



# Action Alert

## New Research on Idiopathic Pulmonary Fibrosis Suggests That 55 Percent of IPF Patients May Be Initially Misdiagnosed

*Findings reinforce the need for early, accurate diagnosis of Idiopathic Pulmonary Fibrosis*

**S**an Jose, Calif. (May 19, 2004) The Coalition for Pulmonary Fibrosis (CPF) recently announced interim findings from a nationwide research initiative for patients and families fighting idiopathic pulmonary fibrosis (IPF). The CPF's Basic Research Questionnaire, established in July 2003, represents the first nationwide effort to quantify the experiences of the IPF patient community by collecting basic information about their diagnosis and treatment.

More than 1,200 patients and families have completed the Questionnaire to date. Interim results of the Questionnaire—based on the first 1,000 respondents collected July through December 2003—continue to demonstrate the need for increased awareness of IPF in the patient community, and in the community of healthcare professionals who treat them. The following findings are of particular importance:

### Key Research Findings

- 55% of respondents indicated that they were initially misdiagnosed with another respiratory or pulmonary condition before being accurately diagnosed with IPF. Overall, 17% were initially misdiagnosed with bronchitis, 13% with an unspecified respiratory ailment, 12% with asthma, 7% with COPD, and 6% with emphysema.
- 15% of patients with IPF had not had their diagnosis confirmed by a High Resolution Computer Tomography (HRCT) or surgical lung biopsy. According to the diagnostic guidelines outlined in the Consensus Statement of the American Thoracic Society on IPF, either test, or both are required to make a conclusive diagnosis.
- 67% of respondents indicated that they had smoked cigarettes; the median length of time smoking was 22 years, and the median time of smoking cessation was 19 years before their IPF diagnosis.
- 22% of respondents indicated exposure to asbestos in their lifetimes, while 21% indicated exposure to molds; and 13% of respondents reported exposure to heavy use of pesticides.

*Continued on next page*

### IN THIS ISSUE

IPF Research ..... Page 2-6

IPF & Heart Disease ..... Page 4

IPF Seminars ..... Page 5

New CPF Partnership ..... Page 7

ACT Update ..... Page 8-9

### 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.coalitionforpfp.org](http://www.coalitionforpfp.org) and complete the registration form by selecting "Update Member Info" in the first selection box. You also can email [info@coalitionforpfp.org](mailto:info@coalitionforpfp.org) or call (888) 222-8541.

- While 44% of patients indicated being diagnosed with IPF within one year of having symptoms of IPF, 18% were diagnosed with IPF a year after the onset of respiratory symptoms, 16% after two years of symptoms, and 12% five or more years after experiencing symptoms.
- One in seven respondents reported having other family members diagnosed with IPF, but overall only 27% recalled physicians having discussed a possible genetic predisposition with them. One-third of patients did not recall their physician asking for their family history of respiratory disease during treatment (published data indicate potential genetic predisposition to IPF in as many as 10-20% of cases).
- Among current patients, 30% of patients responded that their physician has not discussed or even mentioned the topic of lung transplantation; of those patients under the age of 60, fewer than half (47%) said they have been advised to seek a lung transplant (lung transplant can be a potential treatment option for IPF patients under 65).

**"These data, representing patients fighting IPF, reinforces the ongoing need for improved educational initiatives in the clinical community to accurately diagnose and manage this disease."**

*– Marvin Schwarz, CPF Chairman*

"These data, representing patients fighting IPF, reinforces the ongoing need for improved educational initiatives in the clinical community to accurately diagnose and manage this disease," said Marvin Schwarz, CPF Chairman and the James C. Campbell Professor of Medicine at the University of Colorado Health Sciences Center. "The CPF's Basic Research Questionnaire represents one of the largest databases of IPF patients in the United States, and we look forward to an ongoing partnership with the patient and research communities to continue expanding this valuable research initiative."

### **About the CPF Basic Research Questionnaire**

The CPF's Basic Research Questionnaire is an important first step toward gathering information that does not currently exist about the experience of living with IPF. Research findings are based on responses from pulmonary fibrosis patients or their family members and caregivers. As a result, reliability of patient recall on issues related to specific diagnoses or diagnostic tests, for instance, limits the degree to which data can be used to accurately evaluate provider compliance with diagnostic guidelines. Results are indicative, rather than definitive. The CPF's Basic Research Questionnaire 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 the five Galvin family members who have passed away from IPF.

### **Research Results to Be Used to Deliver New Peer-Reviewed Patient Educational Materials**

Based on the interim results of the questionnaire, the CPF is developing important patient educational materials to improve awareness of lung transplantation as a potential treatment option for IPF. The CPF is also developing a patient educational tool to improve awareness of the role of pulmonary rehabilitation and oxygen management in the overall treatment regimen of IPF patients.

Data from the CPF's Basic Research Questionnaire will also be used to:

- Advance awareness of IPF in the patient and healthcare professional communities;
- Strengthen the CPF's ongoing advocacy efforts on behalf of patients and families by presenting peer-reviewed data;
- Identify the educational needs of healthcare professionals treating IPF; and
- Fuel research efforts to find a cure by establishing the first national registry of IPF patients.

"The CPF serves as a national voice for the IPF community, and this interim data allows us to accurately represent the experiences of those fighting the disease," said Mark A. Shreve, chief operating officer of the CPF. "We will continue to deliver programs and services that raise awareness of IPF and improve diagnosis and treatment standards, while advocating for all those affected by IPF."

To review the complete interim report of the Basic Research Questionnaire, please visit [www.coalitionforpfp.org](http://www.coalitionforpfp.org). Data collection is ongoing, and patients and families may participate in the program by visiting [www.coalitionforpfp.org](http://www.coalitionforpfp.org).

## Actelion Pharmaceuticals Phase III "BUILD" Clinical Trial Expands With Addition of New Clinical Trial Site

**A**ctelion Pharmaceuticals has announced that a new clinical trial site has been added to fuel patient enrollment for the company's Phase III "BUILD" (Bosentan Use in Interstitial Lung Disease) clinical trial currently underway in the United States. The newest participating center for the clinical trial is:

**Miami, Florida**  
**Marilyn K. Glassberg, M.D.**  
**University of Miami/Jackson Memorial Hospital**  
**(305) 243-6388**

Bosentan is an oral dual endothelin-1 receptor antagonist. Endothelin-1 is expressed in a variety of pulmonary pathological conditions including pulmonary vascular disease and pulmonary fibrosis.

The BUILD 1 trial is a phase III, double-blind, placebo controlled study assessing the potential benefit of bosentan in patients suffering from idiopathic pulmonary fibrosis (IPF), a condition for which no effective treatment is available.

The BUILD 1 protocol was designed in collaboration with leading respiratory physicians in the field of IPF. This trial will enroll 132 patients in 31 sites (US-Canada-Europe-Israel). Over two-thirds of patients have already been enrolled. The patients will receive the treatment for at least one year. Results are expected early 2006. For a complete listing of investigators and study sites, please visit [www.build-1.com](http://www.build-1.com).

Actelion Pharmaceuticals is an independent biopharmaceutical company (Basel, Switzerland) discovering, developing, and marketing drugs for high, unmet medical needs.



*University of Miami/Jackson Memorial Hospital*

### *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](http://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

### *Pulmonary fibrosis patients at risk of coronary artery disease*

*Study highlights inflammation's role in heart disease*

**L**OS ANGELES, CA (April 6, 2004) A multicenter U.S. study into the interaction of pulmonary fibrosis and coronary artery disease underscores the important role of inflammation in heart disease.

The study of end-stage lung disease patients showed that pulmonary fibrosis patients had twice the prevalence of coronary artery disease as patients with end-stage lung disease due to causes other than pulmonary fibrosis. But when multi-vessel disease was analyzed, pulmonary fibrosis patients had four times the risk of extensive coronary artery disease.

The study was published in the March 8 issue of Archives of Internal Medicine.

"This study gives us insight into the mechanism of coronary artery disease," said co-investigator Dr. David Zisman, now director of the Interstitial Lung Disease Program at the University of California at Los Angeles, who undertook the study while at the University of Pennsylvania.

"The study showed that inflammation is an important part of the pathogenesis of coronary artery disease."

The "first of its kind" study may lead to a greater understanding of both coronary artery disease and pulmonary fibrosis, the researchers reported.

The study adds to the growing body of knowledge of the impact of the inflammation process and disease.

The cross-sectional study included 630 end-stage pulmonary patients, referred for lung transplantation evaluation between 1992 and 2000.

The prevalence of angiographically confirmed coronary artery disease in patients with fibrotic and non-fibrotic lung disease was compared. Patients with known heart disease prior to the diagnosis of lung disease were excluded.

While the results showed that patients with pulmonary fibrosis had four times the amount of extensive coronary artery disease, those numbers would be even higher if compared to a group of normal controls, the researchers said.

"We were surprised by the large number of pulmonary fibrosis patients who also had developed advanced coronary artery disease," said Dr. Zisman.

Both pulmonary fibrosis and coronary artery disease may prove similar in that both cause inflammation that leads to scarring and/or plaque development.

"Inflammation plays a key role in many diseases, from Alzheimer's and heart disease to cancers and pulmonary fibrosis," said Dr. Zisman. "The more we learn about the interaction of such diseases, the better we will be able to direct treatments."

Prior studies have linked two autoimmune diseases to a high risk of heart disease. An association between lupus and a higher incidence of coronary and carotid atherosclerosis has been found, and women with rheumatoid arthritis have a higher risk of myocardial infarction.

The researchers believe there may be a causal relationship wherein the pulmonary fibrosis promotes atherosclerosis.

"There probably are different mediators," said co-investigator Dr. Jorge Kizer, assistant professor of medicine and public health at Weill Medical College at Cornell University in New York. "It is unlikely it is the same offending agent. What we postulate is that something revs up the immune system in the lung. There is a strong inflammatory response in the lung and perhaps a lower grade response elsewhere."

The researchers plan further studies to identify the immune mediators involved in both diseases. "We plan to identify which substances are produced in pulmonary fibrosis that may exacerbate heart disease," said Dr. Zisman.

Further study may provide new treatments for atherosclerosis, in addition to present day treatments for known coronary risk factors, he said. "In addition to a low-fat diet, exercise and smoking cessation, there may be added anti-inflammatory agents to prevent coronary artery disease."

In the meantime, physicians treating patients with pulmonary fibrosis must take heed of the risk factors for coronary artery disease in their patients and treat it aggressively, the researchers said.

*Source: Linda Little, The Medical Post*

## CPF National "Living With IPF" Educational Seminars

### *CPF Co-Hosts Patient Seminar at HealthSouth Rehabilitation Hospital in Sarasota*

The 2004 CPF seminar series kicked off in Sarasota, Fla. with a sold out program co-hosted by HealthSouth Rehabilitation Hospital and the University of Miami on March 6. More than 125 patients and families attended the free seminar, which featured pulmonary and IPF 'specialists Dr. Terrence Kane and Dr. Marvin Hendon of HealthSouth, and Dr. Marilyn Glassberg of the University of Miami. Seminar topics included understanding diagnosis, ongoing research, dealing with the emotional and psychological impact of IPF, oxygen management, pulmonary rehabilitation and support resources. Patient speaker Trudy Vanderbeck also made her second CPF seminar appearance speaking about her experiences living and coping with the disease.

### *CPF Co-Hosts Patient Seminar at the University of Pittsburgh Medical Center*

More than 180 patients, family members and health professionals attended the free seminar co-hosted by the Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease and the University of Pittsburgh Medical Center on April 17. The seminar, featuring IPF experts Dr. Naftali Kaminski, Dr. James Dauber and Dr. Kevin Gibson, had one of the largest seminar turnouts to date. Topics discussed included ongoing IPF research, understanding diagnosis, lung transplantation, improving quality of life, oxygen management and support resources. Patient speaker Charollette Saunders from West Virginia also told her story about living with IPF, and how being involved in an IPF support group has been an important part of living with this disease.

### *IPF Awareness Week 2004, September 25-October 3*

The CPF will kick off IPF Awareness Week this year on Saturday, September 25 with a "Living with IPF" seminar at the University of Michigan in Ann Arbor. In addition to the seminar, new this year will be the first annual Breathing is Glorious (B.I.G.) 5K race fundraising event. Proceeds from the fundraiser will benefit both the CPF and the University of Michigan Health System Division of Pulmonary & Critical Care Medicine. More information about IPF Awareness Week 2004 and these events will be coming soon.

### *California CPF Member Organizes 1st Annual John Wilson 100 Mile Walk/Bike for IPF*

**May 28-31, 2004**

**L**orie Bernal of San Jose, Cali. organized her first annual personal challenge on Memorial Day weekend to walk and bike 100 miles for four days on behalf of her father John Wilson, who is living with IPF. She had family and friends, including her father walk with her at certain times during her journey, and everyone wore t-shirts with a picture of John that her son drew. Lorie also held the event as a fundraiser, and exceeded her goal to raise over \$5,000 for a generous contribution to the CPF. Lorie's walk/run this year fell during the same week as her father's 68th birthday, and she will continue to challenge herself around the same time annually to celebrate John and his fight against IPF.



*Lorie and her father walking together to kick off her fitness challenge to raise funds for IPF.*

## *New Interstitial Lung Disease Support Group Created in Medford, Mass.*

Lawrence Memorial Hospital–School of Nursing  
170 Governor's Avenue  
Medford, MA

The group meets 2-3 times per month through October 2004. Please contact Group Coordinator Catherine Reinhart at 978-930-3000 to RSVP or for additional information.

## InterMune's Pirfenidone Granted U.S. Orphan Drug Designation for the Treatment of Patients with Idiopathic Pulmonary Fibrosis

**B**RISBANE, Calif., March 24, 2004/PRNewswire-FirstCall/ – InterMune, Inc. (Nasdaq: ITMN) recently announced that the Company's investigational drug pirfenidone has been granted Orphan Drug Designation by the U.S. Food and Drug Administration (FDA) for the treatment of idiopathic pulmonary fibrosis (IPF), a disease characterized by progressive scarring or fibrosis of the lungs, which ultimately results in death.

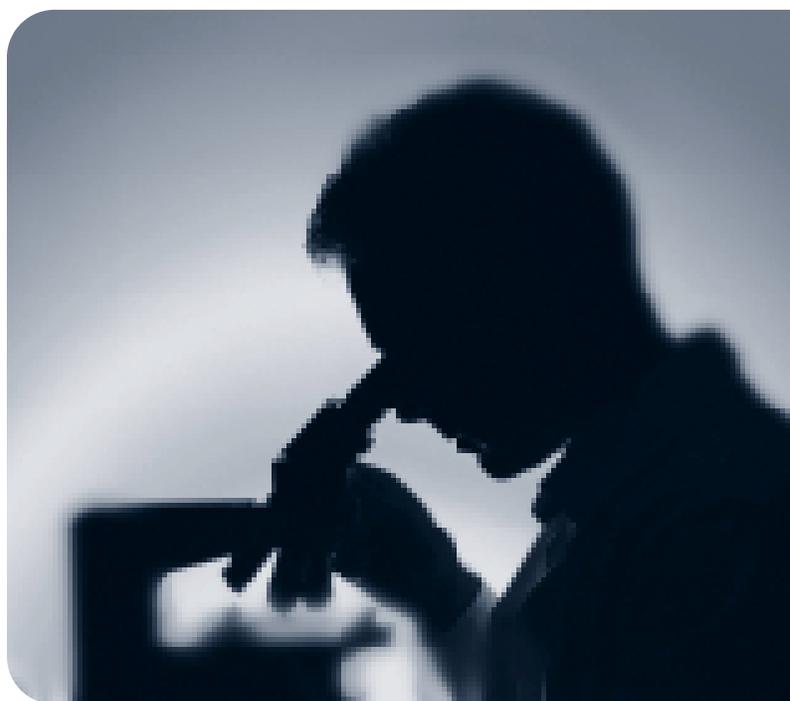
Orphan Drug designation is granted to drug candidates targeting rare diseases or conditions. This designation provides seven years market exclusivity in the United States upon FDA's first approval of the product for the orphan indication provided that the sponsor complies with certain FDA- specified conditions. Other additional incentives include tax credits for amounts spent on human clinical trials and exemptions from user fee payments.

"There is promising clinical evidence to suggest that pirfenidone may offer benefit to IPF patients," said Ganesh Raghu, M.D., Professor of Medicine, University of Washington Medical Center, Seattle, WA. "Orphan Drug designation is a significant step on the path to further clinical development. I look forward to working closely with InterMune, a committed partner and an innovator in the IPF field, to continue to address this seriously underserved disease."

"Due to the complex nature of IPF, the ultimate treatment paradigm will likely comprise multiple therapies administered in combination," said Paul Noble, M.D., Professor of Medicine at Yale University. "Pirfenidone may hold the potential to be an important component of a treatment regimen aimed at this deadly disease."

### *About Pirfenidone*

Pirfenidone is an orally active, small molecule that shows a wide range of biologic activity. In vitro evidence has shown that pirfenidone inhibits collagen synthesis, down-regulates profibrotic cytokines and decreases fibroblast proliferation. Data presented from Phase II clinical trials suggest that pirfenidone may impact disease progression in patients with IPF. In these clinical experiences, pirfenidone was generally well tolerated with the most frequent side effects reported being photosensitivity rash and gastrointestinal symptoms. InterMune has worldwide rights, excluding Japan, Korea and Taiwan, to develop and commercialize pirfenidone for all fibrotic diseases.



## CPF Announces Partnership with National Coalition of Autoimmune Patient Groups to Advance National Advocacy Programs

### *Partnership Further Unifies Efforts to Advocate for Those Fighting Idiopathic Pulmonary Fibrosis*

**S**an Jose, CA (May 1, 2004) The Coalition for Pulmonary Fibrosis (CPF) recently announced that it has partnered with the National Coalition of Autoimmune Patient Groups (NCAPG) to broaden the CPF's national advocacy efforts on behalf of patients and families fighting idiopathic pulmonary fibrosis (IPF) and the healthcare professionals who treat them.

Published research shows a potential connection between certain types of autoimmune disease—such as rheumatoid arthritis, collagen vascular disease, and scleroderma—and pulmonary fibrosis. Patients with these autoimmune diseases have shown to be at increased risk of being afflicted by pulmonary fibrosis. For example, approximately 14% of IPF patients also have rheumatoid arthritis, and close to 60% of those with IPF also have scleroderma.

As part of the organizations' partnership, the CPF will partner with the NCAPG to advance the NCAPG's legislative agenda for 2004, including their advocacy efforts to approve House Resolution 3359, also known as the Upton-Kennedy Bill, to increase awareness of, and research on, autoimmune related diseases such as lupus, multiple sclerosis, rheumatoid arthritis, and scleroderma.

"We are thrilled to partner with the NCAPG, and are confident that our combined advocacy efforts will ultimately lead to improved education and awareness of IPF, while bringing a national voice to those suffering from autoimmune related diseases," said Mark A. Shreve, chief operating officer of the CPF. "Ultimately, we hope that our partnered efforts will lead to improved research funding and expanded programs and services to help the patient community."

### *About the National Coalition for Autoimmune Patient Groups (NCAPG)*

The NCAPG and its 25 nonprofit patient advocacy groups work to consolidate the voice of autoimmune disease patients and to promote increased education, awareness, and research into all aspects of autoimmune diseases through a collaborative approach. The NCAPG is chaired by the American Autoimmune Related Diseases Association, the nation's only organization dedicated to bringing a national focus to autoimmunity as a disease category and supporting collaborative research in order to find better treatments and a cure for all autoimmune diseases. For more information on AARDA or the NCAPG, please visit [www.aarda.org](http://www.aarda.org) or call 1-888-856-9433.

The CPF and NCAPG will also combine efforts to advocate for the need to fund the National Institutes of Health (NIH) Autoimmune Disease Research Plan, established in 2003 by the NIH and the U.S. Department of Health and Human Services in response to a Congressional mandate. The plan presents the first-ever comprehensive integrated research plan for the family of 80-100 autoimmune diseases, which affect a combined 50 million Americans.

The CPF will also serve as a primary resource for the NCAPG in their efforts to serve the IPF community, including access to peer-reviewed IPF educational materials, resources, programs and services for patients and families, and tools to improve awareness of IPF in the clinical community.

**"We are confident that our combined advocacy efforts will ultimately lead to improved education and awareness of IPF..."**

*– Mark A. Shreve, Chief Operating Officer of CPF*

The CPF joined the NCAPG in its Congressional Briefing on Autoimmune Diseases March 25, 2004 in Washington D.C. to advance efforts to approve funding for the NIH Autoimmune Diseases Research Plan, and to raise awareness of autoimmune related diseases with Congressional leaders.

"The CPF has a history of strong member involvement, as demonstrated by their efforts on Capitol Hill last October to launch the first National IPF awareness Week. We are excited to partner with the CPF and value the voice that their nearly 6,000 member organization brings to our patient advocacy efforts," said Kathy Hammitt, Coordinator, National Coalition of Autoimmune Patient Groups for NCAPG.

## Campaign ACT Update

### Action Alert: Supporting the Prevention, Awareness, and Research Autoimmune Disease Act (H.R. 3359)

The CPF is working in partnership with the National Coalition of Autoimmune Patient Groups to advance legislation currently before Congress that would provide funding for autoimmune-related diseases sometimes associated with IPF. Published research shows a potential connection between certain types of autoimmune disease—such as rheumatoid arthritis, collagen vascular disease, and scleroderma—and pulmonary fibrosis. The legislation, H.R. 3359, would increase public awareness and research funding for autoimmune diseases that ultimately could help IPF patients.

The Prevention, Awareness, and Research Auto-Immune Disease Act currently has 21 co-sponsors and is awaiting a hearing in the House of Representatives Subcommittee on Health. CPF members are encouraged to contact their representatives in Washington and urge them to support the Prevention, Awareness, and Research Autoimmune Disease Act (H.R. 3359). If your representative doesn't already support the bill or sits on the Health Subcommittee, he or she needs to hear from you right away.

#### Current co-sponsors:

Rep Abercrombie, Neil [HI-1]  
Rep Deutsch, Peter [FL-20]  
Rep Frank, Barney [MA-4]  
Rep Grijalva, Raul M. [AZ-7]  
Rep Hinchey, Maurice D. [NY-22]  
Rep Hoeffel, Joseph M. [PA-13]  
Rep Kildee, Dale E. - 3/11/2004 [MI-5]  
Rep McCarthy, Carolyn [NY-4]  
Rep Moran, James P. [VA-8]  
Rep Napolitano, Grace F. [CA-38]  
Rep Owens, Major R. [NY-11]  
Rep Rangel, Charles B. [NY-15]  
Rep Rothman, Steve R. [NJ-9]  
Rep Ruppertsberger, C. A. Dutch [MD-2]  
Rep Serrano, Jose E. [NY-16]  
Rep Slaughter, Louise McIntosh [NY-28]  
Rep Stark, Fortney Pete [CA-13]  
Rep Upton, Fred [MI-6]  
Rep Visclosky, Peter J. [IN-1]  
Rep Waxman, Henry A. [CA-30]  
Rep Wexler, Robert [FL-19]

\*If your Representative is already listed as a co-sponsor, please offer him or her your thanks and encouragement.

### House Energy and Commerce Subcommittee on Health:

Michael Bilirakis, Florida  
Sherrod Brown, Ohio  
Ralph M. Hall, Texas  
Henry A. Waxman, California  
Fred Upton, Michigan  
Edolphus Towns, New York  
James C. Greenwood, Pennsylvania  
Frank Pallone Jr., New Jersey  
Nathan Deal, Georgia  
Bart Gordon, Tennessee  
Richard Burr, North Carolina  
Anna G. Eshoo, California  
Ed Whitfield, Kentucky  
Bart Stupak, Michigan  
Charlie Norwood, Georgia  
Eliot L. Engel, New York  
Barbara Cubin, Wyoming

Gene Green, Texas  
John Shimkus, Illinois  
Ted Strickland, Ohio  
Heather Wilson, New Mexico  
Diana DeGette, Colorado  
John B. Shadegg, Arizona  
Lois Capps, California  
Charles "Chip" Pickering, Mississippi  
Christopher John, Louisiana  
Steve Buyer, Indiana  
Bobby L. Rush, Illinois  
Joseph R. Pitts, Pennsylvania  
John D. Dingell, Michigan (Ex Officio)  
Mike Ferguson, New Jersey  
Mike Rogers, Michigan  
Joe Barton, Texas (Ex Officio)

Along with your personal story, following are sample message points you may want to include in your correspondence:

- Published research shows a potential connection between certain types of autoimmune disease and pulmonary fibrosis.
- Autoimmunity as a disease group lacks public awareness more than any other disease category. This creates a platform for misdiagnosis.
- Autoimmune research is one of the most under-funded areas of medical research in the United States while autoimmune diseases are the third most common cause of disability, following heart disease and cancer.
- Pulmonary fibrosis is a progressive, debilitating and ultimately fatal lung disease that affects more than 83,000 Americans. Considering the life prognosis for IPF patients from time of diagnosis is just 2-3 years, IPF patents can't afford to be misdiagnosed.
- The Prevention, Awareness, and Research Auto-Immune Disease Act (H.R. 3359) would increase public awareness and research funding for autoimmune diseases that ultimately could help IPF patients.
- As my representative, I ask that you please support the Prevention, Awareness, and Research Auto-Immune Disease Act (H.R. 3359). Thank you.

For more information on H.R. 3359, visit the CPF Web site at [www.coalitionforpf.org](http://www.coalitionforpf.org). Or to receive information by mail, call the CPF at (888) 222-8541.

## About the CPF Board of Directors

In this edition of the ACT Newsletter, and in future editions, the CPF will profile members of the CPF board of directors and scientific advisory board, many of whom are nationally recognized thought leaders in the treatment and research of interstitial lung disease, and specifically pulmonary fibrosis.

### *Marvin I. Schwarz, M.D., Chairman*

Marvin I. Schwarz, M.D. is the James C. Campbell Professor of Pulmonary Medicine and the head of the Division of Pulmonary Sciences and Critical Care Medicine at the University of Colorado in Denver. He is a nationally and internationally recognized expert in the area of pulmonology and more specifically, in the area of pulmonary fibrosis. He has authored a myriad of pulmonary-focused publications, including various peer-reviewed papers, monographs, editorials, books, chapters and abstracts. As evidence of his ongoing quest to further medical research for effective therapies for the treatment of pulmonary fibrosis, he is currently working as the principal investigator for trials involving the role of Interferon gamma-1b, and a National Institutes of Health (NIH) grant studying the immunopathology of interstitial lung disease and a linkage study of familial pulmonary fibrosis.

He is an active member of the American Thoracic Society, Society of Colorado Pulmonary Physicians, Association of Pulmonary and Critical Care Program Directors, American Heart Association, European Respiratory Association, Society for the Advancement of Science and American Association of Respiratory Care. Dr. Schwarz is also a fellow of the American College of Physicians and the American College of Chest Physicians. Additional notable contributions include participation on the NIH Working Group for Future Research Directions in Idiopathic Pulmonary Fibrosis and a consultancy to the American College of Chest Physicians Interstitial and Diffuse Lung Disease Network.

Dr. Schwarz received his undergraduate degree from Bard College in New York and obtained his medical degree from Tulane University's School of Medicine in New Orleans in 1964. Since graduating from medical school, Dr. Schwarz has served in a number of different clinical capacities including, a three-year stint as the chief of a pulmonary function lab for the U.S. Army, a military consultancy in pulmonary disease as well as a medical staff position at the National Jewish Medical Research Center in Denver.

### *CPF Appoints Marilyn K. Glassberg, M.D. to Scientific Advisory Board*

The CPF is proud to announce the appointment of Marilyn K. Glassberg, M.D. to the foundation's scientific advisory board. Dr. Glassberg is the assistant professor of medicine at the University of Miami/Jackson Memorial Medical Center and University of Miami Hospital and Clinic. Dr. Glassberg is the Director of the interstitial lung disease program at Jackson Memorial Medical Center.

Dr. Glassberg is a graduate of Wellesley College and the University of Miami School of Medicine. She completed her medical residency and pulmonary fellowship at Jackson Memorial Hospital, University of Miami - Affiliated Hospitals. As one of the leading investigators on the role of hormones in interstitial lung disease, she has participated in several clinical trials focused on new treatments for pulmonary fibrosis and directs an active research laboratory. She has written numerous manuscripts in the field of interstitial lung disease and has a longstanding interest in a rare interstitial lung disease found predominately in women, pulmonary lymphangioleiomyomatosis (LAM).



Education. Support. Hope.

## 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
- Baylor University School of Medicine
- California Thoracic Society
- Cleveland Clinic Foundation
- David Geffen School of Medicine at UCLA
- Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease
- 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)
- Mayo Clinic (Rochester, MN)
- Mt. Sinai University School of Medicine at UCLA
- National Heart, Lung & Blood Institute (NHLBI)
- 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](http://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

### NATIONAL COALITION FOR AUTOIMMUNE PATIENT GROUPS (NCAPG)

The NCAPG and its 25 nonprofit patient advocacy groups are dedicated to bringing a national focus to autoimmunity as a disease category and supporting collaborative research in order to find better treatments and a cure for all autoimmune diseases. For more information, contact:

National Coalition for Autoimmune Patient Groups  
22100 Gratiot Avenue – Eastpointe  
East Detroit, MI 48021-2227  
(800) 856-9433

[www.aarda.org](http://www.aarda.org)

### 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](http://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](http://www.2ndwind.org)

## CPF Scientific Advisory Board

Paul W. Noble, M.D. – Chairman  
*Professor of Medicine*  
*Yale University School of Medicine*

Serpil C. Erzurum, M.D.  
*Director, Lung Biology Program*  
*Cleveland Clinic Foundation*

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*Please note our new mailing address for contributions!*

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

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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.

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## About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501 (c) (3) nonprofit organization, founded in 2001 to 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](http://www.coalitionforpf.org) or call (888) 222-8541.



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