

Ten years. A strong beginning.

It is a turning point when the dreams and hopes of the few connect to the many, and together they overcome barriers and push forward to achieve what was once thought to be unreachable.

As we cross our tenth anniversary, we are poised to conquer the challenges, expand our reach, and touch the lives of all those who suffer.

Dear Friends,

As the Pulmonary Fibrosis Foundation (PFF) finishes its first ten years, we look forward to implementing an ambitious agenda for our next decade.

The Pulmonary Fibrosis Foundation was founded by two men, my father Albert Rose and his brother Mike Rosenzweig, who watched their sister Claire die from the disease. They worked tirelessly to build the Foundation and make it financially viable. The support network for those with the disease grew and the Foundation became a beacon for those afflicted with this deadly disease and their caregivers.

In our first decade, some of our achievements include funding nearly \$3 million in research grants and assisting in the development of the Interstitial Lung Disease (ILD) Center at the University of Chicago.

This year has been a pivotal one for the Foundation. We generated congressional support for the Pulmonary Fibrosis Research Enhancement Act (PFREA). The legislation directs the CDC to create a national PF registry. This will provide critical demographic and epidemiological information. The Foundation is also developing a pilot registry at four collaborating institutions.

Additionally, we increased fundraising events to 43, totaling a record \$300,000 in 2010. We updated our website to serve our constituency more effectively, and we sponsored three patient education webinars.

We took a significant step forward with the appointment of Patti Tuomey, Ed.D., as our Chief Operating Officer. Patti is extremely accomplished and has extensive experience working in the non-profit community. Her leadership is helping the Foundation expand its infrastructure and set the course for our second decade.

In the coming year we have an ambitious agenda for growth: holding an international healthcare conference on idiopathic pulmonary fibrosis in Chicago in December; establishing eight regional affiliate groups; and expanding our annual giving program in order to fund critical research.

Through your support, we have established a remarkable record of achievement in just ten years. We are excited about the challenges and accomplishments ahead that will help us realize our mission to find a cure.

Sincerely,

Daniel M. Rose, M.D.

President and Chief Executive Officer

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Above: Daniel M. Rose, M.D. and Patti Tuomey, Ed.D.

What is Pulmonary Fibrosis?

Can you imagine what it would feel like if you were chronically short of breath all day, every day, and unable to take a deep breath? For more than 200,000 Americans that is the case. They suffer from pulmonary fibrosis (PF), a disease with no FDA-approved treatment and no cure.

Pulmonary fibrosis is a result of chronic progressive scarring of the lungs. This scarring interferes with ordinary breathing by disrupting normal oxygen diffusion into the blood stream. As lung scarring worsens, it further lowers the oxygen level in the blood stream and breathing becomes progressively more difficult.

There are more than 200 related lung disorders that result in pulmonary fibrosis. These are known as interstitial lung diseases (ILD), the most common and serious form of PF is idiopathic pulmonary fibrosis (IPF).

A Stealth Killer

There is recently published information that estimates more than 200,000 Americans have idiopathic pulmonary fibrosis (IPF). While IPF is most commonly diagnosed between the ages of 50 and 70, it can occur in any age group. Each year, 40,000 people die from the disease, and approximately 48,000 new cases are diagnosed.

An estimated 10–15 percent of individuals diagnosed with pulmonary fibrosis have a familial form of the disease, which affects multiple family members from parents, children, and siblings to aunts, uncles and cousins

The Source

The cause of pulmonary fibrosis remains unknown but there is data that attributes the start of the disease to microscopic lung injury. Pulmonary fibrosis can also be associated with autoimmune diseases, such as scleroderma, lupus, and rheumatoid arthritis. Occupational and environmental exposures to some elements and fumes have also been blamed. Some cancer treatments,

10 years of dedication.

2000

Founders Albert Rose and Michael Rosenzweig, Ph.D., brothers both diagnosed with idiopathic pulmonary fibrosis (IPF), create the Pulmonary Fibrosis Foundation (PFF) in Denver, Colorado.

2002

Founder Albert Rose passes away from IPF.

2003

PFF receives the Public Service Award from the American Thoracic Society.

2005

Dr. Michael Rosenzweig relocates PFF to Chicago, Illinois.

PFF advocates for the creation of the IPFnet, a network of clinical research centers dedicated to the study of IPF.

Awarded \$20,000 to Dr. David Schwartz at Duke University to study genetics.

2004

Albert Rose donates \$1 million to start the Pulmonary Fibrosis Foundation.

2001

radiation therapies, heart regulating medicines, and antibiotics for urinary tract infections can cause PF.

Certain infections and gastroesophageal reflux disease (GERD) may also play a role in development of the disease. Genetic factors and cigarette smoking are believed to increase the risk of developing pulmonary fibrosis.

For Those Who Have the Disease

The most common symptoms of PF are progressive shortness of breath and the presence of a chronic cough. Some individuals may also experience fever, weight loss, fatigue, or muscle and joint pain.

Typical treatment may include prescription medications to control cough and lung inflammation, supplemental oxygen to improve blood oxygen levels and breathing, pulmonary rehabilitation to increase fitness levels, smoking cessation, and for those individuals who qualify, lung transplantation. Because there currently are no FDA-approved therapies to treat PF, patients should discuss lung transplantation or participation in a research study with their healthcare provider as soon as possible.

What's Ahead?

Researchers are investigating ways to slow the course of pulmonary fibrosis, prevent, and ultimately cure this devastating disease.

2006

PFF establishes a \$1,000,000 multi-year funding partnership with University of Chicago to develop the Research Center of Excellence at the University of Chicago.

PFF forms partnership with family of Evel Knievel, legendary daredevil who later died of IPF, to increase awareness.

2008

PFF funds a total of \$789,000 in research grants.

PFF funds a total of \$389,000 in research grants.

2007

The Pulmonary Pacers, PFF's multi-athletic team, begin racing for awareness of pulmonary fibrosis.

Daniel M. Rose, M.D., Albert Rose's son, assumes leadership as President and CEO.

2009

2010

PFF partners with the American Thoracic Society and the Coalition for Pulmonary Fibrosis to create a \$400,000 fund for new research grants.

Foundation Facts

International Demographics

United Kingdom
Canada
Australia
India
Italy
Egypt
South Africa
Ireland
Spain
Argentina
Germany
France
Puerto Rico
Philippines
Greece

Saudi Arabia Pakistan Switzerland

Pulmonary Fibrosis
Research Enhancement
Act (PFREA) In 2010 the
PFREA was introduced
into both the House
of Representatives
and Senate in the
111th Congress. At the
conclusion of the 111th
Congress the PFREA
received bi-partisan
support from 150 cosponsors in the House
and eight co-sponsors in

Grants We committed to awarding \$520,000 in grants in 2010.

the Senate.

2010 Year End Appeal

Donations exceeded \$40,000

Events 43 Events in 2010 raised over \$300,000

More than 5,000 individuals participate in support programming through the PFF, either online or in-person.

10 years of community.

It took four years before Jeffrey Peters' doctors diagnosed the crackling in his lungs as idiopathic pulmonary fibrosis (IPF). He had CT scans and chest X-rays but the physicians couldn't quite figure it out. It took a referral to a pulmonologist in March 2011, who compared all the images, to determine he definitely had developed pulmonary fibrosis.

While he waits for research to make a difference, he finds "it's just getting tougher and tougher to do things." Michele, his wife and caretaker, added there are more and more things he can't do because of his increasing shortness of breath. "We used to love walking to Starbucks in our neighborhood for coffee, but it's too far now. It's little things like that," she explains.

"People facing this problem generally think the shortness of breath is just a factor of getting older," Michele says. "People wait too long and then their diagnosis comes and the disease has progressed to a point where they don't have a lot of time left," she adds.

Hope energizes Jeffrey, who is positive there is research out there that will repair his lungs. Although he participates in some experimental studies with various drugs, he is convinced the stem cell therapies emerging around the world are the answer to regenerating his lung capacity. "I just read an article about how stem cells restored lungs in mice so I am hoping that something like that develops for humans pretty soon."

Both Jeffrey and Michele find support and camaraderie from friends they've made while working to raise funds for the Pulmonary Fibrosis Foundation. "It's great being surrounded and supported by people who know exactly what it is you are going through

and feel the same level of frustration you do," explains Michele, who has been active creating fundraisers for the Foundation.

For patients and caregivers, the PFF website is a source of information. It is a place they turn to if they are feeling overwhelmed or don't know what else to do in a particular situation. "On the web you can try to get some answers or at least find someone who's had the same experience and will walk you through what they did," Michele said.

Online searching is fueling Jeffrey's hope for stem cell research or a cure before his lung function deteriorates further. The Pulmonary Fibrosis Foundation shares the same hope and is working tirelessly to help Jeffrey and others like him before their disease runs its full course.



Liliana Aguirre defies the typical picture of a pulmonary fibrosis patient. She is only 22 and three years ago was diagnosed with pulmonary fibrosis. "I am the only one I know my age who has this," says Liliana.

As a young adult, Liliana took her health for granted. She thought she was ready to start her life, not hear that it could suddenly end. "When I go out with my oxygen, people think I have asthma. When I tell them it's pulmonary fibrosis, they go blank. I want people to understand that not just old people can get this."

Since her diagnosis Liliana has undergone pulmonary rehabilitation, lost weight, and gained muscle strength. At times she has slipped into a depression which is not uncommon in individuals suffering from pulmonary fibrosis. "It's very hard because I think that at such a young age, nobody is going to want to be with me or deal with this," she said. "I miss having a normal life."

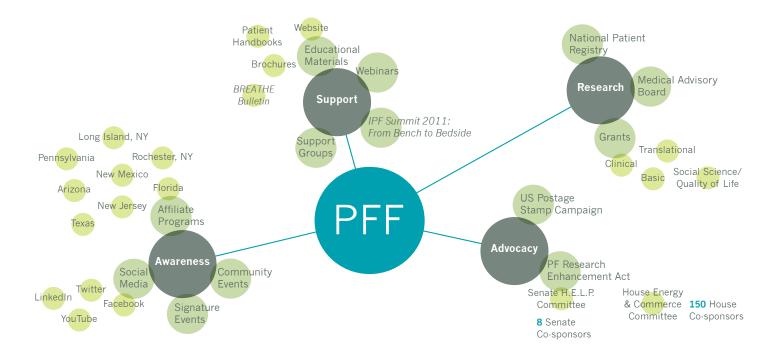
Liliana, like many patients, does not have a family history of pulmonary fibrosis.

Fortunately, her doctors believe she is a good candidate for a lung transplant. While the procedure frightens her, she knows it's her best option to overcoming this condition. "I am trying to be the strongest that I can for this, doing my best to beat it and live through it," she said. "The best result would be to be able to breathe on my own again."

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10 years of connections.

In March of 2009, the day after her father died, Kathy Petrak reached out to the Pulmonary Fibrosis Foundation. Since then, it has been one of her personal goals to spread the word about this devastating disease and link together people who are dealing with a pulmonary fibrosis diagnosis.

That early call resulted in a 45-minute conversation that turned Kathy into a strong advocate for patients and for their families who frequently are unaware of what is happening to their loved one. "I didn't feel like I did enough when my dad was here," Kathy explained. "I don't want another family to feel as helpless as I did."

When Bill Pacella was diagnosed with pulmonary fibrosis he lived in North

Carolina, miles away from Kathy's home in Illinois. It was shortly after the birth of her first child, and consumed with the needs of a newborn, she didn't have much time to figure out what was happening. Her dad minimized it for her, pushing back with "you can't always believe what you read" and "we'll figure this out."

Reality set in when Kathy and her family visited her dad and recognized that "the one thing he wanted to do more than anything else was to use his newly purchased boat to take his grandkids fishing and he couldn't do that kind of family stuff anymore." Bill was very proud and a fighter. "He didn't want this disease to beat him even if it meant he could only play two holes of golf in a round with his friends."

But defeat him it did. Three years after getting the pulmonary fibrosis diagnosis, Bill died. In his honor, Kathy set out to raise funds and recognition for PFF. Her dad loved taking his grandkids to baseball games so she asked the Chicago White Sox to do an awareness night for PFF. More than fifty families and patients showed up and the scoreboard read "Welcome Pulmonary Fibrosis Foundation: In memory of Bill Pacella."

Kathy continues to look for opportunities like this to raise awareness. "If just one person goes home from these events understanding what this disease is, then we've made a connection that can make a difference," Kathy says. "It makes us really proud that we're doing what we can."



10 years of support.

Pulmonary fibrosis is a disease with uncertain origins and no known cure. But the research community believes it is a lot closer to answers thanks to funding from the Pulmonary Fibrosis Foundation. Imre Noth, M.D., a leading pulmonary physician and researcher at the University of Chicago, stated that when he started working in the field, "There were few ongoing clinical trials in pulmonary fibrosis. Now in any given year there are five to ten studies going on."

"If you are a simple betting man and you lay multiple chips on a roulette wheel, the likelihood of hitting success is much, much greater," he explained. "I think we are closer to finding answers and the things we're looking at are more interesting, more directed, and the science has matured, letting us get a better look," he predicted.

A cornerstone of the progress has been the establishment of the University of Chicago Center of Excellence by the Pulmonary Fibrosis Foundation. The money invested generated a robust clinical program, the start of a patient database, and investigations into gene expression data to look for biomarker activity in the blood that could cause pulmonary fibrosis.

The Center's start-up work led to the National Institutes of Health's funding that quadrupled the amount of money available at the University of Chicago to study the

disease. While much progress is being made, Dr. Noth added, the work is still in its infancy.

When Dr. Noth became a pulmonary researcher he was also offered the opportunity to participate in clinical trials for pulmonary fibrosis. "I took it with both hands and I just found it very, very interesting," he said. Today he works with patients in the University clinic, enrolls some patients in clinical trials, and runs the research laboratory investigating the causes of pulmonary fibrosis at the genetic and genomic level.

The problem is that pulmonary fibrosis doesn't get much attention outside the community that is affected, he explained. "It's really about increasing awareness so that more research money can be raised. The money that goes into research is directly proportionate to how much noise is made."

He believes the Pulmonary Fibrosis Foundation is critical to making that noise, raising awareness, and increasing opportunities for research funding. "It's a very young group and a disease that has not garnered a lot of attention," he added. "The result is we have a long, long road to go." But, with the Foundation's help, he is confident he and other researchers will get there.

"What motivates me is the need to fund research. I think that is paramount in the minds of people who have this disease. It's very important to fund research that's going to find the cause and hopefully from that, a cure."

-Barbara Murphy, patient

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Financial Summary

Net Assets and Liabilities

Audited Numbers		
	2010	2009
Total Net Assets	\$3,532,184	\$3,014,784
Total Liabilities	\$ 23,147	\$ 72,939
Total Liabilities & Net Assets	\$3,555,331	\$3,087,723

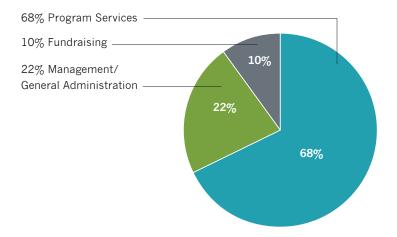
Revenue and Expenses

Audited Numbers		
	2010	2009
Total Revenue	\$1,627,376	\$1,156,582
Total Expenses	\$1,109,976	\$1,173,441
Surplus/Deficit	\$ 517,400	\$ (25,328)

Allocation of 2010 Expenses

Audited Numbers

Program Services	68%	\$751,109
Management/General Administration	22%	\$246,258
Fundraising	10%	\$112,609





Pulmonary Fibrosis