

# Breathe Bulletin



A Quarterly Newsletter of the  
Pulmonary Fibrosis Foundation  
Volume 7 Issue 3 - September 2007



## President's Message

New research indicates that an effective treatment for Pulmonary Fibrosis may be closer than initially thought. This is based upon a number of factors. The first of which is that we now have a greater understanding of the disease. This involves both the etiology and the mechanisms underlying the factors which cause IPF to progress. There appears to be two forms of Pulmonary Fibrosis: one is the rapid progress form in which there is an "accelerated clinical course to end stage disease". According to Dr. Moises Selman this group consists predominately of males who smoke. The second form of "slow progressors" showed genetic differences from the first group. (see page 4)



Research at Rice University has found a naturally occurring blood protein called serum amyloid P (SAP) which has proven effectual at preventing fibrotic disease from developing in the hearts and lungs of lab animals. They are planning human trials shortly. (see page 4)

Gene therapy holds a great deal of promise as an effective treatment for IPF. However, there have been some high profile cases recently where gene therapy has caused severe illness and death. The main obstacles have been in designing safe and efficient delivery systems.

I recently participated in a stem cell research seminar in Burlington, Vermont. I was amazed at the progress that has taken place in the use of stem cells to fight an array of diseases. While embryonic stem cells remain the most reliable source of stem cells, research has discovered that amniotic fluid provides an efficacious source of stem cells. Orisis Therapeutics Inc. has developed an effective stem cell treatment for heart disease and is currently working on a similar method to treat lung disease.

Dr. Daniel Weiss of the University of Vermont and the Pulmonary Fibrosis Foundation are jointly setting up a research program which will use these stem cells to find an effective treatment for IPF. We are hoping to obtain NIH support for this research. Orisis has agreed to provide the stem cells at no cost to the research program. Your help and support will accelerate our efforts to find a cure for Pulmonary Fibrosis.

*Michael Rosenzweig, Ph.D.*  
President and CEO

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### **Disclaimer**

The material contained in this newsletter is for educational purposes only and should not be considered as medical advice. Always consult your Health Care Practitioner for treatment options and medical advice

## Julie climbs 46 mountains in Adirondack Park to raise funds for Research

Many of you do not know me so it would make perfect sense that you aren't aware of a small goal I have for myself. This summer, I am planning to become an Adirondack 46er. "What the heck is an Adirondack 46er??" you ask. Well, an Adirondack 46er is a person who climbs all 46 peaks over 4,000 feet in the Adirondack Park. While it is not quite in the same category as making an assault on Everest, becoming a 46er has been a goal that I have worked on achieving for several years now. This August, I hope to finally finish my goal on the summit of Whiteface Mountain, where I plan on celebrating at the top with my family and friends.



Adirondack Park

One person who will be unable to be there to help me celebrate is

my dad, Bo Willis. For the past 3 years, he has been suffering from pulmonary fibrosis. Pulmonary Fibrosis is an insidious and incurable disease that robs people of their ability to breathe and eventually to live. In my family it is a hereditary disease. It affects 5 million people worldwide. My dad has handled this disease with the same usual grace and courage that he has met all his life's challenges. Despite hopeless odds, both my Mom and Dad have remained upbeat. Their indomitable courage and unselfish love and devotion to one another have been inspirational to me. Theirs' has been one of my life's most cherished gifts.

In celebration of my climbing my final mountain, I want to honor my parents as they find the courage to climb their own mountain everyday in dealing with this horrible disease. I hope you will consider sponsoring me with \$1 a mountain or any other multiple of 46 that you feel is appropriate and make a donation in my father's name to the Pulmonary Fibrosis Foundation. The Pulmonary Fibrosis Foundation is a non profit organization run by people who are suffering themselves with this disease. 85% of your contribution will go directly to research.

You can write the check to Pulmonary Fibrosis Foundation, 1332 North Halsted St. Suite 201, Chicago, IL 60622. Any amount will be greatly appreciated.

Your donation (big or small) will give reaching the summit of this final peak a special meaning for me. Finishing will be bittersweet. Not having my dad and mom there when I finish will deeply sadden me. However, the knowledge that my efforts might help someone else afflicted with Pulmonary Fibrosis will provide me with tremendous joy. I am truly excited to finally complete my goal of climbing all 46 mountains. I hope the day I finish will be clear and sunny. With any luck, I will have a great view from the top! Thank you for your friendship and support.

Source: [Julie Willis O'Connor](#)



Julie O'Connor, Bo and Sally Willis

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## Congressman Brian Baird 3rd Congressional District, Washington State Works to Raise Awareness of Pulmonary Fibrosis

Washington, D.C. – Following the death of his colleague, Congressman Charlie Norwood of Georgia, from Idiopathic Pulmonary Fibrosis earlier this year, Congressman Brian Baird (WA-03) has joined Congressman Nathan Deal (R-GA) in introducing a resolution to bring much needed attention to this devastating disease.

“Pulmonary fibrosis is an often overlooked degenerative and debilitating disease,” said Congressman Baird. “My own father died of this disease, and my good friend and colleague Charlie Norwood died just a few months ago. It is my hope that with passage of this resolution we can increase awareness about this disease. We must aggressively pursue research opportunities into the causes of the disease, a treatment, and eventual cure.”

Idiopathic pulmonary fibrosis is a serious lung disorder causing progressive, incurable lung scarring and an irreversible loss of the lung tissue’s ability to transport oxygen. There is no known cause for this disease which affects

approximately 200,000 Americans, with 48,000 new cases diagnosed each year, representing a 158 percent rise in mortality since 2001. Two-thirds of idiopathic pulmonary fibrosis patients die within five years, and approximately 40,000 patients die each year.

The resolution calls for the designation of a “National Idiopathic Pulmonary Fibrosis” week; supports the work of advocates and organizations in educating and supporting those who suffer from pulmonary fibrosis and their families; and urges research into the causes, a treatment and eventual cure.

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## Senator A. Specter Introduced the Following Amendment to the 2008 Appropriations Bill on Pulmonary Fibrosis

“The Committee previously has expressed concern regarding the need to expand public health strategies to combat lung disease, particularly pulmonary fibrosis. Many individuals are

diagnosed too late to initiate treatment regimens that could reduce morbidity and mortality.

The Committee urges the NHLBI to increase funding for lung research, particularly in the area of pulmonary fibrosis. The Committee further urges the NHLBI to convene a consensus conference of experts in the area of lung disease and other stakeholders to lay the groundwork for a formal Pulmonary Fibrosis Disease Action Plan for prevention and control of this deadly disease.”

**We need your help. Please write your Senators and Representatives asking them to support this amendment.**



Senator A. Specter Dr. Mike Rosenzweig

# Pulmonary Fibrosis

## Extra-aggressive Form of Idiopathic Pulmonary Fibrosis Identified

Idiopathic pulmonary fibrosis (IPF) is a chronic and progressive lung disorder from which most patients die within 5 years after diagnosis. The disease is characterized by the insidious onset of dyspnea or cough and usually evolves slowly. Now, Selman and coworkers present strong evidence indicating that a subset of IPF patients has a short duration of symptoms before diagnosis and display an accelerated clinical course to end-stage disease. The authors postulate that these “rapid progressor” patients, predominantly males who smoke, represent a distinct clinical phenotype compared with the usual “slow progressors” patients.

“These findings highlight the variability in the progression and outcome of IPF, and may explain, in part, the difficulty in obtaining significant and reproducible results in studies of therapeutic interventions in patients with IPF,” said Dr Selman, who is the Director of Research at the National Institute of Respiratory Research in Mexico City and the lead author on this publication.

“They also suggest that physicians should pay more attention to the time of onset of symptoms, and to look for other signs that allow the identification of these rapid progressor patients.” In this study the authors performed global gene expression analysis and other molecular studies in a subset of patients and identified a number of genes that were differentially expressed in both groups. This suggests that rapid progressors are biologically distinct from slow progressors.

“While preliminary, these results may allow investigators to identify biomarkers of disease progression,” said Dr King, who is the Chief of Medicine at San Francisco General Hospital and an internationally renowned expert in research and management of pulmonary fibrosis.

The senior author on this paper, Dr Naftali Kaminski, who is the Director of the Simmons Center for Interstitial Lung Disease at the University of Pittsburgh, added that this research highlighted the need to collect as much information on patients with IPF as possible. “We are only now starting to really understand the disease and characterize it,” he said, “therefore, it is critical for patients with the disease to be seen in centers that are actively involved in IPF research.” Better identification and understanding of these differences may provide insights into the pathogenesis of IPF and assist in the development of therapeutic interventions for this devastating lung disease.

Source: [Science Daily](#)

## Breakthrough Could Prevent Multiple Fibrotic Diseases

A scientific breakthrough at Rice University could lead to the first treatment that prevents the build-up of deadly scar tissue in a broad class of diseases that account for an estimated 45 percent of U.S. deaths each year. “Fibrotic diseases kill so many people because they can crop up in almost any part of the body, and cardiac fibrosis is a particular problem for anyone who’s had a heart attack,” said Richard Gomer, professor of biochemistry and cell biology at Rice. “We’ve discovered a naturally occurring blood protein that

prevents dangerous scar tissue from forming.” The protein, which is called serum amyloid P, or SAP, has proven effective at preventing fibrotic disease from developing in the hearts and lungs of lab animals, and Gomer and colleagues hope it will eventually save thousands of lives once it is developed for human use. Fibrosis occurs when the body’s natural healing process goes awry, creating extra scar tissue that does more harm than good. There are dozens of fibrotic diseases, including atherosclerosis, asthma, cirrhosis, scleroderma and pulmonary fibrosis.

Since there are no FDA-approved treatments to prevent fibrotic tissue from forming, doctors typically consider fibrosis to be an irreversible process, and they try to slow it as much as possible with anti-inflammatory and immunosuppressive drugs. The biopharmaceutical company Promedior Inc., of Malvern, Pa., has licensed Rice’s SAP technology for use against fibrotic diseases. The company is engaged in animal testing, but has not yet set a date for the first human clinical trials of SAP.

Gomer said initial animal tests of SAP at Rice have proven very promising. The tests were conducted on animals that were pre-disposed to developing fibrotic disease in the lungs. The tests found that SAP treatment protected animals from developing dangerous scar tissue. Gomer said SAP is a naturally occurring protein that circulates in the bloodstream and plays a crucial role in regulating wound healing. SAP’s role is to inhibit the activity of immune cells called fibrocytes, which make excess collagen that the body uses to heal wounds.

Gomer said the tests at Rice show that SAP therapy was successful in preventing fibrotic scarring.

# Current Research

## Commentary A Paradigm Shift For Medical Research

The U.S. was founded on the radical notion that by independently pursuing our dreams we can build a future that's better for everyone. That's why it's always been home to great thinkers and doers, risk-takers and entrepreneurs--people who insist on questioning the status quo and finding a better path forward. That insistence, individual and collective, has made this country a world leader in many fields, including science and technology. Yet when it comes to the vast enterprise of biomedical research, there's room to question how well the system we've created serves our needs. Do we put enough emphasis on producing new therapies and cures for disease? Are we making progress fast enough in the eyes of the millions touched by illness or injury?

Over \$100 billion is spent on biomedical research each year. Roughly a third of that money goes toward expanding our understanding of the basic mechanisms of life. That seems reasonable: Basic research is vital to advancement over the long haul. The other two-thirds goes to the business end of things, where venture capitalists and the pharmaceutical industry are mostly concerned with making a profit for their shareholders. To patients observing from the sidelines, it can feel--on our cynical days--as if the lion's share of today's commercial investment focuses on tweaking innovations from a decade ago.

So we burn through this pile of cash, yet we're left with a major problem: Who's investing in innovation right now? Only a minuscule fraction of our current efforts are strategically allocated to converting basic discoveries into truly new

therapies. This is a higher-risk and higher-reward investment arena--for my money, a classic challenge for American ingenuity. Bold action today will pay off for years to come in the form of improved, practical treatments with a chance to benefit people living with disease now.

I'm certain we can achieve tangible results faster. In fact, that's the premise on which I set up my foundation, where we come to work every day to accelerate the best ideas on their path from the labs to the patients. Our goal is to improve the daily lives of people with Parkinson's disease today and find a cure within the decade. But this is a complex problem that requires a better strategy than throwing billions more dollars at biomedical research and hoping for the best.

It's time for a broad-based paradigm shift, one that reflects what America is all about: rapid innovation toward practical results that we can feel in our everyday lives. The good news: This actually isn't a question of throwing more money at the problem. (Not hitting up the taxpayers for more money--how's that for a radical notion?) It is a question of deploying our financial, scientific and intellectual capital differently, creatively and urgently and designing new solutions to complex challenges. Where we go from here is up to all of us.

Through our experience at the foundation, we know firsthand that America is home not only to many of the most talented and innovative people in the world, but also to some of its most generous. We must figure out how to hold onto the best of what we have--infrastructure and resources that attract the best and brightest scientists; the benefits that accrue from basic research--while pushing ourselves to go still further. Let's think big about new ways to stimulate innovation

and seed the drug development pipeline with the next generation of therapies assuring investors of transformative results--high returns on financial capital, yes, but also on human health.

It may be a tall order, but I'm optimistic. When we work together and use our talents and resources for the collective good, everything is possible. To me, that's the core of the American Dream.

by *Michael J. Fox*

## BioE confirms stem cell breakthrough in lung disease

BioE has confirmed its Multi-Lineage Progenitor Cell is the first human cord blood stem cell to differentiate into a type of lung cell. The study showed that the stem cell could differentiate into a type II alveolar lung cell. This advance in adult stem cell research could someday lead to treatments for patients with lung diseases. Type II alveolar cells are responsible for secreting a material that helps stabilize the lung's air sacs during respiration. The Multi-Lineage Progenitor Cell (MLPC) is a rare stem cell derived from human umbilical cord blood that was discovered by BioE and has shown the capacity to turn into multiple cell and tissue types.

As a result of the research the University of Minnesota and BioE recently entered into a joint research collaboration to further evaluate the use of the MLPC for creating airway epithelial cells, such as type II alveolar cells, that could aid in combating diseases such as emphysema, pulmonary fibrosis and pulmonary injury. This new research is expected to conclude in mid-2008.

By *Victoria Harrison*

## Experts Predict High Mortality Rates From Pulmonary Fibrosis Will Continue To Rise

Mortality rates from pulmonary fibrosis (PF) have increased significantly in recent years, and are predicted to continue to rise, according to researchers from the University of Colorado. Between 1992 and 2003, the age-adjusted mortality rate from PF--an often fatal disease which involves scarring of the lung--rose by nearly 28.4 percent in men, and 41.3 percent in women. Over the same time period, an increasing percentage of patients with PF died of the disease itself rather than of coexisting conditions.

“Rates rise with increasing age, are highest among older people, and are consistently higher in men than in women,” wrote the researchers. “However, mortality rates in women with PF are climbing more rapidly than in men.” Dr. Olson and five colleagues analyzed the cause of death listed on death certificates for more than 28 million decedents using data compiled by the National Center for Health Statistics. Of that larger group,

more than 175,000 deaths were linked to PF. In developing a model to predict future mortality rates, the researchers applied a multivariable analysis to current data, finding a predicted significant increase in men over the age of 65 and for women in all age categories. “Our study is the first large-scale study to examine age-, sex-, race-, and ethnicity-stratified mortality rates in decedents with PF,” said Dr. Olson.

In addition to finding a large disparity in mortality rates among women and men, which researchers suggest may be attributable to changes in historically gendered smoking patterns. The investigators also found significant geographical variation in mortality rates, but were unable to determine whether these differences represent true differences in mortality rates, which would suggest an environmental factor in the pathogenesis of PF, or if differences reflect variation in diagnostic criteria used and testing available in different localities, or

variation in coding and certifying cause-of-death on death certificates. Similarly, the researchers were unable to determine whether the increased percentage of patients with PF dying from the disease itself represents an improvement in treatments for commonly co-existing conditions such as cardiovascular disease, reflects diagnostic changes, or the result of a new classification system implemented in 1997 that excludes patients with more hopeful prognoses.

“Although once considered an orphan disease, our results suggest that PF should no longer be considered a rarity,” Dr. Olson concluded, noting that current death rates for the disease are higher than multiple myeloma and bladder cancer “These findings indicate an important and growing problem and provide an argument for more resources focused on the pathobiology of and therapy for this disease.”

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

## 2007 50/50 Calendar

The 50 Events in 50 States Fundraising Campaign creates awareness of pulmonary fibrosis and raises funds for research. These fundraising events are vital to our success. More information can be found at: [www.pulmonaryfibrosis.org/events.htm](http://www.pulmonaryfibrosis.org/events.htm). To host an event call (312) 587-9272

### The following events still scheduled for 2007:

#### California

- "An evening in Sonoma and Napa Valley" Winetasting event hosted by Kathryn Smith in memory of Wilbur Smith on September 5th

#### Florida

- Chris Burns ([www.cbradio.com](http://www.cbradio.com)) and CC Management are hosting a charity concert in memory of his Mom, Kathleen Burns on November 3rd.

#### Illinois

- Dinner Fundraiser in memory of Gjordis Keith hosted by Kim Lee on Oct. 7th

#### Massachusetts

- 3rd Annual Leverone/O'Leary "drive to a cure" golf tournament planned and organized by the O'Leary and Leverone families on October 1st

#### New Jersey

- Hope and Remembrance Ball - Hope for 9/11 Rescue Workers. Jessica Gilmour will be hosting a dinner/ cocktail party on September 27th in memory of her grandfather, Chief Robert Minugh

#### Pennsylvania

- 3rd Annual Wescoe Walk planned by Jennifer Wescoe-Schaninger - October 27th

#### Ohio

- Team Poleon - Race for Hope. Christine Poleon is running her 1st Marathon in honor of her father Robert Poleon

#### Texas

- Fundraising calendar sent out to family and friends in loving memory of Lisa Herschelman by her husband, Randy and family and friends
- John Robertson has plans to run a triathlon in memory of William Mosley Robertson to raise funds for the Foundation in November

### By press time, 23 events have been completed:

#### California

- 6th Annual Bernice F. Dunlop Golf Tournament hosted by her daughter Jasmin Powell

#### Connecticut

- Jon Allard ran a half marathon on June 24th in memory of Ann Urciuoli while raising funds for research

#### Georgia

- John Wade Event - Concert performed by the Dread Clampitts - Hosted by Jim Vianneau

#### Illinois

- Susan Heizer conducted a letter writing campaign to raise funds for the Foundation in honor of her sister Diana Larson

#### Massachusetts

- Doug Bernard and family hosted a fundraiser in memory of his mother, Judith A. Bernard and his Aunt Cheryl Williamson on April 21st
- CARS4ACURE - Car Show hosted by Doug Reinbold for Tom Mournighan on June 9th

### Completed events continued

#### Michigan

- 3rd Annual "Paddle out Pulmonary Fibrosis" canoe outing in memory of the Dery and Willacker families on August 4th organized by Matt & Fred Dery

#### Missouri

- "Washers for Wellnes" - In memory of Hank Hopfinger hosted by Jen Etling. [www.washersforwellnes.com](http://www.washersforwellnes.com)

#### Montana

- Evel Knievel days in Butte, July 26, 27 and 28th

#### New Hampshire

- Cathleen Brown completed a half marathon in honor of her mother Patricia Vaudreuil while raising funds for research on April 1st

#### New Jersey

- "A Breath of Fresh Air" cocktail party hosted by Sandra Lewis in honor of her mother Judy Bean on May 11th in Princeton
- Marilyn Fread participated in the NJ Marathon in memory of her good friend Bob Schmuldt

#### New York

- 3rd annual wine tasting hosted by Arizona State University Alumni in memory of Jim Stephens held on January 18th
- Texas Hold 'Em Tournament on June 23rd hosted by Mary Jane Borst in memory of her mother, Georgia Jean Williams Gorton
- "Love to find a cure" Tennis tournament hosted by Nancy Feldman on June 23rd in memory of her mother Ruth Lang
- 4th Annual "Drive to a Cure" in memory of Joe Maltese Sr. on August 19th
- Team Toby - Ongoing fundraiser in memory of Toby Wilgoren - [www.teamtoby.net](http://www.teamtoby.net)
- Julie Willis O'Connor has climbed all 46 of the Adirondack Park's highest peaks in honor of her father Bo Wills who suffers from Pulmonary Fibrosis. (see article on page 2)

#### Ohio

- "Comedy Rocks" Benefit held on January 19th and 20th in memory of Fred Leeds
- Lawrence Bray memorial barn sale hosted by Vicki Mountain
- Charity Golf Scramble in memory of Patricia J. Haueter

#### Pennsylvania

- 2nd annual benefit bike run and picnic hosted by Rob Fiorillo and family in memory of Barbara A. Fiorillo on June 30th

#### Texas

- Fathers's Day Concert held in memory of Greg Miller hosted by Janan Miller and family and friends on June 17th

**Total raised to date from 50 in 50 events - \$142,194.00**

## Breathing exercises: Decrease anxiety, strengthen lungs

*He who half breathes half lives. —Yoga proverb*

Certain breathing techniques can help compensate for the impaired lung function caused by pulmonary fibrosis, emphysema, or chronic bronchitis, and may even benefit people with healthy lungs by reducing stress, lowering blood pressure, and perhaps modestly boosting exercise capacity.

### Belly breathing.

Several studies have shown that learning to take deep, slow breaths—a feature of some yoga and meditation techniques—can ease stress and anxiety, which in turn may help protect the lungs. Moreover, it can also relax the blood vessels and, if done regularly, cause a sustained reduction in blood pressure. Most people can learn the technique by following these instructions: Place one hand on your belly, the other on your chest. Consciously relax your abdominal

muscles when you inhale, then gently tighten them as you exhale. Breathe in slowly and deeply through your nose, so that the hand on your abdomen moves more than the one on your chest. (Once you've mastered that, you can further deepen your breathing by expanding your chest right after your belly.) Then exhale slowly through pursed lips; it should take roughly twice as long to breathe out as in. Try to do the exercise once or twice a day for 10 to 15 minutes. And try to make belly breathing (without the extended exhalation) a regular habit throughout the day.

### Inspiratory muscle training.

Other exercises designed to strengthen the breathing muscles in your chest and abdomen may help people with emphysema,

chronic bronchitis, or pulmonary fibrosis, and possibly elite or even everyday athletes. These exercises require that as you breathe in, forcing you to inhale extra hard. Studies generally show that using the technique for about 3 minutes twice a day can produce a small but potentially important improvement in symptoms of emphysema and pulmonary fibrosis, and reduce reliance on medications. Less evidence supports the device's benefits in healthy people. One study found that practicing the technique for about 10 to 15 minutes a day, three times a week for two months, slightly increased how long average people could exercise at peak capacity. Several studies have shown that more rigorous training schedules can modestly improve the race times of elite cyclists, rowers, and swimmers.

*Source: Health Daily & Reuters News Service*



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