



PF NEWS

Pulmonary Fibrosis Foundation . . . finding a cure through Research, Education, and Advocacy.

Newsletter

Volume 6 Issue 2 - June 2006



A Message from the President:

After one year of planning, negotiating, and fund-raising, we have established the Pulmonary Fibrosis Research Institute. We received a pledge of \$250,000 from the University of Chicago School of Medicine, which, of course, is just a starting point, and will have to raise an additional \$500,000 annually to make this dream become a reality. This agreement will give us the power to hire our own dedicated research staff. Hopefully, this venture will lead to a cure for IPF, which has eluded us for many years. I feel that obtaining greater control over the quality of research will turn out more productive findings.

The Institute will be using office and lab space in The Ellen and Melvin Gordon Center for Integrative Science on the University of Chicago campus. The Gordon Center encompasses 400,000 square feet. The



or cutting-edge
21st century with
control cleanliness,
ner environmental
brosis Research
us company with
stry and Molecular
s Medical Institute,
rch Institute, and

the James Franck Institute.

*View of the Gordon Center for Integrative Science
Photo by Peter Kiar of the University of Chicago*

“We all dream of a day when there is less suffering and pain in the world. Thanks to institutions like the University of Chicago we have made enormous progress toward that day, but there is still much more to do,” said Ellen Gordon.

This dream will become a reality, but we will need the support of of the entire Pulmonary Fibrosis Community including patients, their family and friends, and all those wonderful people who have supported us in the past with their generous contributions. This is a unique opportunity, and we cannot let it fail. There has been research into Pulmonary Fibrosis for 35 years with extremely limited success. We now have a chance to find a cure. It is a tremendous opportunity, and we have no choice, but to seize it.

Michael Rosenzweig, Ph.D., President and CEO

June 2006

Inside this Issue

- Page 1 President’s Message
- Page 2 Introducing New Staff
Stamp Campaign
- Page 3 NHOPA
News In Brief
Refer a doctor
- Page 4 Hopes & Fears of a New
Generation
- Page 5 Organ Donation
Research News
Shop for a Cure
- Page 6 Painless Giving
Funding Explained
- Page 7 50/50 Campaign Update
- Page 8 Donation Form

Introducing Our New Staff

The Pulmonary Fibrosis Foundation has welcomed two new staff members in recent months.

Abigail McGlothen joined the Pulmonary Fibrosis Foundation as Communication Coordinator in February 2006 and was recently named Communication Director. She comes from a strong nonprofit background with The Center for Holocaust and Humanity Education and the University of Cincinnati, where she received her Bachelor of Arts in Communication. She brings to the team professional writing skill as well as media relations and publication design experience.

Along with the addition of a Communication Director, Myrrick Liontonia has been brought on board as the Foundation Administrative Assistant. Myrrick is an anthropology student at University of Illinois in Chicago.

The new employees join the already strong team of Dr. Michael Rosenzweig, President and CEO of the Foundation, and Leanne Storch, Executive Assistant and Patient Advocate. The Foundation is very excited to welcome these new team members and is confident that their skills will be valuable in the growing awareness of Pulmonary Fibrosis and support of the Foundation.



*The Pulmonary Fibrosis Foundation Staff
From left to right: Abigail McGlothen, Myrrick Liontonia, & Leanne Storch*

Stamp Campaign Reminder

The Pulmonary Fibrosis Foundation is still urging the Citizens Stamp Advisory Committee to issue a Pulmonary Fibrosis Awareness Stamp. We are encouraging everyone to inundate the committee members with letters asking them to acknowledge the widespread national significance of Pulmonary Fibrosis. Those wishing to participate in our letter writing campaign may write personal letters or request form letters from the Foundation. For more information, please visit www.pulmonaryfibrosis.org/stamp.htm or call 312.587.9272.



We Need to be Next!

Foundation Staff

Michael Rosenzweig, Ph.D.
President and CEO

Leanne Storch
Executive Assistant and Patient Advocate

Abigail McGlothen
Communication Director

Myrrick Liontonia
Administrative Assistant

Medical Advisory Board

David Kamp, MD – *Medical Director*
Kevin Brown, MD – *Chairman*
Marvin I. Schwarz, MD – *Past-Chairman*
Rany Condos, MD
Roland M. du Bois, MD
Gary W. Hunninghake, MD
Naftali Kaminski, MD
Joseph Lasky, MD
Geoffrey Laurent, Ph.D.
Joseph Lynch, MD
Albert Niden, MD
Imre Noth, MD
Ralph J. Panos, MD
Ganesh Raghun, MD
Jesse Roman, MD
Moises Selman, MD
Charlie Strange, MD
Robert Strieter, MD
Jacob Iasha Sznajder, MD
Galen Toews, MD
Rolf Ziesche, MD
David A. Zisman, MD

Board of Directors

Daniel Rose, M. D., *Board Chairman*
Michael Rosenzweig, Ph. D.
President and CEO
Joseph Borus, Esq.
Secretary
Leslie Bull
Nicol Corbin, M. D.
Gregory Davis, Esq.
Jennifer A. Galvin, M. D.
Thomas Hales
Heather Leverone
Joseph Maltese
Susan Rattner, M. D.
Nancy Rodriguez
Carl Salzano
Thomas Terrill

Organization Working for Oxygen Patients



The Foundation would like to inform our supporters of an excellent resource for those using supplemental oxygen. The National Home Oxygen Patients' Association (NHOPA) was established in the late 1990's to improve the lives of individuals who require supplementary oxygen on a regular basis.

The goals of NHOPA fall into four areas:

Education

NHOPA provides a wide range of information regarding supplementary oxygen including information on day-to-day care, traveling with oxygen, new technologies, current research, etc.

Grass Roots Activism

NHOPA works with its members to encourage state and federal policymakers to take into consideration patient input when developing health policies which may

affect patients who require supplementary oxygen. Anticipated issues include payment and coverage for home oxygen services, easing restrictions associated with air travel, and funding for continued research associated with home oxygen therapy.

Ombudsman

NHOPA recognizes that frequently patients have a difficult time communicating with their physician, Medicare, and their provider regarding their care. While the Association's budget precludes intervention on individual matters, the Association will serve as ombudsman when members identify recurring problems related to their care.

Research

As NHOPA grows, it hopes to coordinate its own research related to oxygen therapy, including new techniques that improve patient health.

For more information about NHOPA membership, visit www.homeoxygen.org.

News In Brief

Canadian Chapter

The Pulmonary Fibrosis Foundation has begun the process of opening a Canadian chapter. The chapter is in the very early stages, but we are excited about the expansion possibilities. Any individuals interested in helping our efforts should contact Linda Woodhouse, RN at 419-975-1613 or by email at lkwoodhouse@hotmail.com.



Research Registry

Please participate in our patient registry by completing a research questionnaire. We will be using this information to build a Pulmonary Fibrosis Database. The database will provide researchers with valuable information about similarities or differences among Pulmonary Fibrosis patients and help us better understand the causes of this disease. Contact the Foundation for a copy of the research questionnaire.

Refer a Doctor!

If you have doctor you want us to know about, please fill out this form and mail it to:

Pulmonary Fibrosis Foundation

1332 N. Halsted, Suite 201
Chicago, IL 60622-2691

Your Information:

Name: _____

Address: _____

City: _____

State: _____

Zip: _____

Phone Number: _____

Doctor Information:

Name: _____

Address: _____

City: _____

State: _____

Zip Code: _____

Phone Number: _____

Hospital: _____

Comments: _____

The Hopes and Fears of a New Generation

What is it like to look on helplessly as your loved ones are diagnosed, one after another with Pulmonary Fibrosis? When it all begins with a cousin from your own generation, followed by aunts, uncles, grandmother and your own father or mother being stricken with this deadly ailment? Is it something environmental that each was exposed to or is it something in our genetic makeup that pre-disposes us to this fate? The answers are elusive. The devastation is real. Is this disease to be our genetic inheritance?

I was asked by the staff of the Foundation to write an article about my family and the impact that this disease has had on our lives. This writing makes no attempt at answering what the scientific and medical communities have been working on solving for decades. Rather it documents the perspectives of my family members which are directly affected by these tragedies. Collectively, we believe that this disease is passed on genetically. It may have all started with environmental influences somewhere in our family history, but more startling is that it was passed on to our generation in the loss of our cousin, Karl Willacker.

As of this writing, we have lost eight Willacker family members to what we believe is the familial form of PF. Our grandmother, Florence, her children, Martin, Verta, Maxine, Doris, Donald, Vernon, and her grandson, Karl,

have all succumbed to PF.

All of our aunts, uncles, parents and grandparents grew up on a farm. There were exposures to animals, animal byproducts, fertilizers, well water used for everyday living, and wood-burning heating appliances. There were many things that could have contributed to the disease. But many generations of people in other families in this world grew up in those conditions as well. What made these

“this disease reaches beyond the patient and touches the souls of every family member and friend”

folks unique? Why were they more susceptible to these environmental exposures than anybody else? In Karl's case, he never lived on a farm. He grew up in suburbia away from all those elements.

Several family members have participated in testing with the research team at Duke University. We hope that these tests yield some answers to our questions. Even a little step toward discovering the causes would give hope to our family and the many other families who live with PF. We believe that more resources need to be dedicated to this research and the sooner the better.

If you are reading this you likely know someone close to you that is afflicted with this disease. We are well aware of the lack of treatments that can effectively reverse the damage caused by PF. The problem with this disease is that it reaches beyond the patient and touches the souls of every family member and friend that is close to the patient. We live with uncertainty, fear, sadness, grieving, anger and depression. Until there are answers and effective treatments, we have only our hopes and prayers to comfort us.

We support the efforts of the Pulmonary Fibrosis Foundation and the medical community in the hope that researchers will fulfill the promise of a brighter future for PF patients and their families. God bless all of you for your efforts to eradicate this killer disease.

The Pulmonary Fibrosis Foundation would like to thank Mr. Matthew Dery for sharing his story with our supporters. His family is hosting a fundraising event in memory of all those taken by this disease. More information on their event is listed below.

**If you would like to share your story with the Foundation, please call Leanne at 312-587-9272.*

The 2nd Annual Paddle Out Pulmonary Fibrosis Fundraiser

When: Saturday, August 5, 2006 □ **Where: Alcona County Park** □ **What: Canoeing and Picnic**

Camping is available Friday and Saturday nights at Alcona County Park and at the Alcona Canoe & Campground. Cabins are available at both facilities. Canoeing takes place on Saturday followed by a BBQ, picnic, and bonfire in the evening. Tubing trips are also available.

For those who don't like water... just come and enjoy staying dry!

For more information or to request a pledge sheet, contact:

Bob Gramer: 313-537-1970

Rick Dery: 248-360-1293



All proceeds go to the Pulmonary Fibrosis Foundation to support research to find the cure for Pulmonary Fibrosis.

Donate Life

Some Pulmonary Fibrosis patients have the option of getting a single or double lung transplant as a treatment for pulmonary fibrosis. In order to have this option available, viable organs need to be available. Despite continuing advances in medicine and technology, the demand for organs is vastly greater than the number of organ donors.

Organ donation is all about LIFE. When you donate your organs, you give someone the most precious gift - a chance to live. Transplants provide hope for thousands of people with organ failure. Your commitment to organ and tissue donation can save lives. **The most important part of deciding to be a donor is telling your family.** It means talking to your family about the opportunity to give another person a second chance at life and clearly stating your decision to be an organ donor.

Thousands of Americans are in need of vital organs and tissues. For many, the chance to live a full life won't come unless many more of us consider organ and tissue donation. Discuss organ donation with your family and friends. Help others find a chance to live a full life. Talk to your family about donating life.

Please visit the following websites for additional information on organ and tissue donation.

www.donatelife.net - Find out how to become an organ/tissue donor in your state

www.unos.org - United Network for Organ Sharing

www.transplantliving.org - Your prescription for transplant information

www.optn.org - The organ procurement and transplant network

www.trioweb.org - Transplant Recipients International Organization

Research News Updates

Advanced Genomics and Proteomics Improve the Diagnosis and Treatment of a Deadly Lung Disease

A study conducted by Foundation Medical Board Member, Dr. Naftali Kaminski, Dr. James Dauber, and their colleagues at the University of Pittsburgh identified a protein found in excess amounts in the lung tissue of patients with Idiopathic Pulmonary Fibrosis. The discovery of this protein may lead to more accurate diagnosis and may be the appropriate target for treatments. Read the full article at: <http://newsbureau.upmc.com/Science/DauberLungStudy2006.htm> (Source: University of Pittsburgh Medical Center)

Antifibrotic Effect of Hepatocyte Growth Factor Is Impaired in Lung Fibroblasts Isolated from African-Americans

Of the more than 40,000 persons who die each year in the U.S. from Pulmonary Fibrosis, the mortality rate among African-Americans is twice as high as Caucasians. Galina Bogatkevich, a physiologist from Belarus working at the Medical University of South Carolina, used modern physiological technology called proteomics to compare healthy and diseased lung fluid and found that a key growth factor that is supposed to inhibit fibrotic growth is malfunctioning. This proteomic approach finds lowered antifibrotic HGF among African-American patients. The study demonstrates that these effects may be due to the deficiency in c-Met receptor function. Bogatkevich says, "now that we know what to study, that further work on scleroderma (nine out of ten patients with scleroderma develop Pulmonary Fibrosis) itself will be more productive . . . and since PF develops from these diseases . . . going up stream in the pathogenesis could yield even more useful results. Read the full article at <http://www.news-medical.net/?id=17217>. (Source: www.news-medical.net)

Shop for a Cure

By shopping on the www.helpfightpf.com website you will create the opportunity to share information and promote awareness of Pulmonary Fibrosis.

One hundred percent of the proceeds from your purchases will go directly to research to find a cure for Pulmonary Fibrosis. You may purchase individual Pulmonary Fibrosis items OR purchase items in bulk for a fundraiser that you are hosting. You can even customize your merchandise. Put your family member's name on your t-shirt, the name of your fundraiser on a visor, or even a picture of your loved one on any of the items. Let your imagination run wild!!

Items available for purchase:

- Hats
- T-shirts
- Sweatshirts
- Visors
- Mugs
- Bracelets
- Tote Bags



Resources for Painless Giving

We understand that not everyone is in a position to make large contributions to the Foundation. However, the Internet has provided ways to make giving possible without digging deep into your pockets. Here are a few resources to consider:



The iGive charity mall has made it possible to give to the Pulmonary Fibrosis

Foundation just by shopping for the things you need. Simply open an account at www.igive.com, select your charity, and start shopping through the site's online mall. Every

time you make a purchase from a store in their mall, a percentage of your purchase is sent to the Foundation. The iGive mall features over 600 stores including Barnes and Noble, Drugstore.com, JCPenny, PetsMart, The Disney Store, and even The Wall Street Journal. There is no cost to join, and privacy is guaranteed. For information, visit www.igive.com.

Goodsearch is an Internet search engine powered by Yahoo! that allows you to donate to the Pulmonary



Fibrosis Foundation just by searching the Internet. Every time you search, money, which is generated by advertising, is donated to your cause. To start donating, go to www.goodsearch.com, and type Pulmonary Fibrosis Foundation into the "I'm supporting" window at the bottom of the screen. Then, click "verify," and our name will appear in the window. You are now set to begin searching and funding pulmonary fibrosis research.

Both sites have been profiled by the Wall Street Journal and Smartmoney.com as being safe and easy giving alternatives.

Funding Options Explained

The Foundation frequently receives calls asking about the various forms of donations. In order to clarify how we organize donations, we have broken them down as follows:

General Donations

A general donation is any gift made to the Foundation in the form of cash, check or credit card payment. These can be general or in honor or memory of a loved one. If the donation is made in someone's honor or memory, please include a short note with the person's name and the names and addresses of any family members who you would like to be notified of the donation.



Research Restricted v. Greatest Need

Any donation made to the Pulmonary Fibrosis Foundation can be restricted for research or used where the need is greatest. A Research

Restricted donation means that it cannot be used for any administrative costs. A Greatest Need donation means that it can be used for overhead costs such as postage, office equipment, and publications. In order for a donation to be restricted, it must be acknowledged that it should be. To do so, attach a small note to the donation or check the appropriate box if using a Foundation form. The exception is those donations made to an established memorial fund, which are always restricted for research.

Memorial Funds

While donations made in a loved one's honor or memory are welcomed, they may not necessarily be considered memorial funds. A memorial fund is established when the amount donated in a person's memory reaches \$10,000. This can be done either by an initial donation of that amount, or it can be accumulated over time. Families may request that the Foundation regularly update them with donation totals in

order to monitor progress toward a memorial fund. Memorial funds are 100% restricted for research.

Matching Gifts

The Pulmonary Fibrosis Foundation accepts matching gifts from any company willing to join its employees in the fight against Pulmonary Fibrosis. When you make a donation to the Foundation, be sure to check with your employer to see whether a matching gifts program is offered.

Donations can also be made in the form of securities, wills and bequests, annuities, and remainder trusts. For more information on these or any forms of donations, contact the Foundation at 312.587.9272. As always, the Foundation greatly appreciates all gifts regardless of size.

50/50 Campaign Update

Fundraising events are vital to the success of the Pulmonary Fibrosis Foundation. The Foundation would like to thank the following individuals for offering their time to host an event. More information about upcoming events can be found at www.pulmonaryfibrosis.org/events.htm.

The following events scheduled for later this year:

Arizona

- The Donna C. Price memorial archery "Shoot for a Cure" at Granite Mountain Archery range in Prescott.

Illinois

- Pub Crawl hosted by Jo Rexer and Del Krause

Massachusetts

- 2nd annual golf tournament hosted by Heather Leverone to honor her father, Bob Leverone and his best friend, Joe O'Leary who are battling pulmonary fibrosis.
- 2nd annual golf tournament in memory of Dick Hallion

Maryland

- Golf tournament hosted by Barb Hunter in honor of her good friend Greg Marble
- Benefit hosted by Carl Salzano in memory of his father, Joseph Salzano

Michigan

- 2nd Annual "Paddle out Pulmonary Fibrosis" canoe marathon *(full story on page 4)*

New Jersey

- Bowling party hosted by Stephanie Shupack in memory of her father, Ronald Schuster.
- Sandra Lewis will be hosting a benefit in the Princeton area to help find a cure for pulmonary fibrosis.

New York

- 3rd annual golf tournament hosted by board member Joe Maltese, Jr. to honor his father, Joe Maltese Sr.

Pennsylvania

- Rob Fiorillo and family are hosting a run and picnic – and will be raffling off a Harley Davidson!
- 2nd annual Wescoe Walk hosted by Jennifer Wescoe-Schaninger and family and friends in memory of her father, Ron Wescoe.

Virginia

- Marjorie Hodges is honoring the memory of her husband, King Hodges, by raising awareness and funds for pulmonary fibrosis through the Langley Speedway where he was the Vice President and GM.

By press time, eight events have been completed:

California

- Cathedral Oaks Athletic Club dedicated a one-hour swim to Marcia Rowlands who is currently battling pulmonary fibrosis. They swam a combined total of 127,335 yards and donated over \$2,000.00 to the Foundation.

Florida

- Maria Morgan is in the process of a letter writing campaign as well as raised awareness and funds for research by having a percentage of the seats sold at two Florida Panthers hockey games sent to the Pulmonary Fibrosis Foundation in memory of her mother, Olga Lopez

Massachusetts

- Doug Bernard and his family and friends hosted a fundraiser at the Quincy Knights of Columbus in memory of his mother, Judith A. Bernard.

Michigan

- Marion Genia hosted a "Celebrating, Life, Love and Family" benefit to help her brother-in-law Randy with the mounting health costs due to pulmonary fibrosis.

Missouri

- 4th annual "Washers for Wellness" tournament hosted by Jan Etling honoring Hank Hopfinger

New York

- 2nd annual cocktail party hosted by Shane Parouse and friends in memory of Jim Stephens – Former President of the Greater New York alumni Chapter of Arizona State University

Ohio

- 4th annual 2006 Mother's Day Gift Basket Raffle and bake sale hosted by Vicki L. Mountain in memory of Lawrence O. Bray.

Canada

- Tania Farrell hosted a Pub Event to remember her father, Peter Joseph Farrell.

Want to be Involved?

Fundraising and Awareness-raising doesn't have to be hard or time consuming. It can even be fun! Will you consider representing your state this year?

Call Leanne at the Pulmonary Fibrosis Foundation to plan your event.

PLEASE REMOVE ME FROM THE MAILING LIST

If you would like to be removed from the mailing list please fill out this form and mail it to:

Pulmonary Fibrosis Foundation
1332 N. Halsted, Suite 201
Chicago, IL 60622-2691

Name: _____

Address: _____

City: _____

State: _____

Zip: _____

Yes! I want to support the work of the Pulmonary Fibrosis Foundation by making a contribution.

Here's my check for: \$5,000 \$1,000 \$500 \$100 \$50 Other_____

Restrict my donation for Research **Use my gift where the need is greatest**

Name_____

Address_____

City_____ State_____ Zip_____

Phone_____ Email_____

Please send your check to:

**Pulmonary Fibrosis Foundation,
1332 N. Halsted Street, Suite 201,
Chicago, IL 60622**

If you would like to charge your Contribution: Visa MasterCard Discover American Express

Account Number_____ Expiration Date_____

Credit Card Contributions may also be made by Phone: (312) 587-9272 or Fax (312) 587-9273

Published quarterly by the **Pulmonary Fibrosis Foundation**, 1332 N. Halsted Street, Suite 201,
Chicago, IL 60622-2691

phone: 312.587.9272 **fax:** 312.587.9273 **email:** breathe@pulmonaryfibrosis.org

web: www.pulmonaryfibrosis.org

Pulmonary Fibrosis
Foundation

1332 N. Halsted Street, Suite 201
Chicago, IL 60622-2691

Nonprofit Org.
U.S. POSTAGE
PAID
PERMIT No. 178
Wilmette IL