

Pulmonary Fibrosis Foundation

finding a cure through Research, Education and Advocacy

Pulmonary Fibrosis Foundation Newsletter

Volume 8 Issue 4 - October 2005



PRESIDENT'S MESSAGE

Thus far the year of 2005 has been one of great achievements and some disappointments. This year we celebrated our fifth anniversary. During these five years we have developed from a small organization in Denver, Colorado to a point where we now have chapters in Chicago, (National Headquarters) New York, Washington D.C. and New England. If you would like to start a chapter in your area, please call 312.587.9272.

Another major achievement has been the establishment of a National Network for Clinical Research in Pulmonary Fibrosis funded by the National Institutes of Health. The network consists of 11 major research centers who will attempt to find a drug or combination of drugs which will be effective in the treatment of Pulmonary Fibrosis.

We have donated just under \$1,000,000 to various University Research Programs in the hope that they would find a cure for Pulmonary Fibrosis. Unfortunately, they have not found an effective treatment for the disease. This does not appear to be money well spent and is a major area of disappointment.

In order to have greater control over the quality of research we will be establishing the Pulmonary Fibrosis Research Institute. The focus of the institute will be on clinical research that will find an effective treatment for Pulmonary Fibrosis. We will hire only dedicated researchers who will have a 100% commitment to this goal. We estimate the cost of establishing the institute at \$10,000,000. The first million dollars has been pledged by an anonymous donor from New York. Raising the balance is now a top priority for the Foundation. We have no choice. We must find a cure! I have lost a brother, sister and innumerable friends to Pulmonary Fibrosis. I don't want to lose any others. If we all do our part we will succeed!

Michael Rosenzweig, Ph.D., President and CEO

October 2005

Inside this Issue

Stamp Campaign.....	2
Support Groups.....	2
Board of Directors.....	2
Clinical Trials.....	3
Ask Leanne.....	4
Fundraising in Massachusetts.....	4
Web Resources.....	4
50 in 50 Fundraisers.....	5
Re-Cap on our 5th Year Anniversary Event.....	6
Superman Letter.....	6
Volunteer of the summer.....	6
Pulmonary Fibrosis Merchandise.....	7
The oxygen "experience"	7

Pulmonary Fibrosis Foundation Stamp Campaign

Your help is needed!!! Please participate in a letter writing campaign to support the approval of a first-class Pulmonary Fibrosis stamp. The Advisory Committee only considers "events and themes of widespread national appeal and significance." It is quite possible that they do not know the widespread national significance of Pulmonary Fibrosis. Your letters will inform and educate them. We are asking each of you: family members of pulmonary fibrosis patients, pulmonary fibrosis patients, friends, coworkers, and caregivers to write multiple letters to the Advisory Committee. Let us tell them that this disease is insidious in nature and as of 2005 does not have a treatment let alone a cure. Let us tell them that the number of patients is increasing.....Let us tell them that Pulmonary Fibrosis is significant!!

The USPS receives about 50,000 requests a year for commemorative stamps, so this is a very selective process.

We Need to be Next!!

Please act today! Send your letter in support of a Pulmonary Fibrosis stamp to:

Citizens Stamp Advisory Committee
c/o Stamp Development
U.S. Postal Service
475 L'Enfant Plaza, SW, Room 5670
Washington, DC 20260-2437

For a sample letter please visit
<http://www.pulmonaryfibrosis.org/sletter.htm>
or call the Foundation at 312.587.9272



New Support Groups in Your Area

Support Groups are a place where education, hope and information are shared. They also are social events where people can be with others who are undergoing similar experiences. Knowing that you are not alone can provide emotional support and information; this reassurance can change how you cope with and feel about your illness.

Where: 27555 Diehl Rd - Naperville, IL
When: 1st Thursday of each month, 10:00-11:30 AM
Contact: Donna Serlin, BS, RRT, at (630) 527-3389

Where: Berkshire Medical Center - Pittsfield, MA
When: 3rd Thursday of each month 4:00-6:00 PM
Contact: Dolores Eckert at doleckert@msn.com

Where: Legacy Meridian Park Hospital - Tualatin, OR
When: 1st Thursday of the month, 3:00-4:30 PM
Contact: Karen Saveride at (503) 692-2158

Where: Inova Fairfax Hospital - Falls Church, VA
When: Varies
Contact: Jane Harrison at (703) 776-3203 or
jane.harrison@inova.com

For other on-going support groups in your area please refer to
<http://www.pulmonaryfibrosis.org/groups.htm>

Executive Committee

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An Introduction to Clinical Trials

What is a clinical trial?

A clinical trial is a research study using human volunteers to answer specific health questions. Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people. Interventional trials determine whether experimental treatments or new ways of using known therapies are safe and effective under controlled environments.

Why participate in a clinical trial?

Participants in clinical trials can gain access to new research treatments before they are widely available, and help others by contributing to medical research.

Who can participate in a clinical trial?

All clinical trials have guidelines about who can participate. Using inclusion/exclusion criteria is an important principle of medical research that helps to produce reliable results. These criteria are based on such factors as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. Some research studies seek participants with illnesses or conditions to be studied in the clinical trial, while others need healthy participants.

What happens during a clinical trial?

The clinical trial process depends on the kind of trial being conducted. The clinical trial team includes doctors, nurses and other health care professionals. They check the health of the participant at the beginning of the trial, give specific instructions for participating in the trial, monitor the participant carefully during the trial, and stay in touch after the trial is completed. For all types of trials, the participant works with the research team. Clinical trial participation is most successful when the protocol is carefully followed and there is frequent contact with the research staff.

What is informed consent?

Informed consent is the process of learning the key facts about a clinical trial before deciding whether or not to participate. To help someone decide whether or not to participate, the doctors and nurses involved in the trial explain the details of the study. Then the research team provides an informed consent document that includes details about the study, such as its purpose, duration, required procedures, and key contacts. Risks and potential benefits are explained in the informed consent document. The participant then decides whether or not to sign the document. Informed consent is not a contract, and the participant may withdraw from the trial at any time.

Risks Include

- There may be unpleasant, serious or even life-threatening side effects to experimental treatment
- The experimental treatment may not be effective for the participant
- The protocol may require more of their time and attention than would a non-protocol treatment, including trips to the study site, more treatments, hospital stays or complex dosage requirements
- There have been cases where participants have died while in the trial
- In most trials half of the participants receive a placebo which has no medical benefit
- Adverse reactions to the medication range from mild to life threatening

Current Clinical Trials



Clinical trials are generally conducted by Universities, research institutes and government agencies. They normally run for a period of 2 to 4 years. You should be prepared to devote the necessary time to these trials before making a commitment to them. Clinical trials that are currently accepting participants change over time. To get the latest available trials contact www.clinicaltrials.gov.

Treatment of Pulmonary Fibrosis with Thalidomide

Objective: Determine the safety, feasibility and efficacy of 400 mg. of thalidomide administered daily for one year in patients with idiopathic pulmonary fibrosis who have failed or are not candidates for treatment with corticosteroids and/ or cytotoxic drugs.

Eligibility: 50 years – 80 years, genders eligible for study: Both

Location: Johns Hopkins Medical Institutions located in Baltimore, Maryland

For more information: please refer to clinicaltrials.gov reference ID number #CG00519

IPF Registry

Objective: To create a database of demographics and samples in Idiopathic Pulmonary Fibrosis.

Eligibility: Genders eligible for study: Both, IPF diagnosis by ATS criteria or by tissue biopsy

Location: NYU School of Medicine

For more information: please contact Sue Chow at 212.263.6411 or sue.chow@med.nyu.edu

Study of GC1008 in Patients with Idiopathic Pulmonary Fibrosis (IPF)

Objective: Investigate whether GC1008, an antibody that neutralizes TGF β , is safe in treating patients with IPF. The highest dose without excessive side effects will be identified. Test will determine how long GC1008 is in the body and how it is excreted.

Eligibility: 18 years - 79 years, Genders eligible for study: Both

Location: National Jewish Medical Center, Denver, Colorado

For more information: please contact: Marianne Morrison at 303.270.2053 or MorrisonM@njc.org

ASK LEANNE

Dear Leanne,

Can I get a lung transplant?
Joe in Illinois

Due to the unpredictability of idiopathic pulmonary fibrosis, anyone who has the possibility of getting a lung transplant should at least look into it to see if it is an option. Your doctor can help you with this decision. At this point in time, it is the only cure for pulmonary fibrosis. Unfortunately, not all people qualify.

Your pulmonologist will put you through a battery of tests to make sure that you have no other pre-existing conditions. The transplant team needs you to be in the best physical shape you can be in.

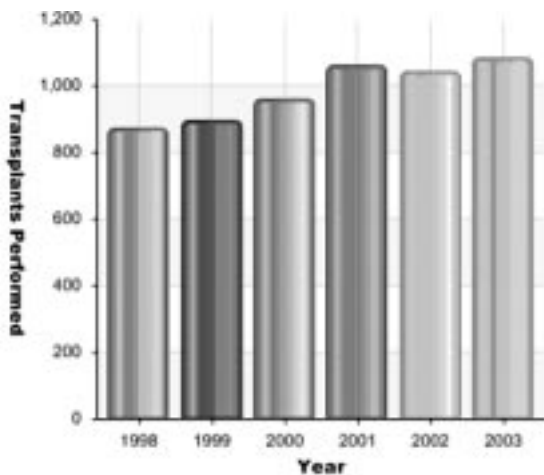
United Network for Organ Sharing (UNOS) has recently changed their transplantation guidelines. Once you have been accepted as a transplant candidate, you are registered on the national organ transplant waiting list. Every patient gets an allocation score to determine priority and this is updated every six months or less. Depending on the transplant center, age may not matter. The prior age cut off for most centers was 65, but now older people are being transplanted successfully.

Did you realize the first successful single lung transplant was performed in 1983 and a double lung transplant in 1986?

Lung transplantation is not an easy answer and not a choice for everyone. A friend of mine procrastinated about getting on the lung transplant list which ultimately limited his options. If it may be an option for you, you owe it to yourself to at least check it out.

Leanne

Great web resources if you are thinking about a transplant are:
www.unos.org www.transplantliving.org www.optn.org
For more information call: 888.894.6361



Check out Massachusetts

All across the state of Massachusetts communities are coming together to advocate educate and raise funds for Pulmonary Fibrosis!! During the months of September and October there have been three fantastic fundraising events. Heather Lippert, Rob Hallion, and Heather Leverone would not have known each other if Pulmonary Fibrosis had not brought them together. Today they have all become close friends and are planning to hold fundraisers throughout the years to come.

Heather Lippert lost her father, Jeffrey O. Congdon, to pulmonary fibrosis almost four years ago. Last year she held her first annual fundraiser in memory of her father and she did it again this year at Applefest Streetfair in Northborough, MA raising over \$4,000!

Rob Hallion lost his father, Dick Hallion to pulmonary fibrosis in March of this year. Not one to sit around, Rob and his family had their first annual Dick Hallion Golf Tournament at the New England Country Club in Bellingham, MA and raised over \$20,000!

Heather Leverone's father Bob Leverone and his good friend Joe O'Leary are currently battling the disease. The Leverone family and O'Leary family will host a golf tournament "Drive to a Cure" at Captain's Golf Course in Brewster, MA on Monday October 24, 2005. They have already raised \$30,000!

Web Resources

In addition to our website www.pulmonaryfibrosis.org we would like to suggest the following resources for pulmonary fibrosis.

<http://www.portableoxygen.org/flyingwitho2.html>

<http://www.nlm.nih.gov/services/guide.html>

<http://www.breathineasy.com>

<http://www.homeoxygen.org/>

<http://www.clinicaltrials.gov>

<http://www.publiclibraryofscience.org>

OUR GOAL FOR 2005 - 50 EVENTS in 50 STATES

**With all of your help we have raised over
\$100,000 in over 15 states and the year is not even over!!**



2005 UPCOMING EVENTS
CHECK YOUR STATE AND JOIN US!!
TO PLAN YOUR OWN EVENT PLEASE CONTACT THE FOUNDATION AT
312.587.9272

St. Augustine, FL- Stacey and Steven Stanfield are planning a Bike-a-Thon while their children have already sold lemonade in honor of their grandfather and raised \$500!! For more information, please call Stacey and Steven at: 904.827.9844.

Florida - Maria Morgan started a letter writing campaign in memory of her mother with sincere hope that the funds raised will generate hope for an effective treatment and a cure for Pulmonary Fibrosis. For more information, please contact Maria at: 305.423.3800.

Chicago, IL- LuAnn Luizza will host her 3rd Annual Cocktail Benefit in memory of her father Nicholas Mormando. The cocktail benefit will be in Chicago early November of 2005. For more information, please contact LuAnn at: 773.489.1648.

Chicago, IL- Teresa Amalfitano is donating 25% of her Mary Kay sales for the month of November and December in memory of her nephew Joey Amalfitano. To purchase Mary Kay products from Teresa please contact her at: 630.428.1348.

St. Louis, MO- Deborah Speas and her family made 100 fans and passed them out at Busch Stadium during the Cardinals vs. Astros game on July 17th, 2005 to raise awareness of Pulmonary Fibrosis in memory of her father Wilbert Crumes.

Brewster, MA- The Leverone family and O'Leary family will host a Golf Event, "Drive to a Cure" in honor of Bob Leverone and Joe O'Leary. It will be held at The Captains Golf Course in Brewster, MA on October 24, 2005. For more information, please email Heather Leverone at: hmlevrone@msn.com.

Short Hills, NJ- Maria Giambone will host a pot luck lunch at Bloomingdales Department Store in memory of her father who passed away September 2003. The event will take place on November 10, 2005. For more information please contact Maria at: 908.238.9885.

North Carolina- Tamara Watts a Pulmonary Fibrosis patient will Bike Across America beginning in Cape Hatteras, North Carolina. Tamara is planning to cover 40 miles per day "if my lungs hold out." For more information, please email Tamara at: tcabikeusa2005@yahoo.com.

Bethlehem, PA- The Wescoe family and their community are celebrating and remembering Ron Wescoe on Saturday, October 29, 2005. Join them on a 2 mile walk in Upper Saucon Township Park. For more information please email Jennifer Wescoe-Schaninger at: jwschaninger@hotmail.com.

Columbia, SC- Icy's Bar and Grill are hosting a Charity Golf Tournament in loving memory of Sarah Starkey. The golf tournament will take place at Woodcreek Farms Country Club on Tuesday, September 27, 2005. For more information please contact Rick Kerr at: 803.736.5775 or Patrick Mills at: 803.419.1500.

Texas/New Hampshire- Kathy Bascom collected favorite recipes of her sister Linda Bascom Taylor who died of PF. The recipe book is now available. All proceeds will be donated to the Pulmonary Fibrosis Foundation. For more information on how to purchase a recipe book, please contact Kathy at: 512.248.2838.

“An Evening of Recognition”
Fifth Year Anniversary Celebration

After a year of planning “An Evening of Recognition” was a success!! It was a night that brought people together in ways they didn’t think could happen. Over 100 people came from Chicago and the suburbs to as far as North Carolina and Florida to enjoy an evening that was dedicated to the progress that has been made by the Pulmonary Fibrosis Foundation in our short five years of operation. With only a staff of five, the office helps people deal with everything from diagnosis thru bereavement on a global level.

Guest enjoyed themselves at the Tasting Room in Chicago, nibbling on appetizers, sipping wine, and listening to jazz. But for all those who attended there was an even bigger reason, raising more money for research for pulmonary fibrosis, an incurable lung disease. Patients who were not able to attend but were able to participate included Ellie Olmstead of Janesville, WI who lovingly hand stitched a quilt in memory of all of those who have passed from this disease. Another great silent auction item was a jewelry box filled to the brim with antique and vintage jewelry donated by Barbara Syphrett in Texas. An added treat was the raffle. The winners of the raffle were:

- First Place: Wilda Lambert
Work of Art Basket
- Second Place: Todd Kramer
Sebastiani Wine
- Third Place: Scott and Helen McCullough
Broadway Lost Treasure DVD Set

The event would have not been successful without our generous corporate sponsors, individual donors, and in-kind donations. Our sponsors consisted of: The Chest Foundation, The Lung Association, Charter Steel, GaiaTech, and Merle Cooper. We would also like to thank Mayor Richard M. Daley, Governor Rod R. Blagojevich, Senator Barack Obama, Senator Richard J. Durbin and Attorney General Lisa Madigan. Thank you all for joining us for an evening of recognition.

Volunteer of the Summer

Thank You

Andrew Wong

For all of your hard work & dedication!!

Dear Pulmonary Fibrosis Foundation,

My name is Carolyn DeGrazia. I am eleven years old and my grandpa just passed away from the Pulmonary Fibrosis disease. He died at the very young age of 66 on June 21st, 2005. I miss him very much.

I just wanted to let you know that I appreciate everything that you are doing for people who have this horrible disease, from trying to find a cure to helping lot's of sick people.

My Grandpa was diagnosed with it two years ago but he was a fighter and he told jokes till the very last day. He touched about 700 people's lives including mine. His birthday was October 17th. The same year as superman and he was my superman. Still is!!

If there is something I could do or get more involved in learning about the dreadful disease that killed my BEST FRIEND FOREVER, let me know. Please! I loved him so much with all of my heart. Still do. Thank You!

Sincerely,

Carolyn DeGrazia



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: _____

Question??

Where is the place you can visit and create awareness, advocate and raise funds for Pulmonary Fibrosis Research??

www.helpfightpf.com

The Hewitt family from North Carolina recently lost a very special member of their family Paul Hewitt to Pulmonary Fibrosis. He was a loving husband, father, and grandfather. Paul was born in Vermont on April 29, 1952 and passed away on February 11, 2005 at the age of 52. Paul made a difference in everyone's life that he touched and his family and friends continue to miss him and ask why?? One thing that they do know is that Paul continues to make a difference in the world. To date contributions to the Pulmonary Fibrosis Foundation in the name of Paul Hewitt have totaled more than \$7,000.

The Hewitt family has decided to continue Paul's legacy and create a place where the Pulmonary Fibrosis Community can begin increasing awareness of a disease that is not well known across the country. By shopping on the **www.helpfightpf.com** website you will create the opportunity to share information about Pulmonary Fibrosis and promote awareness with others.

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. The Hewitt family has even gone as far as allowing you to customize your merchandise. Put you 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

Sharing the Oxygen Experience

Don "I have been on oxygen for 15 months. I know I have to use it and take it in stride"

You hold the key to your oxygen therapy and your life.

Grace "I have been on oxygen for 14 months, and it's like second nature. Without it, it's too silent! It doesn't bother me at all if people look at me - I just smile back!"

Marcia "Little children are inquiring minds that want to know. I didn't explain my oxygen situation well enough to one little inquiring mind because I heard a mother say to him "no it's not a fire extinguisher." Another child asked me if it was a pain in the butt to carry around. Fresh kid. I assured him that it was - he wanted to know in case he ever needed it. You just have to realize that you need it. It helps you go where you want to go and do what you want to do. It is a great adventure."

It is in your best interest to remain an active participant in choosing the oxygen system that is best suited for you.

Frank "My daughter had to convince me that oxygen was the way to go. I didn't want to be hassled with it. I was unable to walk across the street to get the mail. Now, I cut grass (on a riding mower) and I am able to do much more than when I was without oxygen." [like play with my grandkids!]

Pat "I was put on oxygen 6 years ago and really fought going on it because of how it looked and just the bother of it. In retrospect, I realize that without oxygen I may not be here and that I feel better when I use oxygen versus when I don't"

No, you can't get addicted to oxygen.

Everett "Don't think twice about it. It's something that I need and I do what it takes to be able to go out and do things. People stare at me but it doesn't bother me. It's a great teaching experience."

Pulmonary Fibrosis Foundation Staff

Michael Rosenzweig, Ph. D. Vakarie M. Roberts
President and CEO *Development Associate*

Leanne Storch Elyssa Jacobs
Executive Assistant *Communications Associate*

Jennifer Bulandr
Director of Community Relations

Yes, Sign Me Up! I want to support the work of the Pulmonary Fibrosis Foundation and would like to make a contribution.

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

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

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