Pulmonary Fibrosis Education Day

April 14, 2016

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WHO WE ARE

The Pulmonary Fibrosis Foundation mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will lead longer, healthier lives.

By actively engaging the PF community, the PFF has developed essential programs available to those living and working with pulmonary fibrosis.

Our signature programs include:

- PFF Care Center Network
- PFF Patient Registry
- PFF Patient Communication Center
- PFF Ambassador Program
- PFF Support Group Leader Network
- PFF Disease Education Webinar Series
- PFF Summit
PFF Programs
The PFF Care Center Network (CCN) is 40 sites in 27 states with:

- Proven experience and expertise in treating patients with fibrotic lung diseases
- A dedication to improving the clinical care of those living with this disease.

PFF CCN sites provide:

- experts to fully manage each patient’s disease
- a multidisciplinary approach to care
- engagement opportunities for patients, caregivers and family members to actively learn from and connect with others impacted by the disease.
OUR CURRENT NETWORK HAS 40 CCN SITES
The PFF Patient Registry will collect information on patients living with PF at any of the participating CCN sites. These data and samples are collected in a consistent manner from each site, combined, made anonymous, and made available to PF researchers to better understand the disease and develop more effective care strategies.

- Patient demographics
- Smoking history
- Family ILD history
- Diagnosis and process
- Co-morbid conditions
- Medications
- Lab results
- Test results

HRCT images

Patient Reported Outcomes (PRO) Responses

Plasma
Serum
DNA
RNA
The PCC is a dedicated call center staffed by health care professionals that provides patients, caregivers, and health care providers with the most up-to-date medical information, communicates the availability of support services, and provides information about other essential resources.
In 2015, the PCC received over 2000 phone calls and 900 emails from patients, caregivers, family members and health care professionals.

Top 5 States of Callers:
- Texas
- California
- New York
- Illinois
- Florida

Top 5 Inquiries of PCC:
- General Disease Information
- Educational Resource Request
- Treatment Options
- Medical Center Referral
- Support Group Referral

Top 5 Countries:
- UK
- India
- Canada
- Pakistan
- Mexico
- Australia
The following materials are available online or through the PCC:

- Patient Information Guide
- Disease Awareness Brochure
- Physician Notepad
- Disease Awareness Poster
- Capabilities Brochure
- Breathe Bulletin
PFF AMBASSADOR PROGRAM

PFF Ambassadors are trained to be spokespeople for the PF community on behalf of the PFF to promote disease awareness, provide up-to-date information, and share the story of their journey with PF.
Since the PFF Ambassador Program started in 2014, the Ambassadors have shared their story with over 1700 people in person.
The PFF Support Group Leader Network, launched in 2012, provides a forum for our volunteer PF support group leaders to connect, exchange ideas, learn from one another, and discuss best practices for use at their meetings.

**What we provide for leaders**

- Support Group Leader Guide
- Patient education materials
- Quarterly teleconferences, eNewsletters and training webinars
- Access to The Leanne Storch Support Group Fund which provides grants to those looking to start a PF support group, develop their current group or hold an educational event
105 total PF support groups

93 groups in the United States in 32 states

13 international groups in Canada, Ireland, Italy and the UK

23 new groups started in 2015 and 9 new groups so far in 2016
This program allows the pulmonary fibrosis (PF) community to virtually learn from, connect with, and pose questions to leading pulmonary fibrosis specialists. Topics for patients and caregivers as well as healthcare professionals.

**Topics Include**

- What is PF?
- Ask a Doc: Clinical Trial Updates
- Pulmonary Rehab & Support Groups
- Caregiving 101
- Supplemental Oxygen
- Autoimmune-related PF
- Coping with PF
- Lung Transplantation
- Occupational & Environmental PF
- PFTs
- GERD and Sleep Apnea
- Update on PF Research
PFF SUMMIT

Started in 2011 and held biennially, the *PFF Summit: From Bench to Bedside* is an important event for the pulmonary fibrosis community that allows those affected by this devastating disease to learn and exchange ideas.

Experts present the most-up-to-date information to patients and caregivers, who are joined a diverse group of physicians, researchers, allied health professionals, and industry representatives.
More than 700 health care professionals, patients, caregivers, and industry leaders from 18 countries gathered in Washington DC for the PFF Summit 2015 from November 12 to 14, 2015.
Raising Awareness
RAISING AWARENESS

• Team PFF
• Global PF Awareness Month
• Shop PFF
• Social Media
When you become a volunteer Team PFF Event Leader, you will join forces with the passionate individuals and families from around the globe! Team PFF Event Leaders host a variety of events from climbing mountains to bake sales to internet fundraisers.

The PFF will provide resources and tools to make the planning of your event a success!
GLOBAL PULMONARY FIBROSIS AWARENESS MONTH

Let the world know: September is Global Pulmonary Fibrosis Awareness Month. Together we can make a difference in spreading disease awareness!
BLUE IT UP!

Pulmonary Fibrosis Foundation
Start the conversation and join thousands in spreading PF awareness!
FOLLOW PFF ON SOCIAL MEDIA

- Facebook
- Twitter
- Instagram
- LinkedIn
Thank you!