

Pulmonary Fibrosis

FOUNDATION

2013 ANNUAL REPORT

ADVANCING KNOWLEDGE

CREATING HOPE
FOR TOMORROW.

The mission of the Pulmonary Fibrosis Foundation is to serve as the trusted resource for the pulmonary fibrosis community by raising awareness, providing disease education, and funding research.

MISSION

DEAR FRIENDS,



AS I REFLECT ON THE PAST YEAR, I am somewhat overwhelmed but extremely gratified by all that has transpired and all that has been accomplished. The landscape in pulmonary fibrosis is rapidly changing. As of this writing, there are two new therapies under review by the FDA, which if approved could initiate a whole new era of treatments for patients. Additionally, during the past year the Foundation conducted an extremely successful *PFF Summit*, announced plans to move forward with the PFF Care Center Network (CCN) and the PFF Patient Registry, implemented a number of initiatives to enhance disease awareness, and completed a patient survey to provide important information that will enable us to better respond to the needs of the PF community. I will expand upon some of these endeavors and milestones in the following paragraphs.

The highly praised and successful *PFF Summit 2013: From Bench to Bedside*, was attended by over 500 people from 15 countries.

The conference brought together a spectrum of physicians, researchers, allied health professionals, industry representatives, patients, and caregivers. The *Summit* promoted education and collaboration among the entire PF community. We are extremely grateful to our Everest sponsors, Boehringer Ingelheim and InterMune, Inc. and our Shasta sponsor, Genentech. All their support was instrumental to the success of the meeting.

Online webinars of the *Summit* presentations can be viewed at www.pffsummit.org. Please make plans to attend *PFF Summit 2015*, November 12–14 in Washington, DC. We are certain that it will be a highly informative as well as an inspiring event.

Two of 2013's most important accomplishments, the PFF Care Center Network (CCN) and the PFF Patient Registry, will enable investigators to learn more about PF and will bring us closer to a cure. Also, physicians will be able to standardize care and develop evidence-based, "best practice" protocols. The CCN is composed of medical centers with demonstrated multidisciplinary expertise in fibrotic lung diseases. The Registry, the first national, multi-center database of standardized information about PF patients, will collect data that is essential for clinical research. This network will also allow patients and health care providers to collaborate on a national scale.

As part of Global Pulmonary Fibrosis Awareness Day on September 7, we launched the website www.globalpfawareness.org to help communicate with patients, caregivers, health care professionals, legislators, and the general public. During the month there were a variety of *Team PFF* events ranging from walks and wine tastings to art shows and raffles. All of these events helped to open eyes and create interest on a grassroots level.

I'm proud of all that we attained in 2013.

None of this would have been possible without the combined support of individual contributors, volunteers, foundation grants, and corporate donors. We're extremely grateful for all the dedication you've shown and for your continued commitment, which will help us move forward to eradicate this deadly disease. Once again, thank you for all you do for the PF community.

Sincerely,

A handwritten signature in black ink that reads "Daniel M. Rose". The signature is written in a cursive, flowing style.

DANIEL M. ROSE, MD
CHIEF EXECUTIVE OFFICER

TO OUR COMMUNITY,



EXPANDING AVAILABLE RESOURCES FOR A RARE DISEASE IS A TOUGH JOB—but fortunately, it’s an effort that has a snowball effect. The more people who recognize the importance of supporting pulmonary fibrosis (PF) awareness, education, and research initiatives, the more they in turn influence others and attract new supporters to the cause. Little steps add up to big distances traveled when those numbers keep multiplying.

In the PF community, we’re beginning to see the many payoffs from that snowballing support. Although we’re a young organization, we’ve already established the Pulmonary Fibrosis Foundation (PFF) as the most reliable, accessible point of access for information about this rare disease. Patients and caregivers consider us their trusted source for the latest PF community news, education about PF, and information on finding quality medical care.

The PFF is also the first choice for support services for patients and caregivers. Participating in support groups—connecting with others facing similar experiences and obtaining practical information—can have a positive impact on patients’ health and emotional well-being. Support groups also can be a valuable resource for caregivers, family, and friends. PF support systems have grown significantly to include social media networks, independently run online and in-person support groups, and a PFF-sponsored Support Group Leader Network. Wherever PF patients are in the world, PFF support resources are there for them.

All of these programs are making a tangible difference in PF families’ quality of life. I invite you to join our efforts with a gift that will help sustain our established support initiatives as well as several new programs. We are proud to have received a four-star rating from Charity Navigator and accreditation from the Better Business Bureau and can assure you that your gift will go a long way. The recently launched PFF Patient Communication Center is a central information hub offering patients, health care providers, and the general public the most up-to-date medical information and resources. The PFF Ambassador program empowers patients, their caregivers and health care professionals as spokespersons for the PF community. Through sharing their own experiences with pulmonary fibrosis, these Ambassadors promote awareness, disseminate the latest medical information, and provide hope and inspiration to others touched by PF. The new PFF Disease Education Webinar Series allows the PF community to virtually learn from, connect with, and pose questions to leading pulmonary fibrosis specialists.

We’re deeply grateful to all the PFF sponsors and donors who help keep PF families up to date, connected, and mutually supportive. In 2014 and beyond, join the PFF “snowball” in helping pulmonary fibrosis patients and their caregivers make informed decisions supporting their physical and emotional health.

Sincerely,


PATTI TUOMEY, EdD
PRESIDENT AND CHIEF OPERATING OFFICER

ABOUT

WHAT DOES THE DISEASE LOOK LIKE?

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.

The medical term 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 thickened, 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.

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 radiologic or pathologic criteria are met, the disease is called idiopathic pulmonary fibrosis (IPF).

There are more than 200 related diseases that affect the lungs with inflammation and/or 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 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. IPF appears to affect more men than women and 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 include: shortness of breath (dyspnea), chronic cough, fatigue and weakness, discomfort in the chest, loss of appetite, and weight loss.

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 is currently being reviewed by the US Food and Drug Administration as a possible treatment for IPF. Two large clinical trials showed that nintedanib slowed down the loss of function in IPF.
- **PIRFENIDONE:** Pirfenidone is an anti-fibrotic and anti-inflammatory drug approved to treat IPF in the EU, Canada, and Asia. It is currently being reviewed by the US Food and Drug Administration as a possible treatment for IPF. Pirfenidone has been shown to slow progression of mild-to-moderate IPF.
- **PREDNISONE:** Prednisone is an anti-inflammatory therapy that can help some people with inflammation in the lungs.

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.

ABOUT THE DISEASE

HIGHLIGHTS

7/10–13

Attended the [British Association for Lung Research's \(BALR\)](#) Summer Conference and co-hosted [PF Patient Support Day](#) in conjunction with the meeting

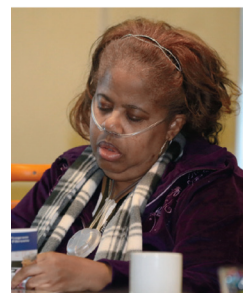


5/15

One-year anniversary of PF community on [InspireSM](#)

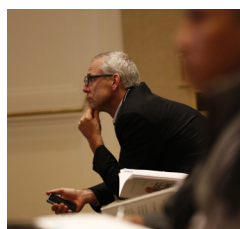
5/17–22

Exhibited at the [American Thoracic Society \(ATS\)](#) International Conference



2/25

[Broadway Belts for PFF!](#)



IN DEDICATION TO ITS MISSION OF SERVING AS THE TRUSTED RESOURCE for the pulmonary fibrosis (PF) community by raising awareness, providing disease education, and funding research, the Pulmonary Fibrosis Foundation (PFF) participated in a variety of events across the country and globe in 2013. From hosting *PFF Summit 2013* to taking part in scholarly conferences to sponsoring fundraising events, the PFF creates opportunities for patients and health care providers to connect and learn more about the disease, family members to honor loved ones, and researchers to make new discoveries that will one day lead to a cure for PF.

10/26

Hosted **Breathe Benefit 2013: Community Inspiring a Cure** and announced the PFF Research Awards and Leanne Storch Awards recipients



10/26–31

Exhibited at the **American College of Chest Physicians (CHEST)** Conference



12/5–7

PFF Summit 2013: From Bench to Bedside and PFF Care Center Network and PFF Patient Registry announcement



9/7–11

Global Pulmonary Fibrosis Awareness Day Debuted new patient education materials in ten languages. Hosted patient education events at PFF Chicago headquarters and in Barcelona in conjunction with the ERS Annual Congress



FOR MORE INFORMATION ABOUT these activities, please visit www.pulmonaryfibrosis.org/2013highlights.

AWARENESS

Raising awareness of a rare disease is challenging. It takes time, perseverance, and community involvement to let the world know about pulmonary fibrosis (PF), but these awareness-building efforts yield significant payoffs. The Pulmonary Fibrosis Foundation (PFF) engages in multipronged efforts to heighten awareness that extends beyond the patient and caregiver community, also reaching health care providers, researchers, legislators, and the public. These initiatives boost research and funding, increase drug development and enrollment in clinical trials, promote faster and more accurate diagnoses, improve patient care, encourage legislators and regulatory agencies to help, and pave the way toward more effective treatments. Every mention of PF brings us a step closer to finding a cure.

“I HAVE BECOME INVOLVED WITH THE PULMONARY FIBROSIS FOUNDATION BECAUSE IT WAS SOMETHING MY DAD WAS REALLY PASSIONATE ABOUT. THEY PROVIDE SUPPORT AND INFORMATION TO PEOPLE AFFECTED BY THIS TERRIBLE DISEASE.”

JEANETTE POHLEN

PF ADVOCATE AND INDIANA FEVER WOMEN'S BASKETBALL TEAM MEMBER



TEAM PFF HOSTED 100-PLUS EVENTS IN MORE THAN

25 STATES IN 2013

Spreading Awareness... On and Off the Court

The combined efforts of the PF community helped make **GLOBAL PULMONARY FIBROSIS AWARENESS DAY 2013** a success. Jeannette Pohlen, PF advocate and member of the Indiana Fever WNBA team, lost her father to idiopathic pulmonary fibrosis in 2012. Pohlen, her teammates, and her coaches donned wristbands and posted a photo (above) on social media to raise PF awareness. The PFF was the Fever's Community Spotlight Partner during the final game of the season. At that game, the Fever aired a PSA about PF and recognized the PFF in an on-court presentation.

EDUCATION

The more patients and caregivers know about pulmonary fibrosis (PF), the better the quality of life. Pulmonary Fibrosis Foundation (PFF) education materials provide practical information about PF symptoms, diagnostic tests, treatment, monitoring, lifestyle changes, and palliative and hospice care. PFF events including the biennial PFF Summit, Team PFF fundraisers, and social gatherings offer opportunities to learn about how to live with the disease and get involved with the PF community. Support groups and social media networks help patients and caregivers connect and share information with other PF families. At a community level is the PFF Support Group Leader Network, which institutes best practices and shares resources among support group leaders who guide meetings in medical centers across the country.

“PFF SUMMIT 2013 BROUGHT VALUE TO ALL MEMBERS OF THE PF COMMUNITY— AS AN EDUCATIONAL RESOURCE, A CATALYST FOR CHANGE, AND A SYMBOL OF HOPE.”

MARTIN KOLB, MD, PHD
SUMMIT 2013 CO-CHAIR



PF COMMUNITY MEMBERS FROM FIFTEEN DIFFERENT COUNTRIES

ATTENDED THE PFF SUMMIT 2013

Biennial Summit Brings PF Community Together

Gathering physicians, researchers, allied health professionals, industry representatives, patients, and caregivers, the **PFF SUMMIT 2013: FROM BENCH TO BEDSIDE** in La Jolla, California, presented the most up-to-date medical information with the goal of improving care, management, and quality of life for those living with PF. The PFF recognized that coupling health care professionals with patients and caregivers in one Summit provides the PF community with a unique opportunity. Sessions for medical professionals ran concurrently with events for patients and caregivers, including opportunities for the two groups to interact, share information, and network.

RESEARCH

Increased research is key to developing more effective treatments for pulmonary fibrosis (PF) patients, ultimately leading to a cure. The Pulmonary Fibrosis Foundation (PFF) directly funds research, promotes advocacy efforts, encourages collaboration between industry and academic researchers, and develops solutions to bridge gaps in PF research. The PFF's I.M. Rosenzweig Junior Investigator Awards and Albert Rose Established Investigator Awards support projects with a high likelihood of widening PF knowledge in the areas of basic science, translational research, clinical medicine/research, and social science/quality of life. The PFF also partners with other professional organizations and foundations to support research that empowers the PF community today—and brings a brighter future to tomorrow's patients.

“OUR GOAL IS TO CREATE A BROAD, REPRESENTATIVE, WELL-THOUGHT-OUT CCN AND REGISTRY. FROM THERE WE CAN IMPROVE THE CARE OF, AND EVENTUALLY FIND CURES FOR, PF PATIENTS.”

DR. KEVIN R. FLAHERTY

CHAIRMAN OF THE STEERING COMMITTEE OF THE PFF CARE CENTER NETWORK AND THE PFF PATIENT REGISTRY



THE PFF GRANTED AWARDS TO ALL NINE PILOT PFF CARE

CENTER NETWORK SITES

Expanding Information Accelerates Discovery

The **PFF CARE CENTER NETWORK (CCN)** and **PFF PATIENT REGISTRY** are increasing our fundamental understanding of the disease. Members of the CCN, a growing group of medical centers with proven, multidisciplinary expertise in treating patients with fibrotic lung diseases, share knowledge that will elevate the standard of care of PF patients. The Registry is a collaborative effort that brings together patients, health care providers, and researchers. This database will collect anonymous information from patients at designated PFF sites to help PF experts develop more effective care strategies and therapies, benefitting PF patients around the globe.

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.

2013 PFF RESEARCH FUND AWARDS

GENERAL RESEARCH GRANTS

Dr. Aldo T. Iacono / University of Maryland – “Open Label Use of Inhaled Cyclosporine in Lung Transplant Recipients” (Final Year)

Dr. Daniel J. Kass and Dr. Naftali Kaminski / University of Pittsburgh – “Targeting the Relaxin Pathway in Pulmonary Fibrosis” (Final Year)

Dr. Imre Noth / University of Chicago – “miRNA Expression in Patients with Rapidly Progressive IPF Versus Stable IPF” (Final Year)

Dr. Patricia J. Sime / University of Rochester – “Translational Studies of New Therapeutic Targets & Biomarkers in PF” (Final Year) FUNDED IN PART BY THE GREG CHANDLER AND GUY F. SOLIMANO MEMORIAL GOLF TOURNAMENT

Dr. Andrew Tager / Massachusetts General Hospital – “Profibrotic Mechanisms of the LPA Pathway” (Final Year) FUNDED IN PART BY THE TIGHE FAMILY TRUST AND ROUINE RUN, INC.

I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARDS

Dr. Haitao (Mark) Ji / University of Utah – “Design and Synthesis of Selective Beta-catenin/T-Cell Factor Inhibitors for the Treatment of Idiopathic Pulmonary Fibrosis” (Year 2) FUNDED BY A GRANT FROM INTERMUNE, INC.

Dr. Rebecca Keith / University of Colorado, Denver – “Therapeutic Targeting of PTPN-13 in Idiopathic Pulmonary Fibrosis” (Year 2)

Dr. Kristen Tropea Leeman / Harvard Medical School, Boston Children’s Hospital – “Characterization of Endogenous Lung Stem Cells in a Pulmonary Fibrosis Model” (Year 1)

ALBERT ROSE ESTABLISHED INVESTIGATOR AWARDS

Dr. James S. Hagood / University of California, San Diego – “Extracellular Vesicles Alter Cell Phenotype in Pulmonary Fibrosis” (Year 2)

Dr. Glenn Rosen / Stanford University – “Analysis of Novel Functions of Human Telomerase RNA in IPF” (Year 2)

Dr. Michael F. Beers / University of Pennsylvania – “Modeling of Epithelial Cell Dysfunction in Pulmonary Fibrosis using SP-C BRICHOS Mutations” (Year 1) FUNDED BY A GRANT FROM BOEHRINGER INGELHEIM

Dr. Mauricio Rojas / University of Pittsburgh – “Senescent Stem Cells Increases Susceptibility to Pulmonary Fibrosis” (Year 1)

ATS FOUNDATION/PFF INTERNATIONAL PARTNERSHIP GRANT

Dr. Anthony Shum / University of California, San Francisco – “Defining the Molecular Basis of Interstitial Lung Disease in Rheumatoid Arthritis” (Year 2)

ATS FOUNDATION/PFF/CPF PARTNERSHIP GRANT

Dr. Chi Hung / University of Washington – “Role of Collagen I-Derived Cells in Pulmonary Fibrosis” FUNDED BY THE PETE DEVITO MEMORIAL FOUNDATION

2013 SPONSORSHIPS

Yale University – Seventh Annual Yale Fibrosis Symposium

Center for Interstitial Lung Diseases / University of Washington Medical Center FULLY FUNDED BY THE FRIENDS OF THE CENTER FOR ILDS AT UNIVERSITY OF WASHINGTON MEDICAL CENTER

Interstitial Lung Disease Program / University of California, San Francisco, Stanford, and UC Davis – 3rd Annual ILD Patient Seminar

National Jewish Health – Familial Pulmonary Fibrosis Genetic Counseling Program

University of Maryland – Hales Lung Conference

University of Vermont – Vermont Stem Cell Conference

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2013 TEAM PFF

Remo & Sharon Turchi	1st Annual John Juul Memorial Benefit for the PFF
Ahmet Tutuncu, MD	2nd Annual Molly K. Walk
Craig Underwood	2nd Annual Pilot for a Cure Yard Sale
United Consulting	3rd Annual Boston Walk
United Way California Capital Region	3rd Annual John F. Tighe Walk for Pulmonary Fibrosis
United Way of Delaware	3rd Annual Octoberfest 10K & Half Marathon
Donna Upton	3rd Annual Pete DeVito Memorial Golf Outing
Urology Associates, LLC	3rd Annual Ready, Set, Breathe!
Matthew Valentino	3rd Annual Team Dan Walk-A-Thon
Autumn Vannatta	4th Annual 5K Rouine Run for Pulmonary Fibrosis
Srihari Veeraraghavan, MD	4th Annual Willacker Family Pulmonary Fibrosis Golf Outing on Global PF Awareness Day
Viele, Solimano, Swagler & Chapman, CPA PC	5th Annual Garden State 5K Run/Walk for Pulmonary Fibrosis
Jay Vora	6th Annual Charity Cycling Challenge
Pramathesh Vora	6th Annual Greg Chandler & Guy F. Solimano Memorial Golf Tournament
Giup Van Vu, MD	8th Annual Barbara A. Fiorillo Memorial Bike Run/Picnic
Marla Wagner	A Quilt for Mom
Judith Wahler	Air is Rare
Christine Waldron	Alamance Force Volleyball Camp
Mark Walker	AMP Jeans Week for PFF
Steven Walsey	Avon American Legion Post 145 Fish Fry Dinner for PFF
Eugene Walter	Baheti and Vora Happy Hour
Jason Waters	Band'ing Together for Global PF Awareness
Sharon Waters	Battle for Breath, Zumba for a Cure
Nikki Wayne	Bike the Drive – Jennifer Bollero's Team
John Webster	Bike the Drive – Laura Williams' Team
Herron & Cary Weems	Bike the Drive – Maureen Hardy's Team
Weh2 Foundation	Bike the Drive – Michael Stein's Team
Alan & Marie Weiss	Bike the Drive – Team Runamuk
Pamela Weiss	Bill Torres: San Diego Century Bicycle Tour
Martin & Maureen Weitzel	Book Proceeds for "Keep Breathing"
Lewis Wesselius, MD	Brad Cook Runs the Bull City Race and Raleigh City of Oaks Marathon
Eric White, MD	Branford Road Race: Tony's Team
Jim & Brenda White	Breath of Fresh Air
Stephanie Whitmer	Breathe for Duffy (Rhode Island Public Defenders Fundraiser)
David Wilkes, MD	Breathe.Dance.Zumba for Global PF Awareness Day
Felice Wilson	Brianna Broderick Helps Pummel Pulmonary Fibrosis
Richard & Patricia Woelpper	Brock Powers Wristband Sales
Paul Wolters, MD	Brownlee 50th Wedding Anniversary
George & Jan Woltman	Caroline M. Fell 5K Memorial Walk/Run
Laurie Wonsil	Celebration of Life for Donald Bagley
Woodrun V Condominiums Association	Cheryl Runyon's Bumper Sticker Fundraiser
The Y Cross Ranch Elk Hunting Club	Chicken Soup for the Soul Dinner
Stuart Yarbrough	Chris & Rani McElrath's Wedding
Kathleen Ybarra	Coins for PFF
Mark Yoder, MD	Comedy for a Cause
Karen Young	Crawfordsville Ironman MX
Claudette Zaccardi	Cruisin' Towards a Cure for PF – Because Breathing Matters!
Hasmukh & Rinkal Zalavadia	Dan Holden Memorial Golf Outing
Jim Zarroli	Daniel Mullaney Runs the New York City Triathlon
Yingze Zhang, PhD	Dine Out for Global PF Awareness
Joseph Zibrak, MD	Donna Pioli Online Fundraiser for Global Pulmonary Fibrosis Awareness
Stewart Zuckerbrod	Donna Schwartz Memorial Walk
	Eric & Jamie Debole's Wedding

2013 TEAM PFF (continued)

First Church Unitarian's Share the Plate Program
First Midwest Bank's Jean Day for PFF
Free Throws for Fibrosis
Fulton Fithouse Charity Bootcamp
Fundraiser for Irv Feldman
Get Air
Grade 3 Craft Fair
Hats Off for PF
Huff-N-Puff Prom-A-Thon 2013 – DON'T COME!
IN THE BLOOD Family Art Show
ISP Pay it Forward – Jerusalem Ave. Elementary Bake Sale
ITW Foam Fest Race
Jason Ford's Tough Mudder Fundraiser
Jewelry Party for Global PF Awareness
Joe & Cindy Rinaldi's Wedding
Julie Willis O'Connor's Bike Across MA
Just Blue It!
Katherine O'Brien Memorial Fundraiser
Katie Hart Runs the Lilac Bloomsday Run
Katie Hart Runs the Seattle Rock'n'Roll Marathon
and Half Marathon
Kevin & Claire Lichty Run the New York City Triathlon
Kevin Rice in the South Haven Triathlon
Lieven Nuyttens Runs the New York City Triathlon
McKeehan Hart Bake Sale
McKeehan Hart's Dress Down for Global PF Awareness
New York City Triathlon presented by Aquaphor
Night at the Old Ball Park Benefiting the PFF
Oak Creek Bake Sale for Global PF Awareness
Oceans for Julie
Owen's Longhorn Ironman Triathlon Fundraiser
PFF Brenda (The Survivor) Wilson
PFF Heavy Breathers
PFF Kuhn Family and Friends Walkers
PFF Lili's Lungs
PFF Mar's SOB Squad
PFF Team Eva
PFF Team Jeffery
PFF Team M&M
PFF Team SuperStella
PFF Walk with Pat
PFF Walkers
Recycle for Research
Roger Wallace: John Deere Golf Classic
Rosemont Women's Soccer
Running 4 A Reason
Sandy Warshauer's Beads for Bob
Scottsdale PF Walk Through the Park
Stephen Mills Runs the New York Marathon
Steve Lublin Memorial Golf Scramble
Student Dress to Impress Fashion Show
Studio X Zumbathon for PFF
Tab Scramble for Global PF Awareness Day
Team Cindy Sweetland
Team Cornerstone For Kathy
Team Grover Fundraiser
Team Jeffery Trivia Night
The Bernice F. Dunlop Memorial Golf Tournament
The Tom Rutledge Memorial Ready, Set, Breathe
Fun Run & 5K
Thirty One Party
Three on Three Basketball Tournament
Tricia Gunyon's Pampered Chef Fundraiser
Vannatta's Yard & Bake Sale for Global PF Awareness
Wendy Peoples Runs the Richmond Half Marathon
Xenofondas Polychronopoulos and
Catherine L. Sampson's Memorial Fundraiser
Yoga for PFF

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EVERYONE FOR THEIR GENEROUS CONTRIBUTIONS.

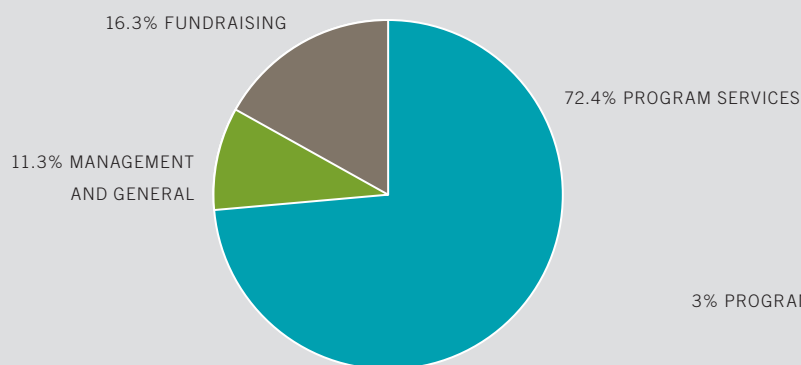
STATEMENT OF FINANCIAL POSITION

AUDITED NUMBERS		
	2013	2012
Total Assets	\$3,962,848	\$3,724,437
Total Liabilities	345,830	63,632
Total Net Assets	\$3,617,018	\$3,660,805

STATEMENT OF ACTIVITIES

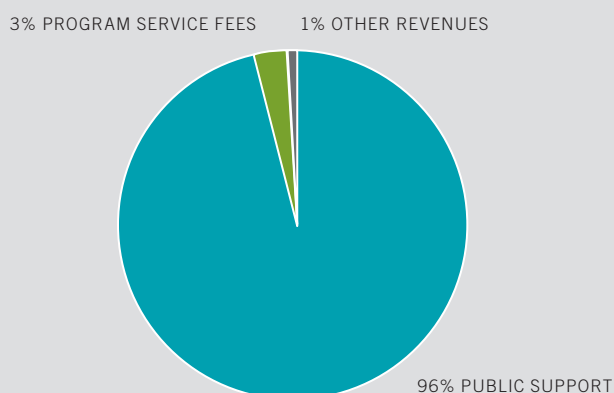
AUDITED NUMBERS		
	2013	2012
Total Revenue		
Unrestricted	\$3,243,356	\$2,256,757
Temporarily Restricted	453,033	398,144
	\$3,696,389	\$2,654,901
Total Expenses	3,740,176	2,330,977
Change in Net Assets	\$ (43,787)	\$ 323,924

FINANCIAL SUMMARY



ALLOCATION OF 2013 EXPENSES

AUDITED NUMBERS		
Program Services by Category		
Summit	\$ 856,052	
Care Center Network	554,428	
Registry	246,166	
Research	516,269	
International	285,364	
Physician and Patient Education	150,254	
Patient Outreach	40,267	
Shop PFF	40,151	
Support Groups	15,614	
Advocacy	3,162	
Program Services Total	\$2,707,727	72.4%
Management and General	423,436	11.3%
Fundraising	609,013	16.3%
Total 2013 Expenses	\$3,740,176	100.0%



SOURCES OF 2013 REVENUE

Public Support	\$3,542,521	96%
Program Service Fees	118,860	3%
Other Revenues	35,008	1%
Total 2013 Revenue	\$3,696,389	100%

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