

Breathe Bulletin



A Quarterly Newsletter of the
Pulmonary Fibrosis Foundation

Volume 7 Issue 1 - January 2007



President's Message

As 2006 drew to a close, I found myself looking back over the past year as well as the six years since the Foundation was started. I began to realize just how far we have come – growing from a one person to a six person staff, increasing research funding by more than 1.5 million dollars, and, the largest accomplishment of all, the creation of the Pulmonary Fibrosis Foundation Center of Excellence at the University of Chicago.

While I am proud of these successful milestones, I am saddened as I think of all those patients that were lost during 2006 and those whose health continues to deteriorate. These individuals have instilled in me a constant sense of urgency to find a cure and provide hope to patients, like myself, who are so desperately in need of it. This need for hope has led the Foundation to partner with the University of Chicago to form a Center of Excellence with the sole purpose being to increase understanding of pulmonary fibrosis and to find a cure.

We, as a community, may look back with trepidation over what seems like years of insufficient progress; however, it is important to remain optimistic about what the future may hold for this disease. The newly-formed Center has already begun work, and I am extremely confident in the possibilities presented by this endeavor. The Foundation will work closely with Dr. Joseph Garcia, Chairman of the Medical School, Dr. Imre Noth, Director, Interstitial Lung Disease Program, and the rest of the University of Chicago team to ensure that a strict focus is placed on finding treatments and a cure for pulmonary fibrosis. I feel that this increase in control over the quality of research will turn out more results than past studies have provided. More specific details about the objectives of the Center can be found on page 5.

A venture of this magnitude does not come without cost. The Foundation is committed to contributing \$1 million over a three year period. This means that the Foundation needs the support of the entire pulmonary fibrosis community. You can help us meet this challenge by joining our funding program. Your generosity is always greatly appreciated.

As we look forward into 2007, I hope all of you will keep in your thoughts and prayers those who are struggling with pulmonary fibrosis and also remember all those who have lost a loved one to this dreadful disease. I also hope you will continue to support the mission of the Pulmonary Fibrosis Foundation and work in your communities to raise awareness of pulmonary fibrosis. On behalf of the Foundation staff and myself, I wish you all a happy and fruitful new year!

Michael Rosenzweig, Ph.D., President and CEO

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Support Groups Offer Great Rewards

When dealing with a chronic illness, such as pulmonary fibrosis, support can be the most valuable coping mechanism available for both patients and their loved ones. A support group is a gathering of people who share a common condition or interest. Members of the group share their experiences and practical information about the way they cope with the disease and discuss treatments or therapies that have been beneficial to them. They also offer emotional comfort and moral support.

Good support groups can offer a variety of benefits, from the emotional to the practical. The benefits of support groups include:

- Making connections. Meeting others with pulmonary fibrosis may make you feel less alone or isolated. A safe and welcoming environment, filled with compassion and understanding, can also make you feel comfortable enough to share feelings about your condition that you may have been unable to share with your family and friends.
- Improving your coping skills. Support groups offer the chance to draw on collective experiences. Others who have “been there” may

have tips or advice about coping with the disease that hadn't occurred to you. Brainstorming with others may inspire even more ideas.

- Getting motivated. Support groups can encourage you to seek professional treatment if you haven't yet. They also may encourage you to take a more active role in your treatment or stick to your treatment



Members of the Pulmonary Fibrosis Foundation support group in Hammond, IN with Patient Advocate Leanne Storch

plan when you feel like giving up. Also, they may help you tap into community resources, such as supplemental oxygen providers and pulmonary rehab.

- Finding hope. Sharing experiences and making connections can make you feel better about life in general. Speaking with others who are battling pulmonary fibrosis may give you

hope about your own future.

There are a variety of support groups available to pulmonary fibrosis patients and their friends and family members. One option is the Pulmonary Fibrosis Foundation on-line support. The Foundation offers three groups: patient, caregiver, and grief. For those that may not be computer literate or do not have access to the Internet, another option is a face-to-face support group. These groups are generally run by volunteers or health care professionals in a community. These may be for specifically pulmonary fibrosis or they may be open to those suffering from a variety of lung diseases. For information about support groups in your area, please contact the Foundation at (312) 587-9272. If there is not a support group in your area, you may want to consider creating one (see opposite page for tips on starting a support group in your community).

You may be nervous about sharing personal issues with people you don't know. At first, you may reap benefits simply by listening. Over time, contributing your own ideas and experiences can help you get more out of a support group.

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Create a Support Group in Your Community

If you are interested in a face-to-face support group for pulmonary fibrosis but do not have one available in your community or are dissatisfied with what is offered, then you may want to consider creating your own group. Starting a group in your area provides you with all the support and benefits you seek and also allows you to provide a service to others in your community who may also be suffering from pulmonary fibrosis. Below are a few tips to help you get started:

- Choose a place for your group to meet. Keep in mind that the meeting place should be accessible to as many people as possible. Some examples include: restaurant, public library, community center, church, synagogue, hospital or medical center, public school, or your home.
- Decide how often you would like your group to meet—monthly, bi-monthly, once a quarter, etc. This can always be changed to meet the needs of the group members, but it is important to

start off with a set schedule of meetings.

- Determine if your group would benefit from guest speakers. Bringing in speakers can be a great way to serve the group in ways that you may not be able to. For example, bringing a counselor trained in the area of terminal illness. Other examples include: respiratory therapists, oxygen representatives, nutritional experts, doctors, etc.
- If desired, you may want to consider providing refreshments.
- Advertise and promote your group. Spread the word about your group to get more people involved. Post your group's information on the Pulmonary Fibrosis Foundation's website. Some local newspapers have space to advertise support groups. Contact local respiratory therapists to let them know about your group as well. Make up flyers for pulmonologists to give their pulmonary fibrosis patients.

When it comes time for your first meeting, contact your list of potential attendees to confirm the meeting time and place. If possible, keep the first meeting small—2 to 3 people at first is fine. Allow 1 to 2 hours for this meeting, and, then, you can let the group decide the time, length and place of future meetings. Introduce yourself and share your story. Invite others to share their stories, but no one should be forced to talk before they feel comfortable. Remember, the goal of a support group is to create a warm, non-judgmental atmosphere where members can talk about life's challenges without embarrassment as well as give support and encouragement to each other, so all information should be kept confidential within the group. Before the meeting ends, ask if anyone would be interested in helping to plan or run future meetings and assign specific roles to those who volunteer.

This is just a short guide to help you get started. If you are interested in starting your own group and you have any questions, please contact Leanne Storch at 312-587-9272 or by e-mail at ls_pulmonaryfibrosis@yahoo.com.

Celebrating a Year of On-Line Support

On November 7, the Pulmonary Fibrosis Foundation on-line support group celebrated its one year anniversary. The group has been a great success in its inaugural year growing to 303 members at the end of 2006 and has an average of 900 posts per month making it the most active on-line support group for pulmonary fibrosis patients. The group has also branched off to form groups for caregivers and those dealing with the loss of a loved one.

"The on-line support group has become a great resource for patients to learn about this disease and to relate to others dealing with the same problems," says Leanne Storch, Patient Advocate of the Pulmonary Fibrosis Foundation and group moderator. "It is invaluable to patients like me who want to share what they are going through and gain support and insight from others in the same situation."

To join the on-line patient support group, please visit <http://health.groups.yahoo.com/group/Breathe-Support/>. In July 2006, the Foundation created an on-line support group for those who are the primary support of patients with pulmonary fibrosis which can be accessed by visiting <http://health.groups.yahoo.com/group/Breathe-SupportCaregivers/>. A third support group for those grieving the loss of a loved one to pulmonary fibrosis was also created and can be viewed at <http://health.groups.yahoo.com/group/Breathe-SupportGrief/>.

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: _____

Proteins May Predict Lung Transplant Rejection

A recent study using the latest in high tech tools has given hope to patients seeking lung transplant surgeries. The study, conducted by a team at the University of Minnesota, Minneapolis, identified three proteins that were highly predictive of chronic lung rejection up to 20 months before the rejection occurred.

In the past, lung transplant patients have experienced the highest mortality rate of organ recipients. According to lead investigator and pulmonologist Chris Wendt, individuals who undergo a lung transplant may suffer from bouts of acute or chronic rejection. Acute rejection often responds to therapy whereas chronic rejection, which results in scarring of the lung's airways, is irreversible. In most cases, signs of chronic rejection appear too late to reverse it.

The researchers used the power of computers and new, sophisticated methods of analysis to find the proteins that form a "biosignature" or "biomarker" of organ rejection from among the thousands of proteins that exist in the lung.

"Preliminary evidence suggests these biomarkers will be an early sign of lung transplant rejection," the authors wrote. The research is continuing to determine which protein combinations are the best predictors and whether some biomarkers may be better than others at different points of the disease's development.

"We want to identify people at risk of chronic rejection before they have the clinical manifestations"

The information could offer inroads to new therapies, said Wendt. Doctors may be able to increase the dose of anti-rejection drugs when the early markers of rejection appear. Or, they may reduce anti-rejection drugs for people who do not show early signs of rejection. (Anti-rejection drugs have their own side effects, including an increased chance of developing kidney disease or malignancies.)

"We want to identify people at risk of

chronic rejection before they have the clinical manifestations," Wendt said. In addition to early identification, the researchers hope to eventually open the door to developing a preventative treatment and also gain insight into the physiological mechanisms of lung rejection.

The study, "Proteomic biomarkers of chronic lung allograft rejection," was carried out by Wendt, Tereza Cervenka, Madelaine Haddican, Yan Zhang and Gary Nelsestuen, of the University of Minnesota, Minneapolis.

In addition to pulmonary fibrosis, lung transplants are a common therapy for many other end-stage lung diseases including chronic obstructive pulmonary disease, cystic fibrosis, and pulmonary hypertension.

To view this article in its entirety, visit <http://www.medicalnewstoday.com/medicalnews.php?newsid=55929>.

(Source: The American Physiological Society)

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

Donation Amount: \$5,000 \$1,000 \$500 \$100 \$50 Other _____

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Account Number _____ Expiration Date _____

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

Foundation Establishes Center of Excellence in PF

The Pulmonary Fibrosis Foundation is excited to announce the establishment of a research program with the sole purpose of developing new treatment options for pulmonary fibrosis patients.

The Pulmonary Fibrosis Foundation Center of Excellence at the University of Chicago, which began operations in the fall 2006, provides a unique opportunity to launch a major program focusing exclusively on pulmonary fibrosis to generate new ideas, to promote research to enhance diagnostic and patient care programs and to establish a nucleus of activity to advance scientific knowledge concerning the causes and treatment of pulmonary fibrosis.

"It is my greatest hope that this endeavor will enable physician scientists to better understand the causes of pulmonary fibrosis and to more effectively treat it in order to improve the chance of survival for many individuals with this devastating disease," says Dr. Michael Rosenzweig, President and CEO of the Foundation.

The Center has the following three integrated cores:

1. The Clinical Research Core where patients will be entered into a carefully phenotyped IPF and lung transplant database critical for the success of any genomic and genetic strategies
2. The Genomic and Genetic Core will oversee the extensive gene expression studies and genome wide association studies planned as part of this initiative
3. The Animal Model of Lung Disease Core will develop the radiation rodent model of pulmonary fibrosis and continue the exciting development of the lung transplant rodent model.

Through these cores the Foundation hopes to meet the following objectives:

1. Build a robust phenotype-intense clinical research database and biobank in IPF and lung transplantation
2. Determine molecular signatures for both patients with "stable" IPF or lung transplantation and those with rapid progression

"It is my greatest hope that this endeavor will enable physician scientists . . . improve the chance of survival for many individuals with this devastating disease,"

of the disease

3. Conduct gene expression studies in humans and animal models to generate new candidate genes and novel molecular and therapeutic targets
4. Conduct genome wide association studies in a deeply phenotyped cohort of IPF and lung transplant patients
5. Develop and implement an animal model of pulmonary fibrosis
6. Develop and implement

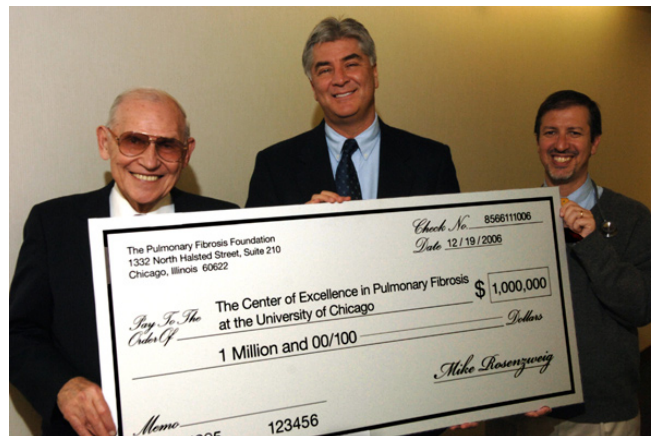
an animal model of lung transplantation

The Center is jointly led by Joseph G.N. Garcia, M.D. Ph.D., Chairman of the Department of Medicine, and Imre Noth, M.D., Assistant Professor of Medicine and Director of the University of Chicago Pulmonary Fibrosis Program. The research will be located at the Department of Medicine Laboratory and will utilize key members of its staff.

"We are extremely blessed to have at our disposal the minds and talent of Dr. Garcia, Dr. Noth, and the rest of the University of Chicago team," says Dr. Rosenzweig. "I am confident that if anyone can make progress toward a cure for this disease, then this team will be the one to do it."

To maintain consistent contact, the University of Chicago Department of Medicine will provide quarterly on site updates on the work of the Center of Excellence. These meetings will provide an opportunity for Foundation officers and directors to talk directly with faculty and researchers involved in the Center and address any questions or comments on a first hand basis.

The Foundation has agreed to contribute \$1 million over a three year period to the project. This grant will be used for the sole purpose of establishing the Pulmonary Fibrosis Foundation Center of Excellence at The University of Chicago. All funds will be directed to the research, diagnostic and patient care efforts in pulmonary fibrosis. No administrative or indirect costs will be charged to this award. For more information about the Pulmonary Fibrosis Foundation Center of Excellence at the University of Chicago, contact the Foundation at (312) 587-9272 or by e-mail at breathe@pulmonaryfibrosis.org.



Dr. Michael Rosenzweig, President and CEO of the Foundation, (left) presenting a check for \$1 million to Dr. Joseph Garcia, Chairman of the University of Chicago School of Medicine, (center) and Dr. Imre Noth, Director of the Pulmonary Fibrosis program at the University of Chicago (right).

Watch Those Wescoes Walk



Ron Wescoe may have left this world on October 29, 2004, but his memory continues to live on through the hard work and dedication of his family. The Wescoe Walk was born in an idea by Ron's daughter, Jennifer Wescoe-Schaninger, who sought a way to

his cheeks," says Jennifer of the first Wescoe Walk.

For the 2nd Annual Wescoe Walk, held on October 28, 2006, Jennifer wanted to focus on different avenues to remember her father as well as educate the public and raise funds for research. She decided to plant a memorial tree at the home of the Wescoe Walk, Upper Saucon Township Park.

"I chose a Red Bud tree with heart shaped leaves," says Jennifer. "This tree signified the love my family and our friends have for my Dad. During the walk, all our family and friends were able to see the tree and remember a great man."

able to see the tree and remember a great man."

Jennifer also reached out to educate the participants in three ways. First, she created an informational website, with the help of childhood friend Jill Brown. The site (www.wescoewalk.org) has information about the disease, a listing of local support groups for patients and families coping with pulmonary fibrosis, and details about



Participants at the 1st Annual Wescoe Walk

immortalize her father and at the same time raise awareness and funds for pulmonary fibrosis research.

The Wescoe family held the inaugural Wescoe Walk on October 28, 2005 at Upper Saucon Township Park in Center Valley, Pennsylvania. For Jennifer, raising funds was not enough. She felt she needed to educate people about this disease as well, so she invited her father's pulmonologist Dr. Gerard Petersen to speak briefly about the symptoms, prevalence, causes, and treatments of pulmonary fibrosis. The family also posted signs along the route reiterating all that Dr. Petersen discussed. The walk drew 150 participants and raised almost \$3,000 for the Foundation.

"We all knew that while we were walking my Dad was watching us with a big smile and tears rolling down

the Wescoe Walk. Secondly, Jennifer invited the local Cedar Crest College to conduct health screenings while participants waited for the walk to begin. Lastly, she again posted signs along the route specifying the symptoms, prevalence, causes, treatments, and how to live with pulmonary fibrosis.

Despite being stricken with torrential downpours the day of the walk, the 2nd Annual Wescoe was a great success



Participant gets a health screening from Cedar Crest College student at the 2nd Annual Wescoe Walk

drawing 75 participants and raising over \$2,300 for the Foundation. Local television station, WFMZ Channel 69, also featured the event on its evening news.

"I thought to myself, someone out there, watching the local news, might not have heard about pulmonary fibrosis until now, and they might want to check out a cough and/or shortness of breath," says Jennifer. "The snowball is getting BIGGER!"

Planning for the 3rd Annual Wescoe Walk has already begun. The walk will be held on October 27, 2007 at Upper Saucon Township Park beginning at 9:00am. For more information, visit www.wescoewalk.org or call (484) 553-6340.



A Red Bud tree is planted at Saucon Township Park in memory of Ron Wescoe

The proceeds from the Wescoe Walk are divided between the Pulmonary Fibrosis Foundation and The Temple Lung Center in Philadelphia, Pennsylvania.

Jennifer has also offered her services to help the Foundation produce a handbook for other volunteers looking to host walks of their own. To request a copy of this handbook, please contact the Foundation at (312) 587-9272.

Help Kick Off the 2007 50 in 50 Fund raising Campaign

Want to help the Foundation beyond making a personal donation? Why not plan a fund raiser? Planning a fund raiser can be an opportunity for you to network, utilize your skills and enjoy yourself while supporting a good cause. A fund raiser does not have to be a huge black-tie event or cost thousands of dollars. Talk to your friends, family, and colleagues and ask them for ideas on what type of event would appeal to them. The list below can give you some ideas – use your imagination to add your special touch to your event.

Walk-a-thon/Marathon/Bike Ride: Contact your local park district, schools, etc., and ask for permission to sponsor a walkathon.

Golf Outing: Many of our patients and families have sponsored successful golf outings. Invite your friends, family, neighbors and colleagues to participate and include a dinner, lunch or reception. Ask sponsors to donate water, food, raffle prizes or solicit them to advertise on one of the golf holes.

Restaurant/Bar Event: Ask your favorite restaurant or local tavern to help you hold a fund raiser. You can ask guests for admittance donations or buy tickets in advance and provide them with a free beverage ticket or free appetizers.

Raffle Basket/Silent Auction: A successful raffle or silent auction is dependent upon the generosity of sponsors and the willingness of guests to purchase a ticket or bid on an item. Both should hold a variety of items to appeal to many interests.

Bingo night: Host a Bingo Night at your church or banquet hall. Invite friends, family and neighbors. Advertise there will be a small buffet table. Proceeds will be donated to the Pulmonary Fibrosis Foundation.

Entrepreneur: Do you own your own business? Perhaps you sell jewelry, artwork, or t-shirts. Inform your customers a percentage of their purchase(s) will go to the Foundation. This encourages people to purchase your product knowing that a portion of the sale goes toward philanthropy.

Garage/Yard sale: If you are planning to move or just want to get rid of the clutter, trade your junk for research. Proceeds from your sale will benefit research to find a cure.

The 50 Events in 50 States Fund raising Campaign aims to spread awareness of pulmonary fibrosis and raise funds for research across the nation. These fund raising events are vital to our success. The Foundation would like to thank the following individuals for offering their time to host an event. More information can be found at www.pulmonaryfibrosis.org/events.htm.

Events scheduled for 2007:

California

- A wine tasting will be held on September 5th in memory of Wilbur Smith

New Jersey

- Sandra Lewis will be hosting “A breath of fresh air” cocktail party in honor of her mother Judy Bean on May 11th

New York

- Charity wine tasting on January 18th hosted by Greater New York Alumni Chapter of Arizona State University in memory of its former president Jim Stephens
- Bike and Poker Run on June 16th in Vernon, NY held by Mary Jane Borst

North Carolina

- Robbie Knievel motorcycle jump in Raleigh on March 17th

Ohio

- Charity Improv Comedy Show at The Shoe Factory Antique Mall in Lebanon, OH hosted by Matt Derda on January 19th & 20th in memory of Fred Leeds

Tennessee

- Jeff Schnieder motorcycle jump at Smokey Mountain Harley Davidson in April

In lieu of gifts (birthday, holiday, etc.): A good way to remember or honor a loved one is to send a donation to their favorite charity, the Pulmonary Fibrosis Foundation.

Wine tasting: Is an intimate and fun event to share more information about the Foundation and raise money.

The Foundation's Events Coordinator Krysten Knievel is available to help any one interested in planning a fund raiser regardless of size. To speak with Krysten or to request the Foundation's Event Planning Guide, please call (312) 587-9272.

The Pulmonary Fibrosis Foundation would like to extend a heartfelt thank you to all the amazing volunteers who offered their time to host fund raising events in 2006 with a total of \$153,113.00 raised.

Shane Parouse, Doug Bernard, Maria Morgan, Tania Farrell, Jasmin Powell, Rachel Wilgoren, Stephanie Shupack, Andrew Weinfeld, Rob Fiorillo, Fred Price, Krysten Knievel, Alicia Knievel Vincent, Matt Dery, Rick Dery, Bob Grarner, Barb Hunter, Joe Maltese, Jr., The Leverone and O'Leary Families, Ken Galyas, Todd Kramer, Rob Hallion, Jennifer Wescoe-Schaninger, Doug Danger, Vicki Mountain, Alan Noah, Amy Elers, Heather Lippert, Joseph DeGrazia, AJ Jackson, Jerry McClellan, Leslie Bull, Kathy Bascom, Maureen Chambers & the Cathedral Oaks Athletic Club Master Swimmers

Laughter is the Best Medicine

Laughter has long been noted for having a positive effect on mental and emotional health, but now it may be beneficial for lung health as well.

Researchers at the University of Maryland School of Medicine found in 2005 that laughing causes the inner linings of blood vessels to dilate or expand to increase blood flow. Laughter exercises also work the diaphragm and encourage deep breaths, which is particularly helpful for patients with chronic respiratory diseases such as pulmonary fibrosis.

A local respiratory therapist for Christ Medical Center in Oak Lawn, Illinois, Brenda Celmer, traveled to Toronto, Canada for a two-day course to become a "certified laugh leader" through the World Laughter Tour. Celmer used what she learned to introduce a series of silly and humorous exercises to her monthly Easy Breather sessions.

"The World Laughter Tour espouses to the belief that laughter can bring about peace and joy, and I wanted to be a part

of that," says Celmer. "Once I completed the workshop, I realized that in addition to benefiting the general population, the population of people with chronic lung disease would reap huge benefits as well, and I couldn't wait to try it with the patients in my rehab program."



Brenda Celmer and the Oaklawn Easy Breathers Support Group

According to Celmer, her group members not only love the laughter itself, but have experienced many healthy benefits as well including "better air movement in and out of the lungs, good exercise of the diaphragm

and the intercostals, and, frequently, the laughter can be a form of airway clearance."

"It's not a stand-up comic routine," says Celmer. "I teach people to laugh at nothing and yet at everything."

Celmer uses laughter-inducing exercises in her group such as pretending you have ants in your pants, riding an imaginary roller coaster, and other visual humor.

Celmer's Easy Breather group meets every third Monday of the month from 1pm to 3pm at the Oak View Center in Oak Lawn, IL. She also travels to bring the benefits of laughter therapy to others. In February, she will be at a conference for Hermansky-Pudlak Syndrome patients and, in March, she will present at the annual conference for Illinois Society for Cardiopulmonary Health and Rehabilitation. For more information on how to incorporate laughter into your group or session, please contact the Foundation at (312) 587-9272.



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