

Pulmonary Fibrosis
FOUNDATION

2015

ANNUAL REPORT

SHORT FISCAL PERIOD ENDING
JUNE 30, 2015

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.

DEAR FRIENDS



We're making a change at the Pulmonary Fibrosis Foundation (PFF) — one that builds on our successes and expands our ability to deliver quality programs and services.

In these pages, you'll read about the notable strides we made in our programs and services during the first half of 2015. From new educational offerings and greater support options to new volunteer opportunities and a larger social media presence, the Foundation keeps expanding outreach, awareness, and involvement. Our ongoing commitment to fund and support groundbreaking pulmonary fibrosis (PF) research is further strengthened through the PFF Care Center Network and the PFF Patient Registry. Once fully operational, these initiatives will work in tandem to facilitate patient and clinician engagement in future clinical research — and ultimately transform the experiences of those living with PF.

Read more starting on page 6 — and we invite you to look for ways to become even more engaged. Contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or pcc@pulmonaryfibrosis.org to get involved.

Since the PFF's inception, our fiscal year has operated on a calendar year. As the Foundation evolves, so does our budget planning process, which last year included consideration of changing the fiscal year. To aid planning and more closely align revenues with expenses going forward, the PFF Board of Directors voted to change the Foundation's fiscal year to take place July 1–June 30, effective this year. This adjustment means our first new fiscal year is a short one and does not include the traditionally significant nonprofit year-end giving season from October to December. This report provides both a financial and programmatic overview of our busy and successful first six months of 2015. Next year, the Foundation's annual report will cover a full fiscal year, from July 1, 2015 through June 30, 2016.

Thank you again for your continued support of the Pulmonary Fibrosis Foundation. Your generous involvement helps lead us toward a world without pulmonary fibrosis.

A handwritten signature in black ink, appearing to read 'Scott Staszak', written in a cursive style.

SCOTT STASZAK
CHIEF OPERATING OFFICER

ABOUT PULMONARY FIBROSIS

WHAT IS PULMONARY FIBROSIS AND WHAT ARE THE CAUSES?

Pulmonary fibrosis (PF) is a condition in which the walls of the air sacs of the lungs become thickened and stiff due to a build up of scar tissue. This scar tissue makes it more difficult for the lungs to transfer oxygen into the bloodstream.

Pulmonary fibrosis can result from a number of causes: certain environmental agents (molds, birds, fibers, dusts), medications (antibiotics, chemotherapy), radiation therapy, autoimmune diseases (scleroderma, rheumatoid arthritis), or a genetic predisposition.

However, in most situations the cause is unknown. There are many types of PF for which we don't know the cause. One specific type of PF of unknown cause is called "idiopathic pulmonary fibrosis" or IPF. IPF is diagnosed when either a CAT scan or a lung biopsy show certain findings in the absence of an identifiable cause. IPF is a progressive, fatal lung disease, for which there is no known cure.

WHAT DOES THE DISEASE LOOK LIKE?

There are no reliable data to determine how many people are affected by PF, possibly due to the large number of conditions under which it can arise. However, one recent study estimates IPF affects 1 out of 200 adults over the age of 65 in the United States. Approximately 50,000 new cases are diagnosed each year and as many as 40,000 Americans die from IPF each year. The current estimate of the incidence of IPF in the EU is between 37,000 and 40,000 people. It is anticipated that the number of individuals diagnosed with IPF will continue to increase as a result of people living longer, an improved clinical understanding of IPF, and earlier and more accurate diagnosis.

PF can strike at any age, affects both men and women, and is found among all racial and ethnic groups. IPF is more common among older adults and is rare in adults under the age of 50. About half of people diagnosed with IPF will live longer than three or four years, but the other half will pass away within three or four years.

Symptoms include: breathlessness upon exertion, dry cough, and fatigue.

Treatments include: supplemental oxygen, pulmonary rehabilitation, optimizing weight and exercise, lung transplantation for those who qualify, and medications to manage symptoms. Some patients may benefit from disease-specific therapy for IPF:

NINTEDANIB: Nintedanib is an anti-fibrotic drug that has been approved to treat IPF in the US and the European Union (EU). Nintedanib slows the progression of IPF.

PIRFENIDONE: Pirfenidone is an anti-fibrotic drug approved to treat IPF in the US, EU, Canada, and Asia. Pirfenidone slows the progression of IPF.

PREDNISONONE: Prednisone is an anti-inflammatory therapy that can help some people with inflammation in the lungs.

Pulmonary fibrosis is a devastating disease. It is the Foundation's goal to fund research to help find effective treatments and ultimately a cure. As we strive to accomplish that goal, the Foundation is committed 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.



THE FOUNDATION'S ACCOMPLISHMENTS

PFF CARE CENTER NETWORK

Launched in 2014, the PFF Care Center Network (CCN) connects leading medical centers with specific, multidisciplinary expertise in treating fibrotic lung diseases that are often difficult to diagnose and complicated to manage. Initially comprised of nine sites, the Network today includes 40 medical institutions across the United States. The care team at each CCN site includes representatives of pulmonary medicine, rheumatology, radiology, and pathology, all specializing in interstitial lung disease. Patients benefit from a more accurate diagnosis, recommendations for continuing care, easy access to essential support services, and the opportunity to participate in collaborative research. To find a CCN site, visit pulmonaryfibrosis.org/life-with-pf/find-medical-care.

PFF PATIENT REGISTRY

The PFF Patient Registry, which is strategically linked to the PFF Care Center Network, collects patient medical data to facilitate biomedical research and clinical trials. Throughout 2015, planning continued for the Registry, which, when fully realized, will be an electronic database of de-identified patient medical information collected during routine clinical visits. Together, the CCN and Registry are expected to facilitate future clinical research, better document the patient experience, and increase much needed awareness and support for those living with the disease — fulfilling vital needs within the pulmonary fibrosis community.

PFF PATIENT COMMUNICATION CENTER

The PFF Patient Communication Center (PCC), an information hub about pulmonary fibrosis, received nearly 3,000 phone calls and emails in 2015. Top requests were for general disease information and treatment options. Questions came from 48 states; the top five were Texas, California, New York, Illinois, and Florida. The UK, India, Canada, Pakistan, Mexico, and Australia were among 45 different countries represented. Contact the PCC at **844.TalkPFF (844.825.5733)** or pcc@pulmonaryfibrosis.org.



PFF SUMMIT 2015

During the first half of 2015, PFF staff and volunteers worked hard to plan the *PFF Summit 2015: From Bench to Bedside* conference, held November 12–14 in Washington, DC. To maximize attendee interaction and ensure the *Summit* provided useful information to all members of the pulmonary fibrosis community, offerings included plenary sessions on the future of PF drug development and collaborative networks as tools for improving clinical care, as well as a variety of breakout sessions targeted to health care professionals, patients, and caregivers. A record number of over 700 people from 18 countries attended.

SUPPORT GROUP LEADER NETWORK

The PFF significantly expanded the Support Group Leader Network (SGLN) in 2015. The SGLN today serves 88 support groups in 32 states and has three committees headed by longtime SGLN participants. In the first half of 2015, committee work was focused on initial development of the following projects: expanding and standardizing the grant process for the Leanne Storch Support Group Fund, creating webinars to train new and continuing support group leaders, and revising the existing guide for support group leaders to include expanded information and resources.

PFF AMBASSADOR PROGRAM

PFF Ambassadors offer hope and inspiration to those affected by the disease. Ambassadors are patients, caregivers, and health care professionals who share their stories, disseminate reliable disease information, and provide guidance to PFF support resources. Last year, members of the PFF Ambassador group were active at a variety of events, including a Rare Disease Day Congressional Briefing in Washington, DC; a Rare Disease Day event in Hartford, Connecticut; the 8th Annual Greg Chandler & Guy F. Solimano Memorial Golf Tournament in Webster, New York; a Sterling Heights, Michigan Support Group Meeting; a South Miami, Florida Hospital Support Group Meeting; and Bristol Myers Squibb's "Voice of the Patient" meeting in New Jersey.



VOLUNTEER MEETING

June 2015 marked the first time a full-scale volunteer meeting was held to bring together Support Group Leader Network steering committee members, PFF Ambassadors, PFF Care Center Network representatives from 21 sites, PFF board members, and other volunteers to make connections, learn about each other's work, and make a deeper investment in their own involvement. The group broke into separate meetings and training sessions depending on their roles, and gathered for an all-volunteer networking reception.

PFF DISEASE EDUCATION WEBINAR SERIES

The popular PFF Disease Education Webinar Series—a boon to patients and caregivers and a regular feature at support group meetings—began offering topics based on viewer surveys in 2015. Also in response to viewer requests, the series added a quarterly “Ask a Doc” webinar in which members of the PFF Medical Team answer questions previously submitted by participants. Since May 2014, webinars in the PFF Disease Education Webinar Series Archive were viewed over 1,500 times. Archived webinars are available for viewing 24/7 at pulmonaryfibrosis.org/webinars.

GLOBAL PULMONARY FIBROSIS AWARENESS MONTH

A new toolbox created in early 2015 included a variety of useful materials for pulmonary fibrosis (PF) community members planning Global Pulmonary Fibrosis Awareness Month events. Visitors to globalPFawareness.org found links to information about physician and patient educational events, tools for PF community members to create their own grassroots awareness campaigns and fundraising events, downloadable educational materials, and PF community members' stories and photos. Participants went on to golf, run, bowl, dine, paint and much more to raise funds during the September observance of Global Pulmonary Fibrosis Awareness Month.



BROADWAY BELTS FOR PFF!

Celebrating its fifth anniversary in February 2015, *Broadway Belts for PFF!* raised more than \$150,000 for the Pulmonary Fibrosis Foundation. Hosted each year by award-winning actor and dedicated PFF advocate Julie Halston, the event brings together some of Broadway's best vocal talent. The show's stars presented an intimate evening of melody under the musical direction of Christopher McGovern and returning director Carl Address. In total, the annual celebration has raised almost \$700,000.

TEAM PFF

Members of *Team PFF*—volunteers who host fundraising events that benefit the Pulmonary Fibrosis Foundation—continue to provide meaningful support to pulmonary fibrosis education, awareness, and research. Some supporters are able to put together larger events, but even smaller gatherings make a big difference in spreading the word and raising funds. In the first half of 2015, nearly 50 *Team PFF* events were held including “Comedy for a Cause,” organized by Karen Westphal; Julia Lager-Mesulam’s participation in the Eugene, Oregon, Marathon; and the 8th Annual Alamance Force Volleyball Camp in Burlington, North Carolina, led by Linda Osterman.

SOCIAL MEDIA

Patients and caregivers often can't travel to events, so the PFF focuses on inclusion in its expanding social media presence. The PFF Facebook page reached nearly 25,000 followers by June 2015. In the first half of the year, the Foundation also began using Storify (visit storify.com/PFFORG) to bring together information and photos on PF events ranging from education sessions to fundraisers to the *PFF Summit*. The PFF also started planning early last year to use Periscope (visit periscope.tv/PFFORG), and went on to debut its live streaming feature during the *PFF Summit*.

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TEAM PFF EVENTS

2nd Annual Kickin It Full Throttle For A Cure Classic Car Show Benefiting the PFF
2nd Annual NJ5K for PF James Lynam Memorial 5K Run/Walk
2nd Irv Feldman Texas Hold' Em Tournament & Casino Night
3rd Annual Caroline M. Fell 5K Memorial Walk/Run
3rd Annual Janet Hovey Memorial Fundraiser
5th Annual Comedy for a Cause
5th Annual Pete DeVito Memorial Golf Outing
8th Annual Alamance Force Volleyball Camp
8th Annual Greg Chandler & Guy F. Solimano Memorial Golf Tournament
Beth Shore's Bridal Shower for PFF
Bravelets for PFF
Breathing for Maria Elena Flores
Bridal Tea Honoring Amy Deaton and Stephen Corlew
Bridgnorth Walk in memory of Tony Bean
Broadway Belts for PFF!
Change Makers Coin Jar Game
Chuck Kozora Cycles for Pulmonary Fibrosis
Eugene Marathon in memory of Robert Lager
Every Breath Counts Memorial 5K Walk/Run
Fashion Project
Ferris' 50th Wedding Anniversary
Five Guys Dine In and Donate to the PFF
Flatten Pulmonary Fibrosis! Pancake Breakfast Fundraiser
Inhale to Exhale One Pitch Softball Benefit Tournament for PFF
Irakleia Giannakou's Fundraiser for PFF
Jack Lim's Birthday
Just Breathe: Senior Project
Kimberly Cole's Afghan Fundraiser
Mammoth Lakes Half Marathon in memory of Steven Magnuson
Mowery Clinic Jeans Day
Nat's Lung Transplant Anniversary
Neil and Laura Brogan's Wedding
Pajamas for a Cause
PFF and Mary Kay Cosmetics! hosted by Enzo Pro
Psych out Pulmonary Fibrosis
Quincy Mutual Jeans Day for PFF
Seahawks 12K Run at the Landing in memory of Mike McKeehan
Shamrock Shuffle for Ron Ware
St. Mary School No Uniform Day for PFF
Steve Cochran Memorial Primal Bootcamp
Steven and Jaclyn Carpio's Wedding
Team Joyce Challenge
Todd Tullis' Birthday
Wristbands in honor of John Parrish

FINANCIAL SUMMARY

FOR THE SIX MONTH PERIOD ENDED JUNE 30, 2015

STATEMENT OF FINANCIAL POSITION

AUDITED NUMBERS

	2015
Total Assets	\$4,372,205
Total Liabilities	778,850
<hr/>	
Total Net Assets	\$3,593,355

STATEMENT OF ACTIVITIES

AUDITED NUMBERS

	2015
Total Unrestricted Revenue	\$1,823,440
Total Expenses	2,316,803
<hr/>	
Change in Net Assets – Unrestricted	(493,363)
Net Reduction in Temporarily Restricted Revenue	(511,842)
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Change in Net Assets – Total	(\$1,005,205)

SOURCES OF 2015 REVENUE

Public Support	\$1,290,549	98%
Other Revenues	21,049	2%
<hr/>		
Total 2015 Revenue	\$ 1,311,598	100%

ALLOCATION OF 2015 EXPENSES

AUDITED NUMBERS

Program Services by Category		
PFF Patient Registry	\$ 288,017	
PFF Care Center Network	298,505	
Research	64,263	
Outreach and Awareness	121,482	
Program Support	275,778	
PFF Patient Communication Center	47,044	
Physician and Patient Education	120,477	
PFF Summit	142,560	
Support Groups	139,316	
Advocacy	13,417	
<hr/>		
Program Services Total	\$ 1,510,859	65%
Management and General	334,458	15%
Fundraising	471,486	20%
<hr/>		
Total 2015 Expenses	\$2,316,803	100%

The summary financial information presented here reflects activity for the short fiscal period ended June 30, 2015. The full audited financial statements are available online at pulmonaryfibrosis.org or can be requested by calling 888.733.6741.

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