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Upcoming Events

Patient Seminar to Kick Off National IPF Awareness Week in Washington, D.C.

To kick off National IPF Awareness Week, the CPF is hosting a free seminar on Sunday, October 5 at the Hyatt Regency for patients and families living with idiopathic pulmonary fibrosis (IPF).

Leading experts from Inova Fairfax Hospital; Univ. of Pennsylvania Medical Center; National Heart, Lung and Blood Institute (NHLBI) and the Centers for Medicare and Medicaid Services (CMS) will be presenting at the seminar.

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, health care coverage and support resources for patients and families.

For more information, or to register, please contact the CPF at 888-222-8541 or by email at info@coalitionforpf.org.

CPF Coordinating Effort for State Proclamations for National IPF Awareness Week

Thanks to CPF members' advocacy efforts, a proclamation has already been secured in North Carolina, and state proclamations recognizing National IPF Awareness Week have been requested in the following states:

Arizona	California
Colorado	Connecticut
Florida	Massachusetts
New York	Ohio
Oklahoma	Pennsylvania
Texas	Virginia
Wisconsin	

If you would like to request a proclamation for IPF Week in your state, please contact Jake Reint at 952-346-6190 or jreint@webershandwick.com

National IPF Awareness Week October 5 - 11, 2003

The Coalition for Pulmonary Fibrosis has established National IPF Awareness Week to be held in Washington, D.C., during the second week of October. **The goal of IPF Week is to heighten awareness of IPF within the congressional community and federal agencies.** CPF members will accomplish this by meeting with congressional representatives and staff in person, on Capitol Hill and in their home districts, and by contacting them by telephone, letters and email. CPF members are also requesting state proclamations for IPF Week, and the CPF will conduct media outreach to educate the general public about IPF and the rising prevalence of the disease.

IPF patients and families from around the country will make their way to Washington D.C. to meet with members of Congress on Capitol Hill on Monday and Tuesday, October 6-7.

The CPF will also drive efforts at the local level through coordinated activities with IPF support groups and patients, families and physicians in cities across the country. Local level activities to promote IPF Awareness Week include: state proclamations, announcements at support group meetings, videotape and email messages to congressional representatives and media outreach to local media outlets.

We encourage all CPF members to become involved in the National IPF Awareness Week efforts. If you are interested in coming to Washington, D.C. for Capitol Hill visits, please contact Mark Shreve at 888-222-8541 or info@coalitionforpf.org.

If you're not able to make the trip to Washington, D.C., there are many ways you can participate in National IPF Awareness Week. These include:

- Call or write members of Congress. For information on contacting your representatives in Washington and other key lawmakers please visit our Web site's ACT section at: www.coalitionforpf.org.
- Submit a state proclamation request to your governor or write a support letter for those states where a proclamation has already been submitted (see listing in left column).
- Reach out to your local media. For a CPF member media tool kit, please contact Marta Fraboni at 952-346-6348 or email mfraboni@webershandwick.com.
- Bring information about National IPF Awareness Week and the ACT campaign to your next local support group meeting.
- Videotape a message to your Congressional representatives.

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NEWS & UPDATES

CPF Receives Over 650 Responses to Research Questionnaire in First 3 Weeks!

Questionnaires from the CPF's basic research initiative are rolling in. So far more than 650 questionnaires have been received.

The questionnaire is an important first step toward gathering information about the experience of living with IPF. The findings will help drive CPF's ongoing education and advocacy efforts nationwide.

If you do not have email or have otherwise not participated in the questionnaire, the CPF will be mailing a print version to members during the month of September. **Your participation is critical so the CPF can accurately represent your needs and concerns!**

To help ensure privacy, the survey results are being tabulated by Michaels Opinion Research, Inc., an independent research firm based in New York.

The survey was funded through a \$60,000 contribution from the Galvin family.

New English/Spanish Support Groups

MIAMI - The CPF, in partnership with the University of Miami, now provides both English- and Spanish-speaking support groups.

Meetings are held every other month on the third Thursday and topics include new research developments, the benefits of pulmonary rehabilitation and how to maintain spiritual health.

Upcoming meetings are Thursday, Sept. 25, from 12 noon - 2:00 P.M. For more information or to register, please contact Miami group coordinator, Erica Pena, at 305-585-7340 or visit www.med.miami.edu/med/ipf.

New Clinical Trials For IPF Patients in 2003

The CPF is excited to inform you of three new clinical trials underway to both better understand the development of pulmonary fibrosis and to advance the treatment of IPF. In a clinical trial, health care providers use a new treatment for patients to determine if it is safe and effective. Active clinical trials include:

Bosentan: A study to assess the efficacy, safety, and tolerability of bosentan in patients with IPF. Patient participation is limited to male or female patients over 18 years of age. Patients must have a proven diagnosis of IPF (according to ATS/ERS consensus statement). The study will measure the difference between a baseline six-minute walk test distance and a walk test distance following the trial.

Enbrel: A phase II study of the efficacy and safety of Enbrel in patients with IPF. Enbrel blocks TNFalpha binding to cell surface receptors and initiation of intracellular signaling. Inhibiting TNF by Enbrel could potentially lead to therapeutic benefit in this disease. The primary endpoint of the trial is to evaluate the safety and efficacy of Enbrel in patients with IPF, and secondly to evaluate their quality of life. Approximately 100 subjects at 20 to 25 sites will participate in the trial. Duration is about 80 weeks.

Gleevec: A phase II study of the clinical effects of Gleevec. Patients with IPF will be treated initially with Gleevec orally once per day versus placebo for a period of up to two years. Patients will be randomized into the trial. A total of 100 patients will be enrolled into the trial (50 active drug and 50 placebo). The study population consists of male and female outpatients with IPF ages 20 to 79.

For more information on these clinical trials, and other clinical research underway to help find a cure for IPF, please visit our Web site at www.coalitionforpf.org or ask your physician.

Four New Support Groups Planned for Fall, 2003

Thanks to the efforts of our local volunteers, the CPF is proud to announce that support groups are being planned in Los Angeles (David Geffen School of Medicine at UCLA- November), Houston (Baylor University School of Medicine- November), Peabody, KS (September), and Nashville, TN (Vanderbilt Clinic, 1st meeting September 4). To participate in a CPF-sponsored support group in these regions, please call us at 888-222-8541 or contact us by email at info@coalitionforpf.org. **We are proud to say that the CPF now sponsors 28 groups nationwide!**