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Action Alert

The Quarterly Publication of the Coalition for Pulmonary Fibrosis

CPF to Host Fifth Annual "National IPF Awareness Week"

CPF team of more than 25 patients, advocates, and health care professionals to convene on Capitol Hill Sept. 22-29, 2007.

CPF is once again proud to announce that it will be hosting the Fifth Annual National IPF Awareness Week in Washington D.C., from Sept. 22-29. Plans for IPF Week include three days of meetings on Capitol Hill and a first-time CPF Congressional reception. Patients will have the opportunity to have a lasting impact by raising awareness of IPF to the Members of Congress and beyond.

To prepare for the week's events, U.S. Rep. Brian Baird (D-WA) and Rep. Mike Castle (R-DE) held a training conference call in July for more than 25 CPF advocates. They provided first-hand tips for making the most impact, as well as the most efficient and effective use of their time on Capitol Hill. Congressman Baird lost his father to IPF, and Congressman Castle lost his sister and a brother to the disease.

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Fundraiser Celebrates IPF Patient Gary Furbish

Kimberly Furbish-Curlless was determined to demonstrate to her dad, Gary Furbish, that he had many reasons to fight IPF, and to do all the right things to support his health despite his diagnosis. She became concerned after his diagnosis in 2005 when he seemed somewhat disengaged from the world around him even though he was not experiencing visible symptoms of IPF.

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Friends and family of Bob Siefert gather for a backyard barbeque benefiting the CPF. Together they raised over \$11,000.

Raising Funds for the CPF is as Easy as a Backyard Barbeque!

A fundraising event doesn't need to be a huge gala with elaborate décor, dinners and dancing to be successful. Amazing results can come in the form of a simple backyard barbeque.

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IPF Awareness Week, cont. from page 1

“I don’t know of any other disease in this country with as many people dying that has less notoriety and less support for it than IPF,” said Rep. Castle during the training call. “I don’t know another disease that has as much mystery to it.”

Rep. Baird will host a Congressional reception during IPF Week on Tuesday, Sept. 25, 2007, from 2:00 p.m. to 3:30 p.m. in the Caucus room of the Cannon Building on the House side of the Capitol. The reception will include a tribute to the late Congressman Charlie Norwood who was also an IPF patient. Congressman Norwood was the first Member of Congress to introduce IPF legislation in Congress, working closely with the CPF.

There will also be a “Living with IPF” patient seminar in partnership with INOVA Fairfax Medical Center. It will

be held at the Hyatt Regency Capitol Hill on Sunday, Sept. 23, 2007.

“I don’t know another disease that has as much mystery to it.”

– Rep. Mike Castle

During IPF Week, the CPF will be running ads online with Congressional Quarterly’s *Healthbeat* news site and in *CQ Today*, a daily Washington newspaper.

To learn more about the CPF’s campaign ACT advocacy program and how you can help, please contact Teresa Geiger at (888) 222-8541 ext. 702 or tgeiger@coalitionforpf.org.

Resolution Recognizing IPF and CPF’s National IPF Awareness Week Passes Senate

Legislation, also introduced in the House, formally calls for research into treatment, cure for devastating lung disease

The Coalition for Pulmonary Fibrosis (CPF) applauds the recent passage of important legislation that recognizes the need for research into the cause of idiopathic pulmonary fibrosis (IPF). Senate Concurrent Resolution 42 (S. Con. Res. 42) recognizes the CPF’s National IPF Awareness Week and raises the importance of the urgent need to identify viable treatments and an eventual cure for IPF, a disease that is becoming alarmingly more prevalent in the United States. The House version of the bill was introduced on July 12, 2007, and is still seeking co-sponsors.

“The passage of this resolution in the Senate demonstrates that support is growing for the thousands of Americans who are fighting IPF,” said Mark Shreve, chief executive officer of the CPF. “This is an important step toward increasing awareness of a lethal disease that the average American has never heard of until they or someone they love receives the diagnosis.”

IPF is a devastating and ultimately fatal lung disease. The only treatment to improve survival is a lung transplant, yet most patients don’t survive long enough to receive one. The average life expectancy for IPF patients is just three years. Every 13 minutes, someone dies from pulmonary fibrosis in the U.S.

National IPF Awareness Week 2007 Schedule

Sept. 23

“Living with IPF” Patient Seminar

in partnership with INOVA Fairfax Medical Center
at the Hyatt Regency Capitol Hill

Sept. 25

**Meetings on Capitol Hill
Congressional Reception**

2:00 p.m. – 3:30 p.m., Cannon Caucus Room,
hosted by Rep. Brian Baird (D-WA)
with tribute to late Congressman Charlie Norwood

Sept. 26

Meetings on Capitol Hill

The concurrent resolution, introduced by U.S. Sen. Norm Coleman (R-MN) and co-sponsored by Sen. Richard Durbin (D-IL), further affirms Congress' support for the goals and ideals of National IPF Awareness Week, sponsored by the CPF and scheduled to take place Sept. 22-29, 2007, in Washington, D.C.

"I'm pleased that my colleagues and I have made a commitment to increase advocacy and research on the fatal lung condition, idiopathic pulmonary fibrosis," said Sen. Coleman. "With more than 128,000 people afflicted by this disease nationwide, it is key that we give all idiopathic pulmonary fibrosis patients and their families hope that one day there will be a cure. I believe this new commitment is a step toward real progress."

"I hope our efforts can raise the profile of those who suffer and dramatically increase research into the diagnosis and treatment of this disease. The tireless work of advocates on this issue deserves the recognition we are giving it today," said Sen. Durbin.

"This legislation serves as an incredible endorsement for the work of the CPF and its volunteers in representing the IPF community in Washington," added Shreve. "We're grateful to the Members of Congress who share our hope and commitment to this cause, and we are excited to increase dialog to help our patients and researchers around the country."

The House version was introduced on July 12, 2007, and authored by U.S. Rep. Nathan Deal (R-GA), who carried on the effort for his friend, the late Rep. Charlie Norwood (R-GA). Rep. Norwood was a proponent of increased awareness of IPF following his own struggle with the disease. He championed the cause on behalf of thousands of Americans who suffer from IPF until his untimely death in February 2007. Rep. Norwood received a lung transplant in 2004 and subsequently introduced House Concurrent Resolution 178 for the first time in the 109th Congress. Rep. Deal committed to introduce the legislation again this year, in an effort to bring attention to the disease while also honoring Congressman Norwood's work.

"Pulmonary fibrosis is an often overlooked degenerative and debilitating disease," said original co-sponsor, U.S. Rep. Brian Baird (D-WA). "My own father died of this disease, and my good friend and colleague Charlie Norwood died just a few months ago. It is my hope that with passage of this resolution we can increase awareness about this disease. We must aggressively pursue research opportunities into the causes of the disease, a treatment and eventual cure."

"By introducing H. Con. Res. 182 in honor of my dear friend Charlie Norwood, I hope to continue his efforts to raise awareness of this debilitating lung disorder which struck him in 1998." said Rep. Deal.

What is a Concurrent Resolution?

Concurrent Resolutions are used for expressing facts, principles, opinions and purposes of the two Houses of Congress – the House of Representatives and the Senate. On approval by both Houses, they are signed by the Clerk of the House and the Secretary of the Senate and transmitted to the Archivist of the United States for publication in a special part of the Statutes at Large volume covering that session of Congress.

IPF Legislation Represents an Important Step for the IPF Cause for Several Reasons:

- It advocates for patients who suffer from IPF. In the past five years, IPF prevalence and incidence has increased 156 percent; yet there remains no FDA approved treatment to combat this deadly disease, and research funding remains unacceptably low.
- It creates the foundation on which all future legislation involving IPF may be based.
- It defines the challenges facing the IPF community in the Congressional Record.
- It becomes a permanent vehicle for educating Members of Congress.
- It will lead to greater public awareness of IPF.
- It will initiate a dialog in Congress to increase attention and funding given to the deadly disease that kills 40,000 Americans each year, as many as claimed by breast cancer.

CPF Announces Fall 2007 Fundraising Events in Los Angeles and Chicago



Chicago

"La Nuit de la Papillon" (Night of the Butterfly) Cocktail Party

Date: Wednesday, Sept. 19, 2007
Time: 7:00 – 10:00 p.m.
Location: Bistrot Margot
1437 N. Wells St.
Chicago, IL
Contact: For information, visit the CPF Web site at www.coalitionforpf.org, or contact Deborah Roney at (312) 498-5984 or droney@coalitionforpf.org.

Cocktails, hors d'oeuvres, auction and prizes will be featured.

Los Angeles

Butterfly Garden Party

Date: Sunday, Sept. 30, 2007
Time: 2:00 – 6:00 p.m.
Location: Malibu Ocean View Estate
20538 Seaboard
Malibu, CA
Contact: For information, visit the CPF Web site at www.coalitionforpf.org or contact Corrine Levy at (310) 315-1160.

CPF Establishes Charlie Norwood Memorial Research Fund

The CPF is proud to announce the establishment of the Charlie Norwood Memorial Research Fund, which will further research into the causes of and possible treatments for IPF, and support the programs and services of the CPF. The fund honors former Congressman Norwood who succumbed to IPF in 2007, and it is with gratitude that the CPF thanks his widow, Gloria, and their son, Carlton, for assisting in founding this new fund that will promote high-level research. The funded projects will be selected by the CPF through a peer review board of the top IPF experts in the country.

*"I am really pleased to be able to support research into IPF. **Charlie felt so strongly that we needed research and awareness for this terrible disease, so if this fund in his name can make a difference,***

I will know I've done something very worthwhile," said Gloria Norwood.

The late Rep. Norwood was a proponent of increased awareness of IPF following his own diagnosis. He demonstrated great courage by letting his constituents know of his condition – which was a difficult choice, but one that significantly impacted awareness of IPF. He generously met with patients during the CPF's visits to Washington, D.C. for National IPF Awareness Week, and introduced legislation recognizing IPF for the first time in the 109th Congress. Rep. Nathan Deal recently re-introduced House Concurrent Resolution 182 which is similar to the Norwood bill, in an effort to bring attention to the disease while also honoring the late Congressman's work.



For the last four years, Congressman Norwood met with several delegations of IPF patients, and advocates each year during National IPF Awareness Week on Capitol Hill, and provided hope and support through his own struggle with the disease.

This year National IPF Awareness Week will be held Sept. 22-29, 2007. The CPF is proud to announce that Gloria Norwood will attend a special reception that will include a tribute to Congressman Norwood. The event will be hosted by U.S. Rep. Brian Baird (D-WA), and held Sept. 25 from 2:00 p.m. to 3:30 p.m. in the Cannon House Building Caucus room.

Upcoming "Living with IPF" Patient Seminars

INOVA Fairfax Hospital

National IPF Awareness Week - Washington, D.C.

Time: Sunday, Sept. 23, 2007
11:30 a.m. – 3:30 p.m.
Complimentary lunch and snacks will be provided.

Location: Hyatt Regency Capitol Hill Hotel
400 New Jersey Ave. NW
Washington, D.C. 20001
Hotel phone: (202) 737-1234

University of Washington Chest Clinic

Seattle, WA

Time: Saturday, Oct. 13, 2007
8:45 a.m. – 3:30 p.m.
Complimentary lunch will be provided.

Location: University of Washington, Seattle
Kane Hall, Room 110
Parking at 41st/15th NE
Underground parking is available at the Central Plaza Parking Garage

University of Minnesota

*Pulmonary Fibrosis and Scleroderma Education Day Seminar
in Partnership with the Center for Lung Science and Health
Minneapolis, MN*

Time: Saturday, Oct. 27, 2007
7:30 a.m. – 2:30 p.m.
Complimentary lunch and snacks will be provided.

Location: McNamara Alumni Center
200 Oak St. SE
Minneapolis, MN 55125

"We just had to let you know how inspiring, and how informative the seminar at Mt. Sinai was. You covered everything, and we learned so much. All who participated have so much knowledge of this disease, and their promise to go forward in research is our hope for the future. We will do our best for the CPF. You've helped to make the most difficult time in our lives a bit easier to bear."

– Maureen and John Nunnery,
Wycoff, NJ



All seminars are hosted by the CPF and are free to attend. To RSVP for a seminar, please contact the CPF at (888) 222-8541, ext. 704, or email tgeiger@coalitionforpf.org. Please be sure to leave your phone number and indicate the location of the event you are RSVP'ing for. (For the Washington state and Washington, D.C., events please be clear as these names are similar.) Please consider your voicemail or email to be confirmation of your attendance. We apologize that we cannot return all RSVP calls due to high caller volume.

If you require oxygen, please bring enough for your use throughout the day.

CPF Partners with Medical Centers on Eastern Seaboard to Host IPF Patient Education Events

Events Draw Hundreds of IPF Patients Nationwide

More than 400 patients and family members from across the country attended the CPF's nationally recognized "Living with IPF" seminars along the eastern seaboard during the spring and early summer to learn more about current and future treatments for the disease, attend sessions on pulmonary rehabilitation and clinical trials, and learn more about the programs and services of the CPF to help them.

The CPF partnered with researchers at Medical University of South Carolina (MUSC) in Charleston, S.C., Mount Sinai Medical Center, New York City, N.Y., and Johns Hopkins University Medical Center in Baltimore, Md, to provide updates on the latest information regarding the science of IPF, and provide an interactive forum between IPF medical professionals and the patients they treat.

"Our 'Living with IPF' seminar series continues to be an incredible source of information and education, and support for our patients and their loved ones," said Mark Shreve, chief executive officer of the CPF. "We're grateful to all of our guest speakers

and volunteers who help make these programs as respected as they are in the IPF community."

The seminars featured Steven Sahn, MD, who hosted the MUSC event; Maria Padilla, MD, who hosted the Mount Sinai event; and Sonye Danoff, MD, who emceed the Johns Hopkins event.

The events also featured top IPF doctors Kevin Leslie, MD, of Mayo Clinic; Mark Steele, MD, of Duke University Medical Center; Jim Lloyd, MD, of Vanderbilt University Medical Center; Qanta A. Ahmed, MD, of MUSC; Steven Nathan, MD, of Inova Fairfax Hospital; Joan Gil, MD, Virginia Lytle, MD, Lori Shah, MD, and Neil Schacter, MD, all of Mount Sinai; Steven Mathai, MD, Meredith McCormack, MD, Patrick Sosnay, MD, and Vidya Krishnan, MD, all of Johns Hopkins; and Albert Polito, MD, of Mercy Hospital in Baltimore.



Patients filled the seminar room at the "Living with IPF" seminar held at the Medical University of South Carolina (MUSC) in Charleston, SC, hosted by Steven Sahn, MD.



Maria Padilla, MD, host of the Mount Sinai "Living with IPF" patient event, speaks to attendees on May 12, 2007.

"The CPF is a remarkable source of hope, support and education. You truly live your motto."

– Maria L. Padilla, MD

*Medical Director Lung Transplantation Program & Director Advanced Lung Disease Program
Mount Sinai School of Medicine, New York, NY*

"We would like to thank the CPF for giving us the opportunity to attend the seminar at Mt. Sinai. We found all of the speakers to be most informative and beneficial. We walked away with more knowledge, and also the hope that others care. You are an inspiration to all of us and we wish you well."

– Bob & Donna Schlenner, Washington, NJ

Jazz Bands' Benefit Concert Remembers IPF Patient, Raises Funds for CPF

The Spry Middle School Jazz Bands at Thomas High School in Webster, NY, hit an uplifting note for the CPF with their second annual benefit concert on June 15, 2007, to share information about the debilitating disease and raise funds for further research. The event paid tribute to Greg Chandler, a Webster resident and high school parent, who passed away in May from complications of IPF.

The school's sixth, seventh and eighth grade jazz bands, along with guest musicians from the community, performed at the concert. Music teachers Tony Britt, Al Lis and Kate Thompson, along with the Spry Parent, Teacher, Student Association and many community volunteers, worked together to make the event a success. Gary Wahl, MD, Greg Chandler's pulmonologist, attended the concert and shared important details about IPF with the audience.

Cindy Chandler, Greg's widow, is the assistant principal of Thomas High School and was touched when she learned the band's efforts would benefit the CPF.

"The music was fantastic and truly illustrated why the Webster School District is nationally recognized for their music program," said Chandler. "Their talent truly made the evening

enjoyable for the audience and the generous effort of everyone involved, including the corporate sponsors, helped to raise \$4,800 for the CPF."

To find out more about IPF, or to contribute and support further research, please visit the CPF at www.coalitionforpf.org or contact Mishka Michon at (888) 222-8541, ext. 701.



(left to right) Jamie and Cindy Chandler; Dr. Gary Wahl, pulmonologist at Rochester General Hospital; Tony Britt; Al Lis; and the talented Spry Middle School musicians.

Houston Provides Final Results of Fundraising Efforts, Shares News of Loss

David Houston recently completed a 50-mile endurance run in Auburn, Calif. to raise money and awareness for IPF, and support his father, Lee Houston, who was suffering from IPF (see Action Alert p. 14, April-June 2007 edition). His effort raised more than \$18,000 for the CPF. Sadly, his father, whom he'd run in honor of just weeks earlier, passed away on July 17, 2007.

Houston wrote to his fundraising supporters, "The pain of losing [my father] is unquestionably difficult, but I find a great deal of comfort in reflecting on how many people assisted in the effort to fight the disease that killed my father."

Joe Nichol's Fan Club Partners with CPF to Create a Memorial Gift

Mike Nichols Fund of Hope to Raise Research Funding for Disease that Claimed Life of Country Stars' Father

The CPF has found a new friend in country music star Joe Nichols, who lost his father to IPF in 2002. His fan club paid tribute to him by establishing the Mike Nichols Fund of Hope during arguably the most important week in Country Music – CMA MusicFest, held in Nashville, Tenn., on June 7, 2007.

The Joe Nichols Fan Club and the CPF recently announced the establishment of the *Mike Nichols Fund of Hope* in an effort to raise awareness and research funding for idiopathic pulmonary fibrosis (IPF), the deadly lung disease that claimed the life of Mike Nichols in July 2002 at the age of 46. In a private meeting at his annual fan club party at the Nashville Palace, Nichols gave a plea for others across the country to contribute to the fund, and help others fighting IPF.

"I am honored that my fans would create a fund to remember my father and to help fund much needed research into IPF," said Nichols. "It is my hope that others will join the cause and it will grow to pave the way for a cure for this devastating disease."

"We, the fans, decided to donate to the CPF in memory of Joe's father as this year's gift to Joe. However, after hearing from others who have also been affected by this devastating disease, we decided to create the *Mike Nichols Fund of Hope*. This living memorial will continue to receive donations year round and be a gift that provides hope to thousands of patients diagnosed with IPF," said Marilyn Wigglesworth of the Joe Nichols Fan Club.

"We are so pleased Mr. Nichols' fans want to honor him by creating a fund in his father's name," said Mark Shreve, chief executive officer of the CPF. "So many families have lost someone they love to IPF. This kind of heartfelt support will benefit not only those patients living with IPF, but also those that will be diagnosed in the future."

This fund will help the CPF accelerate critical research into new approaches to understand and treat IPF, while funding CPF programs and services for patients and families nationwide. To make a tax-deductible contribution to the CPF for the *Mike Nichols Fund of Hope*, please visit www.coalitionforpfp.org/nichols, or send your check or money order (made in U.S. dollars) to:

Coalition for Pulmonary Fibrosis
Suite F, # 227
1659 Branham Lane
San Jose, CA 95118-5226

Please remember to write the name "Joe Nichols" on your check or money order, or include it in the "Notes" section of PayPal when making your contribution online.

For more information on the *Mike Nichols Fund of Hope* and the Joe Nichols Fan Club, visit www.joenichols.com.



Country music singer Joe Nichols with CPF's Teresa Geiger.



Joe Nichols on stage at his Fan Club Party during CMA Music Fest on June 8, 2007.

Wife and Daughter Remember Loved One as They Raise Funds for the CPF

Doris Sowards and her daughter, Tracey Jean St. Cyr, from New Hampshire felt helpless as they watched Edward Sowards suffer and his health decline. When the 68-year-old husband and father passed away on June 6, 2007, the two decided to take action and do something to help save other families from the grief they were experiencing.

"We decided to make bracelets and sell them in memory of Dad and to promote awareness of IPF, with all proceeds donated towards research funding," said St. Cyr. "My mom and I are on a crusade to help spread awareness about the terrible disease that took my father's life."

Sowards and St. Cyr make the bracelets themselves. Each one has its own unique design and features a butterfly representing the lungs and the CPF's logo for its fundraising efforts. Sterling silver initials "I. P. F." are also included in each design. The cost for each bracelet is \$12, with a \$5 donation from each bracelet donated to the CPF. For an additional \$5, you may request to have a sterling silver charm added that can hold two pictures, possibly of a loved one.

To view Mr. Soward's online memorial, visit www.mem.com, type in Edward Sowards, and select "everlasting memorial."



Doris Sowards and Tracey Jean St. Cyr design and sell unique IPF bracelets to help raise awareness and funds for continuous research.

For further information, to order IPF bracelets or obtain pricing (including shipping costs), contact:

Tracey Jean St. Cyr
1327 Bound Tree Rd.
Contoocook, NH 03229
Email: tbandgeo@tds.net
Phone: (603) 496-6654

Payments can be made by cash or check and mailed to the address above. Shipping times may vary due to supply and demand.

Fundraiser Celebrates IPF Patient continued from page 1

With tremendous vision, energy and commitment, Furbish-Curless began putting together a special tribute evening for her dad. Held at the Brunswick Golf Club in Maine, the event was successful beyond her wildest dreams.

"I never realized so many people would show up – and be so generous. It was an unforgettable night, so filled with love," said Furbish-Curless. "And my dad seems to have decided to re-engage with life – he's back outside raking the leaves and making plans to do all sorts of things. That is the absolute best gift and it's an outcome I would never have expected. It's all been wonderful."

The May 5 event raised more than \$31,000 for the CPF. Mishka Michon, executive vice president for development, attended the event on behalf of the Coalition. "This was one of the most moving evenings I've experienced. It was clear that Gary Furbish is deeply loved and has a lot of champions behind him in this fight. I felt fortunate to have been included, and to see how one woman's efforts could have such a huge impact."

Kim Block, a local news anchor, also joined the friends and family for the evening. In her remarks to the audience, she said that the information she had read about IPF – especially the details regarding the

lack of treatments and a cure – had shocked her, and that she wanted to continue to help generate public awareness for the cause.

Source: The Times Record, May 27, 2007. Content edited for space.

"I never realized so many people would show up – and be so generous. It was an unforgettable night, so filled with love."

– Kimberly Furbish-Curless

For Peggy Griffin, the idea of a barbeque on a lovely summer day seemed like one that could achieve three important goals at once:

- honor her father, Bob Siefert, who is an IPF patient;
- increase awareness of the disease that was unknown to most of her family and friends until his diagnosis;
- raise much needed funding to support the research, awareness and support efforts of the CPF.

“During my ongoing research for information on the disease, I came across the CPF. I was truly inspired by the stories of families coming together to raise money to try to find a cure,” said Griffin. “Many of

the fundraising efforts were done in memory of loved ones who had since passed away. My four sisters and I decided we wanted to do something ‘in honor’ of our father while he was still with us.”

“Everyone can make an impact, especially in their own backyards - both figuratively and literally,” said Mishka Michon, executive vice president of development for the CPF. “Some of the most successful fundraising events have been those that have been organized by people like Peggy who pull it all together with the help of friends and family. We admire her work to help others by hosting this wonderful event.”

“The outpouring of love for my mom and dad was amazing, and people were so excited to be able to celebrate with my father and to make a contribution in his honor,” said Griffin. “We were surprised how simple it was to throw something together and to end up making a considerable impact. The checks are still coming in. It is a great feeling to know you can make a difference - especially when it is for someone near and dear to your heart.”

If you’d like to plan a fundraising event in your city, neighborhood or backyard, let the CPF know by contacting Mishka Michon at (888) 222-8541, ext. 701.

Medicare Cuts to Home Oxygen Therapy to Exceed \$1.5 Billion in 2009, 2010

By Michael Teitelbaum, CQ Staff

Two recent changes in Medicare payment policy could significantly impact Medicare expenditures for home oxygen therapy in the near future, according to a recent analysis conducted by *Avalere Health LLC*.

The study examines policy changes affecting the home oxygen therapy market that have been enacted by Congress since 1997, including two provisions that came as part of the 2003 Medicare overhaul (PL 108-173) and 2005 budget reconciliation (PL 109-171) laws: a three-year cap on home oxygen therapy rental payments; and implementation of a competitive bidding process for durable medical equipment, including home oxygen.

Both provisions would result in a \$710 million cut in Medicare payments in 2009 and \$880 million in 2010, according to the study.

Until 2006, Medicare made monthly payments to the home oxygen therapy provider for as long as the patient required the therapy, the report states. Under the three-year-cap enacted in the budget reconciliation law, Medicare will discontinue monthly payments to home oxygen therapy providers for equipment rental services after 36 months of continuous use of the equipment by a Medicare beneficiary, according to the study, which contains a state-by-state analysis of the effects of the cap based on the number of Medicare beneficiaries in each state who use home oxygen therapy.

By 2009, for example, nearly 20,000 Medicare beneficiaries in Florida would find their stationary oxygen equipment payments ended, reducing Medicare expenditures by \$38.5 million, the study finds. The competitive bidding process will operate within 10 of the largest Metropolitan Statistical Areas (MSAs), excluding the New York, Los Angeles and Chicago MSAs for logistical reasons. It will apply to 10 of the top durable medical equipment, prosthetics, orthotics and supplies product categories and will be expanded into 70 additional MSAs in 2009. The cap will become effective Jan. 1, 2009. According to the study, the competitive bidding program will reduce Medicare expenditures for home oxygen by an estimated \$260 million in 2009 and by an additional \$380 million in 2010.

Source: *CQ HealthBeat News*

Senate Votes to Give FDA Sweeping New Powers

By Robert Pear

By a vote of 93 to 1, the Senate passed a bill on May 9, 2007, that gives the Food and Drug Administration (FDA) sweeping new power to police drug safety, order changes in drug labels, and restrict the use and distribution of medicines found to pose serious risks to consumers.

The bill calls for a fundamental change in the philosophy and operations of the FDA, requiring the agency to focus on the entire life cycle of a drug — not just the years prior to its approval, but also the experience of patients who later take it.

Senators said the bill was a response to a widespread loss of confidence in the ability of the FDA to protect consumers against the dangers of drugs like Vioxx, a popular painkiller withdrawn from the market in 2004.

The bill would carry out many recommendations from the National Academy of Sciences and appears broadly acceptable to the House.

“This legislation will make a major difference for families in America, ensuring the safety of our prescription drug system,” said the chief sponsor of the bill, Senator Edward M. Kennedy, Democrat of Massachusetts. “We will also have safer food for families and for pets.” Senator Michael B. Enzi, Republican of Wyoming, said the bill was the “most comprehensive drug safety overhaul in more than a decade.”

Under the bill, the government would analyze data on tens of millions of patients, looking for signals that particular drugs posed serious risks. To minimize those risks, the government could order changes in a drug’s label and could require the manufacturer to conduct more studies and clinical trials of a drug already on the market. Under current law, the government and drug companies sometimes haggle for months over changes in drug labeling, and the FDA can request but not compel manufacturers to perform studies.

The bill would require the government to establish a public database of all clinical trials and their results. Lawmakers said the database would make it difficult for drug companies to hide evidence of safety problems, as some have done in the past. The database would also make it easier for patients to learn of clinical trials testing experimental drugs that could save their lives.

Source: The New York Times, May 9, 2007. Content edited for space.

IPF Patient, CPF Member & Advocate in Michael Moore Movie, on “The View”

9/11 Responder Vito Valenti talks about IPF, need for lung transplant

Vito Valenti says he felt like a celebrity on the red carpet in New York recently for the premier of SiCKO, a film by Michael Moore criticizing the U.S. health care system. He appeared in an interview in the Moore film to talk about his illness with IPF. Like thousands of others who suffer from IPF, his only hope is a lung transplant.



“I just want to make a difference,” said Valenti. “I want to raise awareness of this illness

that affects so many, including some 9/11 responders like me, and the critical need for increased research funding to find lifesaving treatments.”

Valenti also spoke to ABC’s “The View” co-hosts Rosie O’Donnell and Joy Behar about his personal struggle to survive.

“Any awareness that is created for IPF by my interviews is a huge step for the IPF community,” said Valenti. “The public knows well what a 9/11 hero is, but it is still the case that few know that there are 9/11 heroes who are dying from an untreatable illness which no one yet understands. Most people have never even heard about pulmonary fibrosis. I am working with the CPF to change that.”

If you have a story to tell and want to reach out to your local media to help improve the awareness of IPF, please let the CPF know by contacting Teresa Geiger at (888) 222-8541, ext. 702.

Enrollment Complete for Phase III Clinical Trial Program Evaluating Pirfenidone in Patients with IPF

InterMune, Inc. announced that patient enrollment has been completed in CAPACITY, the company's Phase 3 clinical program to evaluate pirfenidone as a treatment for patients with idiopathic pulmonary fibrosis (IPF).

"We are very pleased to have completed enrollment of the CAPACITY program seven months ahead of the original schedule, and with 194 more patients than originally planned," said Steve Porter, M.D., Ph.D. and Chief Medical Officer of InterMune. "The rapid pace of enrollment clearly reflects strong interest by investigators and patients. We look forward to sharing

top-line results from CAPACITY, which are now expected to be available around the end of 2008."

The CAPACITY program includes two multinational, randomized, double-blind, placebo controlled Phase 3 trials, named CAPACITY 1 and CAPACITY 2, designed to evaluate the safety and efficacy of pirfenidone in IPF patients with mild to moderate impairment in lung function. The primary endpoint of both trials is lung function, as measured by change in forced vital capacity (FVC). The two trials have enrolled a total of 779 patients at 110 centers in North America and Europe. Enrollment was completed

in less than 13 months following randomization of the first patient into the program in late April 2006.

"Study conduct in CAPACITY has been excellent, as we have experienced a very low patient drop-out rate to date with over 750 patients enrolled and having conducted the program for more than one year," Dr. Porter added. "A well-designed and well-powered study, combined with excellent study conduct, provide confidence that we are well positioned to determine the extent to which pirfenidone can fill the significant unmet medical need for a new medicine to help patients suffering from IPF."

Source: InterMune, Inc., May 16, 2007.

Ohio State Researchers Discover Marker for Pulmonary Fibrosis

Researchers have identified a specific growth factor that appears to contribute to the development of pulmonary fibrosis, suggesting they may be close to finding a cause for the lung disease. The study appears in a recent issue of the American Journal of Respiratory and Critical Care Medicine.

"This research has identified M-CSF as a new marker for pulmonary fibrosis, as well as a potential new therapeutic target," says Dr. Clay B. Marsh, director of OSU Medical Center's Center for Critical Care and principal investigator of the study.

The scientists measured lung inflammation and fibrosis in mouse models and studied fluid from the lungs of patients with idiopathic pulmonary fibrosis. The scientists

observed that M-CSF works to promote inflammatory cell recruitment and induces proteins that recruit and activate fibroblasts in the lungs, all of which contribute to scarring.

The findings by lung and critical care researchers at Ohio State show the growth factor M-CSF initiates a process that promotes inflammation, producing collagen, or scar tissue, that causes fibrosis. M-CSF was found even in lung fluid from patients with idiopathic pulmonary fibrosis, a form of the lung disease with no known cause.

Early observations suggest that decreasing the risk for scarring is linked to reducing the presence in the lungs of monocytes and macrophages - derivatives of blood cells that are involved in fighting infection. The

macrophages are a critical component of this lung disease and appear to direct the recruitment of other cells like fibrosis - the scarring results from the contributions of these cells.

The latest observations are significant because there has been no prior reported link for the role of M-CSF in the development of pulmonary fibrosis in animals or humans, Marsh says. In addition, because M-CSF was found in the lung fluid of patients with idiopathic pulmonary fibrosis, researchers are confident that a new direction in treating this disease may be possible.

Funding from the National Heart, Lung and Blood Institute supported the research.

Source: Ohio State University Medical Center. Content edited for space.

UPMC Researchers Find Gene Expression Patterns, Predict Rapid Decline in IPF Patients

Idiopathic pulmonary fibrosis (IPF) is a chronic lung disease typically characterized by the slow but progressive onset of shortness of breath or cough. Most patients live about five years after diagnosis. However, according to a new study published in the online journal *PLoS ONE*, a subset of patients with a specific genetic profile has a much more rapid progression to complete pulmonary failure and death without a lung transplant.

Based on observations in the clinic that some IPF patients display a more rapidly progressing disease course, researchers at the Simmons Center for Interstitial Lung Disease at the University of Pittsburgh School of Medicine, collaborating with pulmonary scientists in Mexico and California, used DNA microarray analysis to measure the gene expression patterns of 26 rapid progressors and 88 slow progressors. They identified 437 differentially expressed genes between the groups. Specifically, lungs of rapid progressors, who were predominantly males who smoked, overexpressed genes involved in the development of tissues and organs (morphogenesis), oxidative stress, cell migration and proliferation and genes from fibroblasts and smooth muscle cells.

According to Naftali Kaminski, M.D., director of the Simmons Center and director of the Lung Translational Genomics Center, division of pulmonary, allergy and critical care medicine, University of Pittsburgh School of Medicine, these findings offer strong evidence that rapid progressors represent a distinct clinical phenotype compared with the usual slower progressing patients.

“We are only now starting to really understand IPF and to characterize it,” Dr. Kaminski said. “Therefore, it is critical for patients with the disease to be seen in centers that are actively involved in IPF research, so we can help them better decide a course of action.”

These findings also highlight the variability in the progression and outcome of IPF and may explain, in part, the difficulty in obtaining significant and reproducible results in studies of therapeutic interventions in patients with IPF, noted first author Mois’s Selman, M.D., director of research at the National Institute of Respiratory Research in Mexico City. “This study suggests that physicians should pay more attention to the time of onset of symptoms in their patients,” Dr. Selman said.

“Although preliminary, these results may allow investigators to identify biomarkers of disease progression and, more importantly, better evaluate the effectiveness of potential therapies,” added Talmadge E. King Jr., M.D., chief of medicine at San Francisco General Hospital and an internationally renowned expert in research and management of pulmonary fibrosis.

The study was supported by the National Institutes of Health and grants from the Simmons Family Foundation and the Universidad Nacional Autónoma de México.

Source: University of Pittsburgh Schools of the Health Sciences, May 6, 2007. Content edited for space.



Dynamic Duo Creators of Modern Home Oxygen Therapy

Technology From Space Program Originally Used to Develop Portable Oxygen Systems

If you are one of the estimated 1.4 million people who rely on supplemental oxygen to live your life or just to help you maintain your active lifestyle, you can thank two Colorado researchers who pioneered the technology more than 40 years ago.

Tom Petty, MD, and his research partner, Louise Nett, a nurse and respiratory therapist, founded modern long-term oxygen therapy (LTOT) 41 years ago at the University of Colorado Health Sciences Center. They used a prototype of the first liquid oxygen system to test and study. It was a lighter weight – 9.5 pounds – extremely light compared to heavy oxygen cylinders of the time only used in hospitals and long-term care settings.

In 1965, Dr. Petty and Nett took tools used by NASA in preparing for man's first walk on the moon to devise a way for lung disease patients to have supplemental oxygen at home. Called the Linde Walker and Reservoir prototype system, it was shipped from New York to Colorado to Dr. Petty's boss, the late Roger S. Mitchell, MD.

"He told me to figure out a way to use it," said Dr. Petty. And figure it out, he did.

Dr. Petty performed his early investigations of the portable oxygen in a careful, scientific, hospital-based study at the University of Colorado and then later at Echo Lake at 10,000 feet in the Colorado mountains in 1965.

"Our report in the literature in 1967 was the first scientific proof that oxygen really worked. Prior to this, the dogma was that oxygen was dangerous and would reduce the drive to breathe. We proved this dogma wrong," said Dr. Petty. "In 1968 I tested the liquid system myself at 12,000 feet on Rollins Pass, west of Boulder. I had climbed mountains in this region before, and I was excited at how easy it was for me with oxygen."

The research was successful and the concerns about safety were eventually put to rest. Dr. Petty assisted the National Institutes of Health (NIH) to conduct the first controlled trials for an ambulatory study with research sites across the country and long-term oxygen therapy (LTOT) was deemed a success. Today, he is referred to as "Father of Home Oxygen."

Dr. Petty says better technology in the not-too-distant future will allow portable oxygen to be even more efficient and cost effective, providing the cost savings that Medicare may be looking for. "I predict that home filling [filling home tanks] will improve the economics of home oxygen."



Research partners Tom Petty, MD, and Louise Nett, RN, RRT.

Living better now with oxygen is possible, according to Dr. Petty and Nett. They suggest IPF patients attend pulmonary rehabilitation.

"If you get conditioned, you can do more with what you have," said Nett.

They also suggest patients understand what their particular insurance will cover for portable oxygen devices. Dr. Petty suggests patients request smaller, portable oxygen equipment instead of the larger, green tanks. Liquid is the lightest weight system with the longest range – about 5 to 8 hours at 4.5 pounds, versus about 4 hours with a green tank at 18 to 22 pounds.

"Better technology in the not-too-distant future will allow portable oxygen to be even more efficient and cost effective."

– Tom Petty, MD

Pipex Presents Phase I/II Clinical Trial Results of COPREXA for the Treatment of Refractory IPF

Pipex Pharmaceuticals, a specialty pharmaceutical company developing innovative late-stage drug candidates for the treatment of neurologic and fibrotic diseases, announced today that the results of an open-label phase I/II clinical trial of COPREXA (oral tetrathiomolybdate) for the treatment of refractory Idiopathic Pulmonary Fibrosis (IPF) were presented at the American Thoracic Society (ATS) 2007 Annual Meeting in San Francisco by Kevin R. Flaherty, M.D., M.S., Associate Professor of Pulmonology at the University of Michigan. IPF is a fatal disorder with no FDA approved or effective therapy. This clinical trial was partially supported by a grant from the Coalition for Pulmonary Fibrosis.

In a single-center, open-label, phase I/II clinical trial, 20 patients with IPF that had evidence of disease progression despite treatment with prednisone +/- cytotoxic therapy

were treated for one (1) year with COPREXA (oral tetrathiomolybdate) 20mg capsules per oral twice a day with meals plus 20-40mg per oral at bedtime and adjusted as necessary to maintain a targeted serum ceruloplasmin range of 5-15mg/dl.

When pre-treatment forced vital capacity (FVC) values were available, the course of pre-treatment FVC (slope) was compared to the post-treatment FVC at 6 and 12 months. The change in the pre-treatment and post treatment FVC slopes demonstrated favorable trends in the rate of decline of FVC, at 6 months pre-treatment compared to 6 months post-treatment ($p < 0.06$) and at 12 months pre-treatment compared to 12 months post-treatment ($p < 0.12$).

Dr. Kevin Flaherty, the principal investigator of the clinical trial, stated, "Patients with IPF are in

dire need for new potential effective therapies. COPREXA was easy to administer and well tolerated in a group of patients with progressive IPF, refractory to standard therapy. The pre-clinical work and patient tolerance of COPREXA makes us optimistic about this new treatment approach for IPF. We look forward to conducting a multi-center, double-blind, placebo controlled study of this agent."

Later this year, Pipex plans to initiate a twelve month, multi-center, randomized, double-blind, placebo-controlled trial of COPREXA in IPF. A manuscript that further details the clinical trial and its results is in preparation and is expected to be submitted and published in a leading peer reviewed journal.

To learn more, please visit www.pipexpharma.com or call Pipex at (734) 332-7800

Source: Pipex, May 25, 2007. Content edited for space.

NEOPHARM, Inc. Signs Exclusive License Agreement for the Use of Cintredikin Besudotox for the Treatment of Pulmonary Fibrosis

NEOPHARM, Inc. announced that it has entered into an exclusive patent license agreement with the National Institutes of Health (NIH) for the development of Cintredikin Besudotox, or IL13-PE38QQR, for the treatment of Pulmonary Fibrosis (PF) and asthma.

With very few treatments currently available for PF and no known cure, there exists a significant unmet medical need for new therapy options. The pre-clinical studies performed at NIH, the Food &

Drug Administration (FDA) and at University of Michigan demonstrated preliminary evidence of the reversal of PF and its scarring in the animal models of IPF when Cintredikin Besudotox is administered as a nebulized product.

"We are excited to announce the signing of this agreement, which we believe will allow NEOPHARM to further capitalize on the intellectual property it has previously developed to work toward developing a suitable and effective treatment option

for the millions suffering from this disease," commented Laurence Birch, President and Chief Executive Officer of NEOPHARM. "We believe that the experience we have acquired through our pre-clinical and clinical work with Cintredikin Besudotox should facilitate our development of this drug product candidate for its possible use in the treatment of Pulmonary Fibrosis."

Additional information can be obtained by visiting www.neopharm.com.

Source: Neopharm, Inc. Press Release, June 11, 2007. Content edited for space.

Understanding Clinical Research: Knowing the Basics of Clinical Trials

You hear about the results of clinical research all the time. You've probably made a few changes to your behavior – what you eat or how much you exercise – based on a study. Whether you want to understand how to put those news reports in perspective or are thinking of participating in a clinical study yourself, it's time you learned more about clinical research.

There are two general types of clinical research studies. In an *observational study*, scientists observe people to learn more about the cause or progression of a disease or condition. They might compare a group with a particular condition to another similar group without the condition to determine which factors play a role in the disorder. Or they might select participants based on their exposure, for example, to a particular pollutant, and then try to find a similar group of people who haven't been exposed. By comparing the two groups, they might discover whether the factor in question is causing any health problems.

In an *intervention study*, researchers test a particular treatment. The best-known type of intervention study, the randomized clinical trial, is considered the gold standard. People are randomly assigned to two or more study groups. Each group receives a different treatment. One group, the control or comparison

group, receives a *placebo*, or a pill that looks just like the drug being tested but which actually has no effect. Only the pharmacist knows who is receiving which medication so that observations by the research team remain unbiased.

Comparing treatment groups to control groups is the best way to see if a treatment is really effective, but is not always possible. Placebos can't be used if a patient would be put at risk by not having effective therapy. In these situations, studies compare the experimental therapy with an approved one.

You may hear about clinical trial "phases." Each phase has a different purpose and helps researchers answer different questions. In phase I trials, researchers test an experimental drug or treatment in a small group of people (20–80) for the first time. The purpose is to evaluate its safety and identify side effects.

In phase II trials, the experimental drug or treatment is given to a larger group of people (100–300) to begin testing its effectiveness and further evaluate its safety. In phase III trials, the experimental drug or treatment is administered to large groups of people (1,000–3,000) to confirm its effectiveness, monitor side effects, compare it with other treatments, and collect information about how to use the experimental treatment safely.

After a treatment is licensed (approved by the U.S. Food and Drug Administration), researchers track its safety in phase IV trials, seeking more information about its risks, benefits and optimal use. Large groups of participants are needed for these long-term studies to detect any unexpected side effects that might occur in a small percentage of people.

Source: NIH News in Health, May 2007.

VIDA Diagnostics Inc. Receives \$200,000 Medical Imaging Grant from NIH

VIDA Diagnostics (Coralville, IA) has been awarded \$200,000 in grants to continue developing imaging systems used in the diagnosis and detection of lung diseases such as emphysema and pulmonary fibrosis.

Vida Diagnostics' founding was based on research performed at the University of Iowa and on core technology licensed from the UI Research Foundation.

The company develops medical imaging and analysis software for assessing lung structure and function. The company takes advantage of advances in lung imaging technology that provide detailed structural and functional information about lung tissue and airways.

The information is used to precisely locate lung abnormalities and determine pathways through the airways and lungs to access them. New non-surgical treatments, which require exact placement of devices, will rely on the enhanced images.

Source: The Gazette, May 5, 2007. Content edited for space.

Opinion Article in AJRCCM Suggests New Approaches are Needed to Research Cause and Progression of IPF

Researchers have made tremendous headway in understanding the cause of idiopathic pulmonary fibrosis in some patients, yet effective treatments remain a mystery. While the research community is working tirelessly to find effective treatments, new research into the cause of IPF is also critical to improving our understanding of the disease.

Recently published findings about the pathogenesis of IPF has led one researcher to opine that the cause of IPF could be the end result not of one, but of many biological responses in the body, and that new research approaches are needed to better understand the disease.

In an opinion article published in the *American Journal of Respiratory & Critical Care Medicine* on June 1, 2007, David Center, MD, of Boston

University, suggested that as new research is being published about potential causes of IPF, a “call to arms” is necessary in the clinical community to more effectively research, evaluate and manage the disease.

The opinion article, titled *Taking the “Idio” Out of Idiopathic Pulmonary Fibrosis: A Call to Arms*, suggests that researchers are just now beginning to understand why several therapeutic approaches to treating IPF over the past decades haven’t worked, and suggests that researchers should consider approaching research into IPF as oncologists now approach many cancers, by developing individual gene profiles that will help predict prognosis, response to therapy, and, it is hoped, cause.

Specifically, Dr. Center suggests that researchers:

- Support exhaustive searches for nonhuman DNA in all forms of pulmonary fibrosis, not just IPF. If any single case of IPF can be attributed to a treatable infectious agent, then we will have succeeded in this endeavor.
- Initiate high-density single-nucleotide polymorphism and haplotype mapping in sporadic (nonfamilial) cases of pulmonary fibrosis to complement the family-based genetic profiles.
- Support genomic (and eventually proteomic) studies of lung tissue to identify candidate genes and to develop gene profiles that predict prognosis, response to therapy, and initiating factors suitable for individual cases.

Source: Permission from the American Thoracic Society. The complete article is available by contacting the American Thoracic Society and referencing “DOI: 10.1164/rccm.200704-547ED.”

CPF to Present at Tristate Thoracic Society Conference in Door County, WI

The CPF has been invited to participate in the Tristate Thoracic Society’s annual conference in Door Country, Wisc., Sept. 7-10, 2007. The meeting brings together pulmonologists and other pulmonary experts across Wisconsin, Illinois and Minnesota, and is affiliated with the American Thoracic Society.



Doctors fill a large room at the Moscone Center in San Francisco to learn more about IPF during the American Thoracic Society Conference in late May.

CPF’s Teresa Geiger Appointed to ATS Communications Committee

The CPF’s Teresa Geiger was appointed to the American Thoracic Society’s (ATS) Communications Committee for 2007/2008 by ATS president David Ingbar, MD. Geiger will work with the committee to increase the level of communication around and understanding of lung diseases including IPF.

IPF and Transplant Patient Barry Cox Shares Story with Top Docs at ATS



Barry Cox shares news of his successful recovery following his lung transplant with ATS doctors during a national medical meeting.

IPF patient and transplant recipient Barry Cox was one of a group of patients invited to participate in the American Thoracic Society's annual meeting in San Francisco in May 2007. Cox presented his

personal experience with IPF and his successful transplant just nine months earlier. He told hundreds of doctors in attendance about his nearly perfect recovery and how he was now riding horses and planning a sky diving trip.

While admittedly not "typical," Cox said he hasn't had any problems since the day of his transplant surgery on August 17, 2006, at the University of California, San Francisco hospital.

"I go to the gym two to three times a week. I am active as a member of the board of directors of three corporations, I have returned to my [horse] carriage driving, and will go on my first scuba diving vacation in four years later this year. I am again actively engaged in the management of my ranch where I drive horses

and grow grapes. Although I take some precautions as a result of the transplant, and of course take a few medications daily, I have no limitations on my lifestyle," Cox told the ATS doctors.



Study Suggests Treatment of Breathing Disorder May Improve Quality of Life for Certain IPF Patients

A recent study published in the May 2007 issue of the peer-review medical journal *Lung* suggests that treatment of sleep-related breathing disorders (SRBD) may improve the quality of life for IPF patients.

Researchers at the Cleveland Clinic studied 18 patients with IPF. The aim of this study was to describe clinical and polysomnographic features of sleep-related breathing disorders (SRBD) and to identify predictors of obstructive sleep apnea (OSA) in IPF patients. Eight hundred fifty-seven patients with IPF were admitted to the Cleveland Clinic

from 2001 to 2005. An all-night polysomnogram (PSG) was performed to investigate complaints suggestive of sleep-disordered breathing. OSA was confirmed in 11 of the 18 IPF patients with complaints suggestive of sleep apnea, while the remaining 7 patients had a diagnosis of primary snoring or upper airway resistance syndrome (UARS). All patients showed a reduction in sleep efficiency, REM sleep, and slow wave sleep.

The study is the first describing SRBD in IPF patients. An increased body mass index (BMI) and a

significant impairment in pulmonary function testing may be predictors of OSA in IPF Patients. The authors concluded that, in the absence of effective treatments for IPF, the diagnosis and treatment of comorbid SRBD may lead to improvements in patients' quality of life.

Authors: Mermigkis, Charalampos; Chapman, Jeffrey; Golish, Joseph; Mermigkis, Demetrios; Budur, Kumaraswamy; Kopanakis, Antony; Polychronopoulos, Vlassis; Burgess, Richard; Foldvary-Schaefer, Nancy

Source: Lung, Vol. 185:3, May 2007, pp. 173-178. Content edited for space.

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Profile: CPF Board Member

Gregory Tino, MD

Pennsylvania Medical Center, Philadelphia

Gregory Tino, MD, is a board-certified physician in internal medicine, pulmonary diseases, and critical care medicine. He is currently an associate professor of medicine and the director of Pulmonary Outpatient Practices in the Pulmonary, Allergy and Critical Care Division at the University of Pennsylvania Medical Center in Philadelphia. Serving patients and teaching medical students to do the same has always been an important aspect of Dr. Tino's role as a physician and a professor. But his drive to advance research, education and effective treatment for pulmonary fibrosis grew tremendously when he lost his father to the debilitating lung disorder in 1991.

Dr. Tino is an active clinician who is dedicated to teaching and participating in clinical research activities. He has authored a number of original articles and book chapters on various topics in pulmonary and critical care medicine. He serves as a co-investigator on a multicenter trial evaluating the efficacy of interferon gamma-1b in the treatment of idiopathic pulmonary fibrosis (IPF), as well as a multicenter study of lung volume reduction surgery for emphysema, sponsored by the National Institutes of Health. He is a fellow of the American College of Chest Physicians as well as a member of the American Thoracic Society and the American College of Physicians.

He holds a Bachelor of Arts degree in Biology and Political Science from Columbia University and a medical degree from Mount Sinai School of Medicine in New York. His outstanding achievements in medicine are noted by his presence on the list of "America's Top Doctors of Pulmonology" in the Castle Connolly Guide and "Top Docs for the Aging and Pulmonary Medicine" in Philadelphia Magazine. Additionally, Dr. Tino has received several noteworthy teaching awards from the University of Pennsylvania, including the Robert Dunning Dripps Memorial Award for "Excellence in Graduate Medical Education."

The CPF is deeply grateful to its hundreds of volunteers and advocates that are vital to helping us achieve our mission.

To learn how you can help, please contact Teresa Geiger at (888) 222-8541, ext. 702 or tgeiger@coalitionforpf.org.



Education. Support. Hope.

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 IPF, and improving the quality of life for patients fighting IPF nationwide. Through your generous support, the CPF will continue to provide information, resources and support to more than 128,000 IPF patients, caregivers and families, and to the health care professionals who treat them.

To contribute by phone using any major credit card, please call the CPF at (888) 222-8541.

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
Suite F, #227
1659 Branham Lane
San Jose, CA 95118-5226

Contributions are also accepted online by bank transfer or by using any major credit card safely and securely through PayPal. The CPF's PayPal ID is info@coalitionforpf.org. Contributors can visit our secure PayPal link at www.coalitionforpf.org/AboutUs/contribute.

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.

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, while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF is governed by the nation's leading pulmonologists, individuals affected by pulmonary

fibrosis, medical research professionals and advocacy organizations. With more than 13,000 members nationwide, the CPF is the largest nonprofit organization in the United States dedicated to advocating for those with pulmonary fibrosis. The CPF's nonprofit partners include the American Thoracic Society, the Anne Harroun Landgraf Foundation, the Caring Voice Coalition, the Genetic Alliance,

the Mary D. Harris Memorial Foundation, the National Coalition of Autoimmune Patient Groups, the National Organization for Rare Disorders (NORD), The Pulmonary Paper, Second Wind Lung Transplant Association, and more than 35 leading medical and research centers nationwide. For more information please visit www.coalitionforpf.org or call (888) 222-8541.



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