

Breathe Bulletin Goes Green

As of this issue, the *Breathe Bulletin* will be available exclusively online. The PFF wants to do what we can to reduce our impact on the environment. A virtual newsletter will save paper, save energy on printing and shipping, and will allow us to bring you the most up-to-date information. We are happy to accommodate those without access to the Internet.



If we do not currently have your email address, or if your email address has changed, please contact info@pulmonaryfibrosis.org or call 888-733-6741 to update your information.

Registration Now Open for the Inaugural IPF Summit



Please join us for our inaugural scientific conference on idiopathic pulmonary fibrosis (IPF), *IPF Summit 2011: From Bench to Bedside*, this December 1-3 in Chicago, Illinois.

The Summit will feature an innovative two-day continuing medical education (CME) program for physicians, researchers, registered nurses, and allied health professionals. Additionally there will be a separate one-day patient,

family member, and caregiver program to address the growing educational needs of the IPF community. As an adjunct to the Summit we will host the *New Decade, New Reach* dinner at the Chicago landmark Field Museum of Natural History in celebration of our tenth anniversary. You can register for the Summit and dinner at www.ipfsummit.org, or by calling our office at 888-733-6741. Early bird registration for the Summit is available through June 1, 2011.

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Genetic Discovery

A recent report published in the *New England Journal of Medicine* about a genetic discovery offers new hope in the fight against pulmonary fibrosis. Read the details on page 4.

Anniversary Dinner

Join us Friday, December 2, 2011 after the Summit when we will be celebrating our anniversary at The Field Museum with a special dinner. Find out how to join us on page 8.

Project PF

Read the details for our new call to action program, *Project PF*, that will raise awareness of pulmonary fibrosis on page 10.

Letter from the President



Dear Friends of the Foundation:

The Pulmonary Fibrosis Foundation (PFF) experienced a very successful year of service in 2010. Looking forward to 2011 – a year that marks our tenth anniversary – we hope to attain even greater accomplishments. With our anniversary comes a very ambitious set of milestones that will solidify our role as a leading foundation working to cure idiopathic pulmonary fibrosis (IPF).

Initially, I would like to thank everyone that participated in our year-end campaign. The response was most gratifying. The generous donations that we received will permit us to continue to fund original research, provide a broad range of educational activities, renew advocacy initiatives, and maintain our patient support programs.

We are proud to announce our inaugural health care conference, *IPF Summit 2011: From Bench to Bedside*, which will take place December 1-3, 2011 in Chicago. The *Summit* will feature two days of educational programming for physicians, researchers, and other health care professionals and one day of programming for patients, family members, and caregivers. The *Summit* will cover topics that are important to the IPF community and patients, family members, and caregivers will have the opportunity to participate in roundtable discussions with the experts.

As part of the *Summit*, the Foundation will host a tenth anniversary celebration dinner, *New Decade, New Reach*, on December 2, 2011 at the Field Museum of Natural History. The anniversary dinner will include award presentations and some very prominent guest speakers. We encourage all of you, if possible, to attend the *Summit* and the anniversary dinner. More information about these events can be found at www.ipfsummit.org.

In the coming year we will continue to fund original and innovative research through our “Young Investigator” program which we initiated this spring. Additionally, we have continued our unique partnership with the American Thoracic Society. This collaboration will provide \$200,000 in funding new research grants. Since our inception in 2000, the Foundation has awarded more than \$2,900,000 in grants.

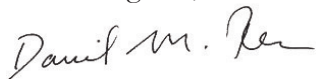
We are renewing our efforts to pass legislation to establish a national pulmonary fibrosis (PF) registry that will be an integral component in developing successful treatments for PF. Originally introduced in the House of Representatives in 2008, and the Senate in 2010, the Pulmonary Fibrosis Research Enhancement Act (PFREA) authorizes \$16 million to establish the first national patient registry for pulmonary fibrosis. This would be extremely beneficial in furthering understanding of the disease and developing successful therapies.

As a member of the PFF community we hope that you will join us in helping to increase disease awareness. The Foundation has many venues in which you can help us “spread the word.” One of the articles in the newsletter provides information on some of our advocacy programs, and how you can participate. **Our members and supporters are our biggest asset, and we want and need you to become involved!**

I would like to let you know that our *Breathe Bulletin* is going exclusively digital. We are doing this in an effort to decrease some expenses so that we can better utilize our funds to support research and patient programs. This will also help the Foundation in our efforts to go green and be more sensitive to the environment.

As always, we will continue to be a source of compassionate support and information for patients, families, and caregivers. The Foundation strives to offer resources and guidance to the PF community. We are continually trying to improve the methods with which we communicate and engage the PF community. We are here to help, empower, educate, advocate, and raise awareness and we will be here until we find a cure.

Warmest regards,



Daniel M. Rose, MD, President and CEO

Pulmonary Fibrosis Foundation

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Daniel Rose, MD
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Patti Tuomey, EdD
Chief Operating Officer

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Dolly Kervitsky, RCP, CCRC
Vice President, Patient Relations

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Associate Vice President,
Patient Outreach

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Director, Community Affairs

Paul Fogelberg
Director, Patient Advocacy

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Disclaimer

The material contained in this newsletter is for educational purposes only and should not be considered as medical advice. Consult your health care provider for treatment options.

Genetic Discovery Offers New Information in Fight Against Pulmonary Fibrosis

On April 20, 2011, the report — “A Common MUC5B Promoter Polymorphism and Pulmonary Fibrosis” was published by the *New England Journal of Medicine* about a genetic discovery that offers new hope in the fight against pulmonary fibrosis.

This study reports that a genetic variant in the MUC5B gene is associated with development of pulmonary fibrosis (PF). The MUC5B gene is part of a family of genes that produce mucin proteins in the lung and other body tissues. Lung mucus in the correct amount and viscosity is important in protecting the lung from inhaled environmental exposures and microorganisms. The findings in this study suggest that poorly regulated MUC5B expression in the lung may be involved in the development of pulmonary fibrosis. While there is not enough information to conclude that this genetic variant is causing idiopathic pulmonary fibrosis (IPF) or the familial form of the disease (FPF) it appears to be increasing the risk of developing IPF and FPF.

The MUC5B variant is reported to have a large effect in terms of risk of development of PF. Based on the findings in this study it is estimated that carrying one (1) copy of the genetic variation increases the risk for PF by 6 - 9 times and carrying two (2) copies of the variation increases risk by 20 - 22 times.

Further research is needed to more clearly define how the MUC5B genetic variant may be involved in the development of PF as well as how other genetic markers may be playing a role in this devastating disease.

Questions and Answers

Question: Is there a test available for MUC5B available and can I be tested?

Answer: A clinical test for this genetic variant is not currently available. There may be a clinically available test developed in the future for those who wish to be tested. Genetic counseling is recommended for anyone who is considering or undergoing genetic testing.

Question: Does the MUC5B genetic variation cause IPF and FPF?

Answer: There is currently not enough information to conclude that this genetic variant causes IPF and FPF. There is an *association*, and it appears that the genetic variation is increasing the *risk* of developing the disease.

Question: If MUC5B is increasing mucus production in the lung should I be taking medications to treat excess mucus?

Answer: More research is needed to better understand the association of this genetic variant and mucus production in the lung. It may be different than other lung diseases such as asthma and COPD. We encourage you to speak with your healthcare provider to determine what the best treatment approach is for your lung disease.

The Pulmonary Fibrosis Foundation encourages members to discuss how these findings may affect you and your family with a qualified genetic counselor and your healthcare provider. To speak with a certified genetic counselor with expertise in PF contact:

**Familial Pulmonary Fibrosis Genetic Counseling Line
National Jewish Health
1.800.423.8891 ext. 1097**

Education

Co-authors of this report will be guest speakers at our *IPF Summit 2011: From Bench to Bedside*. The titles of their sessions include:

Kevin K. Brown, MD — “Treatment Options and Drug Development in IPF”

Dolly Kervitsky, RCP, CCRC — “Understanding Research Trials”

Marvin I. Schwarz, MD — “Treatment Options in IPF”

David A. Schwartz, MD — “Genetic Basis of IPF”

Janet Talbert, MS, CGC — “Familial PF and Genetic Counseling for PF”

Ms. Talbert will also host a one hour roundtable discussion with attendees.

You can read the entire report from the *New England Journal of Medicine*, along with supplemental materials, on the [Pulmonary Fibrosis Foundation website](#).



Pulmonary Fibrosis Foundation names Dolly Kervitsky Vice President of Patient Relations

The Pulmonary Fibrosis Foundation (PFF) has appointed respiratory therapist and certified clinical research coordinator, Dolly Kervitsky, RCP, CCRC, as Vice President of Patient Relations. Ms. Kervitsky leaves leadership positions at National Jewish Health (NJH) where she served as the Program Manager for the Interstitial and Autoimmune Lung Disease Program and founded the Genetic Counseling Program for Familial Pulmonary Fibrosis.

“Dolly Kervitsky is a well-known leader and investigator in the world of interstitial lung disease and has worked with the Foundation since 2009 when she joined our Medical Advisory Board,” said Daniel M. Rose, MD, President and CEO. “We are thrilled to have Ms. Kervitsky join us. I am confident that she will provide superior leadership for our patient relations and research efforts.”

As Vice President of Patient Relations, Kervitsky will oversee patient programming, work with the Medical Advisory Board on the review and awarding of medical research grants, and will lead the development and implementation of a national patient surveillance registry.

“I’m excited to join the Foundation, to have the opportunity to continue to work with the PF clinical and scientific communities while providing support and services to patients, families, and caregivers is an honor,” said Ms. Kervitsky.

Ms. Kervitsky began her respiratory therapy career as a staff respiratory therapist in the Medical, Pediatric, and Burn and Trauma Intensive Care Units at the University of New Mexico. In 1981 Ms. Kervitsky joined National Jewish Health; in 1982 she was named Acting Director of the Respiratory Therapy Department. In 1983 she began working with PF patients and researchers as the Clinical Coordinator for the NIH funded Specialized Center of Research (SCOR) investigating idiopathic pulmonary fibrosis. This NIH project was instrumental to the development of the Interstitial and Autoimmune Lung Disease Program at National Jewish Health where Kervitsky was named the Program Manager in 1992. In 2008, Ms. Kervitsky founded the Genetic Counseling Program for Familial Pulmonary Fibrosis at National Jewish Health. She has served as lead coordinator and steering committee member for several international multi-center research trials. Additionally, Ms. Kervitsky is a member of the American Thoracic Society, American College of Chest Physicians, Association of Respiratory Care, and the Association of Clinical Research Professionals.

Upcoming Events and Fundraisers



Chicago Triathlon 2011 Charity Spots

The Pulmonary Fibrosis Foundation has 8 spots remaining for anyone who wants to participate and fundraise on our behalf in the Life Time Fitness Chicago Triathlon on August 26-28. “Held in downtown Chicago, the World’s Largest Triathlon weekend includes the Multi-Sport & Fitness Expo, the Chicago Kids Triathlon and Fleet Feet Sports SuperSprint.” We are requiring each participant to raise a minimum of \$500 to obtain one of the slots. If you are interested in securing a spot please visit www.pulmonaryfibrosis.org/2011ChicagoTriathlon.



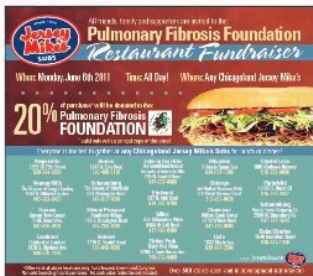
12 5Ks 4 Grandma

Lauren Williams has pledged to run in twelve 5K races this year (one every month), in memory of her grandmother who lost her battle with PF in 2007, to raise awareness and funds to fight this disease. Lauren is sharing her experiences throughout the year on her blog at <http://lnw125ks4grandma.wordpress.com>.



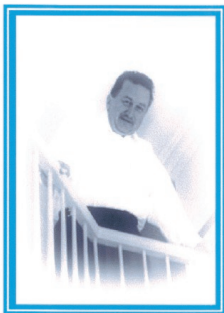
Rouine Run 5K Walk/Run

On June 5, 2011 the Rouine 5K Walk/Run for Pulmonary Fibrosis is being held in support of Mary Rouine, a PF patient who received a double lung transplant in May 2010. The race will take place at the Lowell Elks in Lowell, MA. To register for the run please visit pulmonaryfibrosis.donorpages.com/2011RouineRun.



Jersey Mike's Subs Fundraiser

On June 6, 2011 twenty Jersey Mike's locations in the Chicagoland area will participate in a fundraiser for the Pulmonary Fibrosis Foundation. Bring in a Jersey Mike's Restaurant Fundraiser flyer to any of the participating Jersey Mike's locations and they will donate 20% of your purchase to the Pulmonary Fibrosis Foundation. Download and print the flyer at pulmonaryfibrosis.org/jerseymikes.



Pete DeVito
Memorial
Foundation

Pete DeVito Memorial Foundation 1st Annual Golf Outing

The Pete DeVito Memorial Foundation, part of the Pulmonary Fibrosis Foundation’s Long Island Affiliate Group, is proud to announce its First Annual Golf Outing on June 3, 2011. Join them as they celebrate and remember the life of Pete DeVito and raise money to help find a cure and raise awareness for idiopathic pulmonary fibrosis. For more information please visit www.pulmonaryfibrosis.org/devito.

View all upcoming events at:

www.pulmonaryfibrosis.org/events

Recent Events

Bench Press for PF

February 11, 2011

Waterville, Maine



PF is a cause near and dear to the hearts of the Colby College men's lacrosse team. Two players' fathers were lost to the disease. This year marked the third year that the team muscled up to raise funds to benefit the Pulmonary Fibrosis Foundation. They raised over \$24,000—a record year for the team! We are looking forward to seeing them again next year!



Songs for Mike: A Benefit Evening Honoring Michael Kuchwara

February 28, 2011

New York, New York

PLAYBILL



Celebrating Michael Kuchwara
Monday, February 28, 2011 at 7PM - Birdland

Friends and colleagues of Associated Press theater critic Michael Kuchwara honored his memory with a musical tribute of his favorite Broadway songs on February 28 at Birdland in New York City. Kuchwara passed away from complications of idiopathic pulmonary fibrosis (IPF) in May of last year. Actress Julie Halston (whose husband had a lung transplant for IPF) hosted the event with her impeccable wit and comedic prowess and the show ended with a surprise guest appearance by Liza Minnelli. Ms. Minnelli sang three songs: “Confession” from “The Band Wagon,” “I Must Have That Man” from “Blackbirds of 1928,” and “And the World Goes ‘Round” from “New York, New York.” The event raised \$40,000 and will help spread much needed awareness of the disease.

See more pictures from Songs for Mike at www.pulmonaryfibrosis.org/pictures



Photo by Chris Onyoung



Photo by Chris Onyoung

Skate-A-Thon for Pulmonary Fibrosis

May 1, 2011



Jimmy Pelletier is a professional skateboarder and philanthropist from Washington D.C. On May 1st, Jimmy skateboarded 45 miles between Washington, D.C., Virginia, and Maryland to raise awareness and funds for the Pulmonary Fibrosis Foundation in memory of his childhood hero, Evel Knievel. Jimmy volunteered his company, “DC WHEELS,” to sponsor the entire event and raised funds through Crowdrise. Jimmy was able to exceed his goal of \$3,200 in donations. View a video of highlights from Jimmy’s 45 mile journey at vimeo.com/23345366.



The Pulmonary Fibrosis Foundation presents

IPF SUMMIT 2011

FROM BENCH TO BEDSIDE

DECEMBER 1-3, 2011
Marriott Magnificent Mile
Chicago, Illinois

In partnership with
 National Jewish Health
 The France Foundation



Registration is Now Open!

The Summit will feature an innovative two-day continuing medical education (CME) program for physicians, researchers, and other health professionals. Additionally there will be a separate one-day patient, family member, and caregiver program to address the growing educational needs of the IPF community on December 3, 2011.

The goal of the Summit sessions on December 3rd is to provide information important to the patients, families, and caregivers affected by pulmonary fibrosis (PF). The topics to be covered are intended to help patients and their families better understand pulmonary fibrosis and improve their quality of life. Webinars will be available for those who are unable to attend. Breakfast and lunch will be provided, and oxygen will be available onsite during Summit hours, upon advanced request, to patients with valid prescriptions.

Agenda topics will include:

- What is Pulmonary Fibrosis and What are the Causes?
- What are the Symptoms of PF and What are the Treatment Options?
- Lung Transplantation
- Familial Pulmonary Fibrosis and Genetic Counseling for PF
- Pulmonary Rehabilitation
- How to Establish a Support Group and the Benefits of Participation
- Understanding Research Trials
- Living with PF and How to Improve Quality of Life
- Advocating for PF Issues in Washington, D.C.
- Navigating Medicare and Health Insurance
- Understanding Hospice Care
- Roundtable discussions with the experts during lunch

***All details subject to change. Please refer to www.ipfsummit.org for up-to-date information.**



We invite you to join us for *New Decade, New Reach*, The Pulmonary Fibrosis Foundation's tenth anniversary celebration dinner. The anniversary dinner will be held as an adjunct to the Summit on December 2, 2011 at Chicago's landmark Field Museum of Natural History. The dinner will celebrate our ten year milestone, with a

look back at the last decade and a look forward to our goals for the next decade, highlighted by special guests and award presentations. Tickets for the dinner can be purchased for \$150 each and sponsorship opportunities, including dinner program tribute pages, are available.

Register for the Summit and purchase tickets to the dinner at www.ipfsummit.org.

Guest rooms are available at special rates before and after the Summit dates at the [Marriott hotel](#).

Public Health Threatened By Budget Cuts

Passed by the U.S. House of Representatives on February 19, 2011, H.R. 1 – the Full-Year Continuing Appropriations Act – would, if also passed by the Senate, result in massive budget cuts for the U.S. Environmental Protection Agency (EPA), the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and other agencies that help protect our lungs and general public health.

The Pulmonary Fibrosis Foundation strongly endorses the position of the American Lung Association in opposing passage of this bill. These budget cuts will have dire health consequences for all Americans, especially people with lung diseases including: pulmonary fibrosis, lung cancer, asthma, and emphysema.

Ramifications of the Act would be:

- The EPA's budget will be slashed by approximately one-third and the agency's ability to protect the public health from life-threatening air pollution will be severely limited.
- The CDC's budget will be reduced by 25 percent, limiting its ability to protect children from tobacco and severely hampering its ability to address diseases like asthma.
- The NIH's budget will be cut by \$1 billion—which means less research to find cures and treatments for diseases such as lung cancer, emphysema, and asthma.
- Implementation of the Affordable Care Act will be blocked, meaning pregnant women enrolled in Medicaid will no longer be guaranteed help in quitting smoking; seniors will once again face the Medicare prescription drug "doughnut hole"; and children with asthma will again be denied coverage because of their pre-existing condition.

We need your help. Please send a strong message to your Senators that they must protect public health by restoring funding for these critical agencies, by sending an email to your Senators now.

View a sample letter to send to your Member (courtesy ALA) at: www.pulmonaryfibrosis.org/hr1sample

Find your State Senator at: www.senate.gov/index.htm

This year we are continuing our efforts to pass the Pulmonary Fibrosis Research Enhancement Act (PFREA) through Congress. We also have other initiatives, such as our Stamp Letter Campaign, which our members can help us accomplish. Visit www.pulmonaryfibrosis.org/advocate to see how you can help in our advocacy efforts.



Project PF

A Call to Action!

Project PF is our exciting new grassroots campaign to raise much needed awareness and funds. *Project PF* is fun and easy and we want everyone to know that every action and dollar counts in the fight against PF. We will give you small, fun projects that you can easily accomplish to help the cause. Just think of the power that all of our Facebook friends and Crowdrise activists could have in making a difference to those affected by PF! Join us in *Project PF*!

How it works:

We will use social media to send out projects for everyone in the PFF community to accomplish. The tasks will be simple and easy to complete, but the aggregate results will have a significant impact. For instance, one of the projects we are working on this year is “10,000 for 10 Years,” where we are asking our members to recruit their friends and family to “Like” the PFF Facebook page to help us reach 10,000 fans to celebrate our tenth anniversary. We are currently at 6,300 fans, so please “Like” us now!

We will regularly post new projects, so make sure to check out PFF websites regularly!

Where to look:

The Pulmonary Fibrosis Foundation participates in many different social media websites that not only give you the opportunity to communicate with other PF community members but allow you to raise

funds. Most of you know about our two main social media sites, Facebook and Twitter. If you are new to the PFF social media community, please join us!

The Facebook logo, consisting of the word "facebook" in white lowercase letters on a blue rectangular background.

www.facebook.com/PulmonaryFibrosisFoundation

The Twitter logo, featuring the word "twitter" in a blue, rounded, lowercase font with a white outline.

twitter.com/PFFORG

Sorry, we do not have a Myspace page because, well, nobody has a Myspace page anymore.

The Crowdrise logo, which includes a circular icon with a stylized orange and red flame or 'C' shape, followed by the word "crowdrise" in a bold, lowercase, sans-serif font.

We have a page on Crowdrise, which is an online fundraising and social network website that actor Edward Norton helped create. On Crowdrise, anyone can create a fundraising page on for their favorite charity and the more active you are in the community, the more points Crowdrise will give you. The more points you earn, the more likely you are to win prizes such as an iPod or a bottle of suntan lotion signed by Will Farrell. Two of our members, Paul Fogelberg and Michelle Cox, have collectively raised over \$5,000 through Crowdrise. The site is a lot of fun and we guarantee that you will return to it frequently! You can see our page at

www.crowdrise.com/pffoundation

Awareness

We also have PFF Yahoo toolbar available for you to download and use to search the web. If you use the toolbar to search the web and then click on any sponsored link, ten cents will be donated to the Pulmonary Fibrosis Foundation. Go to the following link to download and install the toolbar. You will be given step by step instructions once you begin downloading.

www.benefitbar.com/benefitbar/subscribe/toolbar.php?toolbarId=10828

The projects:

We will be posting projects like “10,000 for 10 years” on all of our social media sites regularly to help raise awareness and funds. The projects will be posted in our status on Facebook, Twitter, and Crowdrise. Additionally, there is also a scrolling message that appears on the PFF Yahoo toolbar which will share the message.

The next project we are asking our members to complete is to make pulmonary fibrosis the most searched topic on yahoo.com by June 15, 2011. All you have to do is go to Yahoo and type pulmonary fibrosis in the search box and get your friends and family to do the same. It will literally take five seconds to complete this project. If enough people search pulmonary fibrosis then Yahoo will post it as one of the most searched topics. Everyone who visits Yahoo will see it! And, if you use your Yahoo PFF toolbar you can raise money as well!

We've Moved ... Again!

The Pulmonary Fibrosis Foundation is growing as an organization and with the recent addition of key staff members we require more working space. Therefore, the Foundation will be moving to a larger suite within our current building, from 303 to 204. The Foundation would like to thank our building management company, Dan Development, for accommodating our growth and allowing us to upgrade our space. Our new address is:

Pulmonary Fibrosis

FOUNDATION

811 West Evergreen Avenue

Suite 204

Chicago, IL 60642

P 888.733.6741

F 866.587.9158

info@pulmonaryfibrosis.org

www.pulmonaryfibrosis.org

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