

Pulmonary Fibrosis Foundation

Newsletter

July 2003 Volume IV



MISSION STATEMENT

The Pulmonary Fibrosis Foundation funds research which will increase the understanding of and find a cure for Pulmonary Fibrosis. We also function as an advocacy organization, which petitions the congress to increase funding for the National Institute of Health and lobby the NIH to make Pulmonary Fibrosis an area of major focus. The medical community has insufficient knowledge about Pulmonary Fibrosis. Most internal medicine specialists and even many Pulmonologists lack the diagnostic skills required to make an early and accurate diagnosis of Pulmonary Fibrosis which is the only hope for remediation for most sufferers. We have been successful in getting some of the major drug companies to initiate studies, which will find effective treatments for Pulmonary Fibrosis. We are partnering with some of the major drug companies in developing new pharmacological treatments. Finally, we educate the general public to increase awareness and understanding of this disorder.

ACHIEVEMENTS FOR FIRST HALF OF 2003

Young Investigator Awards Program

- * Awarded \$35,000 to Dr. Yingze Zhang of the University of Pittsburgh for research on "The Genetic Predispositions to Pulmonary Fibrosis"
- * Awarded \$ 50,000 to Dr. Pyong Woo Park of the Baylor College of Medicine for research on the "Proteoglycans in Lung Inflammation and Fibrosis. (Co-funded with the American Lung Association).

Awards pending for balance of 2003

- \$ 50,000 Co-funding with the American Thoracic Society for research in Pulmonary Fibrosis.
- \$ 20,000 Co-funding with the American College of Chest Physicians for research in Pulmonary Fibrosis.

Other Achievements

- * The American Thoracic Society awarded the Pulmonary Fibrosis Foundation its Public Service Award in recognition of service in public health in the area of lung-related health issues.
- * The Pulmonary Fibrosis Foundation has a representative on the Health Care Policy Committee of the American Thoracic Society.
- * The Pulmonary Fibrosis Foundation is a founding member of the Rare Lung Disease Council.
- * The Foundation is in consideration for membership in the Board of Directors of The American College of Chest Physicians.
- * We have convinced the National Heart, Lung and Blood Institute of the NIH to initiate two studies in the area of Pulmonary Fibrosis.

Hope and Remembrance

Conferences Funded

Awarded \$ 15,000 to the American College of Chest Physicians to fund a Conference on the Early and Accurate Diagnosis of Pulmonary Fibrosis held on March 22, 2003. The Conference was attended by 35 of the leading researchers in the United States. A permanent Network for the Early and Accurate Diagnosis of Pulmonary Fibrosis was established at the conference. The Network meets regularly to work on the issues involved in developing this program. The goal of the network is to provide physicians with the necessary tools to accurately diagnose this illness. Eventually, a National Screening program will be established to provide an early warning system to patients and their doctors so that they may initiate treatments long before it progresses to the advanced stage where they are beyond medical help.

New Studies by Drug Companies

After extensive lobbying on our part five of the larger Drug Companies have initiated studies involving the development of new drugs with which to treat Pulmonary Fibrosis. These are:

- Wyeth - Enbrel, an Anti-TNF antibody.
- Actelion - Bosentan, a Anti-Endothelin inhibitor
- Genzyme - An Anti-TGF beta, a broad spectrum, monoclonal antibody
- Novartis - Gleevec, an Anti-TNF antibody



Celebration Planned

On Friday, November 21, 2003 the Pulmonary Fibrosis Foundation will host a Hope and Remembrance Celebration at the renowned Chicago Cultural Center (Corner of Michigan and Madison) in Chicago, Illinois. The Event coincides with National Pulmonary Fibrosis Week which is the third week in November. The event commemorates the hope that a cure will soon be found for Pulmonary Fibrosis and remembers those who have passed on as a result of this horrible disease.

Patients, family, friends and the general public are invited to join in this celebration. The attendance is limited to 500 so if you wish to attend we suggest that you make your commitment early. If you are unable to attend but would like to be a sponsor, we are accepting donations and sponsorships. In addition, we are seeking volunteers help make this event a success. Any and all questions will be answered by calling (312) 377-6895.

Hope and Remembrance Flags

To increase awareness of Pulmonary Fibrosis and honor the victims of the illness we have created Hope and Remembrance flags. The flags honor both those currently struggling with the disease and those who have passed. The flags will be approximately two by three feet and in a variety of colors. They will have the name of the person being honored as well as the name of the donor. The flags will be displayed on various prominent public buildings across the United States.

Our purpose is not only to memorialize those stricken with the disease but also to increase public awareness of the existence of Pulmonary Fibrosis. Most people tell us that they never heard of this disease prior to their loved ones becoming ill. The first step in finding a cure for a disease is the recognition of its existence. For too long this disease has been the secret killer. Despite the fact that more than 200,000 people in this country are afflicted with it and more than 40,000 people die from it each year. Flags will be created in response to donations of \$100.00 or more. If there is someone you would like to honor, please call the Pulmonary Fibrosis Foundation at : (312) 377-6895.



Send us Your Stories and Experiences

We are planning to publish a book containing the personal experiences of those who are struggling with events in their lives that are associated with Pulmonary Fibrosis. The book will contain the thoughts and emotions of patients, family or friends whose loved ones have been victims of this horrible disease. The format can be either prose or poetry and photos can accompany the submission. Please put your thoughts and feelings into a short story and send it to us. The books will be distributed to those who attend the Hope and Remembrance Celebration without cost and to anyone else at a nominal fee to cover the expenses of publication.

Writing down your feelings can be a cathartic experience that may bring closure to the pains associated with living with or losing someone to Pulmonary Fibrosis. Please do not feel that your story will be judged on its literary quality. This is not a test and you will not be graded. We want to hear from you and the sharing of experiences is usually beneficial to all concerned. Send us your story via regular mail to: Pulmonary Fibrosis Foundation, 1440 West Washington Blvd., Chicago, IL 60607 (312) 377-6895 or Email: breathe@pulmonaryfibrosis.org



Research Registry

The Pulmonary Fibrosis Foundation Registry, was developed in accordance with the standards of the World Health Organization. It is a confidential database of individuals with Pulmonary Fibrosis. A major hurdle in research is finding a sufficient number of volunteers to participate in clinical studies. By establishing a database of thousands of people with Pulmonary Fibrosis and making it available to the research community, the Registry will aid in the development of new therapies, and eventually a cure for Pulmonary Fibrosis.

The Registry is required to conceal a member's personal information from researchers and organizations unless consent is granted by the Registry participant. Imagine, you can do all this just by participating in the registry.

The National Heart, Lung and Blood Institute of the NIH is conducting two Pulmonary Fibrosis Research Studies.

Familial Pulmonary Fibrosis Research Evaluation Study. If you or two of your relatives have been diagnosed with familial pulmonary fibrosis, you and your relatives may be eligible to participate in a familial research study at NIH Clinical Center.

Pulmonary Fibrosis Research Evaluation Study. If you have been diagnosed with pulmonary fibrosis (or IPF), you may be eligible to participate in a research study at NIH Clinical Center. The purpose of these research studies is to improve the understanding of the natural history of pulmonary fibrosis, both Familial and IPF, and their underlying cause(s).

Eligible volunteers undergo a comprehensive medical and pulmonary evaluation at the NIH Clinical Center in Bethesda, MD. There is no cost to you for travel or medical testing, and should you wish, information from your evaluation will be provided for your physicians. For further information, please contact our research coordinator at toll free telephone:(1-877-644-5864), extension 1 or e-mail: LungStudy@nhlbi.nih.gov.

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Comments, suggestions and criticisms are always welcome. Send your letters to the address above or email: breathe@pulmonaryfibrosis.org. Additional information is available at: www.pulmonaryfibrosis.org

International Chapter of the Pulmonary Fibrosis Foundation opens in Dublin, Ireland

The name of the new organization is the Irish Lung Fibrosis Association. The alliance will commence on June 12th, 2003. For further information contact Dr. Jim Egan at ajegan@mater.ie



Message from the President

The Pulmonary Fibrosis Foundation continues to make significant progress for the year 2003. We are now in alliances with the major lung organizations of this country.

With respect to the American Thoracic Society our foundation is a charter member of its Public Advisory Roundtable.

This committee provides advice and input to the ATS regarding future plans and directions from the patient perspective. We also Chair the Advocacy Committee of the Roundtable. In addition, we have recently been appointed to the Health Care Policy Committee of the Society. Finally, the ATS has awarded us the Public Service Award in recognition of service in public health in the area of lung-related health issues.

To increase the effectiveness of our mission to fund research to find a cure for Pulmonary Fibrosis, we have formed partnerships with the American Lung Association, the American College of Chest Physicians the Chest Foundation and the American Thoracic Society. These organizations have agreed to match us on a dollar for dollar basis to fund much needed research in Pulmonary Fibrosis.

We have exceeded our research budget and will fund more than \$100,000 in research grants this year. Our Young Investigator Research Grant Program has been so successful that we now have 23 proposals pending with a cost of more than \$900,000. We are desperately searching for ways to increase our research budget so we will not have to disappoint so many young researchers. We appreciate any support that our current and future donors can make to resolve this dilemma.

In an effort to increase the funding that will be available for research we are developing three new programs. The first is a Hope and Remembrance Celebration which will take place on Friday evening, November 21th, 2003 at the Chicago Cultural Center. The purpose of this event is to provide Hope for those suffering from Pulmonary Fibrosis that the new research that we are funding will find a cure for this deadly disease. In addition, there will be Remembrance of those who have passed from the illness.

In the second program we will be creating Hope and Remembrance flags to not only honor those afflicted with Pulmonary Fibrosis but also to increase public awareness by displaying the flags on prominent buildings across the country. Our third program involves the publication of a Hope and Remembrance Book to honor the memories of those who have passed from the disease (see page two for details).

Michael Rosenzweig, Ph. D., President

Sign Me Up! I want to support Hope and Remembrance and would like to contribute.

Here's my check for: \$5,000 \$1,000 \$500 \$100 \$50 Other_____

Name_____

Address_____

City_____ State_____ Zip_____

Phone_____ Email_____

Please send your check to: Pulmonary Fibrosis Foundation, 1440 W. Washington Blvd., Chicago, IL 60607

Or Charge your Contribution: Visa MasterCard Discover American Express

Account Number_____ Expiration Date_____

Phone: (312) 377-6895 Fax (312) 377-6896 Email: breathe@pulmonaryfibrosis.org

Save the date !

Hope and Remembrance Celebration

Friday November 21st, 2003 7 - 11 pm

Chicago Cultural Center

Chicago, Illinois

Pulmonary Fibrosis
Foundation

1440 West Washington Blvd.
Chicago, Illinois 60607

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