

INVESTMENT CREATES

results

Pulmonary Fibrosis Foundation

2011 ANNUAL REPORT

Moving our cause forward requires transition, growth, and achievement. Focused on our mission, the Foundation is unyielding in our journey to grow and make a positive impact. With our investments and those of our supporters, we look at how we created unprecedented results.

Dear Friends,

It was over eleven years ago when my father and his brother founded the Pulmonary Fibrosis Foundation (PFF). Their goal was to help those affected by pulmonary fibrosis (PF). I'm proud to say that today's Foundation has evolved from a family foundation into a truly international patient advocacy organization. In 2011, the Foundation made significant strides in advancing the core pillars of our mission.

Last year we achieved a milestone when we presented the *IPF Summit 2011: From Bench to Bedside*—our inaugural scientific conference and our most ambitious initiative up to that time. The *Summit* featured a world-class faculty that included sessions for physicians, researchers, nurses, allied health care personnel, patients, and caregivers. Representatives from the biotechnology, pharmaceutical, and investment communities were also in attendance. This provided a unique opportunity for collaboration with some of the major stakeholders who are working to find a cure for this disease. The curriculum that was presented at the *Summit* will help contribute to improving diagnosis, providing better patient care, and stimulating new research. Our *Summit* in 2013 is guaranteed to be just as innovative.



The Foundation is dedicated to supporting research; the PFF Research Program consists of complementary efforts designed to foster innovation. In 2011, we added four grant awards to the PFF Research Fund. These grants—the Young Investigator and Established Investigator Awards—are given over a two-year period. All grant applications are reviewed by our Research Advisory Committee. One objective of the Committee is to identify key gaps in basic and clinical knowledge that may impede the development of successful treatments. These “bridge grants” play a vital role in supporting investigators at a crucial time and can provide the needed data to secure larger, federal grants.

I am extremely appreciative for all the help we received in 2011. I would like to especially thank the Foundation staff led by Chief Operating Officer Patti Tuomey. Patti's team made this groundbreaking year a reality, and I salute their tireless effort and dedication. I must also stress the importance of the entire PF community—individual donors, corporate sponsors, and volunteers who all help us achieve our goals—thank you. We would not be able to do what we do without your support. Our job is far from over and I am certain you'll continue to support us in the fight against this deadly disease.

Sincerely,

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

Daniel M. Rose, MD

PRESIDENT AND CHIEF EXECUTIVE OFFICER

To Our Community,

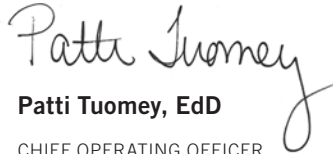
For a young organization with bold and important goals, it is vital that we optimize our opportunities to grow and make an impact. In 2011, we invested time, energy, and resources into initiatives that truly enabled us to help advance our mission. These efforts culminated in the success of our inaugural, international health care conference—*IPF Summit 2011: From Bench to Bedside*—and highlighted a year of achievement, growth, and results.

It was our President and CEO, Daniel M. Rose, MD, who had the vision to create a biennial *IPF Summit*. As a medical professional he knew the importance of such an ambitious endeavor. In successfully executing the *Summit*, the Foundation has made a distinctive leap forward and we have firmly established ourselves as an important international resource for the pulmonary fibrosis (PF) community. *IPF Summit 2011: From Bench to Bedside*, held in Chicago December 1–3, had the largest scope and reach of any Foundation initiative. We invested significant resources to add integral infrastructure and key staff in patient relations, development, marketing, and finance to present the three-day, multi-faceted program. Additionally, the *Summit* set into motion opportunities for collaboration that will greatly benefit the entire PF community.

Another highlight of last year was our tenth anniversary *New Decade, New Reach* dinner. Held in tandem with the *Summit*, over 300 people came together at The Field Museum of Natural History to recognize our achievements and honor those whose tireless work made them a reality. It was a remarkable evening, filled with laughter and tears. We reflected on our previous successes and contemplated some of our ambitious plans for the next decade.

Last year was a milestone in our history. I have great appreciation for our founders and their work that we continue today. The Pulmonary Fibrosis Foundation is more than any one person or team. I thank our tireless and dedicated staff for their commitment to results. And I applaud our volunteers—our Board, medical advisors, and fundraisers. Every day they demonstrate a personal obligation to the community we serve. Our investment in 2011 truly created results and set the stage for greater impact in 2012 and beyond.

Sincerely,


Patti Tuomey, EdD
CHIEF OPERATING OFFICER



About the Disease

WHAT IS PULMONARY FIBROSIS AND WHAT ARE THE CAUSES?

Pulmonary fibrosis (PF) is a progressive, fatal condition in which the lung tissue becomes thickened, stiff, and fibrotic (scarred). As the scarring progresses, the lungs lose their ability to transfer oxygen, and the brain and other organs don't receive the adequate oxygen needed to function properly. Pulmonary fibrosis can be the result of exposure to certain environmental agents (dust, silica), medications (antibiotics, antiarrhythmics), radiation, autoimmune diseases (scleroderma, rheumatoid arthritis), or a genetic predisposition. However, in most situations the etiology is unknown. If there is no known cause, then the disease is called idiopathic pulmonary fibrosis (IPF). There is no cure for IPF, and there is no FDA-approved treatment for IPF in the United States. Extremely limited therapeutic options for IPF are available in the European Union and Asia.

WHAT DOES THE DISEASE LOOK LIKE?

IPF affects approximately 200,000 individuals in the United States with an estimated annual mortality of 40,000. As a result of the difficulty in making a diagnosis and lack of a national surveillance 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.

The median age at the time of diagnosis is approximately 63 years; however, the disease affects individuals of all ages.

Symptoms include:

- Shortness of breath (dyspnea)
- Chronic dry, hacking cough
- Fatigue and weakness
- Discomfort in the chest
- Loss of appetite
- Weight loss

Treatment includes supplemental oxygen, respiratory therapy, maintaining a healthy lifestyle (optimizing weight and exercise), and for those who qualify, lung transplantation.

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 raise awareness, help educate the professional and patient communities, promote patient and legislative advocacy, and provide support to patients, family members, and caregivers.



KNOWLED

In 2011, the Pulmonary Fibrosis Foundation made our greatest single investment in advancing education, fostering collaboration, and increasing awareness of pulmonary fibrosis.

It was the vision of our President and CEO, Daniel M. Rose, MD, to host an international scientific conference to facilitate these initiatives and to identify new approaches to treat and ultimately find a cure for idiopathic pulmonary fibrosis (IPF). Our inaugural biennial conference, *IPF Summit 2011: From Bench to Bedside*, was the culmination of over two years of planning and preparation, and its success set into motion opportunities that will greatly benefit the pulmonary fibrosis (PF) community.

The *Summit* featured innovative continuing medical education programs for physicians, researchers, registered nurses, and allied health professionals to improve their understanding of PF. In addition, there was a one-day program to address the growing educational needs of patients, family members, and caregivers. Sessions were led by a world-class faculty and are available as on demand webinars through our website.



GE inspiring collaboration

The *Summit* was planned in accordance with the Essentials and Standards of the Accreditation Council for Continuing Medical Education, in partnership with The France Foundation and National Jewish Health, and was endorsed by the American Thoracic Society. Clinical and scientific objectives for the *Summit* were identified in a needs assessment. Following completion of the medical sessions participants were able to:

- Explain the pathophysiology of IPF based on the most current data
- Accurately diagnose IPF using a systematic approach
- Effectively implement key diagnostic procedures including HRCT scanning and surgical lung biopsy
- Discuss recent evidence for treatments in the management of IPF
- Recognize genetic components of IPF
- Describe the role of lung transplantation in IPF and the factors that affect candidacy and timing
- Provide patient lifestyle management tools that improve functional status
- Develop a comprehensive approach to the management of IPF that includes both pharmacologic and non-pharmacologic therapies



REACHING THE PF COMMUNITY

IPF SUMMIT 2011 ATTENDANCE STATISTICS

Medical Professionals	244
Patients and Caregivers	127
States Represented	36
Countries Represented	14
Satellite Viewing Groups	225 viewers at 10 national and 3 international satellite locations
Live Webcast Viewers	600 viewers in 9 countries

SUPPORTING NEW RESEARCH

IPF Summit 2011: From Bench to Bedside emphasized the importance of new research; twenty-six young academic investigators were chosen to give poster presentations on their basic, clinical, translational, or social science/quality of life research. All submissions were peer-reviewed and graded; awards were given for the first, second, and third place posters.

1st Place

Jonathan Kropski, MD

VANDERBILT UNIVERSITY

“Herpes Virus Infection Exacerbates Endoplasmic-Reticulum Stress and Acts as a ‘Second-Hit’ in the Development of Lung Fibrosis”

2nd Place

Adam Booth, PhD

UNIVERSITY OF MICHIGAN

“Fibroblast Responses to Decellularized Human Lung Slices Implicate the Extracellular Matrix in Directing Fibroblast Phenotypes”

3rd Place

Adita Mathur, MD

YALE UNIVERSITY

“Role of Semaphorin 7a in Lymphocytes in TGF- β Driven Lung Fibrosis”

Honorable Mentions

Stephenie Takahashi, MD

UNIVERSITY OF CHICAGO

“The Inhibitory Molecule, BTLA, Regulates Pulmonary Fibrosis in a Mouse Model”

Anand Iyer, MD

HAMPTON UNIVERSITY SCHOOL OF MEDICINE

“Angiogenic Mediators Regulate Single-Walled Carbon Nanotube-Induced Fibrogenesis in Human Lung Fibroblasts”

THE SUMMIT FACULTY

KENNETH ADLER, PhD

North Carolina State University

JOHN DAVID ARMSTRONG II, MD, MA

National Jewish Health

BRIAN BAIRD, MS, PhD

Former U.S. Representative to Congress

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University of Pittsburgh School of Medicine

DOLLY KERVITSKY, RCP, CCRC

Pulmonary Fibrosis Foundation

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Tulane University

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Harvard Medical School

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National Jewish Health

SHELIA VIOLETTE, PhD

Stromedix

GAIL G. WEINMANN, MD

National Heart, Lung, and Blood Institute

TIMOTHY P. WHELAN, MD

Medical University of South Carolina

ERIC S. WHITE, MD

University of Michigan Health System

DAVID A. ZISMAN, MD, MS

Sansum Clinic

DOLLY KERVITSKY JOINS THE PFF TEAM

Dolly Kervitsky, RCP, CCRC, joined the Foundation in February 2011 as the Vice President of Patient Relations. She brings 30 years of experience and expertise in interstitial lung disease to the Foundation. Ms. Kervitsky played a key role in developing the programming for the patient and caregiver sessions at the *IPF Summit 2011: From Bench to Bedside*.

The sessions were:

- What is Pulmonary Fibrosis (PF) and What are the Causes?
- What are the Symptoms of Pulmonary Fibrosis and What are the Treatment Options?
- Lung Transplantation
- Familial PF and Genetic Counseling
- Pulmonary Rehabilitation
- Establishing a Support Group
- The Why, How, and What of Clinical Trials
- Advocacy
- Navigating Medicare and Health Insurance
- Managing Advanced Disease and Hospice Care
- Living with PF and How to Improve Quality of Life
- Roundtable Discussions with the Experts





About Dolly Kervitsky

Dolly Kervitsky, RCP, CCRC, began her respiratory therapy career as a Staff Respiratory Therapist in the Medical, Pediatric, and Burn and Trauma Intensive Care Units at the University of New Mexico. In 1981, she joined National Jewish Health (NJH) as a Staff Respiratory Therapist; in 1982, she was named Acting Director of the Respiratory Therapy Department.

Over 950 patients and caregivers attended the *Summit* in person and via webcast. The sessions were archived as webinars and are available at www.pulmonaryfibrosis.org/summit.

In less than ten months at the Foundation, Ms. Kervitsky has set into motion major initiatives that will benefit the PF community in 2012 and beyond. The Foundation is thrilled to have her on our team.



In 1983, she began working with pulmonary fibrosis patients and researchers as the Clinical Coordinator for the Specialized Center of Research investigating idiopathic pulmonary fibrosis, funded by the National Institutes of Health (NIH). The NIH project was instrumental in the development of the Interstitial and Autoimmune Lung Disease Program at NJH where Ms. Kervitsky was named the Program Manager in 1992.

In 2008, Ms. Kervitsky founded the Genetic Counseling Program for Familial Pulmonary Fibrosis at NJH. She has served as a lead coordinator and steering committee member for several international multi-center research trials. Additionally, she is a member of the American Thoracic Society, American College of Chest Physicians, Association of Respiratory Care, and Association of Clinical Research Professionals.



THE EVENING

recognizing passion

We came together to commemorate our ten-year anniversary during a special evening at The Field Museum of Natural History in Chicago.

The Pulmonary Fibrosis Foundation (PFF) began as a family foundation with the noble goal of finding a cure for pulmonary fibrosis. Just ten years later, we have evolved into a leading international organization fighting this devastating disease through important initiatives such as the *Summit* and our PFF Research Program. Over the course of the evening we honored those who have been instrumental in our growth and presented our vision for the future.



The dinner's theme, *New Decade, New Reach: Together We Will Make a Difference*, truly reflects today's Foundation. The evening was strategically timed so that the many different stakeholders that came to Chicago to attend the *Summit* could attend the dinner as well. We take pride in facilitating relationship building, and the dinner was such an opportunity. Old friends were reunited and new connections were made with everyone sharing a common bond of winning the fight against pulmonary fibrosis.

The Foundation thanks our dinner co-chairs, speakers, emcee Mary Ann Ahern, and our dedicated staff for making the *New Decade, New Reach* dinner a tremendous success. The evening was a fitting tribute to the legacy we carry forward. We have our eye on the future and are focused on fulfilling our mission.

IMPACT

fostering innovation

The Pulmonary Fibrosis Foundation places great importance on creating an environment that will assist in the development of effective treatments for pulmonary fibrosis. In 2011, we invested in research through multiple avenues.

DIRECTLY FUNDING RESEARCH

The Foundation funded important peer-reviewed research through our PFF Research Program. All grant requests underwent rigorous review by members of the Research Advisory Committee (RAC) under the direction of Jesse Roman, MD. The RAC decided which projects would provide the best opportunities to advance research.

ADVOCATING FOR LEGISLATION

We regularly communicated with members of Congress and their legislative aides to lobby for the passage of legislation important to the PF community. We also provided resources, information, and tools for our constituents to contact their legislators and to promote disease awareness in their community.

BUILDING KEY RELATIONSHIPS

The Foundation actively fostered relationships and opportunities to enhance research and drug development. We collaborated with other important organizations such as the National Heart, Lung, and Blood Institute (NHLBI); the National Organization for Rare Disorders (NORD); the Food and Drug Administration (FDA); and have worked closely with other disease-specific organizations to advance best practices and work on common advocacy issues.



FOSTERING INNOVATION

The Foundation conducted educational programs such as the *IPF Summit 2011: From Bench to Bedside* to foster a collaborative environment for improved understanding of PF and to provide a forum for discussions regarding development of effective therapies. We also provided support for other organizations' meetings, colloquia, and seminars through partnerships and sponsorships. These platforms offered opportunities for professionals to expand their knowledge of PF, engage with thought leaders in PF, and partner in drug development.

PATIENT COMMUNICATIONS

It is critical for patients to be able to advocate for, and participate in, their own health care. Our patient communications were increased and standardized in 2011 and are an excellent resource for patients, family members, and caregivers to learn about clinical trials, research, safety issues, and advocacy efforts.



ABOUT THE PFF YOUNG INVESTIGATOR AND ESTABLISHED INVESTIGATOR AWARDS

In November of 2011, the Foundation established our Young Investigator and Established Investigator Awards that are offered through the PFF Research Fund. These grants play a vital role in supporting investigators at a critical time in the research process. Referred to as “bridge grants,” these funds provide support for the investigator to accrue enough research documentation to secure larger grants.

The program awards two Young Investigator and two Established Investigator grants per year, each given over a two-year period:

Young Investigator Awards

\$50,000 grant designed to encourage young investigators (individuals within five years of completion of their formal training) to maintain and enhance their interest in PF research during the early stages of their academic career.

Established Investigator Awards

\$50,000 grant designed to help established investigators explore innovative areas of research that may not yet be eligible for a federal grant.

2011 GRANT COMMITMENTS

In 2011, the Pulmonary Fibrosis Foundation solely or jointly funded twelve grants.

Award recipients were:

PFF RESEARCH FUND

- Dr. Erica Herzog of Yale University – “Prospective Evaluation of IPF Biomarkers”
- Dr. Aldo T. Iacono of University of Maryland – “Open Label Use of Inhaled Cyclosporine in Lung Transplant Recipients” (Year 2)
- Dr. Daniel J. Kass and Dr. Naftali Kaminski of University of Pittsburgh – “Targeting the Relaxin Pathway in Pulmonary Fibrosis”
- Dr. Imre Noth of University of Chicago – “miRNA Expression in Patients with Rapidly Progressive IPF Versus Stable IPF” (Year 1)
- Dr. Patricia J. Sime of University of Rochester – “Translational Studies of New Therapeutic Targets & Biomarkers in PF”

ATS/PFF/CPF PARTNERSHIP GRANTS

- Dr. Erica Herzog of Yale University – “Semaphorin 7a and Alternative Macrophage Activation in Idiopathic Pulmonary Fibrosis”
- Dr. Steven Huang of University of Michigan – “The Regulation and Pattern of the DNA Methylome in Pulmonary Fibrosis”
- Dr. Philip Simonian of University of Colorado Denver – “Protection from Inflammation-Induced Pulmonary Fibrosis by IL-22”
- Dr. Beiyun Zhou of University of Southern California – “Endoplasmic Reticulum Stress Induces Epithelial-Mesenchymal Transition in Alveolar Epithelial Cells: Role in Pulmonary Fibrosis”

ATS/PFF INTERNATIONAL PARTNERSHIP GRANT

- Anne Holland, PhD of La Trobe University, Australia – “Where Does Pulmonary Rehabilitation Fit in the Management of Pulmonary Fibrosis?”

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”
- Dr. Yan Sanders of University of Alabama at Birmingham – “Epigenetic Regulation of Caveolin-1 by TGF-β Mediated Signal Pathway in Lung Fibroblasts”

2011 SPONSORSHIPS

- UC Davis Medical Center; University of California, San Francisco; and Stanford University Medical Center – Understanding Pulmonary Fibrosis: A Seminar for Patients, Caregivers, and Families
- National Jewish Health – Familial Pulmonary Fibrosis Genetic Counseling Program
- Pittsburgh International Lung Conference
- Yale University – Fifth Annual Symposium on Nephrogenic Systemic Fibrosis and Allied Systemic Fibrosing Disorders



FLUENCE

empowering voices

To raise awareness and increase support for patients and families affected by pulmonary fibrosis, the Pulmonary Fibrosis Foundation invested in strategic legislative initiatives in 2011.

Most significantly, we focused on the Pulmonary Fibrosis Research Enhancement Act (S. 1350, H.R. 2505) or PFREA. The PFREA requests Congress to set up a national pulmonary fibrosis (PF) surveillance registry, create an advisory board, and establish an education and awareness plan. The PFREA also encourages the National Institutes of Health to “expand, intensify, and coordinate” their activities and research in PF.

The PFREA was re-introduced into the 112th Congress in the summer of 2011, supported by a bipartisan group of Senators—Christopher Coons (D-DE), Mark Kirk (R-IL), Michael Crapo (R-ID), and Patty Murray (D-WA)—along with House Representatives Erik Paulsen (R, MN-3) and Tammy Baldwin (D, WI-2).

During IPF Awareness Week 2011, members of our staff and other advocates from the PFF community traveled to Capitol Hill to meet with legislators and gain support for the PFREA.

Additionally, we introduced CQ Roll Call, a web tool that allowed the PFF community to directly request support for the PFREA from their district representatives.

Through meetings with potential sponsors, grassroots initiatives, awareness campaigns, and partnerships with other organizations including the Pulmonary Fibrosis Advocates and the Coalition for Pulmonary Fibrosis, the Foundation helped acquire the support of 71 co-sponsors in the House and 13 co-sponsors in the Senate.



REACH

expanding community

It is through the actions of those impacted by pulmonary fibrosis — and the passionate, dedicated advocates who share their stories with the world — that strides in raising awareness are made.

Songs for Mike: A Benefit Evening Honoring Michael Kuchwara tells such a story.



Julie Halston, renowned Broadway actress, already intimately knew the dire implications of a diagnosis of idiopathic pulmonary fibrosis (IPF) when she heard that her friend Michael Kuchwara had the disease. Julie's husband, radio personality Ralph Howard, underwent a lung transplant due to IPF in 2010. Now Julie was touched by this devastating disease a second time.



Michael Kuchwara's story is like that of so many others. With no previous illness, the disease struck Mr. Kuchwara unexpectedly and in the prime of his life. He had been the Associated Press theater critic for many years and was widely respected and loved by those in front of, and behind, the Broadway curtain. His death in May 2010 from complications of IPF was a shock to New York's theater community and Julie Halston's call to action.

Julie had never heard of pulmonary fibrosis before her husband's diagnosis and she was stunned to hear that Michael Kuchwara also suffered from the disease. To honor the memory of her dear friend, and to raise awareness of the disease, she collaborated with mutual friends D. Michael Dvorchak, Ed Windels, and Sue Frost to create a musical tribute to Kuchwara. Michael's friends, and the stars of Broadway, honored his memory in an evening of song that showcased the music he loved so much.



Hosted by Julie with her impeccable wit and comedic skills, *Songs for Mike* was held at New York's renowned jazz club Birdland on February 28, 2011. A tremendous success, the night featured over a dozen Broadway stars, and culminated with a surprise appearance by Broadway legend and movie star Liza Minnelli. *Songs for Mike* raised \$40,000 for the Michael Kuchwara Fund benefitting the Pulmonary Fibrosis Foundation, and enhanced the Foundation's work to spread much needed awareness of this little-known disease.

Songs for Mike was just the first of what is now an annual Broadway-inspired signature event for the Foundation. It will continue to bring people together in this fight and move our shared cause forward. We thank the dedicated volunteers who tirelessly work to increase awareness of the disease and raise money to fund support services and research. Together we will help find a cure.



PHOTOS BY CHRIS OWYOUNG

Thank you to all of our donors for investing in us.

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\$100,000+

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\$10,000–\$99,999

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Financial Summary

STATEMENT OF FINANCIAL POSITION

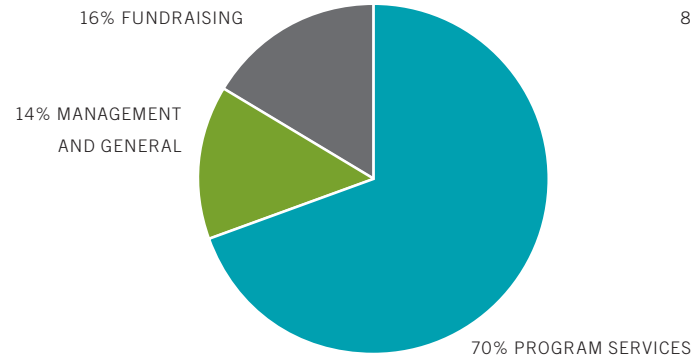
AUDITED NUMBERS

	2011	2010
Total Assets	3,511,296	3,555,331
Total Liabilities	152,316	23,147
Total Net Assets	3,358,980	3,532,184

STATEMENT OF ACTIVITIES

AUDITED NUMBERS

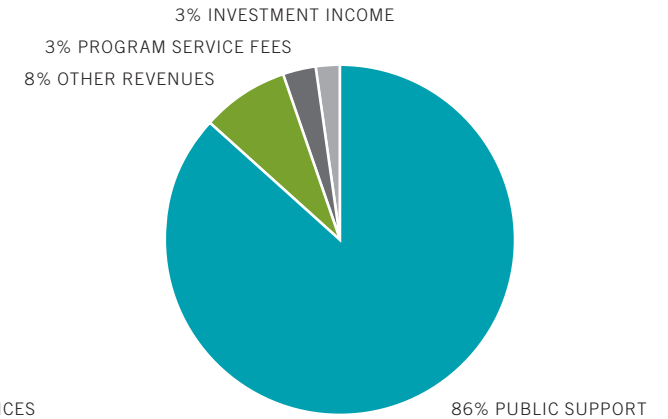
	2011	2010
Total Revenue		
Unrestricted	2,157,840	1,659,871
Temporarily Restricted	97,274	(5,000)
	2,255,114	1,654,871
Total Expenses	2,425,673	1,137,471
Loss on disposal of property and equipment	(2,645)	0
Change in Net Assets	(173,204)	517,400



ALLOCATION OF 2011 EXPENSES

AUDITED NUMBERS

Program Services by Category		
Advocacy	122,676	
Physician and Patient Education	119,480	
Research	364,254	
Affiliates	25,745	
Patient Outreach	114,450	
Registry	25,084	
Summit	913,718	
Program Services Total	1,685,407	70%
Management and General	348,943	14%
Fundraising	391,323	16%
Total 2011 Expenses	2,425,673	100%



SOURCES OF 2011 REVENUE

Public Support	1,950,159	86%
Program Service Fees	70,555	3%
Other Revenues	178,277	8%
Investment Income	56,123	3%
Total 2011 Revenue	2,255,114	100%

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Pulmonary Fibrosis

FOUNDATION

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