



SENATE PFREA BILL INTRODUCED
IMPORTANT DRUG TRIAL INFORMATION INSIDE

May – August 2010

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Action Alert

The Quarterly Publication of the Coalition for Pulmonary Fibrosis

CPF Announces Dates For Eighth Annual National Pulmonary Fibrosis Awareness Week

2010 Awareness Efforts Set for PF Week Sept. 11-18

The Coalition for Pulmonary Fibrosis (CPF) announced it has set its 2010 National Pulmonary Fibrosis (PF) Awareness Week for September 11-18, 2010. The primary goals of this year's activity are to encourage support and passage of the newly introduced Senate version of the Pulmonary Fibrosis Research Enhancement Act (PFREA – S.3703) as well as H.R. 1079, the House version, and to raise awareness of PF issues to Members of Congress and in communities nationwide.

Continued on page 3



First National Media Coverages on Pulmonary Fibrosis Drive New Awareness, Provide Hope to Patients

The Coalition for Pulmonary Fibrosis (CPF) said stories appearing on The TODAY Show and CBS News' website, www.cbs.com, provided the first national major media coverage of pulmonary fibrosis (PF) in history. That coverage, viewed by more than five million people, is helping to drive a new level of awareness for this little known disease and is providing hope for thousands suffering from the disease.

Continued on page 7

Companion PFREA bill introduced in Senate

The CPF is excited to announce that on August 4 the Pulmonary Fibrosis Research Enhancement Act (PFREA S.3703) was introduced in the Senate by Senators Patty Murray (D-WA) and Mike Crapo (D-ID). This is the companion bill to the House version, H.R. 1079, which currently has 136 bipartisan co-sponsors. The CPF will be working to build Senate support for the bill during PF Awareness Week this year, and will be asking its constituents to join in this effort.

Continued on page 7

Dear CPF Friends:



There are thousands of rare diseases, but PF is surely one of the worst. Those of you reading this newsletter will know what this disease does - but that the majority of the American public has no idea that it exists, let alone that it is so devastating to all those touched by it. As you have learned from our email messages, in the last few weeks we have had the great good fortune of help in building awareness as a result of the commitment and generosity of a few individuals.



The seed for this change was planted by a Pasadena, CA patient, Bob O'Rourke, with the help of his wife, Sandy. The picture you see at the top of this page is that of the billboard donated by Bruce Seidel, who, on hearing of Bob's plight, went to the owner of the jumbotron, Terry Long, and asked for help for the PF community via provocative exposure on a well-traveled road in California (see article beginning on the cover).

The idea behind this unorthodox billboard is to catch the public's eye so that they will come to the website and learn more about the symptoms of PF. We understand there are many symptoms and PF can manifest itself in a number of ways, but this slightly dramatic approach may help increase the number of people aware of the potential implications of a long-term cough that could signal something serious, even though the symptom itself seems minor.

Bob and his wife Sandy, as you will read in this newsletter, have taken on the mission of bringing PF out of the shadows. When the O'Rourkes let their friends know what Bob was confronting, they had no idea what the response would turn out to be. Almost immediately their friends began demonstrating their concern and desire to assist by helping to launch a campaign around Bob's story that has reached across the nation. From the local television news, to national coverage on NBC, to internet articles on CBS, to radio interviews and newspaper and magazine coverage, they are contributing in a dramatic way to the work to alert everyone to the threat of PF.

It is with the work of our members, whether patients, family or friends, that change will come. No one else can understand the enormity of the impact of PF as can those who have grappled with it. The CPF staff will always work to promote efforts to find answers, but with a community of people who share our determination to win over PF, we will see accelerated progress towards awareness, funding, treatments and a cure.

With great appreciation,

A handwritten signature in black ink that reads "Mishka Michon".

Mishka Michon

P.S. Please also note the wonderful banners or "skirts" on patient Tommy Spivey's fleet of semi trucks criss-crossing the United States (see photo on Page 14). We owe him a huge thanks as well.



Education. Support. Hope.

Specifically, the CPF is asking its national membership and others affected by PF to take action on the Senate and House Pulmonary Fibrosis Research Enhancement Act Bills, by meeting with their Members in person or by emailing, calling or mailing letters to them.

The CPF will celebrate National PF Awareness Week with more than 30 patients and patient advocates on Capitol Hill, and with hundreds of patients and family members reaching out to their own Members in their districts nationwide that week. In 2009, the organization received recognition for its National PF Awareness Week's efforts when it was a finalist for a national advocacy award by PR Week.

The CPF has been working closely with Congressman Brian Baird (D-WA) and Congressman Mike Castle (R-DE) on PFREA, the lead sponsors of the House bill. The partnership has extended to Senators Patty Murray (D-WA) and Mike Crapo (R-ID), the lead sponsors of the Senate version of this historic legislation which would authorize \$16 million in new federal funding to create the first national patient registry for PF, and provide much needed support for research into the deadly lung disease.

"It takes each PF patient, each family member and their circle of friends to reach out to Congress and get this bill passed," said Mishka Michon, Chief Executive Officer of the CPF. "Having the voice of the patient community heard loud and clear will make things happen to bring attention and awareness to PF in Washington and beyond."

This year, 2010, has been proclaimed international "Year of the Lung" by the American Thoracic Society (ATS) and a coalition of like respiratory societies around the globe. The CPF is partnering with this coalition in a concerted effort to bring attention to lung issues. National PF Week will continue that effort.

This focused effort on the part of the CPF is moving into its eighth year. The progression from a bill of recognition of the disease, H. Con Res 182, which was passed in 2007, to a bill establishing funding for PF research, is indicative of increased responsiveness on the part of Congress. Over the years, the CPF and its advocates have met with hundreds of Members of Congress. 136 House Members are now supporters of the current bill.

PF patients, families and those affected by PF can help with 2010 Awareness efforts and help gain passage of the PFREA by joining the CPF's advocacy campaign, Campaign ACT. For further information, please visit the CPF at www.coalitionforpf.org, call us at (888) 222-8541, or email us at info@coalitionforpf.org.

The CPF encourages you to plan activities in your hometown to raise awareness amongst your friends, family, co-workers, colleagues and neighbors about PF. Come up with a creative way to celebrate PF Week and spread the word about PF.

Thank you for your ongoing support of the Coalition for Pulmonary Fibrosis. Please ask your friends, family, and co-workers to support PF Week, too!



Estate Gift From Eugene Dudley Launches CPF Endowment

Richard Lieboff presenting CPF CEO Mishka Michon with \$100,000 endowment contribution from the estate of his partner, Eugene Dudley. Please see full article in September-October 2009 issue of CPF's Action Alert.

Summer is the Time to Turn up the Heat on Your Member of Congress to Support PF Bills

The Pulmonary Fibrosis Research Enhancement Act (House version H.R. 1079 and Senate version S. 3703) continues to build momentum in the U.S. Congress, and particularly in the House of Representatives, now with 136 members signed onto the legislation. But as a midterm election year, time is of the essence in getting the bill completed in this Congress.

The CPF urges its membership to activate during the summer months for a final push to get the bill passed in the House and Senate. It is particularly important to contact your Senators, as the effort to gain Senate support is still in early stages.

Please call, email, or write your Member of Congress today to help pass the
Pulmonary Fibrosis Research Enhancement Act

We need your help now to insure the bill gets passed this Congress and since it's a Congressional election year, this means we don't have much time. If you can't meet in person — there are other ways you can make a difference. See below for details.

Remember, There are Three Easy Ways to Help

1) Visit your member in district

The CPF encourages you to schedule a meeting now with your member of Congress during the August recess when he/she is in your home district to support the Pulmonary Fibrosis Research Enhancement Act. Letters are important, but having a face-to-face meeting with your Member of the U.S. House of Representatives and your Senator will allow you to share your personal story of your connection to PF and to personally ask for your legislator's support of H.R. 1079 and S. 3703, the first legislation that will directly help PF patients. If your legislator is already a co-sponsor, visit him/her and thank them for their support. To find out who is a current co-sponsor (or who is not), please go to www.thomas.loc.gov, open the website and type the bill number, in the box in the center of the page - H.R. 1079 or S. 3703. That will give you a link to the co-sponsor list.

2) Take action today by calling your Representative and Senator

To contact your Representative call the Capitol Switchboard at (202) 224-3121 and ask for your Representative or Senator or give your zip code if you do not know their name. When you are connected to an office, ask for the Health Legislative Assistant.

3) Send a letter or email

Another effective way to contact your legislator is via email or a letter. Call your Representative's office and ask for the Health Legislative Aide's email address.



Please contact your legislators NOW to request their co-sponsorship of S. 3073 and H.R. 1079 and ask them to support a Congressional hearing on PF

If you leave a voicemail message, include your name and phone number so that they can call you back. Sample phone message:

"I am a constituent and a Pulmonary Fibrosis (patient, family member, friend) and I am calling to ask Rep/Sen. _____ to co-sponsor the Pulmonary Fibrosis Research Enhancement Act, (for the House H.R. 1079 – for the Senate S. 3703). These bills will create a much needed national patient registry so that scientists and researchers can learn more about the disease as quickly as possible so that treatments may be found. There is currently no FDA approved treatment for PF and as many people die to it each year as to breast cancer. Please help us now by signing onto (H.R. 1079 or S. 3703) and supporting a hearing in the house on PF to Rep. Pallone.

Sample letter or email:

Date

Dear [Decision Maker],
As someone among the hundreds of thousands personally affected by pulmonary fibrosis (PF), an ultimately fatal disease that annually takes as many lives as breast cancer, I am writing to ask you to support legislation to help us stop this dreaded disease. (for your Representative, H.R. 1079 – for your Senator S. 3703) calls for the creation of a national patient registry and asks the NIH to increase research into the deadly disease. There are currently 136 Members of Congress signed onto the house bill.

PF is a debilitating disease marked by progressive scarring of the lungs that gradually and cruelly robs people of their ability to breathe. PF yields a median survival rate of fewer than three years and affects more than 128,000 people in this country each year. In fact, 40,000 people die each year from PF. Despite its prevalence, very little is known about IPF and there is no known cause or FDA-approved treatment.

To your Representative: Please consider co-sponsoring the bill - we need your support. Rep. Brian Baird (D-WA) is leading this bipartisan effort along with Rep. Mike Castle (R-DE). Please contact Anne Meyers, Policy Advisor, in Rep. Baird's office or Olivia Kurtz, Health Legislative Assistant, in Rep. Castle's office to sign on as a co-sponsor.

To your Senator: Please consider co-sponsoring the bill – we need your support. Senator Murray (D-WA) is leading this effort with Senator Crapo (R-ID) as a co-sponsor. Please contact Paula Burg, in Sen. Murray's office, or Katie Oppenheim, in Sen. Crapo's office to sign on as a co-sponsor.

Sincerely,
[Your Name]
[Your Address]
[City, State ZIP]

Thank you for your outreach!

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“Year of the Lung” Legislation Needs CPF Member Help to Gain Passage

The CPF is asking its members and their families and friends to reach out to their Members of the U.S. House of Representatives and the U.S. Senate to support a bill that brings attention and builds awareness to lung disease in the U.S. including pulmonary fibrosis. Earlier this year, the CPF committed to partner with the American Thoracic Society and like societies around the globe to celebrate and promote 2010 as Year of the Lung. A key goal is the passage of the legislation that will create a lasting recognition of lung disease in America.

Legislation has been introduced in both houses of Congress – H.R. 1122 in the House and S.R. 432 in the Senate. The bills were introduced in the House by Rep. John Lewis (GA) and in the Senate by Sen. Blanche L. Lincoln (AR). The House bill currently has 13 co-sponsors and the Senate bill has two. “Central to the ATS mission is providing an international forum for scientists, clinicians, health policy experts, patients and other partners to minimize the burden of respiratory disease, critical illness and sleep disorders through prevention,

diagnosis and treatment. Our efforts, however, are hindered by the under-appreciation, generally, of lung disease and the underfunding, specifically, of respiratory research,” said Dean Schraufnagel, ATS President. “By raising awareness through The Year of the Lung, the ATS increase the attention and the resources allocated to preventing and treating respiratory diseases and maximizing lung health.”

CPF, Pulmonary Fibrosis Receive National Media Attention – *A HUGE win for the PF Community*

The Coalition for Pulmonary Fibrosis (CPF) is excited to share with you that Pulmonary Fibrosis (PF) has been the focus of national media attention in recent weeks. In case you missed it, the links to the stories on The TODAY Show and CBS.com are below. Also, the full press release from the CPF about the coverage is below for you, as well.

To view the archives of the stories from The TODAY Show and CBS.com, NBC in Southern California, NPR, Pasadena Star-News and others, please visit this portion of the CPF website: www.coalitionforpf.org/inthenews.php

These media items are groundbreaking because this is record coverage for this disease and delivering the message to millions of viewers nationally via The Today Show remarkably increases awareness of the disease overnight. We are thankful to patient Bob O'Rourke for telling his personal story and choosing to focus on building disease awareness in partnership with the CPF.

You can build on this effort in your town by reaching out to local print and broadcast reporters and encouraging them to tell your story. Please let us know if you're successful in getting their attention and we'll provide information to them on the larger PF story as well.

We can use your help in increasing the impact of this wonderful news event by sending information about the press links to all of your family and friends. Together we will successfully send the message about how important it is to find answers to PF.

NBC TODAY SHOW - Struggling to Breathe with Pulmonary Fibrosis



First National Media Continued from Cover

Both the NBC's TODAY Show story and the CBS.com story focused on the disease in an interview with California patient Bob O'Rourke, who suffers from the disease and will die from it unless he receives a lung transplant in time. He is partnering with the CPF to build an expanded national awareness campaign. O'Rourke is devoting his time to this national media campaign, despite his desperate fight for survival, because of his concern about how few Americans are aware that there is an untreatable lethal disease taking 40,000 lives a year.

O'Rourke, who was the vice president of public relations for California Institute of Technology for more than 20 years, is accustomed to being behind the scenes helping promote other people's stories.

Now, he is stepping out in front as one patient among thousands who suffers from PF, a terminal lung disease that causes irreversible scarring in the lungs.

"Bob provides a human face and a real life drama for viewers and readers," said Mishka Michon, Chief Executive Officer of the CPF. "He is sharing his story in the hopes that he can change things for future and help drive awareness and increased funding for the disease that is threatening to take his life."

O'Rourke was listed for a lung transplant at UCLA on June 10. It's a run against the clock as his chances of survival are completely dependent upon finding a lung match for him before his severely diseased lungs give out. PF matches breast cancer

in lives lost each year – a startling 40,000. The disease is 100 percent fatal unless a patient can receive a lung transplant, but few do in the overall scheme of things – less than one percent. The average life expectancy with the disease is less than three years.

Thus far in O'Rourke's personal endeavor to drive awareness and attention to PF, he has appeared in media coverage on KNBC TV and Southern California Public Radio. O'Rourke was also featured in three articles in the Pasadena Star-News, including an editorial by Public Editorial staffer Larry Wilson about the commitment of O'Rourke and his friends to build awareness around PF. He is hopeful the coverage will help the campaign pick up even more steam across the country.

"I am thankful for the national coverage we have garnered so far and I won't quit until the message is everywhere. As long as I have breath in my body, I'll fight this fight."

– Bob O'Rourke, PF patient and advocate

Companion PFREA bill continued from cover

Senator Murray commented on the importance of the bill, saying, "Pulmonary Fibrosis has devastated so many families across the country, and we need to do everything we can to eradicate this terrible disease once and for all. I was proud to work with Senator Crapo and Representative Baird to introduce this critical bill that would create a National PF Education and Awareness Plan and national PF patient registry. And I am going to keep working to pass this bill and help PF patients and their families."

Speaking of his sponsorship of this bill, Senator Mike Crapo said, "Pulmonary Fibrosis is a rare disease with very few treatment options and no known cure. This bill and the establishment of a patient registry will be an important first step in finding a cure for the many people who suffer from PF. I am pleased to join my colleague Senator Murray in introducing this critical legislation."

"Pulmonary Fibrosis has devastated so many families across the country, and we need to do everything we can to eradicate this terrible disease once and for all."

– Senator Patty Murry

The Third Annual 5K Run-Walk-Hike for Pulmonary Fibrosis Doubles Attendance, Increases Fundraising by 25%

The Third Annual 5K Run-Walk-Hike for Pulmonary Fibrosis doubled its attendance over 2009 and increased fundraising by 25 percent to bring in nearly \$50,000. The event, which was held May 22nd in New York City's Central Park, was hosted by its founder Terence Hales, and benefited the CPF. Funds raised will be allocated toward research and patient services by the CPF.

Hales and his event volunteers further achieved their goal of increasing awareness and getting PF on the map in New York City. In addition, the 200 participants came from the Tri-State area, upstate New York, Pennsylvania, Virginia, Maryland, Pennsylvania, Maine and Washington, D.C. The event has come a long way in three years, from 25 attendees and \$7,500 raised in 2007 to this year's event remarkable success thanks to Hales and his team of volunteers.

"Many families and friends came honoring their loved ones affected by the disease; and there was a strong sense of community among many who, though newly introduced, were able to share their stories and offer one another support and comfort – but the event was also fun and people spoke of their plans to bring even more friends next year" said CPF Chief Executive Officer Mishka Michon. Michon attended the event and shared information on the work of the CPF and the Pulmonary Fibrosis Research Enhancement Act, which the CPF is working to see passed in Congress – the bill will create the first national PF patient registry.

Three lung transplant recipients, including Hales' father, Tom Hales, joined the event, which was given live on-air coverage by WCBS-FM 101.1. The station also provided music and prizes throughout the event.

Several lucky winners left with raffle prizes generously donated by various sponsors. The silent auction prizes included VIP Tickets to Macy's Thanksgiving Day Parade and Tickets to the sold out Lady Gaga Concert on July 6th. The raffle and silent auction raised another \$3,000.

Plans are already underway for the Fourth Annual NYC Run-Walk for Pulmonary Fibrosis in 2011, tentatively scheduled for Saturday, May 22, 2011.

Sponsors and Supporters:

- CBS Radio and CBS Corporation
- Pfizer Inc. for its generous Gift Matching
- Dave Mickool and Cushman & Wakefield, Inc.
- Charles Evans Foundation
- Stan Weinstock and Biener Auto Group
- Mark Paulson (T-shirt design)

Volunteers:

- Barbara Harsch, Joan Fields and Carolyn Zonnino who handled registration, organizing meeting spot, and crowd control
- Rob Vinci for NYC Parks permit coordination and for organizing the hike to Belvedere Castle
- Ryan Grady, Bob Fortunate, Tara Costello, Anne Hogan, Julie Hoffman, Susan Beckett, Tom Hales, Jr., Bill Hales, Jill Elliot, Lianne Hales-Shaw, and Rob Shaw, who coordinated the event and managed Run-Walk-Hike course.



The Hales Family



Warming up for the run/walk/hike

Night of the Butterfly



Continues Family's Commitment to CPF, PF

The Night of the Butterfly was held on June 3, 2010 at the Ivy Room at Tree Studios in Chicago by hosts Roc and Debbie Roney. The event raised \$69,000 for the CPF and continued the Roney family tradition of bringing friends and strangers together to bring awareness to PF and to help fund the services provided to all patients at no charge.

The setting, in the beautiful Ivy Room at Tree Studios, featured a lush courtyard garden where guests enjoyed delicious hors d'oeuvres and refreshing cocktails including the Roney's famous "Butterflytini", sponsored for the fifth year by Grey Goose. Guests enjoyed a D.J.'s mix of dance music as many of them took the opportunity to chat and catch up with friends – new and old.

As a highlight of the event, Roney daughters Isabel, Lola and Stella Roney had the honor of releasing 45 butterflies. Debbie Roney shared that the butterflies are symbolic of hope, metamorphosis and a new life. For her they are a reminder that the best course is to keep our faith

as life takes us through our many transitions. She asked that when the guests see butterflies this summer, they think of the event and remember that they did something to help the hope turn to reality.

Following the butterfly release, guests were invited inside where the Roneys talked about their gratitude for the commitment of their friends and of all those working to find treatments and a cure. CPF CEO Mishka Michon spoke about the CPF's work and what the funds raised mean to the long-term outcomes for the cause.

Guests generously contributed funds for all the opportunity tickets available. The grand prizes this year included a week in a Colorado mountain home and another in a Florida beach home.

"The night was a fun and uplifting event that left guests knowing a little more about PF and a lot more satisfied to be helping us toward a cure," said Debbie Roney, event co-chair. Roney's husband's family has lost several members to PF.

Night of the Butterfly Event Sponsors

Diamond Monarch

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Grey Goose Vodka
Hatch Family Chocolates
The Ivy Room at Tree Studios
Kristy Mau
Sound Investment
Sugar Bliss Cakes



Cindy Chandler and her key supporters



T-shirt designed by James and Gregory Chandler, Jr.

Third Annual Breathing is Glorious Golf Tournament Pays Tribute to Family's Loved Ones Lost to PF, Raises Funds for CPF

The third annual Breathing is Glorious Golf Tournament in Webster, New York raised funds for the CPF and paid tribute to Cindy Chandler's husband, Greg W. Chandler, who succumbed to pulmonary fibrosis (PF) four years ago. On Sunday, June 13th, over 150 golfers packed the course at the Webster Golf Club and the club played host to nearly 275 dinner guests. Greg died of PF in the spring of 2007 and Cindy's father, Guy F. Solimano, also died from an unknown lung fibrosis challenge in 2009.

Since 2007, Chandler, along with her friends and family, has tirelessly rallied the Webster community in the fight against PF. Throughout the years, they have held basketball fundraisers, concerts, and even created online fundraising pages in lieu of wedding registries to raise money.

Greg's passing was especially devastating as he was the young father of their two sons James and Gregory Chandler, Jr. Together the sons created special t-shirts for the event's many volunteers and have been integrally involved in the event's planning with their mother since it started. With a committee of a dozen members, the event has been a resounding success year after year.

The *Breathing is Glorious Day of Golf* began with lunch and a putting contest. The golfers and dinner guests were treated to cocktails as they bid on a long list of silent auction items and were gently encouraged to purchase lots of raffle tickets. Su Hwang, CPF Director, of special events thanked volunteers, guests and donors for their continued support of the event and updated them on current CPF activities made possible by their donations. In memory of Cindy's father, Guy, who lent his support in the first golf tournament, the Guy F. Solimano Extraordinary Volunteer Award was given to Joe Meindl.

Together, the Webster community raised \$24,000 to assist in the CPF's work. The CPF is very grateful for the consistent dedication of the Chandlers and their entire extended family. They have set a high bar for a local family local event and everyone has stepped up to help them reach their goals.

The work of the American Thoracic Society is deeply enriched by the involvement, investment, and commitment of organizations like the CPF. From their efforts to support patient advocacy, to their direct funding of research, CPF makes an impressive contribution to the vital work being done on this lung disease.

I believe the partnership between our two organizations is synergistic and that, working together, we can address that tragedy of PF.

— Dr. Dean Schraufnagel, President, American Thoracic Society

CPF Staffers Hold First Annual Casino Night

CPF Staffers Kristina Unutoa and Su Hwang hosted the first annual Casino Night at Sangria Restaurant in Hermosa Beach, CA. on May 20th, raising funds and awareness for PF. Unutoa, the CPF's Director of Finance & Accounting, and Hwang, the CPF's Associate Director of Development and Director of Special Events held the event in tribute to Unutoa's uncle who was lost to PF and to all patients who suffer from the disease and their families.

Unutoa who has been on staff with the CPF since 2008, has a strong commitment to the cause and wanted to help raise awareness of the disease. When the disease struck home with her own family last year, it set Unutoa into motion to make a difference beyond her daily commitment to the organization. Unutoa's uncle, Dave Cariveau, passed away from PF in late 2008 at the age of 66.

"As a PF professional and family member of a PF patient who recently passed, I am honored to be able to participate actively in supporting the mission of CPF," said Unutoa.

"I am so pleased to not only have these unbelievably dedicated and driven staffers, but to know that they are so passionate about this cause," said Mishka Michon, CEO of the CPF.

Unutoa and her husband, Tony, teamed up with Hwang to hold the event at the Hermosa Beach Pier, where all the guests would enjoy a sunset view of the beach. Casino Night offered activity and excitement for its 90 guests as they played at Casino-style gaming tables and took home some special prizes. The grand prize was a new Apple iPad WIFI and was won by local pulmonologist Vijay KaM.D.ar, who practices medicine at Lynwood & Downey.

The first-time event raised more than \$11,500 for the CPF.



Kristina Unutoa, iPadWIFI winner Dr. Vijay Kamdar, and Timothy Snitily CPT, CRT



CPF Staffers and Casino Hosts: Su Hwang and husband Ryan on left and Kristina Unutoa and husband Tony on right.

Sponsors:

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Murad Spa, El Segundo
Original Pancake House, Redondo Beach
Skechers, Manhattan Beach
Spa to Go, Manhattan Beach
Spectrum Club South Bay and Howard
Hughes
Super Sports, Manhattan Beach
Waterman's, Hermosa Beach
West End Racquet and Health Club,
Torrance
Westchester Golf Course, Los Angeles
World Karate, El Segundo.

CPF Established Honorary Board



Tom Brokaw, news anchor and author, and **Meredith Brokaw**, author and educator



Dick Cook, media executive, former Chairman of Walt Disney Studios, and **Bonnie Cook**



Tommy Hawkins, two time All-American Basketball player, broadcaster, and baseball executive



Tom Johnson, media executive, former President and CEO of CNN, and Edwina Johnson



Jay Leno, Host of NBC's *The Tonight Show*, and **Mavis Leno**, Human Rights Activist and Nobel Peace Prize nominee

“I am proud to be asked to serve on this Honorary Board in support of the CPF and for the patients who are fighting this horrific disease.”

– *Tommy Hawkins*



James Marsden, actor, and **Lisa Linde Marsden**, actor



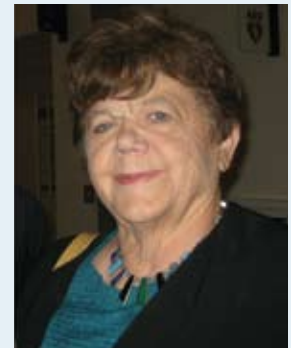
Peter and Merle Mullin, philanthropists



Paul Reiser, actor, writer, and producer, and **Dr. Paula Ravets Reiser**, clinical psychologist



Daniel Stern, actor and director, and **Laure Stern**, youth activist



Olene Walker, former Governor of Utah and PF patient

“PF is a disease that remains unrecognized by the general public. We have seen the pain PF causes patients and their families, and we are pleased to serve in this capacity, so as to help raise awareness of this deadly disease and to support the CPF in its efforts to find treatments and a cure.”

– *Daniel and Laure Stern*

Photos received from individuals and various web sites.

Chili's Is Proud to Support the Coalition for Pulmonary Fibrosis



Friends and family of Richard Dozier were able to enjoy a meal and support the Coalition for Pulmonary Fibrosis at the same time. Chili's hosted a fundraising event during lunch and dinner on June 21st and June 22nd in Yuba City, CA. Ten percent of guests' checks were donated to the CPF, bringing in over \$700 for the work of the CPF. Richard is a member of an active support group in the area, which is coordinated by Sandra Rock, who was also in attendance. For more information on the support group contact Sandra at sandararock@yahoo.com. To hold a Chili's fundraiser in your area contact your local Chili's and let the CPF know so we can help you spread the word.



Upcoming CPF Events In 2010

- | | |
|-----------------|------------------------------------------------------------------|
| September 11-18 | 2010 PF Awareness Week, Washington D.C. |
| October | KidSpace Museum event, Pasadena, CA, <i>date to be announced</i> |
| October 3 | Second Annual Walk for Pulmonary Fibrosis
Mission Viejo, CA |
| October 9 | Butterfly Garden Party – Malibu, CA |
| October 10 | Bank of America Chicago Marathon, IL |
| October 16 | 3rd Annual IPF Walk For Your Next Breath - Franklin, TN |

CPF, Advocates Drive Home the Message for Pulmonary Fibrosis

Fleet of More than 30 Trucks Make Trips Daily Cross Country Potentially Reaching Millions, Jumbotron Ad on Busy CA freeway reaches more than 130,000 People Daily

The Coalition for Pulmonary Fibrosis (CPF) announced July 13 a nationwide advertising campaign to spread the word about Pulmonary Fibrosis (PF) is underway in an untraditional setting – on the nation’s interstates.

The billboard and tractor trailer campaign has the potential to reach millions of Americans each day with messages about PF as more than 130,000 people pass a jumbotron (electronic advertising billboard) ad on Northern California’s Interstate 80 each day and millions of drivers and passengers see Inman Trucking’s more than 30 tractor trailer rigs driving from North Carolina to California and back each day.

“We admit this is not a typical advertising campaign,” says CPF CEO Mishka Michon. “We think it’s just different enough, though, that it may get some traction in helping build awareness of PF across the country. We’re also hoping that more companies, with media to donate, will want to help spread the word. It’s literally a life-or-death story, but we need a larger forum in which to tell it.”

The jumbotron ad copy asks “How Long Have You Had That Cough?” and then lists the CPF name followed by the web address, www.cough-cough.org. The ad space was donated by Terry Long in honor of his friend, Bob O’Rourke who is suffering from PF and currently awaiting a

life-saving lung transplant for the disease. Transplant is the only known cure for the disease, however less than one percent of the 128,000 who suffer from it in the U.S. qualify. O’Rourke has been featured in national media coverage over the last several weeks including a story that appeared on NBC’s The TODAY Show.

The ad on the trucks of national carrier, Inman Trucking, says simply “Stop Pulmonary Fibrosis” and includes the CPF name and the web address, www.gaspingforbreath.org. Both the jumbotron and truck banner web addresses take visitors to the CPF’s website – www.coalitionforpf.org.

The founder and President of Inman Trucking, Tommy Spivey, also suffers from PF and wanted to get the word out to all who see his trucks on the road. “I want everyone to know about this disease so that we can do something about it,” he said. “It may not be soon enough to save my life, but hopefully building awareness will lead to increased funding for the disease and others will be saved,” he said.

“I am pleased I could share the message with people traveling the highway in California to try and increase awareness of this horrible lung disease,” said Terry Long, owner of the jumbotron billboard on Interstate 80.

Jeff Berry donated his time and talents to create the ad for the CPF and thinks the message is pervasive. “I helped the CPF develop a series of banners, posters and outdoor ads with the provocative headline: ‘How long have you had that cough?’ to make people aware of this terrible disease, how it could strike anyone, and get them to go to the website for more information. It’s the kind of thing you might say to someone you care about, and who may not be aware that something as innocent as a persistent cough might be the beginning of something far more serious,” said Jeff Berry, President and CEO of People’s Branding, Ltd.

The trucking company’s ads were produced in partnership with Berry by Chris Prince, a friend of Tommy Spivey. Both ads are available for viewing on the CPF’s website.



FDA Nixes Pirfenidone for Now, Wants New Trial

The FDA has told InterMune that it will not approve its idiopathic pulmonary fibrosis drug pirfenidone (Esbriet), despite an expert panel's vote in favor of approval less than two months ago.

The company said the FDA sent a "complete response" letter indicating that it wants another clinical trial to prove the drug is effective.

"After the positive FDA advisory committee meeting of March 9 at which the committee recommended the approval of the pirfenidone new drug application by a 9 to 3 margin, we are disappointed by this outcome," Dan Welch, chairman and CEO of InterMune, in Brisbane, Calif., said in a statement.

"We will meet with the FDA as soon as possible to understand their points of view and to determine the most appropriate path forward to expeditiously make Esbriet available to the approximately 100,000 patients with PF and their families who suffer from this terrible disease."

In its letter, the FDA requested an additional clinical trial, Welch said during a teleconference.

One listener asked whether the company would be able to use trial data from Shinogi & Co., a Japanese company whose trials in that country helped pave the way for pirfenidone's approval in Japan. InterMune presented some data

from the Shinogi studies at the Pulmonary-Allergy Drugs Advisory Committee meeting in March, but not patient-level data, which were not available at the time. Company officials said they were not sure whether patient-level data from the Shinogi trials would meet the FDA's needs.

And although it will now be possible for InterMune to get such data from Shinogi, "We do not have the electronic Shinogi data sets in hand," said Steven Porter, M.D., PhD, InterMune's chief medical officer. "There are logistical, linguistic, and business issues to obtaining those data sets."

InterMune officials said they hoped to meet with FDA in the next two or three months to get more information about what additional data would be needed for approval. InterMune developed the thrice-daily pill to retard the decline in lung function among PF patients, who have a median survival of three to five years and usually succumb to respiratory failure.

Pirfenidone's exact mechanism of action is unknown, but InterMune says the drug works because it is an anti-inflammatory and antifibrotic. Because there are currently no approved medications to treat PF here, patients are often treated with corticosteroids and immunosuppressive agents, although no trials have vouched for their effectiveness.

Although the FDA advisory panel voted 9 to 3 to recommend approval, the vote was closer, 7 to 5, on whether the drug was actually effective on the basis of clinical trial data that InterMune presented.

Source: Joyce Frieden, News Editor, MedPage Today, May 05, 2010

Familial Pulmonary Fibrosis Counseling Service

The CPF continues to support the first genetic counseling program for PF. The telephonic counseling program is operated by National Jewish, and funded, in part, by the CPF.

The program provides a qualified genetic counselor, who has expertise in familial pulmonary fibrosis, to discuss by phone various issues surrounding FPF. These can include preparation for and interpretation of genetic tests, and various life decisions, such as having children and planning for the future. Experts recommend talking to a counselor prior to having any genetic tests, so that people are prepared to learn the results.

For further information on the FPF genetic counseling program or to speak with a genetic counselor, call (800) 423-8891, ext. 1097

National PF Research Program – The “IPFnet”

The IPFnet is a clinical research network sponsored by the National Heart Lung and Blood Institute (NHLBI) of the National Institutes of Health (NIH). It was formed in 2005, after a national competitive peer review. The mission of the IPFnet is to develop and evaluate clinical treatment

IPFnet Recruiting Patients for Important Research Studies

The IPFnet is a clinical research network sponsored by the National Heart, Lung and Blood Institute (NHLBI) of the National Institutes of Health (NIH). It was formed in 2005 after a national competitive peer review. The mission of the IPFnet is to develop and evaluate clinical treatment regimens for idiopathic pulmonary fibrosis (IPF).

The broad objective of the IPFnet is to conduct multiple randomized, controlled clinical trials to evaluate existing or new medications, combinations of medications, and defined management strategies for patients with IPF.

The primary goal of the IPFnet is to improve outcomes in the care of patients with IPF. The network develops protocols for all patients, including those in the early phase of IPF who have had minimal prior treatment and for those patients with a more advanced stage of the disease. The first of these protocols, Sildenafil Trial of Exercise Performance in Idiopathic Pulmonary Fibrosis (STEP-IPF), was recently presented at the annual meeting of the American Thoracic Society and published in the prestigious journal, the *New England Journal of Medicine*. This innovative study demonstrated that a therapeutic

option can improve quality of life and decrease symptoms in IPF patients with more advanced disease. The IPFnet is also conducting a series of ancillary studies in which subjects who are enrolled in one of the clinical trials may also participate. These studies are investigating markers of disease activity, prognosis, and identification of potential new targets for future therapy.

“What we most need is additional information about the treatment of IPF. We don’t know whether what is considered standard therapy improves, worsens or has no effect on the disease. We don’t know whether early disease patients respond to existent therapies. We need to test the effects of available drugs in state-of-the-art therapeutic protocols. We will also need to train new investigators with clinical, epidemiologic, cell biology and genetics skills who are committed to the discovery of new therapeutic interventions. The Network is a great opportunity to accomplish all these tasks,” said acting IPFnet Steering Committee Chair Dr. Galen B. Toews. “The best treatment option for all patients with IPF at the present is to participate in an IPFnet trial. Physicians, scientist, nurses, study coordinators, the NIH and foundations funds all play crucial roles in discovery, but they cannot do this work without patients who agree to participate in therapeutic trials.”

The network is currently recruiting patients for two important studies:

- 1) **The PANTHER-IPF:** Prednisone, Azathioprine, and N-Acetylcysteine: A Study That Evaluates Response in IPF – trial evaluates the effectiveness of N-acetyl cysteine (NAC) alone, and in combination with prednisone and azathioprine, at preventing the loss of lung function in people with IPF. This trial is available to all subjects with IPF diagnosed in the last 48 months between 35–85 years of age with moderate disease who meet study specific enrollment criteria.
- 2) **The ACE-IPF:** Anticoagulant Effectiveness in Idiopathic Pulmonary Fibrosis trial is investigating whether treatment with warfarin improves clinical outcome in subjects with IPF. This trial is available to all subjects with IPF between 35–80 years of age, regardless of time of diagnosis who meet study specific enrollment criteria.

The participating IPFnet sites have a long history of excellence in IPF-related patient care and clinical research. Participating centers are listed below. If you or someone in your family would like to participate in an IPFnet trial, please contact the appropriate center for you using the contact names and numbers listed.

State	Investigator	Institution	Contact Information
Alabama	Joao de Andrade, M.D.	University of Alabama at Birmingham	Tonja Meadows - 205.934.7630
California	Joseph Lynch, M.D.	University of California at Los Angeles	Eileen Callahan - 310.794.8595
California	Talmadge King, M.D.	University of California at San Francisco	Renee Jeffrey - 415.476.5034
Colorado	Kevin Brown, M.D.	National Jewish Health	Todd Dubois - 303.398.1621
Connecticut	Danielle Antin-Ozerkis, M.D.	Yale University School of Medicine	Jean Estrom - 203.785.7324
Florida	Marilyn Glassberg, M.D.	University of Miami, Miller School of Medicine	Emmanuelle Simonet - 305.243.3728
Illinois	Imre Noth, M.D.	University of Chicago	Cathy Brown - 773.834.7085
Kentucky	Jesse Roman, M.D.	University of Louisville	Tamra Perez - 502.852.1358
Louisiana	Joseph Lasky, M.D.	Tulane University	Sandy Ditta - 504.988.4040
Michigan	Fernando Martinez, M.D.	University of Michigan	Debra Dahlgren - 734.936.8917
Minnesota	Jay Ryu, M.D.	Mayo Clinic	Suson Walsh - 507.293.0637
Missouri	Neil Ettinger, M.D.	Saint Luke's Hospital	Sue Merli - 314.576.4501
New York	Michael Kallay, M.D.	Highland Hospital/University of Rochester Medical Center	Elizabeth Lyda - 585.233.4358
New York	Robert Kaner, M.D.	Weill Cornell Medical of Cornell University	Vanessa Monroy - 646.962.5568
North Carolina	Lake Morrison, M.D.	Duke University Medical Center	Terri Haram - 919.668.4562
Ohio	Jeffrey Chapman, M.D.	Cleveland Clinic Foundation	Susan Lubell - 216.445.5872
Pennsylvania	Milton Rossman, M.D.	University of Pennsylvania	Susan Metzger - 215.662.3115
South Carolina	Steven Sahn, M.D.	Medical University of South Carolina	Kimberly Argabright - 843.792.3168
Tennessee	James Loyd, M.D.	Vanderbilt University Medical Center	Wendi Mason - 615.343.7068
Texas	John Fitzgerald, M.D.	University of Texas Southwestern Medical Center	Barbi Estes - 214.648.6729
Utah	Mary Beth Scholand, M.D.	University of Utah Lung Health Research Center	Laurie Brewster - 801.581.5811
Washington	Ganesh Raghu, M.D.	University of Washington	Carolyn Spada - 206.598.4967

Clinical Trials Q&A:

What is a clinical trial?

Although there are many definitions of clinical trials, they are generally considered to be biomedical or health-related research studies in human beings that follow a pre-defined protocol. ClinicalTrials.gov includes both interventional and observational types of studies. Interventional studies are those in which the research subjects are assigned by the investigator to a treatment or other intervention, and their outcomes are measured. Observational studies are those in which individuals are observed and their outcomes are measured by the investigators.

Why participate in a clinical trial?

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research.

Who can participate in a clinical trial?

All clinical trials have guidelines about who can participate. Using inclusion/exclusion criteria is an important principle of medical research that helps to produce reliable results. The factors that allow someone to participate in a clinical trial are called “inclusion criteria” and those that disallow someone from participating are called “exclusion criteria”. These criteria are based on such factors as age, gender, the type and stage of a disease, previous treatment history, and other medical conditions. Before joining a clinical trial, a participant must qualify for the study. Some research studies seek participants with illnesses or conditions to be studied in the clinical trial, while others need healthy participants. It is important to note that inclusion and exclusion criteria are not used to reject people personally. Instead, the criteria are used to identify appropriate participants and keep them safe. The criteria help ensure that researchers will be able to answer the questions they plan to study.

What happens during a clinical trial?

The clinical trial process depends on the kind of trial being conducted. *See: What are the different types of clinical trials?* The clinical trial team includes doctors and nurses as well as social workers and other health care professionals. They check the health of the participant at the beginning of the trial, give specific instructions for participating in the trial, monitor the participant carefully during the trial, and stay in touch after the trial is completed.

Some clinical trials involve more tests and doctor visits than the participant would normally have for an illness or condition. For all types of trials, the participant works with a research team. Clinical trial participation is most successful when the protocol is carefully followed and there is frequent contact with the research staff.

What are the benefits and risks of participating in a clinical trial?

Benefits

Clinical trials that are well-designed and well-executed are the best approach for eligible participants to:

- Play an active role in their own health care.
- Gain access to new research treatments before they are widely available.
- Obtain expert medical care at leading health care facilities during the trial.
- Help others by contributing to medical research.

Risks

There are risks to clinical trials.

- There may be unpleasant, serious or even life-threatening side effects to experimental treatment.
- The experimental treatment may not be effective for the participant.
- The protocol may require more of their time and attention than would a non-protocol treatment, including trips to the study site, more treatments, hospital stays or complex dosage requirements.

What are side effects and adverse reactions?

Side effects are any undesired actions or effects of the experimental drug or treatment. Negative or adverse effects may include headache, nausea, hair loss, skin irritation, or other physical problems. Experimental treatments must be evaluated for both immediate and long-term side effects.

How is the safety of the participant protected?

The ethical and legal codes that govern medical practice also apply to clinical trials. In addition, most clinical research is federally regulated with built in safeguards to protect the participants. The trial follows a carefully controlled protocol, a study plan which details what researchers will do in the study. As a clinical trial progresses, researchers report the results of the trial at scientific meetings, to medical journals, and to various government agencies. Individual participants' names will remain secret and will not be mentioned in these reports (See Confidentiality Regarding Trial Participants).

What should people consider before participating in a trial?

People should know as much as possible about the clinical trial and feel comfortable asking the members of the health care team questions about it, the care expected while in a trial, and the cost of the trial. The following questions might be helpful for the participant to discuss with the health care team. Some of the answers to these questions are found in the informed consent document.

- What is the purpose of the study?
- Who is going to be in the study?
- Why do researchers believe the experimental treatment being tested may be effective? Has it been tested before?
- What kinds of tests and experimental treatments are involved?
- How do the possible risks, side effects, and benefits in the study compare with my current treatment?

- How might this trial affect my daily life?
- How long will the trial last?
- Will hospitalization be required?
- Who will pay for the experimental treatment?
- Will I be reimbursed for other expenses?
- What type of long-term follow up care is part of this study?
- How will I know that the experimental treatment is working? Will results of the trials be provided to me?
- Who will be in charge of my care?

Does a participant continue to work with a primary health care provider while in a trial?

Yes. Most clinical trials provide short-term treatments related to a designated illness or condition, but do not provide extended or complete primary health care. In addition, by having the health care provider work with the research team, the participant can ensure that other medications or treatments will not conflict with the protocol.

Can a participant leave a clinical trial after it has begun?

Yes. A participant can leave a clinical trial, at any time. When

withdrawing from the trial, the participant should let the research team know about it, and the reasons for leaving the study.

What is a placebo?

A placebo is an inactive pill, liquid, or powder that has no treatment value. In clinical trials, experimental treatments are often compared with placebos to assess the experimental treatment's effectiveness. In some studies, the participants in the control group will receive a placebo instead of an active drug or experimental treatment.

What is a control or control group?

A control is the standard by which experimental observations are evaluated. In many clinical trials, one group of patients will be given an experimental drug or treatment, while the control group is given either a standard treatment for the illness or a placebo.

Source www.clinicaltrials.gov, a service of the National Institutes of Health (NIH); content shortened for space. Please see the NIH website for complete information.



Sildenafil of Mixed Value in Pulmonary Fibrosis

Although drug does not increase walking distance, it may help improve other outcomes

In patients with advanced idiopathic pulmonary fibrosis, treatment with sildenafil does not significantly increase walking distance compared to placebo but may be associated with some symptomatic improvements, according to a study published online May 18 in the *New England Journal of Medicine* to coincide with presentation at the American Thoracic Society (ATS) International Conference in New Orleans.

David Zisman, M.D., of the Sansum Clinic in Santa Barbara, Calif., and colleagues randomly assigned 180 patients to receive either sildenafil or placebo for 12 weeks. In a second 12-week period, all participants received sildenafil in an open-label evaluation.

The researchers found that there was no significant difference in the primary outcome — the proportion of patients achieving an increase in six-minute walk distance of at least 20 percent — between the sildenafil group and placebo group. But they found that the sildenafil group achieved small but significant improvements in such secondary outcomes as arterial oxygenation, carbon monoxide diffusion capacity, degree of dyspnea, and quality of life. They also found that serious adverse events were similar in the two groups.

“Although this study did not meet its pre-specified primary outcome and the therapeutic efficacy of sildenafil is far from established, our data provide the clinical equipoise needed to conduct further trials involving patients



with advanced idiopathic pulmonary fibrosis,” Zisman and colleagues conclude. “While such trials are being designed and implemented, our finding that sildenafil was associated with symptomatic improvement may be of value to patients with advanced pulmonary fibrosis.”

Pfizer donated sildenafil and placebo for the study, and Masimo donated pulse oximeters.

Source: HealthDay News; content edited for space by CPF staff



Education. Support. Hope.

The CPF does not charge for any of its services, all costs are borne by the organization. In order to continue to offer the full range of services needed, your support is essential. Please consider a gift to the CPF and contact us about establishing a legacy gift to allow us to serve the public for years to come.

Hope for Patients With Mild Idiopathic Pulmonary Fibrosis

A new therapy shows promise for patients with mild idiopathic pulmonary fibrosis (IPF)

According to researchers in Japan, inhaled N-acetylcysteine (NAC) monotherapy preserves more lung function in some IPF patients than no therapy.

The findings were presented at the 2010 American Thoracic Society International Conference in New Orleans in May.

“This novel study provides encouraging evidence to pursue the potential of an efficacious treatment with NAC for patients with the early stage of IPF in a well designed clinical trial. In that sense, the finding was expected,” said Sakae Homma, M.D., Ph.D., professor of the Department of Respiratory Medicine, Toho University School of Medicine in Tokyo.

It is hypothesized that an oxidant–antioxidant imbalance may contribute to the disease process in IPF. Acetylcysteine, which is a precursor to the antioxidant glutathione, may be reduced in the lungs of patients with IPF. In this study, Dr. Homma and colleagues compared 48-week declines in forced vital capacity (FVC) and diffusing capacity between 100 IPF patients who were randomly assigned to receive treatment with 352.4 mg of inhaled NAC or no therapy. They then compared baseline FVC—a measure of lung function—to FVC after 48 weeks of treatment.

In a subset of patients with mild IPF (defined as initial %FVC less than 95 percent of predicted, or initial %DLco less than 55 percent of predicted) the rate of decline in lung function was significantly lower in those who had received the treatment than in those with no therapy.

“This shows a significant benefit for patients who received NAC compared with those who received no therapy,” said Dr. Homma.

The researchers also analyzed certain secondary endpoints: change in the lowest oxygen saturation; walking distance during a 6-min walking test; pulmonary function tests; serum inflammatory parameters including; chest computed tomography (CT) images; and subjective symptoms such as dyspnea. Among the secondary endpoints analyzed, a positive treatment effect was also demonstrated in change in %VC predicted in the same subset of mild IPF patients. Chest CT images improved in 8.6 percent of the treated group. Furthermore, there were no serious adverse events in the treated group.

“Our study compared the differences between NAC-therapy arm and a true ‘no-therapy’ arm and demonstrated a therapeutic effect on physiologic measurements in IPF,” said Dr. Homma. “Hence, this randomized

control trial results are novel findings. I expect that our study will serve as a guide to develop a new therapy for IPF in the future.” The researchers intend to continue to monitor the progress of the subjects in this study.

“Since we have obtained positive results in patients treated with NAC for IPF without any immunosuppressive or anti-fibrotic agents, we expect it to be one of the candidates for IPF therapies. At this point, there is no cure for IPF. From that standpoint, it is of a great significance for us to establish a new therapeutic strategy from the early stage of IPF,” said Dr. Homma. “We will continue the follow-up of the patient cohort included in this study to identify whether NAC can contribute to the prolonged survival of patients with IPF. In addition, since NAC is thought to be an antioxidant agent, it is expected that the indication will be extended to interstitial lung diseases other than IPF.

“Other clinical studies of NAC therapy are currently underway in the United States. We hope that our study results will be reproduced in those western clinical studies,” said Dr. Homma.

Source: American Thoracic Society

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Sansum Clinic, Santa Barbara, CA

CPF Announces New Board Members



Stanley Weinstock

Stanley Weinstock is a PF patient who owns and manages an award-winning Audi dealership in New York. He has had a long and very successful career in business, and has served on other corporate boards. Weinstock is the President of Biener Auto Group in Great Neck, New York, which has been the number 1 Audi dealership in New York for 10 years along with being one of the largest in the US. He serves on the Board of Directors of the New York State Auto Dealers

Association and is the President of the New York, New Jersey, Connecticut Audi dealers Association. Mr. Weinstock has served on the Audi National Dealer Council. He serves on the Cardiology Board of the North Shore University Hospital in Manhassat, New York.



Vanessa Balbach Clarke

Mrs. Clarke resides in Illinois and was a board member at the Pulmonary Fibrosis Foundation for 3 years. She has PF in her family, having lost an uncle and a grandfather, and her mother is now a patient. Her commitment to the cause has been demonstrated by her years of support for the cause of PF and for many years now she has been of support to the CPF through the Chicago B.I.G. Ball.

Some of Clarke's past board memberships include: Deborah's Place (a homeless women's shelter); the I Have a Dream foundation; Lake Bluff Open Lands; Glessner House (preserves a National Historic Landmark) and The Allendale Shelter Club, a home for troubled children. She is a graduate of Denison University and her last professional work experience was with Holly Hunt Ltd., where she was Director of Contract Sales for many years.



Terence Hales

Terence has an MBA and B.S. in Finance from Fordham University. He is currently Director of Real Estate, Americas Portfolio with Pfizer Inc. in New York, having been with CBS Corporation in New York, where he was Director of Real Estate from 2007 through 2009. Hales is a Member of the New York Roadrunners Club, the Leukemia Society of New York, and an Active Member of CoreNet Global.

Hales has joined the CPF in its efforts on Capitol Hill, and this year celebrated the 3rd year of his Run/Walk in Central Park, NY. Hales was motivated to take up the PF challenge when his father was struck with the disease (he had a successful lung transplant). Per Hales: "My dad's success story motivated me and family and friends to organize this (N.Y. Run) event, to help others who are faced with this disease today and those who may be in the future."



NeoPharm Announces FDA Grant of Orphan Drug Designation for IL13-PE38QQR for Treating Pulmonary Fibrosis

NeoPharm, Inc. announced that the Office of Orphan Products Development of the United States Food and Drug Administration (FDA) has granted orphan-drug designation for IL13-PE38QQR (IL13-PE) for the treatment of PF.

Dr. Aquilur Rahman, President and CEO, commented, "PF is the most deadly disease of the lungs in humans with very high morbidity. It is estimated that about 55,000 patients are diagnosed with the disease and almost 45,000 of them die with this disease every year in the U.S. There is currently no proven effective treatment to cure this disease. All the studies that NeoPharm has performed in animals and in ex vivo human tissue have shown quite promising results. We look forward to starting our clinical studies with IL13-PE as aerosolized product in humans inflicted with this devastating disease quite soon."

Orphan Drug designation provides a seven-year term of market exclusivity for PF upon final FDA approval. Orphan Drug designation positions NeoPharm to take advantage of a wide range of financial and regulatory benefits, including government grants for conducting clinical trials, waiver of expensive FDA user fees and certain tax credits.

Source: NeoPharm Press Release – edited for space

Whether you are a PF patient, a family member of a patient, or are close to someone with PF, the CPF is always just a phone call away. Our staff has counseled thousands of patients, and we are always here to provide you with the resources and support you need. Please call (888) 222-8541 to learn more.



Education. Support. Hope.

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About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501(c)(3) nonprofit organization, founded in 2001 to accelerate research efforts leading to a cure for pulmonary fibrosis (PF), while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF funds promising research into new approaches to treat and cure pulmonary fibrosis; provides patients and families with comprehensive education materials, resources, and hope; serves as a voice for national advocacy of PF issues; and works to improve awareness of PF in the medical community as well as the general public. The CPF's nonprofit partners include many of the most respected medical centers and healthcare organizations in the U.S. With more than 15,000 members nationwide, the CPF is the nation's largest nonprofit organization dedicated to advocating for those with pulmonary fibrosis. For more information please visit www.coalitionforpf.org or call (888) 222-8541.

Supporting the CPF

The Coalition for Pulmonary Fibrosis (CPF) relies on the contributions of individuals, corporations and associations who share our commitment to improving awareness and education of PF, and improving the quality of life for patients fighting PF nationwide.

Every service we offer is at no cost to the PF community. Through your generous support, the CPF will continue to provide information, resources and support to more than 128,000 PF patients, caregivers and families, and to the health care professionals who treat them.

Should you wish to make a tax-deductible contribution to the CPF, we encourage you to send your check or money order to:

Coalition for Pulmonary Fibrosis
10866 W. Washington Blvd., #343
Culver City, CA 90232

Contributions are also accepted online by using any major credit card safely and securely through our Web site. Please access our contributions page at www.coalitionforpf.org/AboutUs/contribute/contributenow.asp, or click "Contribute Now" from our home page. To contribute by phone using any major credit card, please call the CPF at (888) 222-8541.

If you have any questions about your contribution to the CPF, or if you would like to make a restricted donation to advance specific CPF programs or research efforts, please contact us at (888) 222-8541, or by email at info@coalitionforpf.org.