



ActionAlert

Upcoming Events

CPF to Co-Host Patient Seminar at Duke University

DURHAM, N.C. - The CPF, in partnership with Duke University Medical Center, is hosting a free seminar on Saturday, September 20 for patients and families living with idiopathic pulmonary fibrosis (IPF).

The seminar will be moderated by David Schwartz, MD, Director of the Center for Environmental Genetics, Duke University Medical Center and Director of the Institute for Genome Science and Policy. The seminar will address IPF detection and diagnosis, current standards of care, ongoing research to find a cure, lung transplantation, pulmonary rehabilitation, life management issues and support resources for patients and families. The seminar is the eighth event of the CPF's ongoing national IPF education and awareness efforts.

Additionally, Dr. Schwartz will present information on familial pulmonary fibrosis research underway at Duke, which is being funded by the National Institutes of Health (NIH).

For more information, or to register, please contact the CPF at 888-222-8541 or visit www.coalitionforpf.org. Please note that seating is limited and registration is encouraged!

National IPF Awareness Week October 5 thru October 9 2003

CPF will soon announce the establishment of a National IPF Awareness Week to be held in Washington, D.C. The purpose of this awareness week is to bring focus to CPF's mission to educate the public on the issues that affect IPF patients.

This year's awareness week will kick off with a patient seminar in Washington, D.C., and will also include state proclamations and patient visits to members of Congress on Capitol Hill. Be on the lookout for details in the near future.

CPF Launches National Patient Research Initiative

The Coalition for Pulmonary Fibrosis (CPF) is proud to announce an important research initiative designed to further advance our mission of raising awareness of IPF and advocating for all those affected by the disease.

The CPF's Basic Research Questionnaire is an important first step toward gathering information about the experience of living with IPF. By participating in this research initiative and completing the questionnaire, IPF patients and families like you will help strengthen our education and advocacy efforts for the entire community of 88,000 Americans currently living with the disease.

Your responses will be used to help drive the CPF's ongoing education and advocacy objectives, including to:

- Identify and publish statistically significant results that will advance awareness of a variety of IPF-related issues
- Improve the quality of educational materials we develop for the IPF community
- Identify the educational needs of healthcare professionals treating IPF to improve detection, diagnosis and treatment
- Strengthen our national advocacy efforts on behalf of patients and families by being able to present constituents with credible, peer-reviewed data that represents your viewpoints
- Raise awareness of IPF by accurately portraying the needs and concerns of IPF patients and families to the media and other constituencies
- Encourage and advance research efforts to find a cure

Your participation is critical to the success of this research. **The Basic Research Questionnaire has been mailed out to valid email addresses, and paper copies will be circulated in about eight weeks.** To assure your privacy, the survey results are being tabulated by Michaels Opinion Research, Inc., an independent research firm based in New York, N.Y.

Funding for this questionnaire was provided through a private, restricted grant from Helen and Michael Galvin in memory of their five family members who passed away from IPF. On behalf of the CPF and its board of directors, we would like to offer our sincere thanks for your participation and for your ongoing support of the CPF.



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Challenge.
Take Action.

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NEWS & UPDATES

CPF Co-Hosts Patient Seminar at U Miami School of Medicine

MIAMI - More than 150 patients and families attended a free IPF seminar hosted by the CPF and the University of Miami School of Medicine on June 28. The seminar featured Dr. Ganesh Raghu of the University of Washington- Seattle and Miami-area pulmonology experts, including Dr. Marilyn Glassberg. The seminar addressed IPF diagnosis, current standards of care, life management issues, lung transplantation and support resources.

A local NBC affiliate aired a story about IPF and highlighted the seminar. The story can be viewed on our Web site at <http://www.coalitionforpf.org/aboutus>

New Support Group

CLEVELAND -- The CPF and the Cleveland Clinic Foundation (CCF) recently partnered to host the CCF's first support group meeting for patients and families affected by pulmonary fibrosis. The first meeting drew nearly 100 patients and families from across Ohio and was a tremendous success. The next meeting is scheduled for August 26.

The CPF would like to thank Dr. Jeff Chapman, Stephanie Slattery and local IPF patient, Pat Radomile, for initiating this important meeting. For further information or to register for the next group meeting, please contact the CPF at 888-222-8541 or info@coalitionforpf.org, or call the CCF's Stephanie Slattery, RN at 216-444-4725.

First ACT Action Alert Produces Results!

Letters Catch the Attention of NHLBI

UPDATE: In our inaugural ACT Action Alert we asked CPF members to contact the National Heart, Lung and Blood Institute (NHLBI) and other decision makers about funding for IPF research. More than 75 messages helped prompt this response from the NHLBI:

Dear Mr. Shreve:

I am writing on behalf of the National Heart, Lung, and Blood Institute (NHLBI), a component of the National Institutes of Health (NIH) and the U.S. Department of Health and Human Services. One of your members, Ms. XX, recently alerted us to your organization. When looking at the Coalition for Pulmonary Fibrosis Web site, we discovered that the Coalition has goals and interests that are very similar to other public organizations with which we have relationships . . .

Jonelle K. Drugan, Ph.D., M.P.H.
National Heart, Lung, and Blood Institute

RESULTS: Due to your actions, CPF established a relationship with NHLBI and will participate in the National Institutes of Health Public Interest Organization (PIO) Conference in 2004. The CPF is also now listed as an educational resource for IPF patients on the NHLBI Web site (www.nhlbi.nih.gov).

The PIO conference was organized in 2001 to encourage interactive, small-group roundtables for organization representatives to explore potential areas of collaboration amongst themselves and with the NHLBI. For more information about the NIH and its public interest activities, please visit www.nhlbi.nih.gov/public.

The CPF would like to thank those who participated in our letter writing campaign during May and June. We are already seeing results from your efforts!

Remember that you can easily send emails to members of Congress and/or media by visiting our Web Site at
<http://www.coalitionforpf.org/aboutus/advocacy>