

SUPPORT GROUP LEADER
WORKSHOP

Pulmonary Fibrosis
FOUNDATION

March 31, 2014
2:00 p.m. – 3:00 p.m.
Quarterly Teleconference

Welcome!

Pulmonary Fibrosis

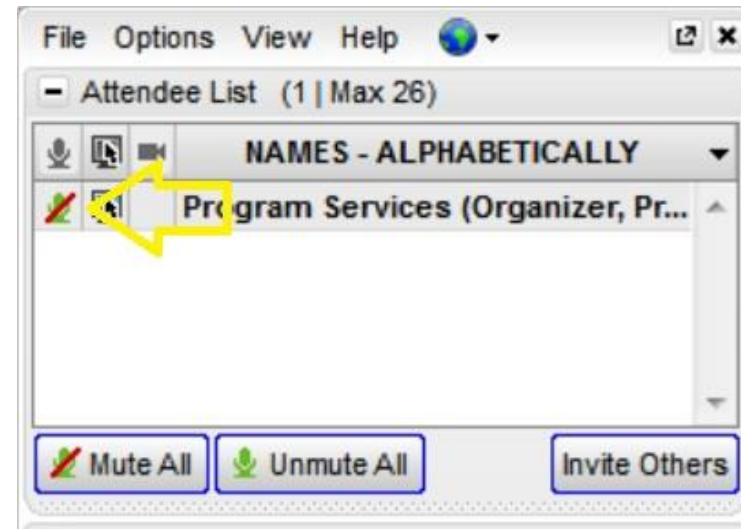
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Audio Controls



The screenshot shows the Zoom audio controls panel. At the top, it says "Screen Sharing" and "Stopped No one sees your screen". Below this are four buttons: "Show My Screen" (highlighted with a blue box), "Stop Showing Screen", "Give Keyboard & Mouse", and "Change Presenter". A "Start Recording" button is also visible, along with "893.7 GB remaining" and a "Settings" link. Below the screen sharing section is the "Attendee List (1 | Max 26)". The "Audio" section is highlighted with a yellow box and contains two radio buttons: "Telephone" (selected) and "Mic & Speakers". Below the radio buttons, the dial-in information is displayed: "Dial: +1 (619) 550-0000", "Access Code: 882-297-333", and "Audio PIN: 1". A pink banner at the bottom says "If you're already on the call, press #1# now." and a blue link "Problem dialing in?" is at the very bottom.

- If you are calling in, make sure to click “telephone” under audio controls and please mute your phone while you are not speaking
- If you are using the mic and speakers on your computer, make sure to click “mic & speakers” and keep yourself muted under the attendee list:



The screenshot shows the Zoom attendee list window. The menu bar includes "File", "Options", "View", and "Help". Below the menu bar is the "Attendee List (1 | Max 26)" section. The list is sorted by "NAMES - ALPHABETICALLY" and contains one attendee: "Program Services (Organizer, Pr...". A yellow arrow points to the microphone icon in the attendee's row, which is currently muted. At the bottom of the window, there are three buttons: "Mute All", "Unmute All", and "Invite Others".

- **Welcome and Introductions**
- **Announcements from the PFF**
 - Updated PFF resources
 - PFF Patient Communication Center
 - Leanne Storch Support Group Fund
 - PFF Patient Ambassador Program
 - Global Pulmonary Fibrosis Awareness Month
 - *PFF Summit 2015*
- **Open discussion**
- **Adjournment**

WELCOME AND INTRODUCTIONS

Pulmonary Fibrosis

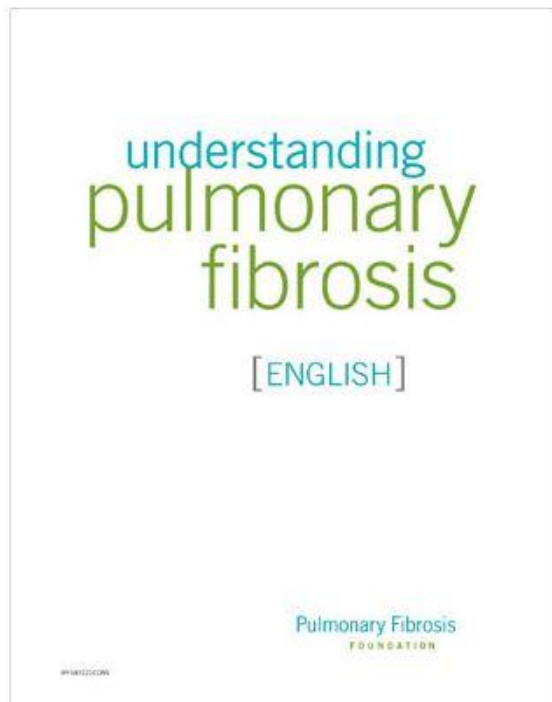
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- **Add in name, location, group of attendees**

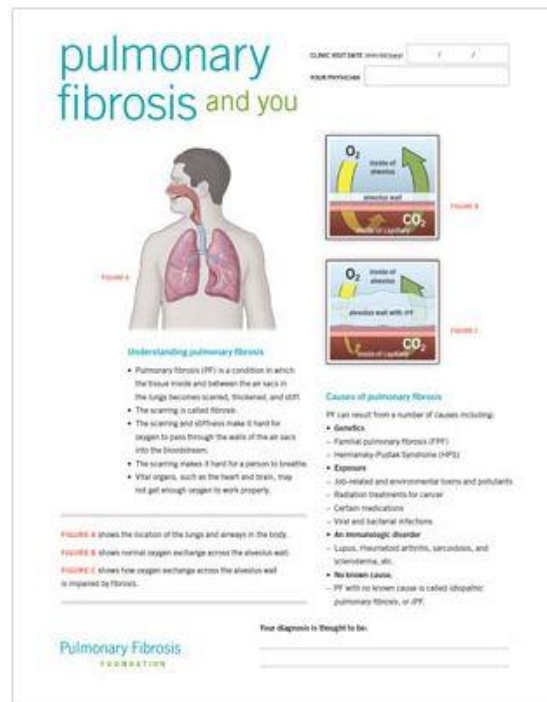
Updated PFF Resources

EDUCATIONAL + AWARENESS MATERIALS

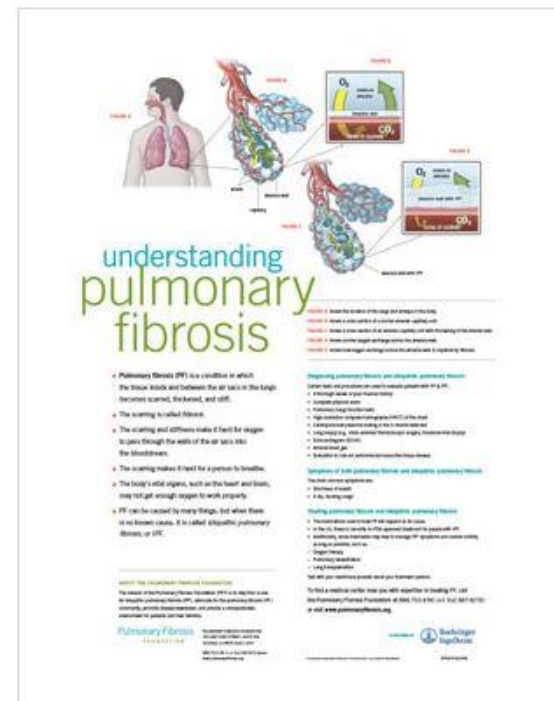
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Disease Awareness Brochure



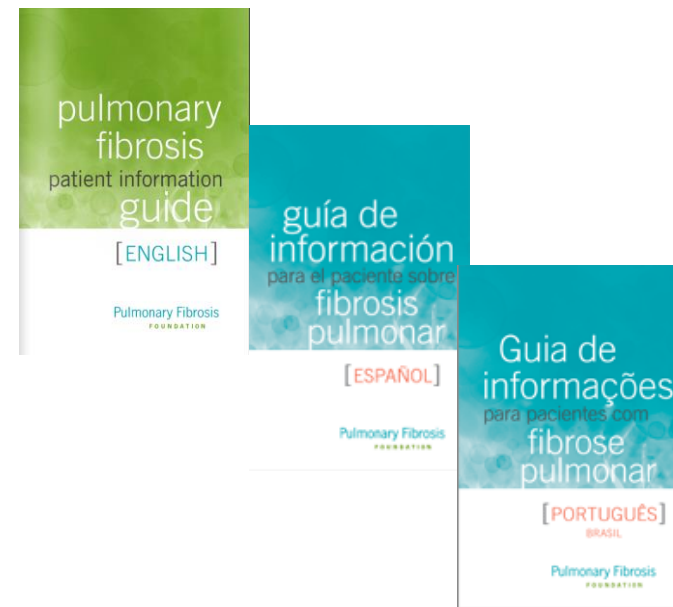
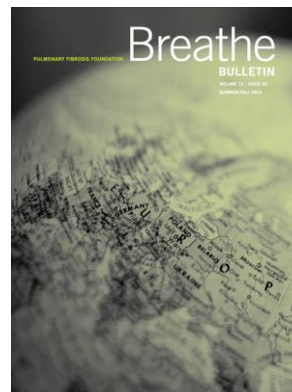
Physician Notepad



Disease Awareness Poster

EDUCATIONAL + AWARENESS MATERIALS

- *Breathe Bulletin*
- *Pulmonary Fibrosis Patient Information Guide*
- *Support Group Leader Guide*
- Disease awareness brochures
- Disease awareness posters
- Physician notepads
- Webinars



PFF Patient Communication Center

Goals

- Create a centralized patient communications to respond to calls, emails, and online discussions
- Facilitate communication among the PF community
- Provide educational support and referral information

ADD LOGO

Implementation

- Call center open 9am - 5pm CST:
 - 1.855.338.0220
- Email inquiries:
 - pcc@pulmonaryfibrosis.org

2013 Leanne Storch Support Group Fund

2014-2015 AWARD CYCLE

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Updates

- 2013: Eight (8) awards available
- 2014: Expanded to eighteen (18) awards for \$500 each

Application Cycle

- April 1st, 2014 – August 1st, 2014
- Awardees announced during Global Pulmonary Fibrosis Awareness Month, September 2014

PFF Patient Ambassador Program

PFF PATIENT AMBASSADOR PROGRAM

Goals

- Promote awareness through patients, caregivers and health care professionals
- Provide up-to-date and accurate disease education
- Provide hope and inspiration to those affected by PF

Implementation

- 8 PF Patient/Caregiver Ambassadors
- 13 Professional Ambassadors
- All ambassadors will undergo training in April
 - Develop patient and caregiver stories and testimonials
 - Develop healthcare professional presentations
- Partnering with SNOW Companies

Get involved

- Contact SNOW Companies
 - 1.855.292.1531 or IPFAmbassadors@snow-companies.com

Global Pulmonary Fibrosis Awareness Month 2014

GLOBAL PULMONARY FIBROSIS AWARENESS MONTH

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Updates

- Expanded to the entire month of September

Events

- Sep. 6-10: European Respiratory Society, *ERS Annual Congress Munich 2014*
- Sep. 16: University of Pittsburgh Simmons Center for ILD, *Daniel & Joan Beren PA-IPF Registry: IPF & Advocacy Event*
- Sep. 20-24: 2014 International Colloquium on Lung and Airway Fibrosis (ICLAF), Quebec, Canada



PFF Summit 2015

PFF SUMMIT 2015

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Dates

- November 12-14, 2015

Location

- Washington, DC



www.pffsummit.org

save the date!
NOVEMBER 12-14, 2015



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Open Discussion

2014 Support Group Leader Meeting Dates

- July 21
- October 20
- December 15

3rd Monday of the Month
2pm-3pm CST

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Thank you.