



# ActionAlert

## Dear Friends of the CPF:

I welcome this opportunity to share with you the achievements of the Coalition for Pulmonary Fibrosis in 2003. With your support, the CPF has made great strides in raising awareness of pulmonary fibrosis among patients, families, physicians and a broad spectrum of healthcare professionals affected by this progressive lung disorder.

We are proud to say that, in 2003, 97 percent of CPF contributions directly funded our public and professional education programs. This year we:

- Added over 1,600 patients, family members and healthcare professionals to our membership, bringing our membership total to more than 4,000
- Provided information—including IPF resources, physician referrals, free educational materials, patient resources and support—to more than 15,000 patients and families
- Helped more than 30 medical centers in the United States recruit patients for Phase II and Phase III clinical trials sponsored by Actelion, InterMune and Novartis, Inc.
- Created a national advocacy program, campaign ACT, and established the first national IPF Awareness Week (Oct. 5-11, 2003), the CPF's first—and highly successful—effort to advocate on behalf of our growing national membership (please see enclosed flyer)
- Added the Caring Voice Coalition ([www.caringvoice.org](http://www.caringvoice.org)) and Second Wind Lung Transplant Association ([www.2ndwind.org](http://www.2ndwind.org)) as non-profit partners, further unifying non-profit efforts to advocate on behalf of the IPF community
- Partnered with the University of Alabama at Birmingham; University of Miami School of Medicine; Duke University Medical Center; Inova Fairfax Hospital; the National Heart, Lung, and Blood Institute; and the David Geffen School of Medicine at UCLA to provide IPF educational seminars for more than 800 patients and their families
- Established 10 new IPF support groups, bringing the number of CPF-sponsored support groups in the United States to 28, directly assisting over 500 IPF patients and their families
- Expanded our Web site to become one of the nation's leading resources for IPF education, support services and research information

The CPF Research and Professional Education Division also advanced efforts to improve detection, diagnosis and treatment standards in the healthcare community. This year we:

- Funded the creation of the CPF Basic Research Questionnaire, which to date has received more than 1,000 responses, and has allowed the CPF to serve as a national voice for IPF patients and families (full data on more than 1,200 responses expected in early 2004)
- Convened an expert panel of IPF specialists to develop evidence-based guidelines for the management of IPF patients
- Raised awareness of IPF through the CPF's "What If IPF" national advertising campaign in the *Archives of Internal Medicine* and the *Journal of Asthma, Allergy and Immunology*

The need for IPF education, awareness and support services has never been greater. It is only through the support of corporations, organizations, medical institutions and individual supporters that we are able to provide our quality resources and services to the IPF community. Through your generous support, volunteerism and advocacy efforts, the CPF will continue to provide valuable resources to more than 83,000 IPF patients, caregivers and families, and to the healthcare professionals who treat them.

We sincerely thank all those who have supported the CPF this year, and appreciate your continued support in 2004. Best wishes for a joyous holiday season.

Yours in health,

Mark A. Shreve  
Chief Operating Officer  
Coalition for Pulmonary Fibrosis

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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](http://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](mailto:info@coalitionforpf.org) or call (888) 222-8541.



## Three New Support Groups Launched

Thanks to the efforts of our local volunteers, the CPF is pleased to announce three new support groups in Kansas, Texas and Alabama.

### NEWTON, KANSAS

#### Pulmonary Fibrosis Support Group

Meeting Location: Elks Lodge, 201 S. Pine St., Newton  
Schedule: Every third Thursday of the month at 6:30 pm  
For more information, please contact Cathy McGaugh  
Phone: (620) 983-2667  
Email: cathymcgaugh@hotmail.com

### HOUSTON, TEXAS

#### Pulmonary Fibrosis Support Group

*In partnership with the Baylor University School of Medicine*

Meeting Location: Kelsey-Seybold Clinic, Main Campus,  
2727 West Holcomb, Houston  
Schedule: Every other month on the 4th Saturday  
For more information, please contact David Davenport  
Phone: (281) 812-7611  
Email: zip88@earthlink.net

### BIRMINGHAM, ALABAMA

#### Pulmonary Fibrosis Support Group

*In partnership with the UAB Medical Center*

Meeting Location: Kirkland Clinic, 2000 6th Ave. South,  
Birmingham: 5th Floor conference room  
For more information, please contact Marty Robbins  
Phone: (205) 934-7557

We are proud to say that the CPF now sponsors 28 support groups nationwide. For a complete listing of CPF-sponsored support groups across the country please visit our Web site at [www.coalitionforpf.org](http://www.coalitionforpf.org) or contact us at (888) 222-8541.

## CPF Co-Hosts Patient Seminar at Duke University Medical Center

Durham, NC – Despite hurricane Isabelle threatening to cancel the event, more than 170 patients and families attended a free IPF seminar hosted by the CPF and Duke University Medical Center on September 20. The seminar featured IPF specialists, Dr. David Schwartz and Dr. Mark Steele from Duke University Medical Center. Dr. Schwartz' research focuses on the familial form of pulmonary fibrosis and the genetic component of the disease. Dr. Steele is a lung transplant specialist at Duke Medical Center. The seminar addressed IPF diagnosis, current standards of care and emerging research, oxygen management strategies, pulmonary rehabilitation, lung transplantation and support resources.

For more information on the Familial Pulmonary Fibrosis study, which is funded through a grant from the National Institutes of Health, please call (877) 587-4411 or visit the Duke University Medical Center Web site at [www.fpf.duke.edu](http://www.fpf.duke.edu).

The CPF will continue to host "Living with IPF" seminars across the country in 2004. CPF members will receive invitations in the mail as specific locations, dates and times are confirmed.

## CPF Basic Research Questionnaire – Update

The CPF is pleased to announce that we have received more than 1,000 completed Basic Research Questionnaires to date through our online program. We are thankful for your time and effort providing this important information to us. We recently distributed a print version of the questionnaire to our entire membership, and we anticipate more than 1,200 responses by the end of 2003, thus creating one of the largest databases of IPF patient information in the United States. The CPF expects to publish interim data from this ongoing study in the first quarter of 2004.

## CPF Launches First National IPF Awareness Week In October

The Coalition for Pulmonary Fibrosis (CPF) launched the first-ever National Idiopathic Pulmonary Fibrosis (IPF) Awareness Week Oct. 5 - 11, 2003. The success of the advocacy efforts led to 16 state proclamations and more than 40 meetings on Capitol Hill with congressional leaders. The goal of the National IPF Awareness Week was to raise awareness of IPF, advocate for IPF patients and their families and advocate for increased federal funding for IPF-related research. To kick off IPF Awareness Week the CPF held a "Living with IPF" educational seminar in Washington, D.C. in partnership with Caring Voice Coalition; Inova Fairfax Hospital; and the National Heart, Lung, and Blood Institute. More than 130 patients, family members and physicians attended.

Please see the enclosed flyer for a full description of the various components of National IPF Awareness Week and the accomplishments of the week thanks to the volunteer efforts of our CPF members across the country.

The CPF would like to extend a special thank you to all the Washington, D.C. seminar speakers and CPF representatives who made the events in Washington, D.C. possible. Thanks to this dynamic group of patients, partners and physicians, the CPF's first trip to Capitol Hill clearly exceeded our expectations:

Teresa Barnes  
Frank Cabral  
Gerilynn Connors, RRT  
Bernadette Gochuico, MD  
Mary Graybeal  
Pamela Harris  
Johnny Heirs

Steven Nathan, MD  
Sandra & Jim Rock  
Dierdre Roney  
Greg Tino, MD  
Catherine Valenti  
Trudy Vanderbeck

## Education, Support and Hope – A Patient’s Perspective

Trudy Vanderbeck  
CPF Member  
Vincennes, Ind.



**A**fter being diagnosed with Idiopathic Pulmonary Fibrosis (IPF) four years ago, I figured I could simply recover and carry on with my life. Then I started researching IPF. Surely this was wrong. This could not be what I have. Education slammed into reality.

After the initial blows of unanswered questions, desperation, depression and grief, I slowly continued educating myself. In the process I found the Coalition for Pulmonary Fibrosis with its excellent Web site, accurate information and wonderful patient resources. Then something else from the site caught my eye—support groups. I’m an independent kind of person. What on earth was I doing thinking about a support group? I spoke with Mark Shreve at the CPF about forming a support group and hesitatingly stepped out of my solitary battle into a larger one.

Of the more than 83,000 people in the United States with IPF, more than a dozen of them live within a 25-mile radius of me in Vincennes, Ind. Yet, none of us knew anyone else with IPF. Now we are no longer alone. With the help of my local hospital, I founded “LIVING with IPF,” a support group for IPF patients and their families, in March 2002. Together, we have faced changing medical issues, supported each other through crises and grieved together through a death. We’ve laughed and cried together, often simultaneously. Every third Tuesday evening offers education, support and hope to each of us, but somehow I knew there was more still to do.

*“I love to learn, and I love to teach, but I never dreamed I would have to learn about an incurable, life-threatening disease that I now have: Idiopathic Pulmonary Fibrosis.” — Trudy Vanderbeck*

This past summer I noticed that the CPF was holding a patient seminar in Washington, D.C. Not knowing what was in store, I asked if there was anything I could do to help (like giving out nametags or programs, I thought). Instead Mark Shreve asked if I would be the patient speaker at the D.C. seminar. I was stunned. Speaking at a seminar was certainly not something I sought to do, but my husband and I did want to help the CPF, an organization that had already made a huge impact on our lives. We were anxious to hear the other speakers, to learn what was new about IPF, to put names and faces together, and to meet others living with my same disease. Lots of time and thought were poured into my speech, always with the focus on the most important aspect—the audience of other patients. Helping even one other person would be worth it all. I grabbed the chance to tell my support group friends’ stories, to encourage others to do the same, to speak out, to make a difference.

Following the seminar, a group of CPF representatives, including patients like myself, took our actions one step further as part of National IPF Awareness Week. We met with our nation’s leaders on Capitol Hill. Frankly, this part scared the daylights out of me! I don’t mind writing letters to Members of Congress, but face-to-face spontaneous conversation worried me, once again needlessly. Our messages were consistent. We communicated that we need more awareness and more funding for IPF research. Every aide I met treated me respectfully and courteously with only one having heard of IPF. Advocacy was a positive experience for me and one I intend to continue.

Yes, I’m taking chances. I’m expending energy I don’t usually have. I’m stepping way out of my comfort zone. I’m still learning; I’m still teaching by telling others about IPF; I’m still seeking, receiving, and giving support; and I’m still hoping for a cure—perhaps for myself but most certainly for others. You can do the same. You’ll love it!



Raising awareness on Capitol Hill



CPF representatives in Washington, D.C.



Frank Cabral, CPF member from Massachusetts, in front of House Office Buildings



CPF members, Sandra and Jim Rock and Teresa Barnes, with U.S. Rep. David Price (N.C.) and his health legislative asst., Elizabeth Kirkland

## 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  
1685 Branham Lane  
Suite 227  
San Jose, CA 95118

Donors may also contribute to the CPF using Visa, MasterCard, American Express or Discover Card online through [www.JustGive.org](http://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](http://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 Pulmonary Fibrosis Association, the Caring Voice Coalition, Second Wind Lung Transplant Association, and more than 30 leading medical and research centers nationwide.



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