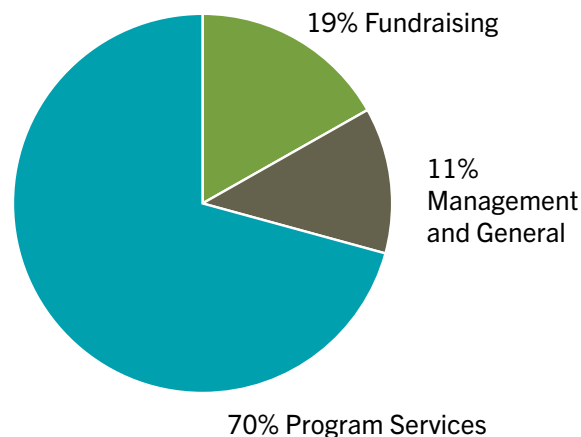
Audited Numbers

| | | | |
|-------------------------------|-----------|------------------|-------------|
| Program Services by Category | | | |
| Education | \$ | 629,722 | |
| Legislative Advocacy | | 200,672 | |
| Outreach and Awareness | | 716,751 | |
| Patient Communication Center | | 83,951 | |
| PFF Care Center Network | | 446,684 | |
| PFF Patient Registry | | 2,313,960 | |
| PFF Summit | | 752,955 | |
| Program Support | | 479,715 | |
| Research Grants | | 238,365 | |
| Support Groups | | 302,200 | |
| Program Services Total | | 6,164,975 | 70% |
| Management and General | | 943,138 | 11% |
| Fundraising | | 1,628,671 | 19% |
| Total Expenses | \$ | 8,736,784 | 100% |

SOURCES OF REVENUE



ALLOCATION OF EXPENSES



2018

Thank you to our donors

With the dedicated support of individuals like you, the Pulmonary Fibrosis Foundation is launching some of our largest and most extensive programs yet to make a difference in the lives of those affected by pulmonary fibrosis.

\$500,000 AND GREATER

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Genentech

\$100,000–\$499,999

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