



finding a cure

Pulmonary Fibrosis Foundation

through Research, Education and Advocacy

Pulmonary Fibrosis Foundation Newsletter

Volume 7 Issue 3 - July 2005

OUR MISSION

The Pulmonary Fibrosis Foundation is dedicated to finding a cure and raising awareness of Pulmonary Fibrosis. The Foundation is devoted to improving the quality of life for those diagnosed with Pulmonary Fibrosis. The Foundation provides hope and inspiration for patients through education, advocacy and funding for clinical research.

PRESIDENT'S MESSAGE



The first half of 2005 has been more successful than anyone of us could have possibly expected. After five years of not so gentle persuasion during over a dozen trips to Washington, the National Network for Clinical Research in Pulmonary Fibrosis is now a reality with eleven of the most prestigious research centers participating. They are planning their first meeting in June to coordinate their research efforts. It is expected that an effective treatment program will result from these efforts. We are grateful to the National Heart, Lung, and Blood Institute (NHLBI) for providing the funding.

In May 2005 at the International Conference, The American Thoracic Society gave the Foundation its second award in recognition of our outstanding efforts in the funding of research. Research funding continues to be the primary function of our Foundation.

Our Advocacy efforts have been equally successful. Senator Richard Durbin of Illinois has introduced into the congressional record a thorough description of Pulmonary Fibrosis including a poignant account of the disease's impact on an Illinois family. In addition, he praised the work of our Foundation in combating this disease. Senator Charles Schumer of New York inserted "Report Language" into the Appropriations Bill asking the NHLBI to increase the funding for research into Pulmonary Fibrosis. In addition he asked Senators Specter and Harkin to join in this effort. We have met with Representative Charlie Norwood of Georgia (an IPF patient who recently underwent a lung transplant) to draft a bill that would provide tax credits to organ donors. We will be conferring weekly to make certain that lungs are included and that the families of deceased donors receive similar benefits. It is hoped that this will result in overcoming the shortage of available lungs.

Our "50 in 50" Fundraising and Awareness program has gotten off to a fantastic start. We have had nine events thus far with commitments for 40 more. If your state is still unrepresented now is the time to join in. Call us at: 312.587.9272 for "how to" information.

We are making great strides in our Education efforts. The first printing of 15,000 copies of the Patient Handbook is down to only a few copies. Our Spanish language version is ready for the printer. The Physicians Handbook is undergoing final revisions. It is apparent that in every area of our Mission: Research, Advocacy, Awareness and Education, we have surpassed our most positive expectations. With your continued generosity in donations, we will meet and exceed our most optimistic goals.

Michael Rosenzweig, Ph. D., President and CEO

July 2005

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Save The Date



Join Us In Celebrating

The Pulmonary Fibrosis Foundation and Our Honory Chairmen Mayor Richard M. Daley Senator Cullerton and Governor Rod R. Blagojevich Invite you to *An Evening of Recognition Five Years of Progress in the Fight Against Pulmonary Fibrosis*
Additional Supporters: Senator Richard Durbin and Attorney General Lisa Madigan

Saturday, September 17th, 2005

The Tasting Room
1415 West Randolph Street
Chicago, IL 60607
7:00-11:00 PM

\$125 per person including 1 free raffle ticket with advance purchase
Admission at the door \$125
Purchase tickets by calling the Foundation at: 312.587.9272

Delight in the skyline of Chicago

Relax while the Damian Espinosa Trio plays for your listening enjoyment. Treat your taste buds to delicious appetizers, cocktails and mouth watering desserts while conversing with new friends.

Raffle & Silent Auction

Purchase a raffle ticket for \$25 and win great prizes and look forward to spectacular silent auction items

Tributes

Honor your loved one with a page in the program book. Please do not submit later than August 17th.

| | |
|--------------|----------|
| Quarter Page | \$75.00 |
| Half Page | \$150.00 |
| Full Page | \$300.00 |

Welcome Out of Town Guests

Please contact the Pulmonary Fibrosis Foundation for suggestions on hotel accommodations, dining and other Chicago Attractions.

**An Evening of Recognition
Five Years of Progress in the Fight Against Pulmonary Fibrosis**

Be an Individual Sponsor or Corporate Sponsor

Publicize your business and enjoy premium benefits while supporting research to find a cure for Pulmonary Fibrosis:

- Company signage or individual name prominently displayed at the event
- Special Recognition at the event
- Company's name or individual name will be printed in Chicagoland newspapers before and after the event
- TV and radio coverage
- Create an ad for our program book that directly effects the people you are supporting
- Exposure in our Foundation newsletter that reaches over 12,000 households across the United States

Place a Corporate Ad in the Program Book

Please do not submit later than August 17th, 2005

Quarter Page: \$125
Half Page: \$250
Full Page: \$500

Corporate and Individual Sponsors



Improving Life, One Breath at a Time

Merle Cooper

For more details on sponsorship levels or placing an ad in the program book, please contact the Foundation at 312.587.9272 or email at breathe@pulmonaryfibrosis.org.

Reservation Form

Number able to attend: _____
Name/Names: _____
Company: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: _____ Email: _____

I am not able to attend but wish to contribute \$: _____
Credit Card Type: _____
Account Number: _____
Exp. Date: _____

If billing address is different from mailing address, please write the billing address below:

Please make checks payable to the Pulmonary Fibrosis Foundation.

The Pulmonary Fibrosis Foundation is a 501(c)3 organization and all gifts are tax-deductible.

**The State of Illinois has proclaimed November
as Pulmonary Fibrosis Awareness Month &
November 22nd as Pulmonary Fibrosis Day**

We are grateful to Senator Cullerton who sponsored Senate Resolution No. 9

STATE OF ILLINOIS
NINETY-FOURTH GENERAL ASSEMBLY SENATE

Senate Resolution No.9
Offered by Senator John J. Cullerton

WHEREAS, Breathing is the single most important act we do to stay alive; and

WHEREAS; Pulmonary Fibrosis is a largely unknown disease that is often misdiagnosed and that most people have never heard of;

WHEREAS; Education of physicians and patients is critical; and

WHEREAS; Support from our communities is imperative so that more people can be aware of symptoms of this disease in order to obtain quicker diagnosis and earlier treatment; therefore, be it

RESOLVED, BY THE SENATE OF THE NINETY-FOURTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS that we proclaim the month of November 2005 as Pulmonary Fibrosis Awareness Month and November 22, 2005, as Pulmonary Fibrosis Awareness Day in the State of Illinois; and be it further

RESOLVED, That a suitable copy of this resolution be presented to the Pulmonary Fibrosis Foundation.

Adopted by the Senate, April 21, 2005.

If you would be interested in having your state adopt a similar resolution please contact Jennifer Bulandr at: 847-971-9669 or Jennifer@pulmonaryfibrosis.org
This is a great opportunity to have the entire United States made aware of our disease.



The Pulmonary Fibrosis Board Chairman, Dan Rose will participate in the Lake Placid Ironman on July 24, 2005 in memory of his father Albert Rose. Albert Rose was one of the founders of the Foundation and Dan is dedicated to continue research so that others may ultimately beat this disease. Dan is a physician and a fortunate cancer survivor (non-Hodgkins lymphoma) and personally knows the incredible benefits of medical research to find a cure for Pulmonary Fibrosis. His goal is to raise \$50,000 through his Ironman Race. All of the money raised will go to medical research to find a cure for Pulmonary Fibrosis. Through Dan's rigorous training, he will complete a 2.4 mile swimming course, 112 mile bike course, and 26.2 mile running course. If Dan succeeds in being amongst the top fundraisers, The Janus Group will make an additional contribution up to \$10,000 to the Pulmonary Fibrosis Foundation. Please help Dan reach his goal of \$50,000!! Donations may be sent to the Pulmonary Fibrosis Foundation at 1332 North Halsted Street, Suite 201, Chicago, Illinois, 60622 or on his website: <http://active.com/donate/imusa/dmrose>. Please note that your contribution is to support Dan's Ironman effort.



**For golfers and non-golfers, the New York State Pulmonary Fibrosis Foundation
Presents the 2nd Annual "Drive to a Cure" Golf Outing & Reception**

Headquartered in Utica, NY, the New York State Pulmonary Fibrosis Foundation (NYSPFF) is hosting the 2nd annual golf/reception benefit on August 21, 2005. This is the organization's major statewide fundraising event of the year and was established by the family and friends of Joseph F. Maltese, Sr., who died from Pulmonary Fibrosis in 2003.

When: Sunday, August 21, 2005
Where: Valley View Golf Club: Utica, NY

Sign-in: 11:00 a.m.
Lunch: Noon
Dinner/Award Reception: 6 p.m.



Guest of Honor: Anthony Chiffie, a successful lung transplant recipient who had Pulmonary Fibrosis
Special Guest: Michael Rosenzweig, Ph.D., President and CEO, Pulmonary Fibrosis Foundation
There will be excellent raffle prizes and exciting golf contests
The Hole in One Contest: Will win a new 2005 car from Carbone Motor Group

For additional details, or to volunteer, be an underwriter, place an ad in the program book or donate a prize, call 315-724-6512 or email: info@nyspff.org.

OUR GOAL FOR 2005 - 50 events in 50 states



UPCOMING EVENTS

CHECK YOUR STATE AND JOIN US!!

TO PLAN YOUR OWN EVENT PLEASE CONTACT THE FOUNDATION AT 312.587.9272

Vacaville, CA- Char Archibald is hosting the 3rd Annual Golf Tournament & Raffle in memory of Bernice Dunlop. It will be held in Vacaville, California on July 12, 2005. For more information, please call Char at: 707.864.9404.

St. Augustine, FL- Stacey and Steven Stanfield are planning a Bike-a-Thon while their children are selling lemonade in honor of their grandfather. For more information, please call Stacey and Steven at: 904.827.9844.

Chicago, IL- The Pulmonary Fibrosis Foundation is Celebrating 5 Years of Progress. It will be held in Chicago at The Tasting Room: 1415 West Randolph, Saturday September 17, 2005 from 7:00-11:00 PM. For more information, please contact the Foundation at: 312.587.9272.

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- John Galvin will participate in the Chicago Triathlon to raise awareness and research funds for Pulmonary Fibrosis. The triathlon will take place on Sunday, August 28th, at 7a.m. to 1p.m. at Chicago's Downtown Lakefront. For more information please contact John at: jgalvi1@uic.edu.

Brownsburg, IN- Tonya Olsen is hosting a car show in memory of her father Lonnie Califar who was a huge car fan. His car club, The Cluster Busters is facilitating the car show. The car show will be held on July 4, 2005. For more information please email Tonya at: tonya92572@sbcglobal.net.

Massachusetts- Christine Richard's is hosting a Fashion Show and Silent Auction in memory of her mother who passed away at the age of 56. For more information, please contact Christine at: 781.662.0860.

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.

Massachusetts- The Imperial Court of Massachusetts held, "A Night at the Sock Hop" on January 30th, 2005. The Sock Hop was in memory of Edward Muldoon and it was an absolute success!!

Michigan- Matthew and Fred (Chip) Dery will host a canoe fundraiser in memory of their mother and other relatives that have died from Pulmonary Fibrosis. The trip will be on the AuSable River in Northern Michigan on August 20 to August 21, 2005. Those interested in participating or sponsorship should contact Matthew Dery at: 248.541.5787.

Short Hills, NJ- Maria Giambrone 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 call Maria at: 908.238.9885.

Lake Placid, NY- Board Chairman, Dan Rose will participate in the Lake Placid Ironman Competition in memory of his father Albert Rose. He will be competing on July 24, 2005. For more information please contact the Foundation at: 312.587.9272.

Utica, NY- The New York State Pulmonary Fibrosis Foundation is hosting their 2nd Annual Golf/Reception Benefit. It will take place August, 21 2005 at Valley View Golf Club in Utica. For more information, please contact the New York State Pulmonary Fibrosis Foundation at: 315.724.6512.

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: tcbikeusa2005@yahoo.com.

Texas/New Hampshire- Kathy Bascom is collecting favorite recipes of her sister Linda Bascom Taylor who died of PF. The recipe book will be available July 1st. All proceeds will be donated to the Pulmonary Fibrosis Foundation. For more information, please contact Kathy at: 512.248.2838.

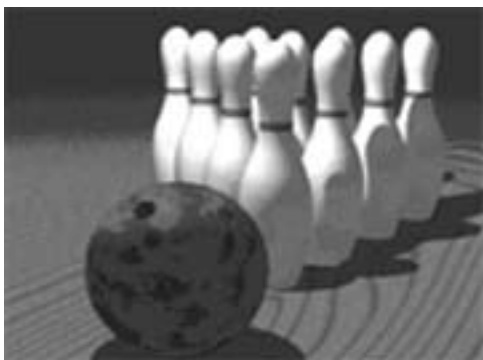
Eules, TX- Co-workers of Tammy Barnes are organizing a golf tournament. This tournament will take place on July 13, 2005 at 1:00p.m. For more information please contact Mark at: 817.685.1545 or Scott at: 817.685.1534.

Wisconsin- Elli Olmstead a PF patient has made a quilt. If interested in making a bid please contact the foundation at: 312.587.9272.

Your participation in these events will help us fulfill our mission. For updates check our website at: pulmonaryfibrosis.org/events.htm/

First Annual JAM for Pulmonary Fibrosis

“When I think of losing such a wonderful person to such a horrible disease it made me angry-so angry I needed to do something to try to fight it in my own way.” The Moran family decided to start their event small considering it was the first time anyone in the family had organized a fundraiser. Through brainstorming on what type of event to hold in memory of their dearly missed father, bowling seemed like a fun idea! “My dad’s initials were JAM- so we called our event “The First Annual JAM for Pulmonary Fibrosis.” Saturday, April 9th, 2005 was a complete success!! The Moran family raised over \$4,000 dollars and ALL of the proceeds came directly to the foundation. Who would have ever thought a fun night at the bowling alley could be such a hit!



Pulmonary Fibrosis Foundation Board Members

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Joseph Borus, Esq.
Secretary

Jennifer Bulandr
Director of Community Relations

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Jennifer A. Galvin, MD
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Joe Maltese, Jr.
Will McFarlane
Susan Rattner, MD
Nancy Rodriguez
Lemuel Tate
Tom Terrill

Creating Your Own Support Groups

Place to Meet

- The public library in your area has a meeting room for free or for a small fee
 - Community center in your town
- Churches will usually let you have a room for free or a small fee
 - Hospital or Medical Center
 - Public Schools
 - Restaurant

How often to meet and for how long?

- Monthly, bi-monthly, once a quarter
- Many groups meet for 2 hours: 1 hour for a speaker and the other hour for support group

Establish the focus of the group

The group decides on what the nature of the meetings would be like

Prepare a list of topics/activities/lectures

- Have a list of topics in case there is a lull
- If the group is interested in hearing from someone such as a Respiratory therapist then work on getting one to give a workshop

Advertise your group

- Some local newspapers have spaces for support groups
- Enlist your pulmonologist to give your information to their other Pulmonary Fibrosis Patients
- Contact your local Respiratory therapist to let them know about your group

This is only a short guide. If you are interested in starting your own group or have any questions please contact Jennifer Bulandr at: 847-971-9669 or Jennifer@pulmonaryfibrosis.org

Thank You

Villa Park Office Equipment

1120 North Villa Ave
Villa Park, IL 60181
www.vpoe.com

For Donating a Conference Table!!!

Schwab Returns to Marquette Sideline

"Basketball Times" written by: Lew Freedman

For the games, Trey was tethered to a portable oxygen tank, a life-generating apparatus that he dragged to the Marquette bench. Hard to coach that way. Hard to breathe that way.

But it was the only way. Schwab's lungs failed him. You open your mouth and you inhale, and the air flows freely. You never think twice about this most fundamental human process. Schwab had to think about it all the time.

He never complained, just wondered how what might have been a cold, might have been the flu, turned out to be idiopathic pulmonary fibrosis, a rare, incurable lung disease that he hadn't heard of and couldn't spell without a medical dictionary. The disease was killing him, and the only answer was a double lung transplant.

Schwab, who turned 40 in April, is stocky, built more like a hockey goalie than a basketball man, and his hair is manicured as short as a golf course. But well before he began a career in basketball, Schwab understood some of the ins and outs of the medical transplant world. His mother was killed in a car when he was 13, and she was a donor.



"I had always been aware of donors," Schwab said. "I knew early on that it could help people." He just never imagined that he might be one of them.

In 2003, Schwab served as a spokesman for National Donor Day, drawing him closer to the cause. About 18 people die every day awaiting transplants, he said. "I wouldn't have been around more than another month or two," Schwab said.

Schwab was part of the 2001-02 Marquette 26-7 resurgence and the 2002-03 Final Four joy ride. But as his condition deteriorated, Schwab depended on that oxygen tank. His carry-on bag for road trips was a cooler of ice containing medicine, syringes and experimental drugs. Then doctors feared a lung collapse and he had to drive to away games rather than flying with the team.

Conference USA fans took turns watching Schwab lug his oxygen to courtside, the tubes coming out of his nose, but Golden Eagle players saw Schwab every day.

It is frequently said of a passionate basketball man that he breathes basketball. For Schwab, it was literally true. Schwab kept working. Schwab made Marquette's travel plans, obtained videos for his boss, Tom Crean, and helped with recruiting.

The two hours or so at Marquette games was Schwab's respite, the only time he blocked out his illness. His cell phone had a particularly strong vibrator, just in case transplant news arrived during the game in a loud arena. The phone stayed silent.

It was a race. Would Schwab get the telephone call saying there was a donor of suitable organs before he died? Late in the afternoon of February 16, 2004, Schwab was sitting in his Marquette office when the summons came.

He had a suitcase in the trunk of his car and within 90 minutes Schwab was almost on the doorstep at the University Of Wisconsin Hospital when doctors called back and told him to forget it, the operation wasn't going to happen. Schwab drove back to Milwaukee and was within a half-mile of his home when a third call came through: "It's on."

"I wheeled around, drove back there and checked in," Schwab said. The nearly eight-hour operation began at 5:30 am on February 17th. Success.

The lungs belonged to a 19-year-old construction worker from Wisconsin who was hit in the head by a beam. The surgeon who operated on Schwab said he couldn't believe what kind of shape his lungs were in. Still, after the operation, Schwab was regaining strength and was preparing to move out of intensive care March 1st. On that day, he took a little walk, but quickly realized something was wrong and called for a nurse.

It was during recovery almost two weeks later that Schwab died. "I had no pulse," Schwab said. "No blood pressure. I was dead." For nearly an hour, he had no vital signs. The feel-good rescue had turned tragic.

Schwab was rushed back into surgery. A massive blood clot, Schwab was classified as clinically dead, and for 53 minutes, his system refused to respond to frantic CPR.

At a press conference a few days after the close call. Schwab's surgeon, Dr. Robert Love, said, "People don't survive if they go to the operating room with no cardiac function, which is the condition Trey was in." He said Schwab's recovery was "unexplainable, supernatural."

A little over three weeks later, Schwab showed up unannounced for a Marquette game, and there were tears in the locker room. He was not alive, and he came back," Diener said. "We're just happy he's with us. God must have been with him through the process and blessed his family.

Schwab takes a multitude of pills daily and submits to weekly lab tests, but he was on the job full-time for Marquette's recently completed 19-10 season.

When Marquette played Louisville on February 17th, Trey Schwab's thoughts sometimes drifted from basketball. He was celebrating his "new" birthday, and his year-old lungs inhaled the wonder of it all.

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

Please contact the foundation if you have moved or wish to be removed from our mailing list

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