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Action Alert

The Quarterly Publication of the Coalition for Pulmonary Fibrosis

Coalition for Pulmonary Fibrosis B.I.G. (Breathing Is Glorious!) Ball Raises More Than \$250,000 for IPF

Event provides foundation for new education and research efforts to fight IPF

The CPF's second annual B.I.G. (Breathing Is Glorious!) fundraising event, held in Chicago, Ill. on Oct. 21, 2006, raised more than \$250,000! The gala was hosted at the Renaissance Chicago Hotel in beautiful downtown Chicago, and was attended by more than 350 supporters.

A percentage of event proceeds will be directed back to the University of Chicago to improve the quality of care provided to IPF patients in the metropolitan Chicago area, and fund research to identify new approaches to treating the disease currently underway at the clinic. The funds will also be used to further the education, awareness, and research efforts of the CPF.

"This year's event was incredibly successful," said Mark Shreve, chief executive officer of the CPF. "We are grateful to all of those who supported the event, and we're especially grateful to once again join forces

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B.I.G. Ball

Breathing Is Glorious!

"The generosity and support of all those involved in the B.I.G. Ball reinforce our longstanding belief that finding a treatment and cure for IPF is only going to happen by working together."

– Mark Shreve, chief executive officer of the CPF

"Your last issue [of the Action Alert newsletter] was very powerful. It was filled with information that I really desperately needed about new developments, drug trials and patient stories. Thank you CPF!"

– Tom Coen, Seattle, WA

Continued from previous page

with the University of Chicago to form a successful partnership. The generosity and support of all those involved in the B.I.G. Ball reinforce our longstanding belief that finding a treatment and cure for IPF is only going to happen by working together.”

Illinois Senator Richard Durbin served as honorary chairman for the event. The CPF also presented its 2006 national awards at the B.I.G. event. Trey Schwab, former Marquette University assistant basketball coach and lung transplant survivor, was the recipient of the Frank Cabral Humanitarian Award, recognizing his efforts to significantly improve awareness of IPF through his work as an advocate and transplant coordinator at the University of Wisconsin, Madison. Talmadge E. King, Jr., M.D., the Constance B. Wofsy Distinguished Professor and vice chairman of the Department of Medicine at the University of California, San Francisco (UCSF), and chief of medical services at San Francisco General Hospital, was awarded the Marvin I. Schwarz Research Award, recognizing his commitment to improving the quality of life for those living with IPF through his compassionate patient care, education and support, while leading research efforts to find a cure for IPF. In recognition of his career’s work, Dr. King was awarded a \$15,000 gift to accelerate research efforts underway at UCSF in pulmonary fibrosis.

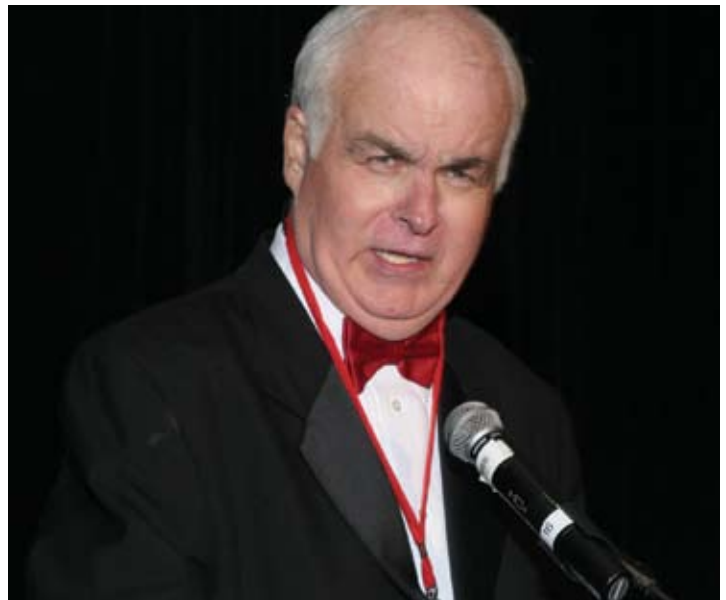
Jack Hurley, an IPF patient from Chicago also gave a heart-felt presentation on his experiences living with IPF. Jack received a life-saving lung transplant in June 2005.

Guests at the gala enjoyed an evening of fine dining, live and silent auctions, music and entertainment. The signature item of the live auction was a private, guided tour by Jay Leno of his world-class car collection, which auctioned for \$26,000. Ski trip packages to Breckenridge, Colo., fine art, custom made jewelry, and private yacht cruises on Lake Michigan also highlighted the auction. Overall, more than 100 items were auctioned off, raising more than \$90,000.

The event provided a fun and elegant atmosphere for guests to mingle with their Chicago friends and share their commitment to furthering this important cause. At the same time, they celebrated the event’s huge success and the hope it gives to thousands of patients around the country suffering from IPF and the physicians who treat them. To learn more about the CPF’s future fundraising activities, please visit www.coalitionforpf.org or call (888) 222-8541.



Mark Shreve (CEO of the CPF), Imre Noth, M.D. (University of Chicago), and Skip Garcia, M.D. (University of Chicago)



Recent lung transplant recipient Jack Hurley shares his experience fighting IPF with B.I.G. Ball guests



B.I.G. Ball Committee members Elizabeth Masterson and Deborah Beggan with B.I.G. Ball co-chair Debbie Roney



“Right now, the only hope for survival for end-stage IPF patients is a lung transplant. The more people we can help to receive transplants, the better off we’re all going to be.”

– Trey Schwab

Organ Donation Champion Honored

Trey Schwab receives Frank Cabral Humanitarian Award
By Kathy Schultz, UW Health

Culminating his two-year struggle with idiopathic pulmonary fibrosis (IPF), Trey Schwab, who received a double-lung transplant in 2004, was essentially dead for 40 minutes following complications from the operation. Surviving by what his surgeon called “a miracle,” Schwab paused to take a look at his second chance at life, walking away from a promising coaching career, leaving his position as assistant basketball coach at Marquette to dedicate his life to improving organ donation. Schwab, who now works at the UW Health Organ Procurement Organization, was honored for his work at the Second Annual B.I.G. (Breathing Is Glorious!) Ball.

The award is named for Frank Cabral, who also suffered from IPF and was successfully transplanted, and has dedicated his life’s work to the disease.

Originally, Schwab used his highly visible coaching position and

connections to the media to get his message out. “I wanted to do whatever I could to promote organ donation,” says Schwab.

“Trey bravely fought a very public fight with IPF and shared his story in such a heartfelt manner that it inspired patients around the country,” says Mark Shreve, CEO of the Coalition for Pulmonary Fibrosis. “He is an inspiration for so many patients; he exemplifies the character and integrity for which the award is named.”

After his transplant, Schwab returned to his team at Marquette and served one more year as their assistant coach, but soon realized he could help a lot more people if his work became official. Schwab joined the UW Health OPO in 2005 and works tirelessly traveling the state educating hospital staff, arranging public events and sharing his story to encourage people to take action and share their intent to be a donor.

“I was 37 years old when I was diagnosed,” says Schwab. “I had never heard of IPF before, but when you’re told you’re going downhill quickly and have maybe six months to live, you do your research.”

“Right now, the only hope for survival for end-stage IPF patients is a lung transplant, it is the end of the line for them,” adds Schwab. “The more people we can help to receive transplants, the better off we’re all going to be.”

“I’m very honored to receive this award,” says Schwab. “It means a lot to me that the Coalition thinks that much of the work I’ve tried to do to promote organ donation. Until we can discover a better treatment – drugs or some other way to help these people who are suffering from this awful disease – many of them will need a lung transplant to live.”

UWHealth

The CPF is deeply grateful for the support of the following sponsors, contributors and auction item contributors that made the B.I.G. (Breathing Is Glorious!) Ball such an incredible success, raising more than \$250,000!



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Thank You!

CPF Concludes Successful National IPF Awareness Week In Washington, D.C.

Contingent of IPF patients, family members and healthcare professionals on Capitol Hill to represent the IPF community



2006 IPF Awareness Week Advocates on Capitol Hill

The CPF recently announced results from its fourth annual National IPF Awareness Week (Sept. 25 – Oct. 1). A delegation of CPF representatives from across the country helped mark National IPF Awareness Week by traveling to Washington, D.C. to educate Members of Congress about idiopathic pulmonary fibrosis (IPF) and the need for improved research funding, and to encourage support for important IPF-related legislation.

“This was our most productive IPF Awareness Week to date with nearly 20 patients and patient advocates on Capitol Hill to meet with lawmakers and to deliver a singular message that more needs to be done to treat and cure IPF,” said Mark Shreve, chief executive officer of the CPF. “There is not a more effective way to educate Members of Congress than by having them hear directly from their constituents who are impacted by their decisions. We carried with us the voices of more than 128,000 people across this country currently fighting IPF.”

The CPF met with nearly 50 staff and leadership of key congressional committees responsible for authorizing the National Institutes of Health (NIH), and with oversight of Medicare and Medicaid to provide

perspective on legislation important to its 11,000 members across the country. Meetings with Members and staff of the U.S. House Energy and Commerce Subcommittee on Health included Rep. Gene Green (TX), Rep. Mike Rogers (MI), Rep. Mary Bono (CA), and Rep. Ralph M. Hall (TX). Meetings with the U.S. Senate Health, Labor, and Pensions Committee included Sen. Mike Enzi (WY), chairman, Sen. Richard Burr (NC), Sen. Hillary Rodham Clinton (NY), and Sen. Orrin Hatch (UT).

CPF representatives encouraged lawmakers to support specific IPF-related legislation currently before Congress that can help improve quality of life for patients, including; The Ending the Medicare Disability Waiting Period Act, which would waive the two-year waiting period for terminally ill patients to receive important benefits, and the Home Oxygen Patient Protection Act, which would protect patients’ interests with respect to oxygen use and equipment management. The meetings were effective in continuing to establish the CPF and its members as the definitive advocacy organization and resource for IPF information, and Congress welcomed the team and its message.

“I am full of energy for this cause,” said Bill Rhodes, CPF member and IPF patient from Penngrove, Calif., as he

reflected on the opportunity of serving as a National IPF Awareness Week delegate on Capitol Hill in Washington, D.C. in September 2006, “I feel as if I have just planted several small, young trees on Capitol Hill, and over the next many years they will grow into a nice big canopy of protection, comfort and love for the generations of IPF patients and their families to come.”

The CPF group also met with leaders of the National Institutes of Health (NIH)/National Heart, Lung, and Blood Institute (NHLBI) to learn about their efforts in IPF-specific research and new research efforts and clinical trials underway to find treatments and a cure for the disease. The NIH plays a critical role in addressing health problems and provides primary research funding for many diseases, including IPF. The CPF will be assisting the NIH in recruiting patients to participate in these trials, which are slated to begin enrollment in January 2007, according to the Agency.

On Sept. 26 the U.S. House of Representatives passed a bill that would reauthorize the NIH for the first time in 13 years and increase the program’s total budget by five percent annually through 2009. The IPF community is further served by the NIH through this legislation, as reports language offered by the House Energy and Commerce Committee included specific references to IPF. The reports language in Section 5 of the bill states “...the Committee is interested in learning more about the research activities with respect to diseases such as...[idiopathic pulmonary fibrosis]...”

This language serves as an important reference for implementing the NIH legislation, which now awaits Senate approval. The IPF-specific reference is supported by the CPF’s advocacy efforts and could bring greater attention to the need to advance IPF-related research.

For additional information about National IPF Awareness Week 2006 activities or the CPF’s Campaign ACT program, visit www.coalitionforpfp.org.

Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease to Explore New Approaches to Understanding and Treating Idiopathic Pulmonary Fibrosis as Part of \$12.8 Million NIH Grant

The Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease in the Division of Pulmonary and Critical Care Medicine at the University of Pittsburgh School of Medicine announced that it has received \$6.4 million to explore new approaches to understand and treat idiopathic pulmonary fibrosis (IPF). The research dollars are a part of a larger \$12.8 million National Institutes of Health grant that establishes Children's Hospital of Pittsburgh and the University of Pittsburgh School of Medicine as a Specialized Center for Clinically Oriented Research in Pediatric and Adult Pulmonology. With this funding, Simmons Center researchers will seek to improve treatment and diagnosis of patients with IPF, a devastating form of interstitial lung disease affecting more than 128,000 Americans, and characterized by progressive scarring of the lung tissue without any recognizable reason.

Investigators from the Simmons Center for Interstitial Lung Disease and the Division of Pulmonary, Allergy and Critical Care Medicine at the University of Pittsburgh School of Medicine will focus most of their attention on designing better methods for diagnosis and treatment of IPF. Naftali Kaminski, M.D., associate professor of medicine, pathology and human genetics, and director of the Simmons Center, and Kevin Gibson, M.D., will follow patients to identify changes in their genes that predict disease progression. These changes may help to understand what causes the

disease and to design better drugs. "The numbers tell us that only 50 percent of patients survive three years," said Dr. Gibson, associate professor of medicine. "In reality, some of them survive much longer, while others do very badly, we currently have no way to tell. This study should allow us to predict how the patient will do and to try and guide their options."

One of the most devastating manifestations of IPF is the acute exacerbation of the disease that leads to significant morbidity and mortality. The cause and course of these exacerbations is not completely understood. The Simmons Center study, which will monitor the changes in the expression of genes in the blood of patients over a period of five years should allow a better understanding of this phenomenon, according to Dr. Kaminski.

Steven R. Duncan, M.D., associate professor of medicine and a co-investigator has discovered that many patients with IPF have exaggerated immune response. This new observation may suggest that not all patients will respond to the same therapy and may suggest that some patients will respond to specific drugs that modify the immune system.

"It is now accepted that you can get lung fibrosis by many mechanisms, but we still try to treat all patients the same way, and often times, we fail," said Dr. Kaminski, who is also the director of the Lung Translational

Genomics Center that aims to use the Human Genome information to understand lung disease. "This project should allow us to identify what genes are active in a specific patient during disease progression and in the future to tailor a therapy."

Prabir Ray, PhD, associate professor of medicine has shown that certain growth factors can protect the lung against the development of fibrosis in mice. He will further study the mechanisms of these protective effects and will examine whether specific therapies could be developed. Dr. Kaminski said that Dr. Ray's experiments are critical because they may help develop approaches not only to halt fibrosis, but maybe even to reverse it.

The Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease was established five years ago through a generous donation by the Simmons family. More than 1,000 patients with interstitial lung disease are being followed in the center; around 350 are patients with idiopathic pulmonary fibrosis. In addition to providing patients access to multiple research protocols, the center provides personal care by physicians who are experts in interstitial lung diseases, information and education programs and an active support group (for more information about Simmons Center please visit <http://simmonscenterild.upmc.com/>).

Source: UPMC Press Release 10/2/2006: Content edited for space

Johns Hopkins Hosts IPF Patient Education Day in Baltimore

Johns Hopkins University Division of Pulmonary & Critical Care Medicine held an IPF patient education day on Oct. 14, 2006. The event was co-sponsored by the CPF, and covered a wide variety of issues that concern IPF patients including diet and nutrition (Dechen Surkhang, RD), social services and support available to patients with IPF (Chih Garbus, LCSW) and common sleep disorders (Loretta Colvin, RN, CRNP). Three physicians involved with IPF patient care discussed the nature of IPF (Sonye Danoff, M.D.), the 'alphabet soup' of tests that patients undergo (Albert Polito, M.D.) and the tricks to traveling with oxygen (Maureen Horton, M.D.). More than 50 patients and family members attended. "We're pleased to support Dr. Danoff and her team at Hopkins by sponsoring this event," said Mark Shreve, CEO of the CPF. "I know the patients are grateful to the event speakers for volunteering their time to improve education and awareness of IPF in the Baltimore area."

"Many thanks to the CPF for helping to make this important IPF patient education and support day a meaningful experience for all involved."

– Sonye Danoff, M.D., Johns Hopkins University



Johns Hopkins team on IPF Patient Education Day

CPF Research Manuscript Accepted for Publication in *Respiratory Medicine*

The CPF is pleased to announce that a summary manuscript from its Basic Research Questionnaire, considered one of the largest databases of IPF information in the country, was accepted for publication in *Respiratory Medicine*, an internationally-renowned, peer-reviewed journal devoted to the rapid publication of clinically-relevant respiratory medicine research. This manuscript represents the first large-scale survey of patient experiences and perceptions regarding the diagnosis and treatment of pulmonary fibrosis published to date.

The paper, titled "Patient Experiences with Pulmonary Fibrosis," was authored by Harold Collard, M.D. (University of California, San Francisco), Marvin Schwarz, M.D. (University of

Colorado Health Sciences Center), Gregory Tino, M.D. (University of Pennsylvania Medical Center), Paul Noble, M.D. (Duke University Medical Center), Mark A. Shreve (CPF), and Maureen Michaels and Bruce Carlson (Michaels Opinion Research, Inc.).

The manuscript focuses on the issues of patient education and resources. A survey of 52 defined-choice and open-ended questions regarding the diagnosis and management of pulmonary fibrosis was delivered. Two-thirds of the total 1,448 respondents reported a clear lack of information and resources on pulmonary fibrosis at the time of diagnosis. Less than half of respondents reported they felt well-informed about treatment options, the role of supplemental oxygen, pulmonary rehabilitation and transplantation. These results

suggest there is a substantial need for improved patient education regarding the diagnosis and management of pulmonary fibrosis.

Overall more than 2,000 patients and families have completed the Basic Research Questionnaire. It is managed by Michaels Opinion Research, Inc., an independent research firm with expertise in healthcare issues. Funding for this program is provided through grants from the DuBrul Family Fund and from Helen and Michael Galvin in memory of their family members who have passed away from IPF.

The manuscript will be available on the CPF Web page upon publication in *Respiratory Medicine*, expected at the end of 2006. To learn more, please visit www.coalitionforpf.org.

InterMune Presents Preclinical Data Showing Additive Anti-Fibrotic Combination Effects of Actimmune® and Pirfenidone

InterMune recently presented preclinical study results involving its two Phase III drug candidates for idiopathic pulmonary fibrosis (IPF), Actimmune® (interferon gamma-1b) and pirfenidone, at CHEST 2006, the annual conference of the American College of Chest Physicians in Salt Lake City, Utah.

The in vitro studies of Actimmune® and pirfenidone show each inhibit fibrotic pathways and, when used in combination, show an additive suppressive effect, indicating the two compounds may offer complementary approaches to the treatment of IPF.

“IPF is a disease characterized by fibrosis or scarring of the lungs, and our in vitro studies further expand our understanding of the

potential anti-fibrotic mechanisms of our two Phase III compounds,” stated Lawrence M. Blatt, Ph.D., chief scientific officer of InterMune. “The data provides insight into the anti-fibrotic activity of Actimmune® and pirfenidone and suggests that co-administration of these two compounds may lead to benefits in patients with IPF.”

In vitro studies conducted by InterMune researchers involved human fibroblast cells pretreated with pirfenidone and Actimmune® that were then stimulated with transforming growth factor beta (TGF-beta). TGF-beta has been shown to be an important mediator of fibroblast proliferation and collagen production by downstream gene activation. Actimmune® and pirfenidone inhibit TGF-beta-induced

gene induction to varying degrees, while combination treatment resulted in additive suppression of all TGF-beta-induced genes. The results of the present studies also confirmed that pirfenidone blocks TGF-beta-induced activation of p38-gamma MAP kinase and subsequent collagen synthesis. Taken in total, these studies suggest that the co-administration of Actimmune® and pirfenidone does not appear to inhibit the individual activity of each compound and that the two compounds may work through complementary pathways.

Both Actimmune® and pirfenidone are currently in Phase III clinical trials as a potential treatment for IPF. To learn more about either clinical trial, visit the Research section of the CPF’s Web site.

Hometown Friend Fights Against Evil Disease for Evel Friend

Evel Knievel battles IPF as his family, friends raise money and awareness

When Bill Rundle first heard his friend Evel Knievel suffered from idiopathic pulmonary fibrosis (IPF), he thought there must be a treatment and maybe even a cure for the disease. “I was amazed that there is no cure,” said Rundle, Knievel’s longtime family friend and fellow Butte, Montana native. “You’d think there’d be some kind of treatment for it. I’ve been around Evel my whole life. He is like a father to me.”

Rundle said he realized IPF was taking a toll on his friend as he watched him struggle to breathe and use supplemental oxygen. “He was used to Florida and here in Montana at 5,400 feet, he was having a tough time.”

Rundle founded an event several years ago to recognize Evel for his contributions to the stunt and entertainment world called “Evel Knievel Days,” which has been an annual event for years. This year, Rundle and the Knievel family contributed a portion of the event’s proceeds to fund IPF research.

The event attracted 10,000 people its first year and hosted more than 80,000 in 2006, with people coming from 43 states in the U.S. and representing 13 countries. It featured daredevils from all parts of the world, many who idolized Knievel as children. Evel’s son, Robbie Knievel, continues in the family tradition performing motor cycle stunts and showcasing his talent for the death defying as well.

The irony, Rundle says, is that Evel has survived incredible feats and stunts, yet he is helpless against IPF. “[I see] the effect that the disease has had on Evel,” said Rundle, as he recalled an event where he could see the toll IPF was taking on his friend. “I introduced him in Daytona at his last personal appearance. We had to help him off stage and I choked back tears. This disease is taking him away. As many things as he has been through – he is obviously a tough man – but here is a disease [he must fight] that no one can help him.”



American Thoracic Society Appoints CPF's Teresa Geiger to Key Advocacy Committee

The CPF is pleased to announce that Teresa Geiger, the CPF's vice president for Patient Outreach & Advocacy, has been appointed to the Public Advisory Roundtable of the American Thoracic Society (ATS), the world's leading professional organization for pulmonary, critical care and sleep physicians.

"Teresa brings the unique perspective to this committee of being able to offer her insights not only through her work with the CPF, but also because of her personal experience of losing five family members to idiopathic pulmonary fibrosis," said CPF CEO Mark Shreve. "We're proud of her and her willingness to participate on this important committee to help direct the advocacy and patient education efforts of the ATS in the coming years."

The ATS Public Advisory Roundtable serves as a bridge between the American Thoracic Society and organizations representing individuals affected by lung disease and breathing disorders by stimulating collaboration in research, education, patient care and advocacy. The committees' current members include organizations such as the Pulmonary Hypertension Association, the Alpha-1 Foundation, the ARDS Foundation and the National Sleep Foundation.

This represents the second partnership effort between the ATS and the CPF. In early 2006, the two organizations also announced the establishment of a jointly-funded research award in pulmonary fibrosis in the amount of \$100,000. The award will be given to a U.S.-based investigator working on translational studies in pulmonary fibrosis. The recipient is expected to be named at the end of the year.

"We're proud of her and her willingness to participate on this important committee and to help direct the advocacy and patient education efforts of the ATS in the coming years."

– Mark Shreve, CEO of the CPF

About the American Thoracic Society (ATS)

The ATS is a non-profit, international, professional and scientific society for respiratory and critical care medicine. The ATS is committed to the prevention and treatment of respiratory disease through research, education, patient care and advocacy. The long-range goal of the ATS is to decrease morbidity and mortality from respiratory disorders and life-threatening acute illnesses in people of all ages. In keeping with these goals, the American Thoracic Society interacts with both national and international organizations which have similar goals. To learn more, visit www.thoracic.org or call (212) 315-8600.





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The CPF is looking for new members!



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CPF, IPF Expert Share Story With WCBS Radio In New York

Radio host, Al Meredith, asked “What is IPF?”

Dr. Maria Padilla, associate professor of medicine and director of the advanced lung disease program at Mount Sinai Medical Center, leaned closer into the microphone and explained that IPF is a debilitating lung disease that has no FDA-approved treatments and no cure. Her voice growing more passionate with each word, Dr. Padilla understands the disease all too well. She has spent her entire medical career trying to stop it.

Padilla, and CPF Vice President Teresa Geiger were interviewed by WCBS-FM and JACK-FM radio stations in New York City on Oct. 5.

“There is a revolution in IPF,” Dr. Padilla said. “We are learning a little about its course and about the complications, but we still don’t know the natural history. We are looking at the pathogenesis to try to understand the disease and to apply novel approaches.”

Dr. Padilla told WCBS much is happening in the IPF community. There are many exciting clinical trials in process and a viable, potentially life-saving treatment could be on the horizon.

Al Meredith first heard about the CPF and idiopathic pulmonary fibrosis (IPF) through production manager Maria Martello, whose father was suffering from IPF and later died. He said it was her compelling and emotional first-hand account of the issues her father and her family faced with the disease, including the hard-hitting realities of IPF, that inspired him to help raise awareness of IPF through his program.



Al Meredith of WCBS interviewing Dr. Maria Padilla



WCBS Production Manager Raises Awareness of the Disease That Claimed Her Father’s Life

When Maria Martello called the CPF to ask for help with her father, who was a patient in the intensive care unit of a New York hospital, she quickly learned that her family was not alone. They share much with other families in their fight against IPF including the shock of dealing with a disease that is more devastating than its name “pulmonary fibrosis” implies.

Though her father has since passed away, Maria has risen above her families’ grief to help other patients with IPF and to help spread the word about the disease that claimed her father’s life.

“The story of IPF needs to be told,” said Martello. “We have to start now to educate people about the deadly disease and to let them know that the CPF is out there to help families and patients who are dealing with it. I am so grateful I was able to do something to help raise awareness of IPF. It has become part of the healing process for me to know that I might be able to help others.”

Lung Patients See a New Era of Transplants

By Denise Grady, *The New York Times*
Sept. 24, 2006

A quiet revolution in the world of lung transplants is saving the lives of people who, just two years ago, would have died on the waiting list. In the past 16 months, waits have shortened, lists have shrunk, and the number of lung transplants has gone up. Further improvements are expected this year.

The changes have all but erased the need for transplants from live donors - desperate, last-ditch operations requiring two donors per patient, usually relatives and friends who risk major surgery in hopes of rescuing a loved one whose time is running out. "It's almost as if it's a whole new day for lung transplantation," said Dr. Cynthia Herrington, a surgeon at the University of Minnesota Medical Center, Fairview, in Minneapolis. "It's amazing."

Nationwide, it is too soon to tell what the impact of the transplant changes will be.

"Are we actually improving overall survival?" asked Dr. Selim Arcasoy, the medical program director for lung transplantation at New York-Presbyterian Hospital/Columbia University. "Or are we transplanting sicker people who don't last as long?"

Transplants are given to people whose lungs fail because of emphysema, cystic fibrosis or other, less common diseases. Since demand exceeds supply, patients must join regional waiting lists that are part of a national network.

Recent changes have revitalized lung transplantation. Starting in May 2005, new rules nationwide put patients who needed transplants most at the top of the list - people who would soon die without a transplant, but who had a good chance of surviving after one. Previously, lungs went to whoever had been waiting longest, even if another patient needed them more. The waiting time was often two years or more, so there was little hope for people with lung diseases that came on suddenly or progressed rapidly.


Another major change is that more lungs from cadavers have become available, for two reasons: more people are becoming organ donors, and doctors have figured out ways to salvage lungs that previously would have been considered unusable. The new methods use drugs, respirator settings and other techniques to prevent damage to the lungs and keep their tiny air sacs open in brain-dead patients.

In the past, lungs could be retrieved from only about 15 percent of organ donors, but at some centers the rates have risen to 40 percent. Dr. Herrington said that in Minnesota, the number of lungs retrieved went to 97 from 25 in a single year. "Good organs 5 or 10 years ago were probably being buried because doctors did not know how to save them," said Dr. Kenneth R. McCurry, director of heart and lung transplantation at the University of Pittsburgh.

The number of lung transplants has risen to 1,405 in 2005, 248 more than the year before. Fewer people are dying on the waiting list: 360 in 2005, down from 488 in 2004. Lungs have always been "the bad stepchild" of organ transplants - harder to get, harder to transplant, more prone to rejection and complications than other organs, said Dr. Scott Palmer, the medical director of Duke University's lung transplant program. Lung transplants were not consistently successful until the mid-1980's, lagging far behind those of kidneys, livers and hearts. From the start, lungs have been offered first to whoever had spent the most time on the waiting list, in the donor's geographic region.

Changes in the system came about partly because of a 1998 federal regulation requiring that all organ transplants go to patients with the greatest medical need. The intention was to even out waiting times around the country and decrease deaths on the waiting list. Changes have been gradual.

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For lungs, figuring out how to measure medical need and rank patients with different diseases took time. “Our concern was that if we used just severity of illness, we might waste a lot of lungs on patients who were so sick they were unlikely to survive anyway,” said Dr. Thomas Egan, a cardiothoracic surgeon at the University of North Carolina, Chapel Hill, who led a UNOS panel that spent several years developing new rules for lung allocation. The panel studied medical records to figure out which patients were most or least likely to survive after a transplant, and worked that into the scoring system. As a result, lungs are now the only organs with transplant rules that consider the recipient’s survival odds.

Almost immediately, the new system cut the waiting list in half. Because waiting time no longer mattered, people who had been listed early in their illness just to hold a place in line dropped in rank or were deleted (unless they needed a transplant right away) but could rejoin the list later if they became sicker.

Overnight, some patients who had waited for years to reach the top of the list suddenly found themselves at the bottom, or even crossed off. Nobody was grandfathered in. “We tried our best to educate and communicate, but many felt they had been cheated,” Dr. McCurry said. But at his center in Pittsburgh there were no deaths among those who lost their places in line, he said, adding that many still received transplants.

Those who remained on the list needed transplants soon. As a result, it became much easier to find

recipients quickly, which was a huge improvement, because once an organ donor is brain dead, organs start to deteriorate. The lungs are especially fragile.

In the past, transplant coordinators might have spent hours calling hospitals, only to hear again and again that the patient at the top of the lung list was not sick enough for a transplant. Meanwhile the clock would be ticking; patients would have been found who needed the heart, kidneys and liver; and surgeons would be standing by, ready to remove them. Doctors say some lungs were probably wasted because recipients simply could not be found fast enough. “Placement is easier now,” Dr. Egan said. “It takes four or five calls. It used to be 16.” The new system has also changed the types of patients who receive the most transplants. Before, a majority had emphysema, a lung disease nearly always brought on by smoking. They received transplants because the disease moves slowly and they could wait, outlasting patients - often younger ones - with other lung diseases.

“People with pulmonary fibrosis or pulmonary hypertension can be diagnosed and go downhill very, very rapidly,” said Dr. G. Alexander Patterson, a surgeon at Washington University in St. Louis, which has one of the country’s largest lung transplant programs, with about 55 to 60 adult patients and 25 to 30 children a year. Pulmonary fibrosis causes extensive lung scarring, and its cause is often unknown. Patients can die within a year of the diagnosis. But patients with emphysema can often live for a long time. As a result, Dr. Patterson

said, many people thought the old system gave an unfair advantage to emphysema patients.

On the waiting list, 5 to 10 percent with emphysema died each year, compared with 30 to 40 percent among those with cystic fibrosis or pulmonary fibrosis. “It was an ethical dilemma,” Dr. Patterson said, adding that some doctors were troubled to see so many transplants go to people with emphysema, which is caused by smoking, whereas “others have disease they didn’t produce.” Now, at most centers, more patients with pulmonary fibrosis are getting transplants.

Dr. Jonathan B. Orens, medical director of the lung transplant program at Johns Hopkins, said that in the past year, more than half the 28 recipients there were people who, under the old system, would have died on the waiting list. Dr. Orens said he and his colleagues had just performed a preliminary analysis of the nationwide data on the first patients treated under the new system, and found that so far, one-year survival rates appeared to have dropped, to about 70 percent, from about 80 percent over all.

Slightly lower survival rates under the new system, he said, “may be the best we can do with lung transplants when patients are this sick.”

The rates may still represent a net benefit, he said, “compared to shortening the lives of patients who did not quite need the transplant.” As more data comes in, the rules may need to be adjusted, Dr. Orens said. “We’re trying to capture just the right patients at just the right time.”

Source: The New York Times



American Lung Association Launches National Influenza Education Initiative

Influenza immunization rates fall far short every year, even though health experts recommend more than 200 million people in the U.S. receive an annual influenza vaccination. The American Lung Association recently launched Faces of Influenza, a multi-year national public awareness initiative to help Americans recognize the importance of an annual influenza immunization as a preventative measure to protect themselves and their families every year.

As part of the campaign, the Lung Association is offering its Flu Clinic Locator as a public service. By visiting www.facesofinfluenza.org and typing in their 5-digit zip code at the Web page, site visitors can receive a list of immunization clinics in their area. Site visitors may also schedule reminders and sign up to receive seasonal influenza news. The Flu Clinic Locator will remain active as long as public flu immunization clinics are offered. Consumers and health care providers can also visit the site to find more information about influenza and the importance of immunization.

The initiative also includes educational materials as well as the national distribution of new television and radio public service announcements directed at target groups recommended for influenza immunization.

Source: American Lung Association

Transplant Recipient Honored

By John Carney, *Shelbyville Times-Gazette (Shelbyville, Tenn.)*
Story edited for space by CPF staff



Ralph Nollenberger at Webb School where he taught mathematics.



Headmaster Albert Cauz, Teresa Geiger of the Coalition for Pulmonary Fibrosis, Ralph Nollenberger, and assistant headmaster Stan Rupley. (T-G Photo by John I. Carney)

The Webb School in Bell Buckle, Tenn., a private prep school, made a contribution to the Coalition for Pulmonary Fibrosis in honor of mathematics instructor Ralph Nollenberger, who suffered from idiopathic pulmonary fibrosis or IPF. He received a transplant in February 2005 at Vanderbilt University Medical Center.

"We are so happy that we can honor Ralph, while at the same time help provide much-needed funds that can fuel research that may someday lead to life-saving treatments or a cure," said Webb headmaster Albert Cauz in a news release.

"It is the research and advances in medicine that saved my life," said Nollenberger. "It is my goal now to give back to the people who made the difference for me. This modest gift can make a difference for so many others who suffer from IPF."

IPF is a mysterious disease which causes scarring of lung tissue. Its cause is unknown, and it eventually becomes so severe that the lungs are prevented from functioning. There is nothing that can be done short of a transplant to remove the failing lungs.

Nollenberger was first diagnosed with IPF in 2001, when he had to get a physical exam in order to be licensed to drive a school bus. He'd had spots on chest X-rays prior to that, but they had been attributed to smoking. Today, Nollenberger hikes, canoes and uses a push lawnmower. Because his immune system is suppressed by drugs which prevent rejection of the new lungs, he must take certain precautions, but he is living an otherwise-active life that he would have thought impossible a few years ago.

IPF Patient Talks to Members of Congress, Asks for Waiver of Mandatory Medicare 24-Month Waiting Period

Elizabeth Darcy shares her story with Members of Congress

Elizabeth Darcy lives in an RV in her 28-year-old daughter's drive way. She suffers from idiopathic pulmonary fibrosis (IPF) and is a candidate for a lung transplant, though her wait for a transplant may not be as long as her wait for much needed disability benefits.

Darcy, like many other patients who suffer from IPF, is desperate, financially strapped and dying. At the same time, remarkably, the 58-year-old is working with the CPF to make a difference for others. Her health status and her age have made her a "poster child" for The Ending the Medicare Disability Waiting Period Act of 2005. Currently, though deemed permanently disabled and thus eligible for Medicare coverage, she must wait 24 months for her Medicare coverage to become effective, per the existing Medicare coverage guidelines. The Waiting Period Act was introduced so patients like Darcy, who may not live long enough to receive their Medicare benefits, would be exempt from current guidelines and provided immediate coverage,

thereby granting patients like Darcy the ability to afford and receive the vital care that they need.

In spite of her own issues, Darcy still recognized the need to travel with other patients and advocates recently to Washington, D.C. for IPF Awareness Week to try and help. She joined the CPF and other patient advocates to share her story with Members of the United States House and Senate.

Darcy, of Charlotte, N.C., was diagnosed with IPF in 2005 and was forced to quit her job as a nursing assistant and her work as a nursing student.

Darcy brought the message home to each of the Members and staffers she met with on Capitol Hill, some from her own state, including Rep. Virginia Foxx. "I think that walking into the offices with my oxygen tank gave the Members a face and name to place with the request for congressional support of much needed legislation," said Darcy. "This is not just a bill, it is something that

can help patients like me to overcome at least the financial burden of this disease."

Darcy changed her major from nursing and continues to attend classes as long as she's physically able to be there. It is her status as a student that is keeping her afloat right now, she says, both emotionally and financially. Until she receives any benefits, she is living off of student loans.

The Ending the Medicare Disability Waiting Period Act of 2005 would grant more immediate Medicare access to the terminally ill and disabled who currently have to wait as long as two years before collecting these benefits. For someone living with IPF, which has a median survival rate of three years, the waiting period is too long and for those without resources, simply cruel. This legislation will be re-introduced early next session. Please contact your Members of Congress to voice your support of the Act.



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Inspector General Says Medicare Still Pays Too Much for Home Oxygen Equipment Despite New Policy

By John Reichard, CQ HealthBeat Editor

A new policy under the budget savings law enacted in February ending a rental-only policy in the Medicare benefit for home oxygen equipment should be revised further, according to a new report by the HHS Office of the Inspector General.

The law (PL 109-171) limits Medicare coverage of rental payments for home oxygen equipment to 36 months of continuous use, after which suppliers must transfer title of the equipment to the Medicare beneficiary. But even with that change, Medicare will pay far more over the 36 months for rentals than the purchase price of oxygen concentrators, stationary devices that are a key component of home oxygen equipment and that concentrate the oxygen in room air before it is inhaled by the patient. Patients also receive portable oxygen equipment under the Medicare benefit.

The report said Medicare will allow payment of \$7,215 for rental payments while concentrators cost just \$587 on average to buy. The report added that beneficiaries also incur \$1,443 in co-insurance costs over the three-year rental period.

Nearly all Medicare beneficiaries who rent home oxygen equipment rent concentrators, the report said. In 2004, concentrator rentals accounted for 84 percent, or \$2.3 billion of all Medicare spending for home oxygen equipment and supplies, the report added.

Limiting Medicare coverage of rental payments to 13 months, a step urged in the Bush administration's fiscal 2007 budget proposal released last February, would save Medicare and its beneficiaries about \$3.2 billion over five years, according to the Inspector General's office.

The study also found that concentrators and portable oxygen equipment that patients receive under the benefit require minimal servicing and maintenance.

In addition to reducing the rental coverage period, the report recommends that Medicare should work with Congress to determine the necessity for and frequency of non-routine maintenance. Suppliers perform routine maintenance without payment from Medicare.

Medicare also should determine if a new payment methodology is appropriate for portable oxygen systems, the report added. Payment for the contents of the portable cylinders is now bundled into the Medicare payment covering rental costs. Once Medicare stops covering rental payments after 36 months, it will pay only for the contents of the portable cylinders, but the current payment rate for contents may not be adequate, the report said.

Source: CQ HealthBeat News [article edited by CPF staff]





Legacy Leaders

are special supporters who remember the Coalition for Pulmonary Fibrosis in the creation of their wills or through other estate gifts, thereby securing the future of our mission of assisting all those affected by idiopathic pulmonary fibrosis (IPF) through education, support, advocacy, and research funding. To learn more, visit the CPF website at www.coalitionforpf.org or contact Mishka Michon at (888) 222-8541, extension 701.



Education. Support. Hope.

Transplanted IPF Patient Plans for His Future, the Future of IPF Research

With each breath, Charlie Cox remembers how difficult it was to breathe with his IPF-damaged lungs. Having survived the fear, pain and coming to terms with an early death, Charlie Cox now celebrates his new lease on life. Each day he remembers the fear of facing death from a terminal illness, and pledges to help the Coalition for Pulmonary Fibrosis (CPF) find a cure.

Cox received a lung transplant two years ago, just days after being placed on the waiting list at the University of California, Los Angeles (UCLA) and after eight months of testing and years of fighting the disease with little hope of extending his life.

His journey was helped by the resources offered by the CPF. "I couldn't believe there was finally a resource that provided information about various drug studies and which experts were doing them, as well as a resource that offered support and research information to patients like me," said Cox.

A PERSONAL COMMITMENT

Although Cox is living comfortably with his new lung, he and his wife feel very emotionally linked to the IPF community. They continue to join the monthly support group that he looked to for support so that he can assist others in coming to terms with their disease. His sense of the need is summed up in these words, "people are really hurting out there."

"When you go to the CPF, and to support groups, you know you aren't in this by yourself," he said. "You know where you can go for help. There are people to help you - people trying to come up with solutions." Cox encourages other patients and family members to seek help from a support group.

More importantly, Cox and his wife have made a commitment to the CPF's Legacy Leader program. As a Legacy Leader, Cox feels he is doing what he can to change the future for other patients. This simple act, for Cox, is a way of taking action that will make a difference.

Although the first nine months after the transplant were difficult, Cox says his life is nearly back to normal. He now plays golf with his sons, a sport he had given up due to his illness. That simple pleasure is something for which he is very grateful.

New Support Groups Established

The CPF currently sponsors more than 40 support groups around the country. Attendance is open to patients, their families, caregivers, and anyone interested in sharing and learning about interstitial lung diseases, including pulmonary fibrosis and idiopathic pulmonary fibrosis. The focus of our support groups is to provide patients and their loved ones with essential educational resources and support, while providing an opportunity to network and share experiences with other patients living with interstitial lung diseases.

Sarasota, FL

Sarasota Pulmonary Fibrosis Support Group

In partnership with Lung Associates of Sarasota

Time: Every other month on the second Monday from 3:00-4:30 p.m. beginning Nov. 13, 2006
Location: HealthSouth RidgeLake Hospital, 6150 Edgelake Drive, Sarasota
Contact: For more information or to register, please contact Karen Erceg at (941) 366-5864 ext. 830 or by email at kerceg@lung-associates.com

Wichita, KS

In Partnership with the Wichita Clinic

Time: Quarterly
Location: Health Strategies, 551 N. Hillside, Wichita, Kansas
Contact: Susan Picotte at (316) 689-9521 or by email at PicottSG@wichitaclinic.com

Charleston, SC

In partnership with the Medical University of South Carolina

Time: Next meeting is "IPF Patient Education Day", Friday, March 23, 2007
Location: MUSC campus (venue to be announced)
Contact: For more information, please contact Ruth Oser at (843) 792-3168 or by e-mail at oserrk@musc.edu

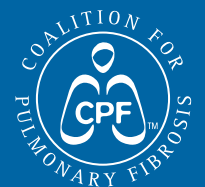
We need your help!

Encourage your friends, family – even your doctor and respiratory therapist – to join the CPF – it's free!

Contribute to the CPF's efforts through a tax-deductible gift.

Raise awareness in your community about IPF - ask us how by emailing Teresa Geiger at tgeiger@coalitionforpf.org or call (888) 222-8541.

Access our website at www.coalitionforpf.org for patient information and resources to learn about how you can be an advocate for all IPF patients and contribute to this important work.



Education. Support. Hope.

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Profile: CPF Scientific Advisory Board Member

Maria Padilla, M.D.

Associate professor of medicine and director of the Advanced Lung Disease Program, Mount Sinai Medical Center

Dr. Padilla's clinical interests center on the pathogenesis and treatment of diseases such as idiopathic pulmonary fibrosis/interstitial lung diseases, sarcoidosis, pulmonary hypertension, cystic fibrosis and collagen vascular-associated lung diseases. Her research focuses on models of pulmonary fibrosis and emphysema.

Dr. Padilla started the lung transplantation program at Mount Sinai Hospital and served as its medical director until recently. She is an active member of the faculty, engaged in the practice of medicine, teaching and clinical research. Her work has been published in several journals. She is a fellow in various pulmonary and transplantation societies and serves on the advisory board of WASOG (World Association of Sarcoidosis and other Granulomatous Diseases), Sarcoidosis Research Foundation, Scleroderma Foundation and on the editorial board of the journal *Sarcoidosis, Vasculitis and Diffuse Lung Diseases*. She has been the recipient of awards in teaching and in the practice of medicine. She has repeatedly been named to the "best doctors" lists in the U.S.

Dr. Padilla graduated with a BS in biology from the City College of New York and pursued her medical studies at the Mount Sinai School of Medicine. Her pulmonary training and research experience were also completed at Mount Sinai Medical Center.

Supporting the CPF

The Coalition for Pulmonary Fibrosis 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 healthcare 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, or by visiting www.paypal.com.

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 CPF Executive Vice President of Development Mishka Michon at (888) 222-8541, or by email at mmichon@coalitionforpf.org.

Don't forget!

Year-end is the time to make charitable gifts to accelerate our efforts to find a cure for IPF. Gifts received by midnight December 31, 2006 can reduce your taxable income for the year.

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 10,000 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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1659 Branham Lane
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