

Pulmonary Fibrosis

FOUNDATION

BREATHE Bulletin

IPF Summit 2011 Edition

IPF Summit 2011 Live Webcast



Registration for the *IPF Summit 2011: From Bench to Bedside* is officially full. If you are unable to join us this December in Chicago for the *Summit* you can “virtually attend” via a live webcast available at www.pulmonaryfibrosis.org. On-demand broadcasts and webinars of the webcast will be offered following the *Summit*.

Find more information about the *Summit* webcast and satellite viewing sites on page 4.

New Decade, New Reach Tenth Anniversary Dinner

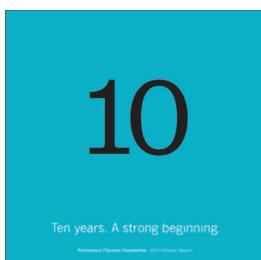
Tickets for the *New Decade, New Reach* dinner at the Field Museum in Chicago are still available. We invite you to join us as we reflect on ten years of service to the pulmonary fibrosis community.



Special guest speakers and an exclusive video presentation will be featured during the dinner.

Find out how you can purchase tickets on page 7.

2010 Annual Report



The PFF is pleased to share with you our 2010 annual report, now available on our website at www.pulmonaryfibrosis.org/report.

Highlighted in our annual report are stories of some of the patients, family members, and researchers who have been fighting this disease with us.

As the PFF finishes its first ten years, we look forward to implementing an ambitious agenda for our next decade.

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Oxygen at Summit

We would like to thank Lincare for supplying oxygen to patients during the Summit. See page 5 for details.

New Advocacy Tool

Learn how to send your legislators messages about PF issues in just seconds on page 8.

IPF Summit 2013

The dates have been set for the *IPF Summit 2013*. Mark your calendars! Announcement on page 5.

Letter from the President



Dear Friends of the Foundation:

This year is a milestone for the Pulmonary Fibrosis Foundation as we celebrate our tenth anniversary. The Foundation was the brainchild of my father Albert Rose and his brother Mike Rosenzweig, who both had recently been diagnosed with IPF. Their sister Claire had died from pulmonary fibrosis a few years earlier, and they felt a profound need to help find a cure for this devastating disease. My father died in early 2002, but his brother continued to work tirelessly and passionately to build the Foundation, fund research, and create a financially viable entity. Over the past decade the Foundation has also significantly expanded its support network and has become a beacon for those afflicted with this deadly disease. I am extremely honored to carry on their legacy as President and Chief Executive Officer for the Foundation.

I would like to thank everyone who has supported us through the past ten years with their compassion, energy, and financial support. Without your help we would not have been able to make these great strides.

As we near the end of 2011, I hope that you will join us at two major events that we have planned in December. The first is our inaugural conference, *IPF Summit 2011: From Bench to Bedside*, that will take place December 1-3, 2011 in Chicago. Although registration for the *Summit* is full we will be providing a live webcast to those who are unable to attend. Details for the webcast are provided in this issue.

The second event is our *New Decade, New Reach* tenth anniversary dinner, which will be held on December 2, 2011 at Chicago's landmark Field Museum. We will reflect on some of the accomplishments during the last decade and focus on our goals for the future. More information on the *New Decade, New Reach* dinner, including awards and guest speakers, is also highlighted in this issue.

Additionally, I am pleased to share with you our 2010 annual report, which is available to view on our website. The annual report describes some of the more notable events of the last year and highlights members of the pulmonary fibrosis community including patients, family members, and researchers. A link to the annual report is included in this issue of the *Breathe Bulletin*.

I have been doing quite a bit of traveling during the last few months attending some medical conferences, participating in fundraising events, and engaging in advocacy activities for the Pulmonary Fibrosis Research Enhancement Act. A couple of things have greatly impressed me. There is considerable interest in drug development for IPF. The research community is working hard to discover new and successful treatments. There are a number of exciting therapies that are in early development while others are working their way through the clinical trial process. Parenthetically, it is critically important for the patient community to participate in clinical trials. This is the only way we can develop new, effective therapeutic agents.

Finally, I am continually impressed and motivated by the courage and commitment of the patients and their family members. They are a constant source of inspiration for all of us that are associated with the Foundation, and I assure everyone that we will work tirelessly and passionately to find a cure for this illness!

Warmest regards,

A handwritten signature in black ink that reads "Daniel M. Rose". The signature is written in a cursive, flowing style.

Daniel M. Rose, MD
President and Chief Executive Officer

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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.

IPF SUMMIT 2011

FROM BENCH TO BEDSIDE

December 1-3, 2011 • Marriott Magnificent Mile • Chicago, Illinois



IPF Summit 2011 Live Webcast

An essential component of the Pulmonary Fibrosis Foundation's mission is to provide up-to-date information to patients, caregivers, and family members. Our inaugural *IPF Summit* is an integral part of this effort.

Topics for patient and caregiver sessions will include:

- What are the Symptoms of Pulmonary Fibrosis and What are the Treatment Options?
- Lung Transplantation
- Familial PF and Genetic Counseling
- Pulmonary Rehabilitation
- Establishing a Support Group
- The Why, How, and What of Clinical Trials
- Advocacy
- Navigating Medicare and Health Insurance
- Managing Advanced Disease and Hospice Care
- Living with PF and How to Improve Quality of Life
- Roundtable Discussions with the Experts

We are pleased to announce that anyone with internet access can view the *Summit* in the following ways:

On Saturday, December 3rd:

- A live webcast will be available through a link on our website, www.pulmonaryfibrosis.org.
- A live satellite webcast will be available at 12 sites throughout the US and 3 sites in Canada.

Following the *Summit*:

- During the week of December 4th the entire webcast will be available through a link on our website.
- Early in 2012 an on-demand webinar will be available through the PFF website. Specific sessions or the entire program can be viewed.

For more information about the webcast or satellite viewing sites please visit www.pulmonaryfibrosis.org/summitwebcast or call 888.733.6741.



Oxygen Available During Summit for Patients

We would like to thank Lincare for their generosity in providing oxygen at the *Summit*. Oxygen refills will be available during the *Summit* on December 2nd and 3rd. Please let us know in advance if you will need oxygen. A copy of your oxygen prescription will be required to receive refills during the *Summit*.

If you have registered for the *Summit* and have not provided the Pulmonary Fibrosis Foundation with a copy of your oxygen prescription or if your prescription has changed please contact Lyla Conrad at 888.733.6741 or lconrad@pulmonaryfibrosis.org as soon as possible. Once again, advanced requests must be made to receive oxygen.

Save the Date: IPF Summit 2013 Announced

We are excited to announce that the *IPF Summit 2013* will take place on December 5-7, 2013!

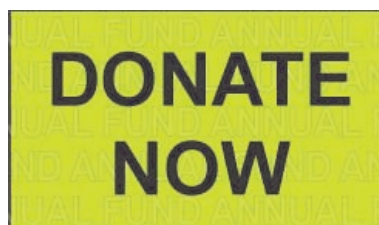
We've set the date, now help us choose the location. Cast your vote by sending an email to summit@pulmonaryfibrosis.org with the city of your choice in the subject line. All votes must be received by January 15, 2012.

To obtain information for *IPF Summit 2013*, or to be placed on the pre-registration list, please email [summit @pulmonaryfibrosis.org](mailto:summit@pulmonaryfibrosis.org) or call 888.733.6741.

Help Us Fund Future Conferences

You are the reason why we want to conduct important educational programs on this devastating disease. It is our shared mission to help find better treatments for idiopathic pulmonary fibrosis, and the *Summit* will help us achieve this.

To make a donation to help us fund future events please visit www.pulmonaryfibrosis.org/donate. Every donation, large or small, is greatly appreciated and will help us continue to make this conference a success.



Chicago: Home of the PFF

Are you planning on attending the *IPF Summit 2011* and unsure of what to do in Chicago during your visit? We have put together some suggestions of things to do and see in Chicago in the month of December.

Skyscrapers – Chicago is the home of many famous tall buildings. Take the elevator up to the observation deck of the **John Hancock Center**, and you will be afforded exceptional views of Lake Michigan, the city, and several states. One can also travel to the top of the **Willis Tower** which is the tallest building in the Western Hemisphere. Special Tip: general admission to the Observatory Level of the Hancock is \$15, but you can go to the Signature Room (on the 95th floor) and get the same views for the price of a cocktail!

Parks – It may be getting colder, but Chicago’s famous **Millennium Park** is still a hub of activity. While there, take the “required” picture in front of “the Bean” and be sure to check out Frank Gehry’s beautiful Pritzker Pavilion. Special Tip: ice-skating begins in December in the park’s lower plaza.

Art Museum – Visit the **Art Institute of Chicago** and see well-known favorites like Seurat’s *Sunday Afternoon on the Island of La Grande Jatte*, and Grant Wood’s *American Gothic*, or one can take in some contemporary art in the Renzo-Piano designed Modern Wing. Special Tip: visit the museum’s famous miniature Thorne Rooms, decorated (in miniature) for the holidays.

Science Museums – **The Field Museum**, **Shedd Aquarium**, and **Adler Planetarium** are all neighbors making them easy to visit. Special Tip: the PFF is holding its tenth anniversary dinner *New Decade, New Reach* at The Field Museum with a special opportunity



“the Bean” in Millennium Park

to see its *Chocolate: Around the World* exhibition. More information about the dinner can be found at <http://bit.ly/pff10dinner>.

Pizza – In Chicago, it is all about deep dish, and Chicago has plenty of “joints” offering pizza pie. Staff favorites include **Lou Malnati’s** and **Giordano’s**. Special Tip: deep dish pizza takes a while to bake, but you can avoid waiting by calling in your order in advance!

Theater – Chicago is the home of many world famous theaters. These include the **Goodman**, **Steppenwolf**, and **The Second City**. Special Tip: if you catch a show at The Second City you may see some of the next stars of *Saturday Night Live*. Tina Fey, Steve Carell, and Chris Farley all got their start at The Second City.

Worried about the weather in Chicago at this time of year? The average temperature in Chicago in December is 22 - 36 °F. The beginning of December is usually mild but make sure to bring warm clothing. Winter coats, hats, gloves, and scarves are strongly encouraged.

NEW DECADE NEW REACH

A graphic consisting of a vertical rectangle and two overlapping circles. The rectangle is on the left, and the circles are on the right, overlapping each other and the right side of the rectangle. The shapes are outlined in a light blue and yellow color.

Together we'll make a difference in pulmonary fibrosis

Purchase Tickets for the PFF Tenth Anniversary Dinner

The Foundation invites you to join us for our tenth anniversary dinner, *New Decade, New Reach*. The dinner will take place during the *Summit* and will be held on December 2, 2011 at Chicago's landmark Field Museum. We will reflect on some of the accomplishments during the last decade and focus on our goals for the future.

The dinner includes opportunities to view the Field Museum's world-famous *Tyrannosaurus Rex*, "Sue," and to stroll through the museum's mouth-watering *Chocolate: Around the World* exhibition. A cocktail reception with hors d'oeuvres will be followed by a three-course dinner. The evening will include guest speakers, award presentations, and a unique video compilation highlighting the Foundation's past and future.

Co-Chairs

Julie Halston – award-winning Broadway actress

Ralph Howard – reporter for the *Howard Stern Show*

Brian Baird, Ph.D. – Former U.S. Congressman

Mark Kirk – U.S. Senator for Illinois

Master of Ceremonies

Nesita Kwan – reporter and anchor at NBC 5 Chicago News

Tickets for the *New Decade, New Reach* dinner can be purchased for \$150 at <http://bit.ly/pff10dinner>.

Don't miss this inspiring event.

Advocating for PF Just Got Easier

Becoming an advocate for pulmonary fibrosis is as easy as entering your zip code! The PFF is excited to announce a new web tool that allows an individual to contact Members of Congress with just a few simple clicks. This new tool, known as Capwiz, will greatly aid in our efforts to gain at least 150 co-sponsors for the Pulmonary Fibrosis Research Enhancement Act (H.R. 2505, S. 1350).

Congress wants to hear from its constituents directly. We need you to reach our goal!

Take action now, visit pulmonaryfibrosis.org/takeaction.

What is the Pulmonary Fibrosis Research Enhancement Act (PFREA)?

The PFREA is a bill that has been recently re-introduced in both the House and Senate.

This bill will establish a national Pulmonary Fibrosis Registry, create a national advisory board, and calls for a national pulmonary fibrosis education and awareness plan. The PFREA also encourages the National Institutes of Health to expand, intensify, and coordinate the activities of the Institute with respect to pulmonary fibrosis research. All of these components are necessary to advance pulmonary fibrosis research and awareness.

How can I help?

The first step is to visit our website, pulmonaryfibrosis.org/takeaction. Next, click “Take Action Now!” Complete the “Sender Information” section, and then click “Send Message.”

Also, tell a friend!

2 SENDER INFORMATION

This system requires that you provide your name and contact information. This information will not be used for any purpose other than to identify you to the recipient.

Your Contact Information:

Prefix (required by some officials)
Select... ▾

First * Last *

Email *

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City *

State * ZIP * ZIP + 4
Alabama ▾

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Remember Me! (what's this?)
 Sign me up for the Action E-List.
A copy of your message will be sent to the e-mail address entered above.

Send Message
(Please click only once.)

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Visit our website, pulmonaryfibrosis.org/takeaction. Click “Take Action Now!” Fill in your information and click “Send Message.”

You can have an even greater impact by calling and visiting your own Senator or Congressional Representative. Visit pulmonaryfibrosis.org/takeaction for tips and tools to maximize your impact. No matter how you choose to take action, don’t forget to tell family and friends about this important initiative. Remind them why this is so important and ask them to join you by contacting their Member of Congress.

I’ve contacted Congress, now what?

There are many ways to continue your advocacy efforts. We depend on motivated individuals like you to help raise awareness of pulmonary fibrosis and support the Pulmonary Fibrosis Foundation. More information can be found at pulmonaryfibrosis.org/involve.

Questions? Email info@pulmonaryfibrosis.org.

Black to Black: The Forest to the Sea



Tom, Woody, and Ezra at the Black Sea, the finish line.

Over the past summer, three friends Tom, Woody, and Ezra, embarked on a 3,000 kilometer cycling tour along the Danube River, from the Black Forest in Germany to the shores of the Black Sea in Romania. Hence, Black to Black. The 3,000 km journey inspired them set a fundraising goal of \$3,000 dollars (\$1 for every kilometer) to support the Pulmonary Fibrosis Foundation in memory of Ezra’s mother, Jan, who passed away from the disease in 2010.

The three adventurers cycled through ten countries, taking in the sites, visiting pubs along the route, and succeeded in cycling the 3,000 kilometers. They documented their journey through a blog so that others could follow their progress. “It was one way that we could give back to people who donated,” said Ezra.

Tom, Woody, and Ezra exceeded their fundraising goal of \$3,000 by raising over \$4,500. The Pulmonary Fibrosis Foundation would like to recognize and thank Tom, Woody, and Ezra for their wonderful support. We also congratulate them on accomplishing their remarkable goal of cycling 3,000 kilometers from the Black Forest to the Black Sea, and for exceeding their fundraising goal.

For more information, pictures, video, and entertaining commentary about the Black to Black journey, visit the cyclists’ blog at danubecycling.wordpress.com.

PFF Events and Fundraisers

For a full listing of all upcoming PFF events and fundraisers visit www.pulmonaryfibrosis.org/events.

If you are interested in starting your own fundraising event contact us at 888.733.6741 or events@pulmonaryfibrosis.org. Our staff will provide you with assistance to help plan and execute your event.

Whether you are bicycling 3,000 kilometers across Europe, or simply having a bake sale in your neighborhood, all events are important to help raise awareness and resources to combat pulmonary fibrosis.

To start a PFF fundraising page now visit www.firstgiving.com/PulmonaryFibrosisFoundation.

Stromedix Initiates a Phase II Study of STX-100 in IPF Patients



Stromedix, Inc., a biotechnology company based in Cambridge, Massachusetts, announced they have

begun a Phase II study of STX-100 in patients with idiopathic pulmonary fibrosis. Founder and CEO, Michael Gilman, started the company in 2006 to develop innovative therapies for the treatment of fibrosis and organ failure.

Stromedix's lead compound, STX-100 (anti-alpha v beta 6 [$\alpha v\beta 6$] monoclonal antibody), is being developed as a novel therapy for the treatment of patients with fibrosis or fibrotic-inducing conditions. In fibrotic disease, active transforming growth factor-beta (TGF- β) is thought to be critical to the initiation and maintenance of fibrosis. STX-100 blocks the binding of $\alpha v\beta 6$ to the latent form of TGF- β , thereby inhibiting its activation in response to tissue injury or inflammation. The integrin $\alpha v\beta 6$ is expressed at low levels in healthy adult tissues but is highly up-regulated on epithelial cells during tissue injury and fibrosis. Knockout mice lacking the integrin $\alpha v\beta 6$ and mice treated with a blocking antibody to $\alpha v\beta 6$ are protected from fibrosis in multiple animal models of lung, liver, and kidney injury.

Following a favorable safety and pharmacokinetic (PK) profile in a Phase I study in healthy volunteer subjects, a Phase II study is now underway to evaluate the safety, tolerability, PK, and impact on biomarkers of STX-100 in patients with idiopathic pulmonary fibrosis. The study has begun recruitment and is enrolling patients at sites across the United States.

A complete description of the study is available at ClinicalTrials.gov (<http://clinicaltrials.gov/ct2/show/NCT01371305>), including contact information for participation.

Stromedix has also licensed the rights to a monoclonal antibody to the integrin $\alpha v\beta 5$ from the University of California. This is the second Stromedix asset to be sourced from the laboratory of Dean Sheppard, M.D., at University of California, San Francisco, reflecting a long-standing collaboration between Dr. Sheppard's lab and the Stromedix staff. Preclinical research suggests that $\alpha v\beta 5$ plays an important role in a variety of acute and chronic organ failure settings. For more information on Stromedix, please visit www.stromedix.com.

For more information on clinical trials and a list of active research visit:
pulmonaryfibrosis.org/activeresearch.

Commonly Used Three-Drug Regimen for Idiopathic Pulmonary Fibrosis Found Harmful

The National Institutes of Health (NIH) announced the discontinuation of one treatment arm of a three arm clinical trial for idiopathic pulmonary fibrosis (IPF). The PANTHER-IPF treatment trial being conducted as part of the IPFNetwork found that people in the study receiving triple drug therapy, consisting of prednisone, azathioprine and N-acetylcysteine (NAC), had worse outcomes than those who were in the arm of the study receiving placebo or inactive substances.

Ganesh Raghu, M.D., Professor of Medicine at the University of Washington, Seattle, co-chair of this IPF study and Medical Advisory Board Member of the Pulmonary Fibrosis Foundation, advises patients:

“Anyone on some combination of these medications with questions or concerns should consult with their health care provider and not simply stop taking the drugs. It is important to realize that these results definitively apply only to patients with well-defined IPF and not to people taking a combination of these drugs for other lung diseases or conditions.”

The IPFNetwork Investigators will continue to analyze the study data to investigate why this particular combination of therapies may be detrimental in people with IPF.

The other two arms of the study, NAC alone and the placebo arms are planned to continue.

To view the press release: <http://pulmonaryfibrosis.org/node/679>.

Pulmonary Fibrosis Foundation Launches Research Fund to Cure Pulmonary Fibrosis

On October 17, 2011 we announced the establishment of the PFF Research Fund to Cure Pulmonary Fibrosis. The Fund was created to support research that will assist in the development of successful therapies for pulmonary fibrosis. The goal of the Fund is to help identify new treatments, and ultimately a cure for PF.

For more information on the PFF Research Fund to Cure Pulmonary Fibrosis please visit:

<http://pulmonaryfibrosis.org/research/PFFgrants>.

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