



Action Alert

2004 IPF Awareness Week Raises More than \$110,000 for IPF; CPF Works to Build Partnerships on Capitol Hill

60 meetings held with Members of Congress to raise awareness of fatal lung disease; including meetings with key committee leadership and IPF patient, Rep. Charlie Norwood of Georgia

The Coalition for Pulmonary Fibrosis (CPF) in mid-October announced results from its second annual National IPF Awareness Week, Sept. 26 – Oct. 1, 2004. The CPF kicked off awareness week activities with its "B.I.G." (Breathing is Glorious!) 5K race/walk in Ann Arbor, Mich., on Sept. 26. The B.I.G. Race raised more than \$110,000 to support all those affected by IPF and to fund CPF's patient and physician education, support, research and advocacy programs throughout the country.

"We more than doubled our goal of raising \$50,000 during awareness week," said Mark Shreve, chief operating officer of the CPF. "The B.I.G. Race represents the largest fundraising event in the United States dedicated to helping the IPF community. We're incredibly grateful to the 300-plus race participants, those who contributed, and of course the many volunteers who helped make it such a success."



Runners begin the first B.I.G. Race in Ann Arbor, Mich. to support those affected by IPF.

The B.I.G. Race was made possible thanks to the efforts of the race coordinators, Meg Galvin-Board and Katherine Galvin, whose family has been deeply affected by IPF.

"Supporters came from around the country ...as far away as New York, New Jersey, Tennessee and Georgia, to participate in honor of a loved one affected by IPF. Some IPF patients even participated in the B.I.G. Race."

- Meg Galvin-Board, race coordinator

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CPF introduces two new educational brochures

See page eight for more details and how to get copies



IPF patients, Sandra Rock and Trudy Vanderbeck, were among the CPF representatives on Capitol Hill during IPF Awareness Week.

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Equally successful were the CPF's advocacy efforts on Capitol Hill during IPF Awareness Week. IPF patients and CPF representatives met with more than 60 members of Congress in Washington, D.C., to discuss the importance of funding IPF research and the need to advance IPF-related legislation currently before Congress. The highlight of the week were a number of meetings with Rep. Norwood (R-GA), who recently announced he has IPF and just days later underwent a lung transplant surgery to save his life.

"Congressman Norwood was extremely generous with his time and very supportive of our efforts to raise awareness of IPF and to advocate for increased federal funding for research to find a cure," said Shreve. "Our membership knows first hand how difficult the fight against IPF can be, especially in such a public role, and we truly appreciate his willingness to share his personal story and aid our efforts on Capitol Hill."

Prior to his surgery, Rep. Norwood drafted a Concurrent Resolution that will be introduced on the House floor, acknowledging the need to increase awareness of IPF and recognizing the CPF for its efforts advocating on behalf of those fighting IPF. This was an important step in furthering CPF's mission to inform policy makers of the importance of addressing the concerns of IPF patients and caregivers.

The CPF also received a number of commitments from members of Congress to support IPF-related legislation, including "Ending the Medicare Disability Waiting Period Act of 2004" (S. 2566; H.R. 104).

"Our efforts last year helped build a base for IPF-awareness in Washington; this year we built on that improved awareness by focusing on specific legislation that will help IPF patient and families," said Shreve. "The median survival rate for IPF patients is less than three years, yet IPF patients under 65 must wait two years to qualify for Medicare coverage and patients may not survive that long due to the relentless progression of the disease."

Other key meetings included: Rep. Joe Barton (R-TX), Chair of the Energy and Commerce Committee; Rep. Michael Bilirakis (R-FL), Chair of Subcommittee on Health; Rep. Ted Strickland (D-OH); and Rep. Gene Greene (D-TX), sponsor of H.R. 104.

IPF Week Accomplishments

Meetings were conducted with the following Members of Congress in Washington, D.C., during the week of Sept. 26, 2004:

U.S. SENATE

AZ Sen. Jon Kyl
 AZ Sen. John McCain
 CA Sen. Dianne Feinstein
 CA Sen. Barbara Boxer
 CO Sen. Wayne Allard
 CO Sen. Ben Nighthorse Campbell
 FL Sen. Bob Graham
 ID Sen. Larry Craig
 ID Sen. Mike Crapo
 IL Sen. Richard Durbin
 IN Sen. Richard Lugar
 IN Sen. Evan Bayh
 LA Sen. John Breaux
 MA Sen. John Kerry
 MD Sen. Paul Sarbanes
 ME Sen. Olympia Snowe
 MI Sen. Debbie Stabenow
 MN Sen. Mark Dayton
 MN Sen. Norm Coleman
 MS Sen. Trent Lott
 NY Sen. Charles Schumer
 OK Sen. Don Nickles
 OR Sen. Gordon Smith
 PA Sen. Arlen Specter
 SD Sen. Tim Johnson
 UT Sen. Orrin Hatch
 WY Sen. Craig Thomas

U.S. HOUSE OF REPRESENTATIVES

AZ Rep. J.D. Hayworth
 AZ Rep. John Shadegg
 AZ Rep. Raul Grijalva
 CA Rep. Henry Waxman
 CA Rep. Doug Ose
 CA Rep. Lois Capps
 CO Rep. Diana DeGette
 CO Rep. Tom Tancredo
 CO Rep. Bob Beauprez
 FL Rep. Michael Bilirakis
 GA Rep. Charlie Norwood
 HI Rep. Neil Abercrombie
 ID Rep. Butch Otter
 IL Rep. John Shimkus
 IL Rep. Bobby Rush
 IN Rep. Steve Buyer
 IN Rep. John Hostettler
 KY Rep. Ed Whitfield
 MA Rep. Barney Frank
 MI Rep. Mike Rogers
 MI Rep. Dale Kildee
 MD Rep. Dutch Ruppersberger
 NC Rep. Brad Miller
 NY Rep. Eliot Engel
 NY Rep. Charles Rangel
 NY Rep. Jose Serrano
 OH Rep. Sherrrod Brown

OH Rep. Ted Strickland
 PA Rep. Joe Hoeffel
 PA Rep. Joseph Pitts
 RI Rep. Patrick Kennedy
 TX Rep. Joe Barton
 TX Rep. Gene Greene
 TX Rep. Ralph Hall
 VA Rep. Jim Moran

Concurrent Resolution to be Introduced Recognizing CPF

Following CPF's meeting with Rep. Norwood, the Congressman drafted a Concurrent Resolution acknowledging the need to increase awareness of IPF and recognizing the CPF for its efforts advocating on behalf of those fighting IPF.

State Proclamations

In addition to the Concurrent Resolution, a number of proclamations recognizing IPF Week or IPF Month were issued in the following states thanks to the efforts of CPF members, physicians and partners across the country:

- California
- Georgia
- Massachusetts
- Oklahoma
- Texas
- Vermont

Web Advocacy

As part of the National IPF Awareness Week, CPF members and partners were encouraged to take action via the internet to send a message to Capitol Hill to encourage support for CPF endorsed legislation via the CPF Web site at www.coalitionforpf.org to help the IPF community. More than 125 messages were sent to Members of Congress and President Bush.

Local Media Outreach

To help extend the reach of the National IPF Week awareness campaign, the Coalition for Pulmonary Fibrosis designed a media tool kit for CPF-sponsored support groups. The tool kit included tips on how to work with the media, who to contact in their local market, sample press releases and fact sheets on IPF. Tool kits were distributed to IPF patients, support group leaders and family members, wanting to raise awareness of IPF in their local communities.



CPF representatives met with Congressman Charlie Norwood (front center) during IPF Awareness Week, just one week before he underwent a lung transplant for IPF.

From Left to Right:
 Teresa Barnes, CPF Board Member
 Deirdre Roney, CPF Board Member
 Pam Harris, Caring Voice Coalition
 Cathy Valenti, Caring Voice Coalition
 John Vanderbeck, Family Member
 Jim Rock, Family Member
 Rep. Charlie Norwood, (R-GA)
 Mark Shreve, Chief Operating Officer, CPF
 Trudy Vanderbeck, IPF Patient
 Sandra Rock, IPF Patient

Local IPF Awareness

CPF Member Uses Visuals to Tell the IPF Story in Her Community

Trudy Vanderbeck, an IPF patient from Vincennes, Ind., has been working diligently to spread the word about IPF in her local community, as well as nationwide. From radio interviews, to speaking at "Living with IPF" seminars around the country, to visiting Members of Congress on Capitol Hill, she is finding effective ways to share her IPF story and support other patients, as well as reaching out to lawmakers who can help make a difference for the IPF community.

During IPF Awareness Week this year, Trudy and her support group found a creative way to reach the general public and create awareness by organizing an IPF informational display case at her local library. The display included resource books on IPF, sample oxygen tanks, pictures from her trips to Capitol Hill, and a copy of the proclamation declaring October IPF Awareness Month in Vincennes. She also used banners, posters and other signage to educate the library audience on the definition of IPF and her support group information. The display showcased IPF for the entire month of October.

"We're going to continue doing awareness activities throughout the year rather than just during IPF Awareness Week," said Trudy. "Being involved makes all of us in our support group feel better – it's especially rewarding to know we are doing something that might help others in their fight against IPF."

If you have an event, or other venue where CPF materials can help tell your own IPF story and raise awareness of the disease, please contact the CPF at 888-222-8541, or email info@coalitionforpf.org.



Trudy's Library Display



Frank Cabral, IPF Patient

IPF Patients Share Their Personal Stories and Create Awareness Through Local Media

Sandra Rock of Sacramento, Calif., is an IPF patient and dedicated advocate for awareness of the disease. In addition to venturing to Capitol Hill during IPF Awareness Week, and organizing an IPF information table at her local hospital, Sandra has been working with Sacramento Fox affiliate KTXL-TV to share her personal story with her community. Sandra and her support group were featured on Fox 40 in February 2004, and again in September as she prepared for her trip to Washington, D.C. The story highlighted Sandra and her support group, symptoms and effects of IPF, the need for research and Sandra's trip with the CPF to meet with Members of Congress during IPF Awareness Week this year. Fox 40 is planning to follow up with her again in a few months.

Frank Cabral is an IPF patient from Fall River, Mass. who is also communicating via local media to spread the word about IPF. He too has traveled to Capitol Hill during IPF Awareness Week in 2003, and is now focusing on local awareness efforts in his community. Most recently, Frank and his doctor were interviewed on a local radio program for WSAR-AM in Somerset, Mass. During the 30-minute program, Frank shared his personal experience with IPF, while his doctor explained the medical aspects of the disease, illustrating a complete picture of what it really means to live with IPF.

The CPF deeply appreciates Sandra and Frank's dedication to improving awareness of IPF, and we commend them for their relentless efforts advocating on behalf of others suffering from the disease. Members of the CPF can make a difference in their community to raise awareness of IPF through efforts like Sandra and Frank's. If you are interested in contacting local media to share your story, the Coalition for Pulmonary Fibrosis can help get you started. Whether you do it alone or team up with your doctor, it is an effective tool to heighten awareness in your community. For more information, or to learn more about other ways to spread the word about IPF in your local area, please contact the CPF at 888-222-8541, or email info@coalitionforpf.org.



David Geffen School of Medicine Hosts Patient Event During National IPF Awareness Week

The Interstitial Lung Disease Program at David Geffen School of Medicine at UCLA presented their third annual "Living with Pulmonary Fibrosis" educational seminar on Saturday, Oct. 2, 2004 with 110 people attending. The speakers included nationally recognized Pulmonary Fibrosis specialists from UCLA including Robert M. Strieter, M.D., Joseph P. Lynch, III, M.D., and David Ross, M.D. The seminar discussed diagnosis, current standards of care, promising new agents, lung transplantation and life management issues.

UCLA's clinical trial coordinators also presented information on current trials available at UCLA for pulmonary fibrosis patients. For further information on clinical trials underway at UCLA, please visit www.coalitionforpf.org/IPFResearch.

The Interstitial Lung Disease Program at UCLA will be celebrating their first anniversary in November for their Interstitial Lung Disease Support Group, coordinated by Susan Golleher, RN. The group is open to any person with an interstitial lung disease. Family members and friends are also welcome to attend. The group meets on the third Tuesday of every month from 1 p.m. – 2:30 p.m. For further information about the group please contact Susan at 310-206-8950 or by email sgolleher@mednet.ucla.edu.



Recommended Reading for IPF Patients and Caregivers

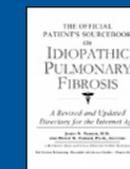
The following books offer information on lung disorders, and are available through the CPF Web site at www.coalitionforpf.org/patient/resources.asp:



Breathe Better, Live in Wellness: Winning Your Battle Over Shortness of Breath
By Jane M. Martin



Shortness of Breath: A Guide to Better Living and Breathing
By A.L. Ries, et al



The Official Patient's Source Book on Idiopathic Pulmonary Fibrosis
By J.N. Parker & P. Parker



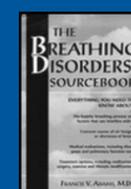
Healing After Loss: Daily Meditations for Working Through Grief
By Martha Whitmore Hickman



The Lung Transplantation Handbook
By K.A. Coulter



Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill
By C. Capossela & S. Warnock



The Breathing Disorders Sourcebook
By F.V. Adams, MD



Coping with Prednisone
By E. Zukerman and J.R. Ingelfinger, M.D.



Taking Flight - Inspirational Stories of Lung Transplantation
Compiled by Joanne Schum, Authored by lung recipients around the world

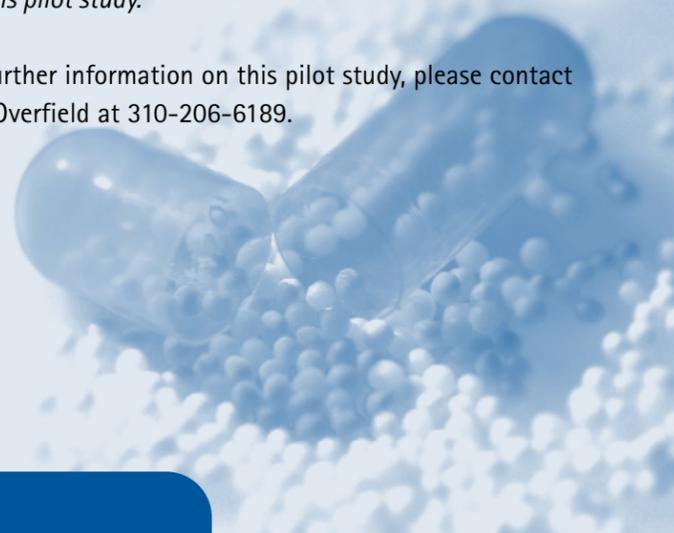
David Geffen School of Medicine at UCLA Initiates Pilot Study of Sildenafil (Viagra) as Potential Treatment for Patients with IPF and Pulmonary Hypertension

David Zisman, MD, Medical Director of the Interstitial Lung Disease Program at UCLA, has initiated a pilot study of Sildenafil (Viagra) as potential treatment for patients with IPF and Pulmonary Hypertension (PH).

The study is a placebo-controlled study of Sildenafil and its effect on walking distance, shortness of breath and blood oxygenation. The objective of this study is to demonstrate that a single dose of Sildenafil improves exercise capacity in patients with IPF and PH as compared with placebo. The study is limited to those patients diagnosed with IPF and PH (PH determined by echocardiography). Eligible patients will be randomly assigned, in a 1:1 ratio, to receive either Sildenafil or placebo.

Please note that patients with known coronary artery disease, recent myocardial infarction (within 1 month of screening), severe congestive heart failure, inability to walk more than 150 m (6-min walk test), patients requiring supplemental Oxygen at rest, patients who currently use drugs to treat PH (bosentan, prostacycline, etc) and patients who have recently started a pulmonary rehabilitation program (<8 weeks prior to baseline visit) are not eligible for this pilot study.

For further information on this pilot study, please contact Troy Overfield at 310-206-6189.



New IPF Support Group in New Jersey

Thanks to the efforts of our local volunteers, the CPF is pleased to announce a new support group in New Jersey for IPF patients and their families. The CPF encourages attendance by patients, their families, caregivers and anyone interested in sharing and learning about interstitial lung diseases.

MORRISTOWN, NJ

Pulmonary Fibrosis Support Group of Central and Northern New Jersey

Morristown Memorial Hospital
100 Madison Ave., Morristown
Conference Rm #3

Meets: Last Wednesday of every month. Next meeting is Wednesday, Dec. 29, 2004 at 7:00 PM

For additional information or to RSVP, please contact Barbara Murphy at 908-276-3394 or by email at barbara.murphy@spcorp.com.

Actelion Provides Update on BUILD-1 and BUILD-2 Clinical Trials in Pulmonary Fibrosis

As part of their announcement of their operating results for the nine months ending Sept. 30, 2004, Actelion, Ltd. (Zurich, Switz.) provided an update on the status of their clinical trials in pulmonary fibrosis.

"In late September 2004, the clinical program evaluating the safety and efficacy of bosentan (Tracleer(r)) in Idiopathic Pulmonary Fibrosis (BUILD-1: Bosentan Use in Interstitial Lung Disease) and the scleroderma-related form of Pulmonary Fibrosis (BUILD-2) have been closed for

enrollment. BUILD-1 has enrolled 158 patients (enrollment target: 132) and BUILD-2 has enrolled 162 patients (enrollment target: 132). These patients are now followed for another 12 months, with final study results therefore expected in late 2005 or early 2006."

Source: Actelion, Inc. (www.actelion.com)



Lung Transplant Program at Jackson Memorial Hospital Receives Medicare Approval

Transplant Program Certified as Meeting CMS Standards; Approval Eases Financial Burden on Hospital and Patients

Jackson Memorial Hospital announced that it has received approval from the Center for Medicare and Medicaid Services (CMS) as a Medicare-approved center for lung transplantation. Medicare certification means that Jackson's transplant program meets volume, survival outcomes and program standards that are required by CMS. Jackson Memorial Hospital is the major teaching facility for the University of Miami School of Medicine, one of the nation's leading centers for the treatment and study of interstitial lung disease, including idiopathic pulmonary fibrosis (IPF).

Jackson now has the only Medicare-approved lung transplant program in South and Central Florida. It joins an exclusive group of only 47 centers across the United States that are Medicare-approved for this type of transplant. This positions Jackson as a center of excellence for transplant candidates from all over Florida and the United States, as well as other parts of the world such as Latin America.

"Receiving Medicare approval means that our program meets the highest standards of treatment, care and health outcomes for our transplant patients," explained Si Pham, M.D., professor of surgery and director, Heart/Lung Transplant and Artificial Heart Programs, and director, Heart/Lung Transplantation Program. "This is particularly good news for lung transplant candidates from South Florida who will no longer have to travel far from home for an extended period of time, placing a heavy burden on themselves and their families."

Based on the volume of transplant surgeries, Jackson's transplant center is ranked among the 10 busiest in the nation, and is the only Florida hospital to perform every kind of organ transplant (according to the United Network for Organ Sharing {UNOS}). The Lung Transplant program at JMH began in 1995, and its first transplant patient is still alive today.

Source: Jackson Memorial Hospital (Miami)

Coalition for Pulmonary Fibrosis Announces Publication Of New Educational Tools for Patients

The Coalition for Pulmonary Fibrosis (CPF) recently announced the publication of two new educational brochures.

Lung Transplantation: What Every Patient with Idiopathic Pulmonary Fibrosis Should Know

Pulmonary Rehabilitation and Oxygen Management for the Idiopathic Pulmonary Fibrosis Patient

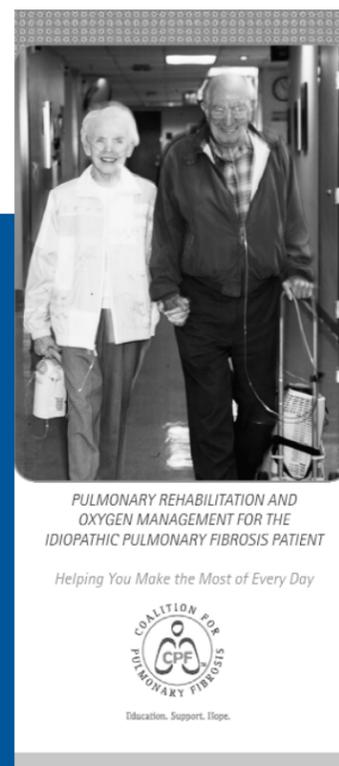
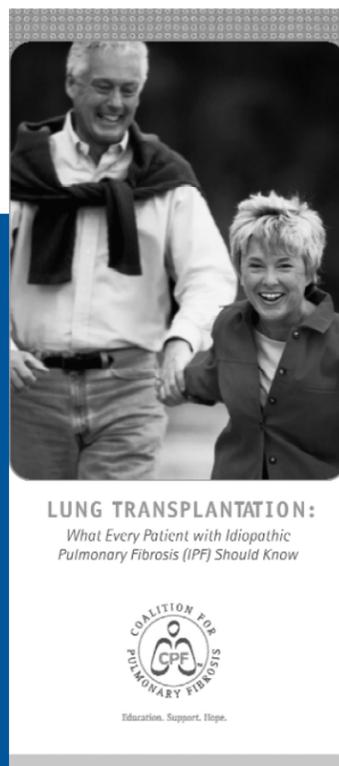
The two brochures were created for patients, family members and physicians alike based on preliminary results of the CPF's Basic Research Questionnaire, an education initiative launched last year to better understand the impact of idiopathic pulmonary fibrosis (IPF) on patients and families, and to help the foundation grasp the educational needs that arise for those fighting the disease.

"We hope that as a result of this educational effort, patients will be empowered to discuss lung transplantation as a potential treatment option for IPF early in their treatment, if not immediately upon diagnosis," said Marvin I. Schwarz,

M.D., Chairman of the CPF and James C. Campbell Professor of Medicine at the University of Colorado Health Sciences Center in Denver.

With regard to pulmonary rehabilitation and oxygen management for IPF patients, the interim results of the Basic Research Questionnaire also found that while 63 percent of patients are currently prescribed supplemental oxygen as a treatment, only about one-third (37percent) of all current patients have ever participated in a pulmonary rehabilitation program or received respiratory therapy (32 percent). Oxygen Management and Pulmonary Rehabilitation for the IPF Patient encourages participation in pulmonary rehabilitation programs, and seeks to improve patient education of the role that pulmonary rehabilitation and oxygen management have in treating IPF.

Copies of the brochures are available by contacting the CPF at 888-222-8541, by email at info@coalitionforpfg.org or by visiting www.coalitionforpfg.org/AboutUs/offerings.asp.



CPF Provides Public Comment to USP Draft Guidelines for Medicare Part D Prescription Coverage

The Centers for Medicare and Medicaid (CMS) will implement the Medicare Part D prescription drug plan in 2006. This will affect millions of Medicare enrollees, many who have not yet been covered for drug benefits in the past.

While this will be good news for many beneficiaries, the Coalition for Pulmonary Fibrosis (CPF) is concerned that the way Medicare plans to implement this coverage may leave many people without access to life-sustaining or life-saving treatments. It is important to note that even people with private insurance may be affected, since historically private insurance companies have followed the lead of CMS when determining coverage and reimbursement for medications.

In an effort to address this access to care issue, the CPF submitted a letter to the United States Pharmacopeia (USP) stating their concerns and asking for consideration for people with rare and orphan diseases, especially Idiopathic Pulmonary Fibrosis (IPF).

The USP is the organization responsible for making recommendations to CMS on drug and biologics coverage, as part of its overall mission of prompting public health by establishing authoritative information about the appropriate use of medicines.

Specific concerns voiced by CPF address the possibility that Medicare Part D insurers will not include certain drugs in their formularies (lists of covered drugs.) These drugs include several that are currently in clinical trials and show promising results in treating patients with IPF. CPF is also concerned that in the future, as these drugs are approved for IPF, Medicare Part D insurers will not be legally obligated to include them in formularies, further complicating patient access to the drugs.

People with IPF know their treatment options are limited. Drugs often used to treat IPF, including corticosteroids and cytotoxic agents, do not appear to help the majority of patients, and may in fact have harmful side effects. At this time there is no Food and Drug Administration (FDA) approved treatment specifically for IPF.

Research scientists are studying several promising drugs to determine their safety and effectiveness for treating IPF. The drugs in Phase II or III clinical trials to treat IPF (bosentan, etanercept, imatinib mesylate, interferon gamma 1-b) are already approved by the FDA to treat other indications. It may be several years before one or more of these treatments are approved by the FDA to treat IPF.

In some cases, physicians treating IPF patients may prescribe off-label use of one of these promising drugs. Off-label use of a drug for IPF means that the drug is approved for certain diseases, but not for IPF. Physicians may prescribe such a drug if usual therapies for IPF are ineffective, causing the disease to progress. Denying reimbursement coverage for these promising drugs in effect denies patients their only chance to access medical treatment that may well help them to survive.

In its comments, CPF stressed the importance of Medicare Part D plans covering drugs that may help save the lives of patients with IPF; specifically those drugs that are in the later stages of clinical trials and have shown promise in limiting or stopping progression of lung disease. Adequate Medicare coverage of these drugs now would also help to ensure they would continue to be covered in formularies after they were FDA approved for IPF. Patients covered under private plans might benefit as well if Medicare sets the precedence for coverage.

The CPF will continue to monitor this situation, and advocate on behalf of the 83,000 people currently diagnosed with IPF, and the 31,000 newly diagnosed patients each year.

If you would like more information on this issue or to learn more about the role of the United States Pharmacopeia in the development of Medicare guidelines, please visit www.usp.org/drugInformation/mmg; for more information on Medicare Part D prescription coverage please visit www.medicare.gov/medicarereform.

FibroGen Announces FG-3019 Found Safe and Well Tolerated in Patients with Idiopathic Pulmonary Fibrosis

Phase 1 Study Results of Investigational Anti-CTGF Therapy Reported at CHEST

South San Francisco, Calif. – Oct. 27, 2004 –FibroGen, Inc., today announced that FG-3019, the Company's lead investigational anti-fibrotic agent, was found safe and well tolerated in a Phase 1 clinical study conducted in patients with idiopathic pulmonary fibrosis (IPF). FG-3019 is a fully human monoclonal antibody designed to delay or halt the progression of fibrotic disease by blocking connective tissue growth factor (CTGF), a protein that plays a key role in fibrosis (excessive and persistent formation of scar tissue). Results of the Phase 1 study of FG-3019 were presented at CHEST, the annual meeting of the American College of Chest Physicians being held Oct. 23-28, Seattle.

"Based on encouraging results of this study, FG-3019 shows promise as a safe therapy for IPF that could be easily administered as an infusion," said Lead Principal Investigator Ganesh Raghu, M.D., Professor of Medicine, University of Washington Medical Center, Seattle, who presented the Phase 1 results at CHEST. "There is growing evidence that CTGF plays a causal role in the progressive lung scarring that is characteristic of IPF, which suggests that FG-3019 may help to prevent disease progression and improve lung function by reducing or preventing the fibrotic effects of this pathological growth factor."

The Phase 1 trial was an open-label, single dose, sequential-group, dose-escalation study designed to evaluate safety, tolerability, pharmacokinetics, and immunogenicity of FG-3019 in patients with a well-established diagnosis of IPF as defined by American Thoracic Society criteria. The study enrolled 21 patients: 1 mg/kg (six patients), 3 mg/kg (nine patients), and 10 mg/kg (six patients). No dose limiting toxicities were reported. The mean plasma levels of FG-3019 varied from patient to patient but were above the minimum effective concentration determined in animal models of fibrosis for approximately 13 days and 23 days for the 3.0 mg/kg and 10.0 mg/kg dose levels, respectively. The results of this study suggest that a single 2-hour infusion of FG-3019 is safe and well tolerated.

"This is an important step in our program to develop a therapy for chronic fibrosis," said Pedro Urquilla, M.D., vice president of Medical Affairs at FibroGen. "Based on these results, we plan to initiate a Phase 2 study of FG-3019 in patients with IPF in 2005."

About CTGF and Pulmonary Fibrosis

Several lines of clinical and preclinical evidence implicate CTGF in IPF. Transbronchial biopsy specimens from patients with IPF showed an increased expression of the CTGF gene. Further, increased expression of CTGF has been found in fibrotic lung tissue and in bronchoalveolar lavage cells from patients with IPF. Other studies show that CTGF is expressed predominantly in activated fibroblasts in the interstitium of fibrotic lung tissues and in proliferating type II alveolar epithelial cells in IPF. CTGF levels were shown to be much higher in fibrotic lung tissues than in normal tissues.

Preclinical models of acute lung fibrosis demonstrate that CTGF acts synergistically with other factors, such as transforming growth factor-beta (TGF-beta), and pathological conditions to induce extensive collagen deposition and massive scarring. Recently, CTGF has been shown to be necessary to cause pulmonary fibrosis in experimental models of lung fibrosis induced by the chemotherapeutic agent bleomycin, suggesting that CTGF is crucial to the pathogenesis of IPF.

CTGF is a key downstream mediator for the critical fibrotic activities of TGF-beta; notably, fibroblast proliferation and differentiation and extracellular matrix production, the primary mechanisms responsible for fibrosis. While mild scarring can be caused by either factor in experimental models, the combination of TGF-beta and CTGF results in massive scarring. Because TGF-beta has other roles outside of fibrosis, including immunosuppression and tumor suppression, complete blockade of TGF-beta activity would be undesirable in a clinical setting.

Similarly, endothelin-1 is a peptide shown to stimulate fibrosis and matrix production through upregulation of TGF-beta and fibronectin. Recent studies suggest that the CTGF gene can be directly activated by endothelin

"Based on encouraging results of this study, FG-3019 shows promise as a safe therapy for IPF that could be easily administered as an infusion."

*– Ganesh Raghu, M.D., Professor of Medicine,
University of Washington Medical Center, Seattle*

stimulation and that CTGF may be a downstream mediator of the fibrotic activities of endothelin-1. While TGF-beta and endothelin-1 are actively studied targets for IPF therapy, FibroGen believes that anti-CTGF therapy could offer a more selective and effective approach to the treatment of IPF and other fibrotic disorders.

Several other proteins implicated in IPF have been shown to operate through CTGF including vascular endothelial growth factor (VEGF), angiotensin II, and thrombin. VEGF, which induces production of CTGF through pathways independent of TGF-beta, is upregulated along with an increase in myofibroblasts in fibrotic lesions in experimental models of pulmonary fibrosis. Angiotensin II, which has been implicated in the apoptosis of activated alveolar epithelial cells in interstitial lung injuries, operates in part by directly upregulating CTGF via a response element on the promoter of the CTGF gene. Similarly, thrombin, which promotes myofibroblast differentiation, endothelial cell activation, matrix deposition, and fibrosis in the development of pulmonary fibrosis, has recently been shown to upregulate CTGF and cause the release of CTGF from activated platelets.

FibroGen research collaborations have also shown that CTGF is a necessary factor in the differentiation of fibroblasts into myofibroblasts, which are characteristic of fibrotic lesions and appear to be involved in extracellular matrix production and tissue contraction. Fibroblasts isolated from IPF patients are characteristically more myofibroblast-like than are those from normal subjects. CTGF has been shown to be a survival factor for myofibroblasts by preventing apoptosis.

For more information about FibroGen, Inc., please visit www.fibrogen.com.

Source: Fibrogen, Inc (www.fibrogen.com)

FIBROGEN

CPF Sponsored Support Groups

Please Check Our Web Page for the Most Up-to-Date Information on Our Nationwide Support Services

The focus of CPF support groups is to provide patients and their loved ones with essential educational resources and support, while also providing an opportunity to network and share experiences with other patients living with interstitial lung diseases.

BIRMINGHAM, AL

Pulmonary Fibrosis Support Group

In partnership with the UAB Medical Center

Meets: Quarterly meetings thereafter at date and time determined by the group.

Location: Kirkland Clinic, 2000 6th Ave. South, Birmingham: 5th Floor conference room

To RSVP or for further information, please contact Marty Robbins at 205-934-7557

SCOTTSDALE, AZ

Pulmonary Fibrosis Support Group

In partnership with the ALA of Northern Arizona

Meets: Second Saturday of every month, from 10:30 a.m. -12 Noon

Location: Via Linda Senior Center; 10440 E. Via Linda, Scottsdale

For additional information or to register for the group, please contact Doris Maley at 480-816-6745 or dmaley@sprynet.com

LOS ANGELES, CA

Interstitial Lung Disease (ILD) Support Group

In partnership with the David Geffen School of Medicine at UCLA

Meets: Third Tuesday every month

Location: David Geffen School of Medicine, 200 Medical Plaza, Room 347, Los Angeles

For more information, please contact Susan Golleher at 310-206-8950 or sgolleher@mednet.ucla.edu

MOUNTAIN VIEW, CA

Pulmonary Fibrosis Support Group

Meets: Every other month; next meeting Monday

Jan. 5 from 3-4:30 p.m.

Location: El Camino Hospital, 2500 Grant Road, Mountain View: Park Pavilion, Meeting Room "O"

For more information, please call 800-216-5556

PALO ALTO, CA

Interstitial Lung Disease Support Group

Meets: First Thursday of every other month starting in April.

Location: Stanford University Medical Center: 300 Pasteur Dr., Administration Conference Room, 3rd floor, Rm H3210

For more information or to register, please call Susan Jacobs, RN, MS, Group Coordinator, at 650-725-8082

SAN DIEGO, CA

Pulmonary Fibrosis Support Group

Meets: Monthly

Location: UCSD Medical Center, 200 West Arbor Drive, San Diego

For more information or to register, please call 619-543-7300

SACRAMENTO, CA

Central Valley Pulmonary Fibrosis Support Group

Supported by the Sutter Medical Center Pulmonary Rehab Dept.

Meets: Third Monday of each month from 1:30 a.m.-3 p.m.

Location: 2800 L Street; across the street from Sutter General Hospital

For additional information, please contact Sandra Rock at 916-354-1324 or sandararock@yahoo.com

DENVER, CO

Pulmonary Fibrosis Support Group

National Jewish Medical and Research Center

Location: 1400 Jackson St., Denver

For more information, please call Carol Blair, RCP at 800-423-8891, ext. 1621

FORT LAUDERDALE, FL

Broward County Better Breathers Support Group

In partnership with the ALA of South Florida

Meets: Third Tuesday of every month, 1 p.m.

Location: ALA of South Florida Headquarters, 2020 South

Andrews Ave., Fort Lauderdale

For more information or to register, please contact the ALA of South Florida at 954-524-4657 or 800-524-8010

FORT MYERS, FL

Pulmonary Fibrosis Support Group

Meets: Monthly from 1-3 p.m.

Location: Health Park Medical Center, Fort Myers Health Park 9981

Health Park Circle

For more information, call the Share Club at Health Park Medical Center at 239-772-6765

MIAMI, FL

Miami Interstitial Lung Disease Support Groups

Note: U Miami provides both English and Spanish speaking support groups

Meets: Every other month on 3rd Thursday

Location: Varies, please contact Erica Pena for exact details

For more information or to register, please contact Erica Pena, Group Coordinator, at 305-585-7340 or www.med.miami.edu/med/ijp

WEST PALM BEACH, FL

Pulmonary Fibrosis Support Group and Educational Forum

In partnership with the ALA of Florida; Southeast Region

Meets: Semi-monthly meetings beginning in January

Location: ALA office at 2701 N. Australian Ave, West Palm Beach

For more information or to register, please contact Mary Shields,

Group Coordinator, at 561-659-7644 or mary_s@inghaleexhale.org

DECATUR, GA

Pulmonary Fibrosis Support Group

Sponsored by the Emory Center for Interstitial Lung Disease at

Emory University

Meets: Last Thursday of each month, from March through October, from 2-3:30 p.m.

Location: Atlanta VA Medical Center: 1670 Clairmont Rd.,

Decatur: Ground Floor, Rm GC-302

For more information or to register, please contact Tamra Perez,

RN, BSN, at 404-321-6111, ext. 7487 or tlp413@yahoo.com

SAVANNAH, GA

Pulmonary Fibrosis Support Group

In partnership with Candler Hospital

Meets: Third Thursday of each month from 12 Noon-1 p.m.

Location: Candler Hospital, 5354 Reynolds St., Savannah;

2nd Floor of the Heart & Lung Building

For additional information or to register for the group, please contact

Lisa Summerford, RN, at 912-692-7354

VINCENNES, IN

Pulmonary Fibrosis Support Group

Meets: 3rd Tuesday of each month from 7-8:30 p.m.

Location: Good Samaritan Hospital, 520 South 7th Street,

Conference Room B

For more information, please call 812-886-8753

NEWTON, KS

Pulmonary Fibrosis Support Group

Meets: Monthly

Location: Elks lodge, 201 S. Pine St.

For more information, please contact Cathy McLaugh at

620-983-2667 or cathymcgaugh@hotmail.com

MEDFORD, MA

In partnership with Lawrence Memorial Hospital- School of Nursing

Meets: 2-3 times per month

Location: Lawrence Memorial Hospital- School of Nursing,

170 Governor's Avenue, Medford

Please contact Catherine Reinhart at 978-930-3000 to RSVP

or for additional information

MINNEAPOLIS, MN

Respiratory Health Club for patients with emphysema, asthma, chronic bronchitis, pulmonary fibrosis and sarcoidosis and their families

In partnership with the ALA of Minnesota

Meets: Third Thursday of each month, from 1-3 p.m.

Location: Lutheran Church of the Good Shepherd, 4801 France Ave. S

For additional information or to register, please contact Cheryl Sassa,

ALA of Minnesota at 651-27-8014 or cheryl.sasse@alamn.org

ST. PAUL, MN

Lung Disease Support Group for patients with emphysema, asthma, chronic bronchitis, pulmonary fibrosis and sarcoidosis and their families

In partnership with the ALA of Minnesota

Meets: Second Tuesday of each month, from 1-3 p.m. (except

January and February)

Location: Gustavus Adolphus Church, 1669 Arcade St.

For additional information or to register, please contact Cheryl Sassa,

ALA of Minnesota at 651-227-8014 or cheryl.sasse@alamn.org

BOZEMAN, MT

Pulmonary Fibrosis & Lung Disease Support Group

In partnership with the ALA of the Northern Rockies and the Bozeman

Deaconess Hospital

Meets: Monthly

Location: Bozeman Deaconess Hospital, 915 Highland Blvd.,

Meeting Room F

For more information or to register, please call 406-587-9091 or

406-585-5040

LAURINBURG, NC

Pulmonary Fibrosis Support Group

In partnership with Scotland Memorial Hospital

Meets: 3rd Wednesday of every month at 2:30 p.m.

Location: Scotland Memorial Hospital, Dulin Rehabilitation Center,

500 Lauchwood Dr., Laurinburg, NC 28352

For more information, please call Jill Brown, RRT, group coordinator,

at 910-291-7472

MORRISTOWN, NJ

Pulmonary Fibrosis Support Group of Central & Northern New Jersey

Meets: Last Wednesday of every month; next meeting

Dec. 29 at 7 p.m.

Location: Morristown Memorial Hospital, 100 Madison Ave.,

Morristown; Conference Rm #3

For more information, please contact Barbara Murphy at

908-276-3394 or barbara.murphy@spcorp.com

CLEVELAND, OH

In partnership with the Cleveland Clinic Foundation

Meets: Quarterly meeting dates determined by the group
Location: Cleveland Clinic Foundation, 5001 Rockside Rd., Independence, OH; Lower Level, Conference Room A/B
For more information or to register for the group, please contact Stephanie Slattery, RN, Group Coordinator, at 216-444-4725 or slattes@ccf.org

TULSA, OK

Pulmonary Fibrosis Support Group

Meets: Monthly on the third Saturday of the month, from 10 a.m.-12 Noon
Location: St John Health Plaza, 1819 E. 19th St.: La Fortune Meeting Room (First Floor)
For additional information or to register for the group, please contact the CPF at 888-222-8541, or info@coalitionforpf.org

EUGENE, OR

Spirited Breathers Support Group for Pulmonary Fibrosis Patients & Families

Meets: Second Thursday of each month 3-4:30 p.m.
Location: Sacred Heart Medical Center, Oregon Heart Center conference room, 1255 Hilyard St., Eugene
For more information, please call 541-686-7442

PITTSBURGH, PA

IPF Support Group

Meets: First Monday of every other month (beginning in January 2004) from 1-3 p.m.
Location: UPMC Presbyterian; Conference Rm 1102, 11th floor
For more information please call 412-802-3275 or email simmonsILD@msx.upmc.edu

WEST COLUMBIA, SC

Pulmonary Fibrosis and Lung Disease Support Group

In partnership with Lexington Medical Center

Meets: Monthly on the second Thursday of the month, September-May only, from 12 Noon-1 p.m.
Location: Lexington Medical Center, 2720 Sunset Blvd., West Columbia; Pulmonary Rehab. Classroom
For more information or to register, please contact Mark Stout at 803-791-2621

CHATTANOOGA, TN

Alliance for Pulmonary Fibrosis at the Diagnostic Center

Meets: Monthly on the third Tuesday of the month
Location: Diagnostic Center, 2205 McCallie Ave, Chattanooga
For more information or to register, please contact Becky Black at 423-697-6151 or bblack@diagctr.com

NASHVILLE, TN

Middle Tennessee Coalition for Pulmonary Fibrosis

Meets: Quarterly; schedule to be determined by the group
Location: The Vanderbilt Clinic, 1301 22nd Avenue South, Second Floor, Rooms 2702-2703
To register, please contact Wendi R. Mason, RN, at 615-343-7068 or wendi.mason@vanderbilt.edu

HOUSTON, TX

In partnership with the Baylor University School of Medicine

Meets: Meets monthly from 10 a.m.-1 p.m.
Location: Kelsey-Seybold Clinic, Main Campus, 2727 West Blvd.
For specific meeting information or to register for the group, please contact David Davenport at 281-812-7611 or zip88@earthlink.net, or Jan Orndorff at 281-348-2378 or Jan3145@aol.com

FALLS CHURCH, VA

Pulmonary Fibrosis Support Group

Meets: Quarterly
Location: Inova Fairfax Hospital, 3300 Gallows Church Rd.
For more information or to register, please contact Jane Harrison, LCSW, at 703-776-3203 or jane.harrison@inova.com

SEATTLE, WA

Pulmonary Fibrosis Support Group

Meets: Last Tuesday of each month, except July and August from 1-3 p.m. Please call to confirm location of next meeting
Location: Meetings alternate between the University of Washington Medical Center and the American Lung Association of Washington
For more information, please contact group coordinator Frank Brewer at 206-367-3032 or frankb4@comcast.net



Education. Support. Hope.

www.coalitionforpf.org

About the CPF Board of Directors

Each quarter the CPF profiles a member of the CPF board of directors or scientific advisory board, many of who are nationally recognized thought leaders in the treatment and research of IPF, family members of patients with IPF, and advocates for all those fighting the disease.

Deirdre R. Roney, J.D.

Deirdre Roney is a family member of eight idiopathic pulmonary fibrosis patients, only two of which survive today. Deirdre has lost her grandmother, mother, and four aunts and uncles to IPF. She serves on the CPF's Board of Directors to honor and remember family members who succumbed to the disease, and to prevent others from experiencing the suffering IPF can inflict. Deirdre has been involved in the development of the CPF's ongoing advocacy programs nationwide, ensuring that the interests of IPF patients and families are always central to the programs, services, and mission of the CPF.

Most recently, Deirdre has actively participated in CPF's advocacy work and National IPF Awareness Week Activities in 2003 and 2004. She has traveled with the CPF, to Capitol Hill to meet with Members of Congress and increase awareness of IPF, as well as support for important legislation currently before Congress that can benefit IPF patients. Deirdre has also been instrumental in devising and implementing successful fundraising initiatives that benefit the

CPF and other organizations that advocate for IPF patients, family members, and research to find a cure. During IPF Awareness Week 2004, Deirdre helped her family organize and raise funds for the first annual B.I.G. (Breathing is Glorious!) 5K run/walk in Ann Arbor, Mich.

Deirdre enjoys a diverse career in public service. She is currently executive director of a nonprofit organization devoted to seriously ill children. She is a public education activist in Malibu, and is past planning commissioner for Malibu city, as well as a past president of the Malibu Parent Teacher Association (PTA). She also spearheaded bond and parcel tax campaigns for local public schools and led measures to improve the city's park system. Before the birth of her two children, she was a prosecutor for the Los Angeles County District Attorney's Office and volunteered her legal services to those seeking political asylum. Deirdre graduated from Harvard Law School in 1987 and from the University of Michigan with a bachelor or arts in political science in 1984. She resides in Malibu, Calif. with her family.

CPF Board of Directors

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Professor of Medicine, Yale University School of Medicine

Deirdre R. Roney

Family member of eight IPF patients

Celeste Belyea, RN, RRT

Editor, the Pulmonary Paper

Teresa Barnes

Family member of four IPF patients

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 83,000 IPF patients, caregivers and families, and to the healthcare professionals who treat them.

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

Coalition for Pulmonary Fibrosis
c/o PNC Bank
POB 31001-0943
Pasadena, CA 91110-0943

Any contributions mailed by overnight delivery or by special couriers should be sent to:

PNC Bank
465 North Halstead, Suite 160
Pasadena, CA 91107
Ref: Coalition for Pulmonary Fibrosis Lockbox #910943

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 <http://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 a specific CPF program such as our educational materials, seminars, support services or research efforts, please contact us at 888-222-8541.

About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501 (c) (3) nonprofit organization, founded in 2001 to further education, patient support and research efforts for pulmonary fibrosis, specifically idiopathic pulmonary fibrosis (IPF). The CPF is governed by the nation's leading pulmonologists, individuals affected by pulmonary fibrosis, medical research professionals and advocacy organizations. The CPF's nonprofit partners include the Mary D. Harris Memorial Foundation, The Pulmonary Paper, the Caring Voice Coalition, Second Wind Lung Transplant Association, the National Coalition of Autoimmune Patient Groups, and more than 30 leading IPF treatment and research centers nationwide. For more information on CPF, please visit www.coalitionforpf.org or call 888-222-8541.



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