



Education. Support. Hope.

www.coalitionforpf.org (888) 222-8541

CPF Goals & Objectives

- Increase public awareness of PF
- Unify nonprofit education/advocacy efforts to help those patients and families fighting PF
- Improve detection, diagnosis and treatment of PF in clinical community
- Encourage, support and fund emerging research to ultimately lead to a cure



Nonprofit Partners Nationwide

- The American Thoracic Society
- Mary D. Harris Memorial Foundation
- The Pulmonary Paper
- Caring Voice Coalition
- AARDA/NCAPG
- Second Wind Lung Transplant Association
- The Anne Harroun Landgraf Foundation
- The Fred J. Brotherton Charitable Foundation
- Pulmonary Fibrosis Association (1996-2003)
- American Lung Association Chapters
- 30+ medical and research institutions nationwide

"The need for IPF education and awareness initiatives for patients and healthcare professionals has never been greater." Marvin Schwarz, MD - CPF Chairman



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What is Awareness of IPF?

- Recent CPF-funded survey of 1,000 American adults
- While 96% of public has heard of Asthma, 88% CF and 85% Lou Gehrig's disease, only 29% had heard of IPF & roughly 20% recognized it by name- only, and had no knowledge of the disease
- 6% of respondents knew someone with IPF (family, friend)
- Given basic information about incidence and prevalence of IPF when compared to other rare diseases (CF, ALS), 85% agreed that IPF should receive more federal funding for research



Services in High Demand

- Free Resource Kit for IPF patients and families, including all educational materials (Let's Talk About IPF, Lung Transplantation, Pulm Rehab, Clinical Trials...)
- Comprehensive Website for patients and medical professionals www.coalitionforpf.org
- 35 Support Groups Nationwide
- “Living With IPF” Seminars
- Patient mentoring, counseling, program referrals, transplant education & support



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Professional Education

- Basic Research Questionnaire (2003-Present)
- “Critical Assessment of Treatment Options for IPF”
-Published 10/05 in J. Vasculitis, Sarcoid. and DLD
- Detection and diagnosis Monograph (2002)
- American Journal of Nursing Mon. (2002)
- Public Opinion Survey (Fall, 2005)
- “What if IPF” Medical Journal Advertorials



Funding Emerging Research

- \$60,000 Grant to University of Michigan – (2/2005)
 - Investigating role of circulating fibrocytes in IPF
 - Investigating downregulation of TGF- β to slow disease progression
- \$60,000 Grant to UCLA
 - Fellowships, patient ed, adult stem cell trial continuation
- \$43,000 Grant to University of Chicago
 - “Natural History of ILD and IPF”: funding dbase/tracking of natural history, QOL, response to therapy, blood tests for genetic studies
- CPF/ATS Partnership Grant for Translational Research – 2007-2008 \$100,000



CPF Research Questionnaire

- Established in October 2003 by private restricted grant
- Accurately represent the experiences of our members
- Identify patient and professional education needs
- Advance research efforts to find a cure for IPF Through NIH, Industry, Medical Center Clinical Trial Recruitment



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Research Questionnaire

Diagnostic Information

- 15% of patients with IPF had not had their diagnosis confirmed by HRCT or surgical lung biopsy
- 44% of patients diagnosed with IPF within one year of having symptoms
 - 18% were diagnosed > than one year after the onset of symptoms, 16% > two years, and 12% > 5 years



Research Questionnaire

- 55% of respondents initially misdiagnosed with another respiratory condition before being diagnosed with IPF
- Of this subset of respondents:
 - 17% were initially misdiagnosed with Bronchitis
 - 13% with an unspecified respiratory ailment
 - 12% with Asthma
 - 7% with COPD, 6% Emphysema



Research Questionnaire

Potential Causes

- 14% of respondents have associated rheumatoid arthritis (RA); 53% GERD
- 67% of respondents indicated that they had smoked cigarettes
- Median length of time 22 years, and the median time of cessation was 19 years before diagnosis



Research Questionnaire

- 22% exposed to asbestos, 21% to molds; 13% to heavy use of pesticides
- Among current patients, 30% responded that their physician has not discussed or even mentioned the topic of lung transplantation; of those under the age of 60, only 24% have been advised to register for a transplant





ACT

Ask.
Challenge.
Take Action.

- Help raise awareness for IPF among policymakers in your state and in Washington
- Urge members of Congress to support funding for IPF education and research efforts
- Monitor and respond to legislation that impacts the IPF community
- Support your local medical centers!



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2005 Campaign ACT

- National IPF Awareness Week 9/25-10/1/05 – 60+ meetings with Leadership in House & Senate
- “H Con. Resolution 178” – Recognized CPF and National IPF Awareness Week (401-0)
- “Ending the Medicare 24 Month Waiting Period Act of 2005”



2006 Campaign ACT

- National IPF Awareness Week 2006 – 9/06
 - Media/Fundraising Tools for Members
- S.R. 236 - Write your Senator for sponsorship!
- “Ending the Medicare 24 Month WP Act of 2006”
- S.R. 1932 – Medicare O2 Reimb.
 - Proposed: No reimb. For O2 equip 36 months of use; patient resp.
 - Current: PMPM reimb. inc. repairs & maintenance
 - Could lead to gaps in svc in addition to increased costs for pat.
- S.R. 1440- Cardiac/ PR Act of 2006
 - Improving coverage of by establishing national policy category; Improved, consistent coverage guidelines



What you can do!

- Do a mail/email/phone campaign to your friends and family to contact their members of Congress (currently, support of S.R. 236)
- Hold a local fundraiser – ask for a free fundraising kit from the CPF to get started!
- Organize a support group (if you don't have one) with your local medical center or rehabilitation department
- Contact members of your local media (ask the CPF for a free media kit); Tell your story!
- Let the CPF know what you are doing – we can include it in our newsletter and website

Contact Information

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