



Action Alert

CPF Continues Alliance with Caring Voice Coalition in 2004 to Broaden Scope of Patient Services Available to the IPF Community

Caring Voice Coalition (CVC), a partner of the Coalition for Pulmonary Fibrosis, celebrated its first anniversary of working with the pulmonary fibrosis patient community in January 2004. More than 500 patients and family members were assisted through one of the CVC programs in 2003. These programs include personal counseling and support, vital relief financial assistance, public advocacy, and insurance reimbursement education and assistance. The CPF is proud to continue its partnership with the CVC through 2004.

One of the fastest growing services CVC offers is its patient mentoring program, designed to offer one-to-one support to IPF patients and family members by individuals sharing similar experiences.

"Our mentoring program offers help in a confidential, safe environment," said Cathy Valenti, CVC Chief Executive Officer. "We work with volunteers within the IPF community who understand the issues and stresses associated with this disease."

The most requested service CVC offers is insurance reimbursement and education. CVC staff assists in obtaining insurance for IPF patients, and writes appeals for insurance denials of treatment or medical devices.

"We work with volunteers within the IPF community who understand the issues and stresses associated with this disease."

- Cathy Valenti, CVC Chief Executive Officer

"We find that many people have trouble navigating the insurance maze," said Pam Harris, CVC President. "It's confusing to make the best choice; for example when deciding on a supplemental Medicare policy. It can be disheartening to try to appeal insurance company denials for treatment."

CVC also helps to educate IPF patients about insurance issues of all types, including Medicare and supplemental insurance, Medicaid, Veteran's Administration, HMOs and private insurance.

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Has Your Contact Information Changed?

Have a new email address? Moved recently? Please take a moment and update your contact information with the CPF. Visit www.coalitionforpf.org and complete the registration form by selecting "Update Member Info" in the first selection box. You also can email info@coalitionforpf.org or call (888) 222-8541.

CVC staff and volunteers have first-hand knowledge of transplant issues, physical, emotional and social changes associated with IPF, financial and insurance considerations, and dealing with grief and loss. They also have access to a comprehensive sourcebook of state and community resources to assist with other needs IPF families may face.

Mentoring is offered through the CVC Personal Support program, which also includes information and education, location of medical resources, referrals to local support groups, and assistance with local agencies and other resources such as long-term counseling.

The Vital Relief Financial Assistance program offers support to qualified individuals who face acute financial need. Although CVC funds for this program are limited, many people have been helped through this service.

Public Advocacy was established to allow patients and families to voice their concerns to legislators and other government officials about laws and rules that affect their lives.

Through letter writing, personal visits, and telephone contact, individuals affected by IPF can make a difference in important health issues affecting their well-being and financial status.

For more information on any of these programs, please contact the CVC toll-free at 888-267-1440, by email at info@caringvoice.org, or on the Web at www.caringvoice.org.



for the treatment of numerous fibroproliferative disorders," said Thomas B. Neff, Chief Executive Officer of FibroGen. "This is an important step in our development program for therapeutics that treat chronic fibrosis, which includes plans to initiate clinical studies in diabetic nephropathy, and potentially other forms of renal fibrosis and scleroderma."

About CTGF and Fibrosis

Fibrosis is a pathological condition in which the normal wound healing process goes awry, culminating in the excessive production and deposition of collagen, a key component of scar tissue. The persistent formation of scar tissue hinders proper tissue function and can lead to organ failure in a wide range of fibrotic diseases. CTGF plays a key role in fibrosis by triggering the production of collagen and is thus an attractive target for anti-fibrotic therapies.

A growing body of clinical evidence supports the role of CTGF in fibrotic disease. Numerous published studies show that CTGF is overexpressed (present in abnormally high amounts) in samples obtained from patients with fibroproliferative disorders of the major organs and tissues including the lungs, skin, kidneys, liver, heart, and eyes. Most recently, at the American Society of Nephrology Annual Meeting, FibroGen and collaborators reported that urine levels of CTGF from patients with Type 2 diabetes and non-diabetic renal diseases predict progression of kidney disease and response to treatment (adjunct therapies, such as ACE inhibitors and ARB's).

In IPF, CTGF has been implicated in all levels of the disease from increased CTGF gene expression to elevated levels of CTGF protein in the cells thought to play an active role in the disease. Researchers have reported increased expression of the CTGF gene in transbronchial-biopsy specimens and bronchoalveolar lavage cells. Further, the presence of CTGF protein in lung tissue of IPF patients appears to be confined predominantly to those cell types believed to play a critical role in pulmonary fibrosis (proliferating type II alveolar cells and activated fibroblasts).

Targeting CTGF to inhibit the fibrotic process is supported by independent studies and FibroGen's pre-clinical work. Models of generalized sclerosis and specific models of kidney and lung disease were all successfully treated with antibodies targeting CTGF, including a model of bleomycin-induced lung fibrosis.

Other studies show that CTGF is a downstream mediator responsible for the persistent pro-fibrotic effects of transforming growth factor-beta (TGF-beta), indicating the importance of targeting CTGF to treat diseases marked by chronic fibrosis. TGF-beta is a regulatory protein that has multiple functions, including an early role in the inflammatory response to injury and a central role in triggering the chain of events leading to the induction of CTGF and scarring. Due to its specialized role in perpetuating the scarring process, CTGF could be a more specific target for anti-fibrotic therapies, which could provide significant clinical benefit without broad side effects.

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

FibroGen Initiates Open-Label, Phase 1 Clinical Trial of FG-3019 in Patients with Idiopathic Pulmonary Fibrosis

New Anti-fibrotic Approach Targets CTGF

South San Francisco, Calif., - December 18, 2003 - FibroGen, Inc., today announced the initiation of an open-label, Phase 1 clinical trial designed to evaluate the safety and tolerability of FG-3019, the company's lead investigational anti-fibrotic agent, in patients with idiopathic pulmonary fibrosis (IPF). FG-3019 is 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).

"The initiation of clinical testing with FG-3019 represents a new and promising, direct anti-fibrotic approach to the treatment of IPF," said Pedro R. Urquilla, MD, Vice President of Medical Affairs at FibroGen. "Elevated levels of CTGF are found in lung tissue from patients with IPF, and preclinical studies show that treatment with FG-3019 reduces scarring in animal models of lung fibrosis. Thus, we believe that FG-3019 is a potential first-in-class anti-fibrotic therapy that could halt or delay disease progression and improve lung function in this difficult-to-treat setting."

The Phase 1 clinical trial is an open-label, sequential-group, dose-escalating study expected to enroll up to twenty-seven patients with IPF and designed to evaluate the safety, tolerability, pharmacokinetics, and immunogenicity of FG-3019. Patients will receive one of three escalating dose levels of study material administered as a single, intravenous infusion. The trial will be conducted at four centers in the United States.

"This is an important step in our development program for therapeutics that treat chronic fibrosis."

- Thomas B. Neff, Chief Executive Officer of FibroGen

"FibroGen was originally founded to discover and develop novel drugs for the treatment of fibrotic disorders. Beginning a Phase 1 clinical trial with FG-3019 is doubly gratifying in that we achieve an important corporate milestone and commence testing of a new anti-fibrotic strategy that we believe holds promise for treating patients with IPF and that addresses a large, unmet medical need



Some Cases of Lung Disease May Be Linked With Tricyclic Antidepressants, Study Suggests

NEW YORK, Jan. 14, 2004 – Some older antidepressant medications may cause a form of lung disease known as idiopathic pulmonary fibrosis in rare cases, suggests a study published by the American Lung Association. According to the lead researcher of the new study, people with this lung disease who are taking tricyclic antidepressants, particularly imipramine, should ask their doctor about switching to another antidepressant drug.

The study examined medication use of 141 people with idiopathic pulmonary fibrosis, and 246 people of similar age and sex without the disease. The researchers at City Hospital in Nottingham, United Kingdom, looked at use of antidepressants, beta blockers, antibiotics, anticonvulsants, and non-steroidal, anti-inflammatory drugs.

The study found that idiopathic pulmonary fibrosis (IPF) was most strongly associated with exposure to several tricyclic antidepressant medications; the strongest association was found with the antidepressant imipramine. The researchers estimated that 10 percent of cases of IPF in the study were caused by antidepressant exposure. No significant association was seen between IPF and the four other categories of drugs studied.

The study appears in the March 2004 issue of the American Journal of Respiratory and Critical Care Medicine, published by the American Lung Association. (Exposure to Commonly Prescribed Drugs and the Etiology of Cryptogenic Fibrosing Alveolitis. R. Hubbard et al. Am J Respir Crit Care Med 1998;157:743-747.)

Breathlessness during exercise can be one of the first symptoms, and a dry cough also may be present. Another name for IPF is cryptogenic fibrosing alveolitis. The incidence of IPF is approximately 3 to 5 cases per 100,000 persons.

Lead researcher Richard Hubbard, M.D., said the findings are most relevant to patients who already have developed IPF. He noted that since IPF is an uncommon reaction to taking tricyclic antidepressant medications, and that since these drugs are very effective in treating depression, that

he would not make any recommendations to switch antidepressant medications in otherwise healthy patients.

"Although these findings need confirmation in other studies, it seems sensible to suggest that any patient with IPF who is taking tricyclic antidepressants, particularly imipramine, should discuss with his or her doctor having this antidepressant changed to another drug," Dr. Hubbard said. "In addition, it seems sensible to avoid starting tricyclics in patients with IPF, particularly now that there are a lot of other effective newer antidepressants available. Clearly, on an individual level, the decision must remain with the physician as depression can also be life threatening, and some cases respond only to tricyclic antidepressants." Dr. Hubbard noted that it is not known how tricyclic antidepressants might damage the lung.

Tricyclic antidepressants are one of four categories of antidepressant drugs. Tricyclic antidepressants alter the balance in the brain of the neurotransmitters (chemical messengers) norepinephrine and serotonin. Other types of antidepressants include monoamine oxidase inhibitors (MAOIs), selective serotonin-reuptake inhibitors (SSRIs), and new-generation antidepressants (venlafaxine hydrochloride and nefazodone hydrochloride).

Gary Hunninghake, M.D., Director of the Pulmonary Division at University of Iowa Hospitals in Iowa City, said the new findings are interesting but need to be confirmed. "For now, I would advise that patients taking tricyclic antidepressants not stop their medications. They may want to discuss this with their personal physician."

Source: American Lung Association (www.lungusa.org)



CPF Continues National "Living With IPF" Educational Seminars in 2004

The Coalition for Pulmonary Fibrosis (CPF) continues its national IPF seminar series in partnership with the nation's leading IPF treatment and research centers in 2004. CPF educational seminars are a wonderful opportunity for patients, family members, caregivers – anyone affected by IPF – to learn about the latest advances in IPF diagnosis, treatment and new research efforts to find a cure. Seminars also offer patients educational sessions on strategies to improve their quality of life, the role of pulmonary rehabilitation and oxygen management techniques, lung transplantation, and resources and support services available to the IPF community. CPF guest speakers include the nation's leading IPF experts and healthcare professionals.

Sarasota, FL

On March 6, 2004, the CPF will kick off the 2004 seminar series in Sarasota, FL with an educational symposium in partnership with HealthSouth Rehabilitation Hospital and the University of Miami. Invitations have already been distributed for this seminar and space is filling quickly. CPF member, Trudy Vanderbeck, (featured in last quarter's newsletter) will be speaking as well.

For further information on our 2004 seminar schedule, please visit www.coalitionforpf.org.

Pittsburgh, PA

On April 17, 2004, the CPF will continue its seminar series with an educational symposium in Pittsburgh, PA in partnership with the Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease and the University of Pittsburgh Medical Center. Invitations will be mailed around March 1st and we look forward to seeing you there!



Recommended Reading

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

- The Breathing Disorders Sourcebook
By F.V. Adams, MD
- Shortness of Breath: A Guide to Better Living and Breathing
By A.L. Ries, et al
- The Lung Transplantation Handbook
By K.A. Coulture
- Coping with Prednisone
By E. Zukerman and J.R. Ingelfinger, M.D.
- The Official Patient's SourceBook on Idiopathic Pulmonary Fibrosis
By J.N. Parker & P. Parker
- Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill
By C. Capossela & S. Warnock
- Taking Flight – Inspirational Stories of Lung Transplantation
Compiled by Joanne Schum, Authored by lung recipients around the world

NIH Establishes Rare Diseases Clinical Research Network

To address the challenges inherent in diagnosing and treating rare diseases, the National Institutes of Health (NIH) recently announced the establishment of the Rare Diseases Clinical Research Network. With \$51 million in grant funding over five years from several NIH components,* the network will consist of seven Rare Diseases Clinical Research Centers (RDCRCs) and a Data and Technology Coordinating Center (DTCC).

"Funding research on rare diseases is a vital aspect of the NIH mission," said NIH Director, Elias A. Zerhouni, M.D. "By encouraging cooperative partnerships among the investigators at these centers, we hope to accelerate the development of diagnostics and treatments that will benefit these important patients."

The RDCRCs and the DTCC will be located at the following institutions:

- Baylor College of Medicine, Houston, TX
Rare Disease Clinical Research Center for New Therapies and New Diagnostics – Dr. Arthur L. Beaudet
- Boston University School of Medicine, Boston, MA
Vasculitis Clinical Research Network – Dr. Peter A. Merkel
- Children's Hospital Medical Center, Cincinnati, OH
Rare Lung Diseases Clinical Research Network – Dr. Bruce C. Trapnell
- Children's National Medical Center, Washington, DC
Rare Diseases Clinical Research Center for Urea Cycle Disorders – Dr. Mark L. Batshaw
- The Cleveland Clinic Foundation, Cleveland, OH
Bone Marrow Failure Clinical Research Center – Dr. Jaroslaw P. Maciejewski
- University of Rochester, Rochester, NY
Nervous System Channelopathies Pathogenesis and Treatment – Dr. Robert C. Griggs
- Weill Medical College of Cornell University, New York, NY
The Natural History of Rare Genetic Steroid Disorders – Dr. Maria I. New
- H. Lee Moffitt Cancer Center and Research Institute, University of South Florida, Tampa, FL – The Data and Technology Coordinating Center – Dr. Jeffrey P. Krischer



"The network will facilitate increased collaboration and data sharing between investigators and patient support groups working to improve the lives of those affected by these diseases and potentially prevent or eliminate these diseases in the future."

– Stephen Groft, Pharm.D., director of NIH's Office of Rare Diseases

Approximately 25 million people in the United States are affected by an estimated 6,000 rare diseases or conditions. Diseases to be studied in the centers include: urea cycle disorders; Angelman's syndrome; Prader-Willi syndrome; Rett syndrome; periodic paralysis; non-dystrophic myotonic disorders; episodic ataxia; aplastic anemia; paroxysmal nocturnal hemoglobinuria; single lineage cytopenias, including granular lymphocyte leukemia, pure red cell aplasia, and myelodysplastic syndromes; vasculitis disorders; inborn defects in steroid hormone pathways; alpha-1 antitrypsin deficiency; lymphangiomyomatosis; pulmonary alveolar proteinosis; and hereditary idiopathic pulmonary fibrosis.

Continued on next page

"The network will facilitate increased collaboration and data sharing between investigators and patient support groups working to improve the lives of those affected by these diseases and potentially prevent or eliminate these diseases in the future," said Stephen Groft, Pharm.D., director of NIH's Office of Rare Diseases. "In addition, knowledge about rare diseases may offer leads for scientific advancement in other rare diseases and in more common diseases."

The creation of the network responds to the Rare Disease Act of 2002, which directed NIH to support "regional centers of excellence for clinical research into, training in, and demonstration of diagnostic, prevention, control and treatment methods for rare diseases." The term "rare (or orphan) disease," as defined in the Orphan Drug Act, is a condition affecting fewer than 200,000 people in the United States or a disease with a greater prevalence but

for which no reasonable expectation exists that the costs of developing or distributing a drug can be recovered from the sale of the drug in the United States.

*The Rare Diseases Clinical Research Network is funded by the Office of Rare Diseases, National Center for Research Resources, National Institute of Child Health and Human Development, National Institute of Neurological Disorders and Stroke, National Institute of Arthritis and Musculoskeletal and Skin Diseases, and National Institute of Diabetes and Digestive and Kidney Diseases, all components of NIH, an agency of the Department of Health and Human Services.

Source: National Institutes of Health (www.nih.gov)

New Concepts in Pulmonary Fibrosis Research

Bone Marrow-derived Stem Cells Active in Pulmonary Fibrosis

Adult stem cells have long been thought to be restricted in their potential to differentiate and regenerate tissues in which they reside. A study by Sem Phan and colleagues from the University of Michigan, in the January 15, 2004 issue of the *Journal of Clinical Investigation*, suggests that the collagen overproduction and deposition in the lung causing idiopathic pulmonary fibrosis may develop from cells derived from bone marrow stem cells, rather than parenchymal lung fibroblasts(1).

The authors induced pulmonary fibrosis in mice that had been altered with bone marrow labeled with a fluorescent green marker protein. In these mice, cells derived from bone marrow-derived stem cells fluoresce green, while those cells that reside in the lung do not. Most of the collagen-producing fibroblasts observed in the lungs of these mice fluoresced green, indicating that they were of bone marrow origin.

In an accompanying commentary, Sarah Dunsmore and Steven Shapiro from Harvard Medical School discuss this new concept in pulmonary fibrosis(2). They state "understanding the mechanisms of engraftment will be important as clinical applications of bone marrow stem cell therapy are explored. The clinical implications of these findings are significant; for example, we might now consider bone marrow stem cell therapy to correct structural alterations in the lung." They conclude "translation of our understanding of disease pathogenesis into clinical practice will bring us closer to our real goal – improving the lives of our patients and ultimately curing disease."

Source: *Journal of Clinical Investigation*

1. Hashimoto, N., et al. 2004. Bone marrow-derived progenitor cells in pulmonary fibrosis. *J. Clin. Invest.* 113:243-252.
2. Dunsmore, S., and Shapiro, S.D. 2004. The bone marrow leaves its scar: new concepts in pulmonary fibrosis. *J. Clin. Invest.* 113:180-182.

InterMune Initiates Phase III Clinical Trial of Actimmune for IPF

BRISBANE, Calif., Dec. 16, 2003 - InterMune, Inc. today announced that consistent with previous guidance the first patient has been enrolled into the INSPIRE Trial, its pivotal Phase III trial evaluating the efficacy and safety of Actimmune® (interferon gamma-1b) as a treatment for idiopathic pulmonary fibrosis (IPF), a debilitating and deadly lung disease. Approximately 83,000 patients suffer from this disease in the United States alone. There are currently no drugs approved by the FDA for the treatment of IPF.

The INSPIRE Trial is a randomized double-blind, placebo-controlled Phase III trial. The trial is designed to evaluate the safety and efficacy of interferon gamma-1b in IPF patients with mild-to-moderate impairment in lung function; the primary endpoint of the trial is survival time. The trial will enroll 600 patients at approximately 70 centers in the United States, Europe and Canada. Patients will be randomized at a ratio of 2:1 to receive either 200 micrograms of interferon gamma-1b three times a week or placebo, respectively. Each patient enrolled will be followed for at least 24 months.

"This trial promises to answer many fundamental clinical questions regarding the use of interferon gamma in IPF, most significantly to further investigate the survival findings from the recently completed GIPF-001 study," said study Co-Chair Talmadge E. King, Jr., M.D., Professor and Vice Chairman, Department of Medicine, University of California San Francisco, San Francisco General Hospital. "The study has been designed to target patients with mild-to-moderate disease, and we hope that it will lead to a definitive outcome on which to base future patient treatment."

In conjunction with thought leaders from around the world, InterMune designed the INSPIRE Trial based on information learned from its previously completed 330-patient randomized, double-blind, placebo-controlled Phase III (GIPF-001) clinical trial and two other independently conducted, randomized, controlled trials. The INSPIRE Trial seeks to confirm observations from these previous studies that suggest interferon gamma may prolong survival in patients with IPF.

"Much of what we learned in the first Phase III trial could not have been predicted based on our previous knowledge of interferon gamma in IPF, but we were encouraged by the potential survival advantage and welcome the opportunity to study patients with milder disease over a longer observation period," said the other Study Co-Chair, Ron M. du Bois, M.D., Professor of Respiratory Medicine, Imperial College of Science, Technology and Medicine, and Consultant Physician, The Royal Brompton Hospital, London. "We are pleased that InterMune is supporting the necessary clinical studies to determine the appropriate role of interferon gamma in this life-threatening disease."

For further information concerning the INSPIRE Trial, please visit www.inspiretrial.com.

Source: InterMune, Inc. (www.intermune.com)



How Was Your IPF Diagnosis Confirmed?

In September 2003, the CPF began collecting information from IPF patients regarding their experience living with IPF through its Basic Research Questionnaire. A critical component of this questionnaire asked patients what diagnostic tests were used to confirm their IPF diagnosis. If you have NOT provided this information to the CPF through your member registration or by completing our Basic Research Questionnaire, we ask that you **complete the enclosed postcard and return it to us at your earliest convenience.**

Patient information collected by the CPF is confidential and anonymous, and an important first step toward gathering diagnostic information that does not currently exist about patients living with IPF. **Information about the test(s) used to confirm your IPF diagnosis will be used by the CPF to better understand practice trends in the physician community and help the CPF to design professional educational tools to help advance early and accurate diagnosis of IPF.**

If you are a family member or caregiver of the individual with pulmonary fibrosis, we ask that you only provide information as it relates to the patient. If you, or another family member or caregiver, has already provided information pertaining to your diagnosis through the CPF's Basic Research Questionnaire, or through our online registration completed either the online or paper version of this survey, there is no need to submit it again.

Please return the completed insert of your newsletter directly to the CPF by mailing to:

Coalition for Pulmonary Fibrosis
1685 Branham Ln, Ste. 227
San Jose, CA 95118

Or, if you wish, you may easily provide your diagnostic information by going to our Web site at www.coalitionforpf.org, clicking on the patient registration link and selecting "Update Member Info" from the drop-down menu. On behalf of the CPF's board of directors, we would like to offer our sincere thanks for your participation in this project.

CPF Receives \$62,000 Private Contribution to Continue Research Initiative

January 15, 2004 - The CPF is proud to announce that it has received a \$62,000 private restricted grant to continue funding the CPF's national IPF Basic Research Questionnaire for IPF patients and their families. The contribution was made by the DuBrul Family Fund in support of the Galvin family, which has lost five family members to IPF.

The CPF's Basic Research Questionnaire was created in September 2003 to accurately capture the experiences of IPF patients and gather information in support of the CPF's national education and advocacy efforts on behalf of IPF patients and families. The questionnaire allows the CPF to collect vital information from IPF patients, including detection, diagnosis, disease management information and access to care, while identifying unmet education and support needs of patients and healthcare professionals throughout the care continuum.

To date, the CPF has received more than 1,200 completed questionnaires, which represents one of the largest databases of IPF patients in the United States. The CPF expects to announce preliminary findings, based on the first 1,000 responses, in early 2004. Data collection is ongoing, and the program is managed by Michaels Opinion Research, Inc., an independent opinion research firm based in New York.

If you have not completed a Basic Research Questionnaire, please contact the CPF at 888-222-8541, or visit our Web page at www.coalitionforpf.org to obtain a copy. Your participation is crucial to help our education and advocacy efforts on your behalf!

National Partners to Advance IPF Education and Awareness

- ALA of California
- ALA of Minnesota
- ALA of Northern Arizona
- ALA of Oklahoma
- ALA of Oregon
- ALA of Pennsylvania
- ALA of South Florida
- ALA of Southeast Florida
- ALA of Washington
- American Thoracic Society – Nursing Assembly
- Apria Healthcare
- Baylor University School of Medicine
- California Thoracic Society
- Cleveland Clinic Foundation
- David Geffen School of Medicine at UCLA
- Duke University Medical Center
- El Camino Hospital (Mountain View, CA)
- Good Samaritan Hospital (Vincennes, IN)
- Health Park Hospital (FL)
- HealthSouth Rehabilitation Hospital (Sarasota, FL)
- Inova Fairfax Hospital (Fairfax, VA)
- Lexington Medical Center (SC)
- Lincare
- Mayo Clinic (Rochester, MN)
- Mt. Sinai University School of Medicine
- National Heart, Lung & Blood Institute (NHLBI)
- North Shore University Medical Center
- Philadelphia Thoracic Society
- University of Alabama Birmingham Medical Center
- University of California–San Diego Medical Center
- University of California–San Francisco
- University of Pennsylvania Medical Center
- University of Pittsburgh Medical Center
- University of Washington School of Medicine
- Stanford University Medical Center
- Temple University Medical Center
- Vanderbilt University Medical Center
- Virginia Association for Cardiovascular and Pulmonary Rehabilitation
- Virginia Association for Respiratory Care
- Yale University Medical Center

CPF Nonprofit Partners

CARING VOICE COALITION

Caring Voice Coalition is dedicated to building relationships with charitable organizations founded to help individuals and families affected by serious chronic disorders and diseases including IPF. For more information, contact:

Caring Voice Coalition
P.O. Box 1384
Meridian, ID 83680
(888) 267-1440
www.caringvoice.org

MARY D. HARRIS MEMORIAL FOUNDATION

This nonprofit organization supports efforts to find a cure for pulmonary fibrosis as well as educational initiatives that help to improve the lives of those living with the disease. For more information, contact:

Mary D. Harris Memorial Foundation
1500 Ashbury Street
Evanston, IL 60201
(847) 869-5276

PULMONARY FIBROSIS ASSOCIATION (2001-2003)

The Pulmonary Fibrosis Association ceased operations in June, 2003. Services previously offered by the PFA are now available through the CPF.

THE PULMONARY PAPER

This nonprofit organization publishes a newsletter with the latest information on respiratory care and products for people with chronic lung problems. For more information, contact:

The Pulmonary Paper
P.O. Box 877
Ormond Beach, FL 32175
(800) 950-3698
www.pulmonarypaper.org

SECOND WIND LUNG TRANSPLANT ASSOCIATION, INC.

This nonprofit organization was founded in 1995 to improve the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concerns and their families. For more information, contact:

Second Wind Lung Transplant Association
P.O. Box 1915
Largo, FL 33773
888-855-9463
www.2ndwind.org

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www.coalitionforpf.org

Supporting the CPF

The Coalition for Pulmonary Fibrosis (CPF) relies on the contributions of individuals, corporations and associations who share our commitment to improving awareness and education of IPF and improving the quality of life for patients fighting IPF nationwide. Through your generous support, the CPF will continue to provide information, resources and support to more than 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 personal check, cashier's check or money order to:

Coalition for Pulmonary Fibrosis
1685 Branham Lane, Suite 227
San Jose, CA 95118

Donors may also contribute to the CPF using your Visa, MasterCard, American Express or Discover Card online through www.justgive.org.

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**.

www.coalitionforpf.org

About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501 (c) (3) nonprofit organization, founded in 2001 to 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, and more than 30 leading medical and research centers nationwide.



Coalition for Pulmonary Fibrosis
1685 Branham Lane
Suite 227
San Jose, CA 95118

NONPROFIT ORGANIZATION
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PERMIT NO. 925



HOW WAS YOUR PFT DIAGNOSIS CONFIRMED? PLEASE PRINT CLEARLY

Patient Name: _____

CPF Member Name (if patient is not the member):

CPF Member Email: _____

Date of Diagnosis (mo/year): _____

FOLD HERE

TEST(S) PERFORMED TO CONFIRM YOUR DIAGNOSIS:

- High-Resolution Computer Tomography Scan (HRCT/CAT)
- Surgical lung biopsy
- X-Ray
- Bronchoalveolar lavage
- Bronchoscopy
- Chest/lung radiography (X-Ray)
- Pulmonary function test (PFT)
- Arterial Blood Gas (ABG) test
- Other _____



PLACE
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