

SUPPORT GROUP LEADER  
NETWORK TELECONFERENCE

Pulmonary Fibrosis  
FOUNDATION

January 26, 2015  
2:00 p.m. – 3:00 p.m.

Welcome!

# Pulmonary Fibrosis

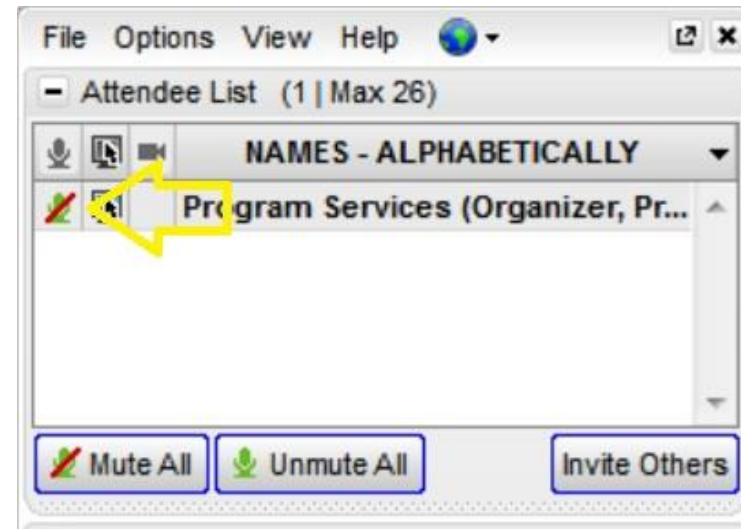
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## Audio Controls



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" (with a play button icon), "Stop Showing Screen" (with a square icon), "Give Keyboard & Mouse" (with a mouse cursor icon), and "Change Presenter" (with a monitor icon). Below these buttons are "Start Recording" (with a red recording icon), "893.7 GB remaining", and a "Settings" link. Below the screen sharing section is an "Attendee List (1 | Max 26)" section. The "Audio" section is highlighted with a yellow border and contains the following information: "Telephone" (selected with a radio button), "Mic & Speakers" (unselected with a radio button), "Dial: +1 (619) 550-0000", "Access Code: 882-297-333", "Audio PIN: 1", and a pink banner that says "If you're already on the call, press #1# now." with a "Problem dialing in?" link below it.

- 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. At the top, it says "Attendee List (1 | Max 26)". Below this is a toolbar with icons for microphone, video, and chat. The list is titled "NAMES - ALPHABETICALLY" and contains one entry: "Program Services (Organizer, Pr...". A yellow arrow points to the microphone icon next to this entry. Below the list are three buttons: "Mute All" (with a red slash icon), "Unmute All" (with a green microphone icon), and "Invite Others".

# AGENDA TOPICS

## Pulmonary Fibrosis

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- Welcome and Introductions
- Announcements from the PFF
  - New PFF Care Center Network sites
  - Support Group Leader Network Survey Results
  - Support Group Leader Network Program Expansion
- Kathy Lindell, PhD, RN will talk about how the support group at the Simmons Center for Interstitial Lung Disease at University of Pittsburgh plans their meeting topics for the whole year.
- Kirk Mathison, RN will talk about how the Calgary Pulmonary Fibrosis Support Group utilizes videoconferencing to reach more people in the Calgary area.
- Open discussion
- Adjournment

# PFF Care Center Network

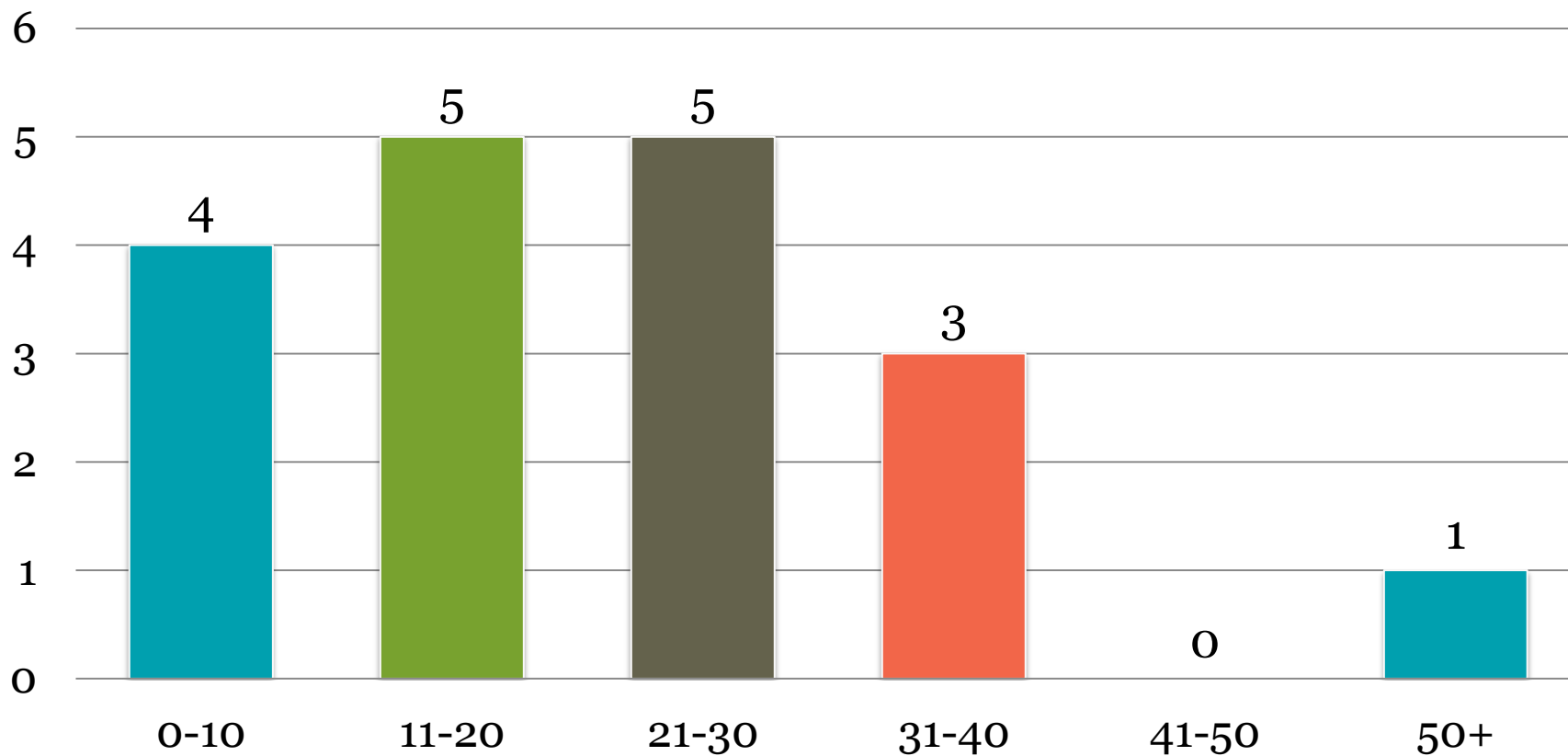
12 new sites were added to the Network for a total of 21 sites

- University of Alabama at Birmingham
- University of Arizona Medical Center-University Campus in Tucson
- University of Miami Miller School of Medicine
- Piedmont Healthcare in Atlanta
- The University of Kansas Hospital
- Tulane University School of Medicine
- Mayo Clinic in Rochester, Minnesota
- Washington School of Medicine in St. Louis
- New York-Presbyterian/Columbia University Medical Center and New York-Presbyterian/Weill Cornell Medical Center
- University of Pennsylvania
- Medical University of South Carolina
- Inova Fairfax Medical Campus

# PFF Support Group Leader Network Survey Results

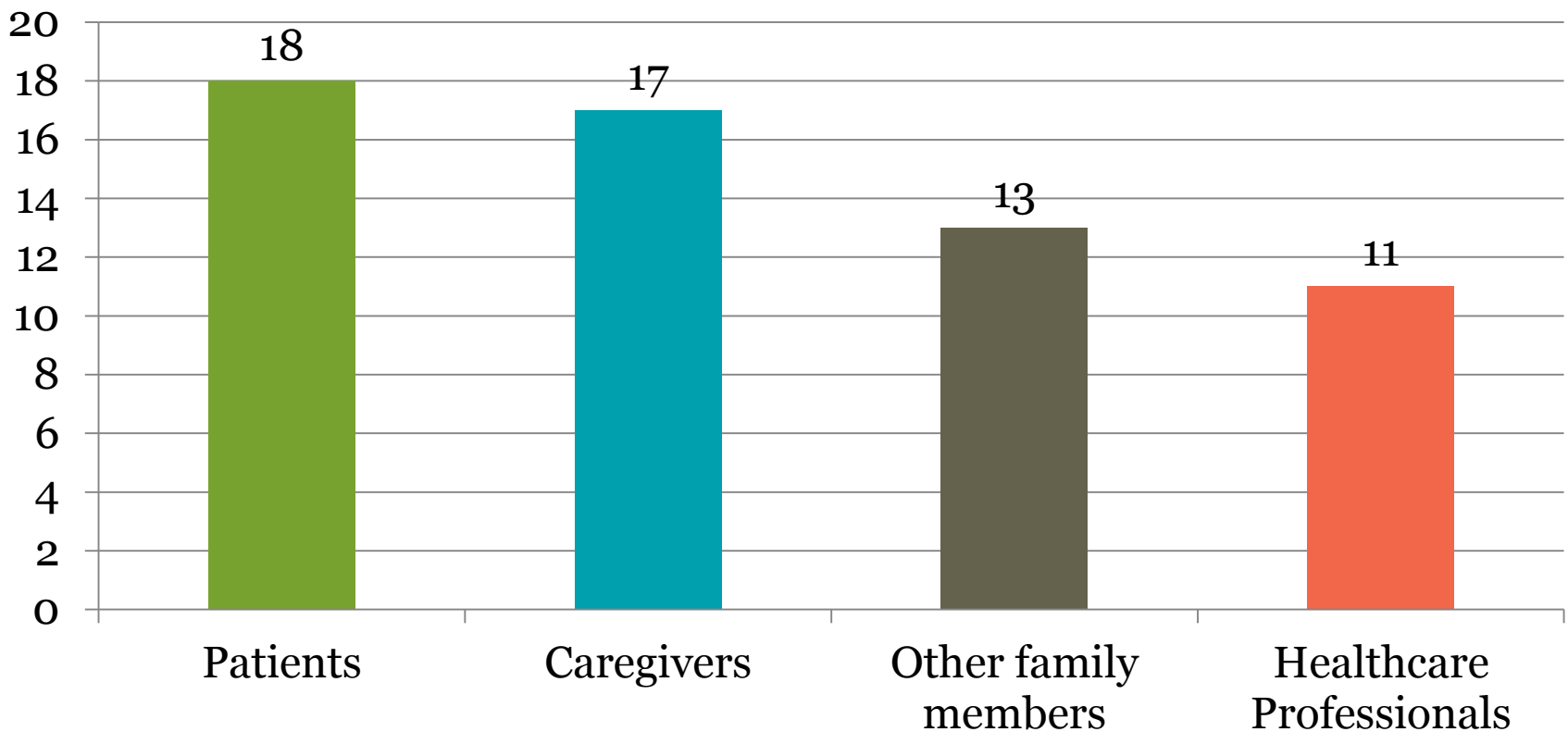
# SUPPORT GROUP LEADER NETWORK SURVEY RESULTS

## Number of Support Group Members



18 responses

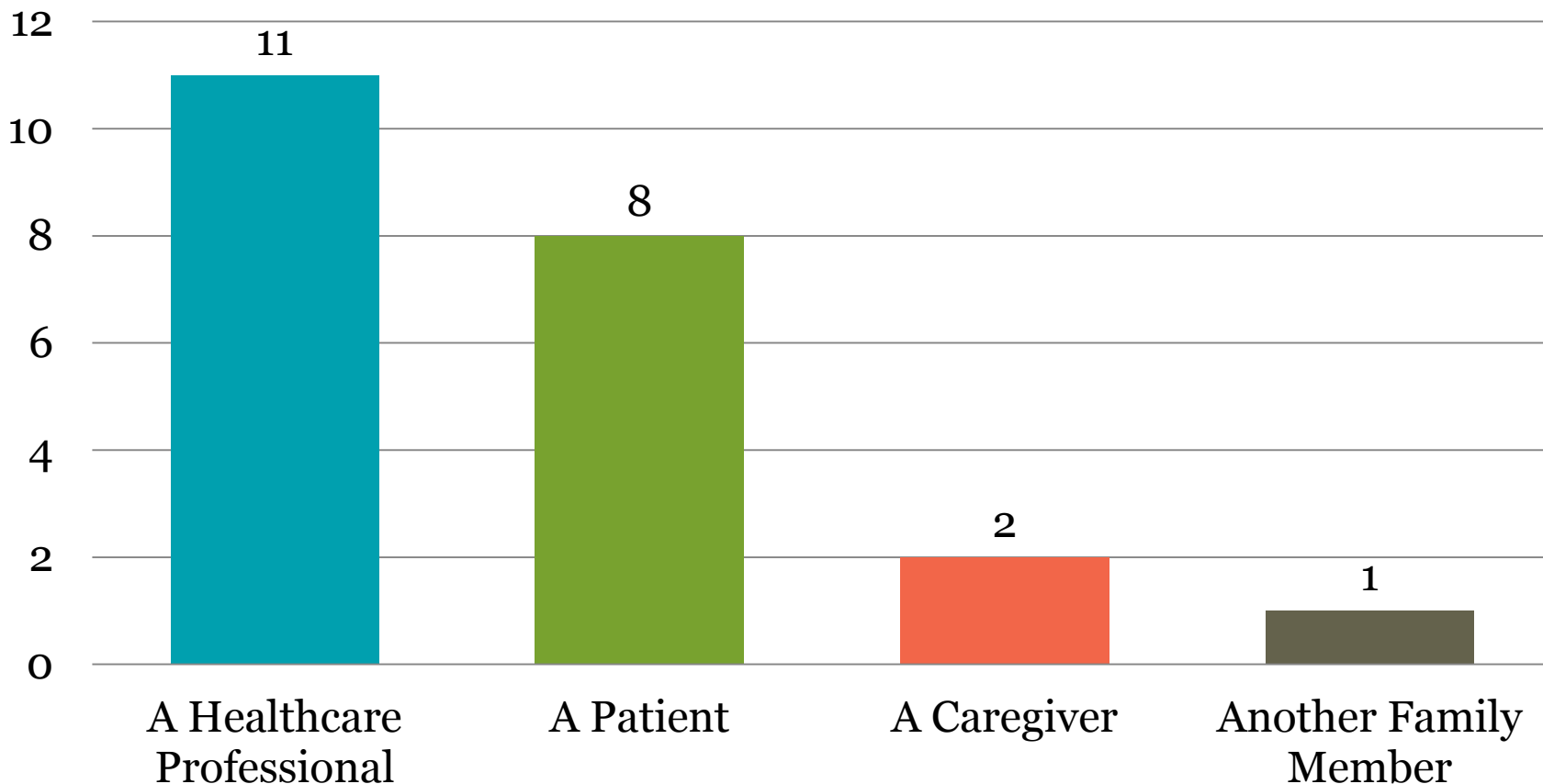
## My support group has the following types of members regularly attend





# SUPPORT GROUP LEADER NETWORK SURVEY RESULTS

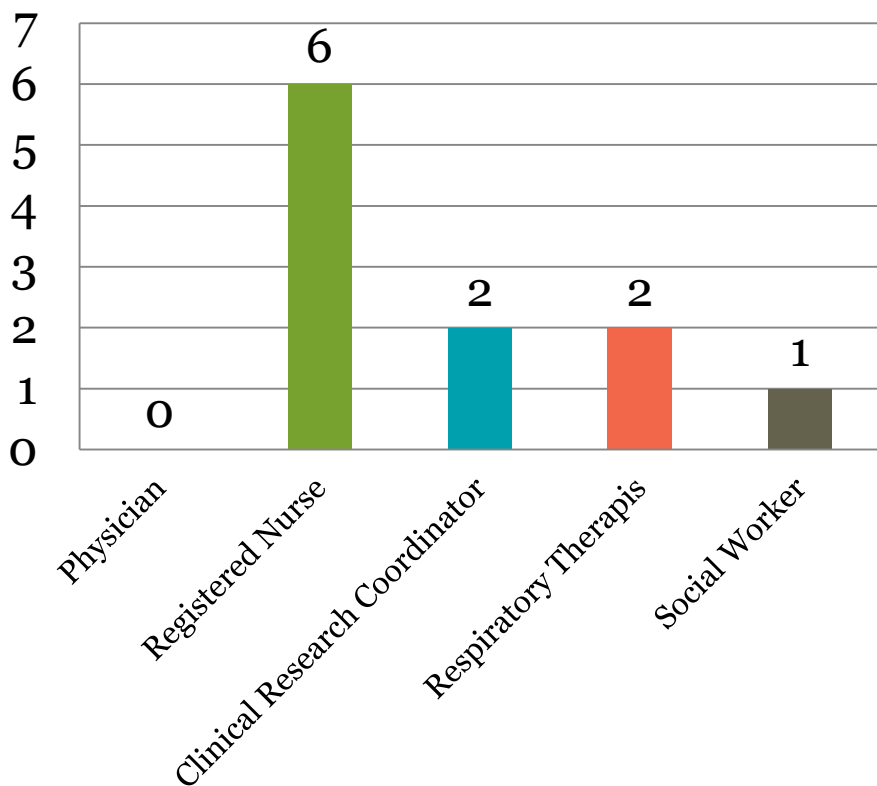
**As the Support Group leader, are you...**



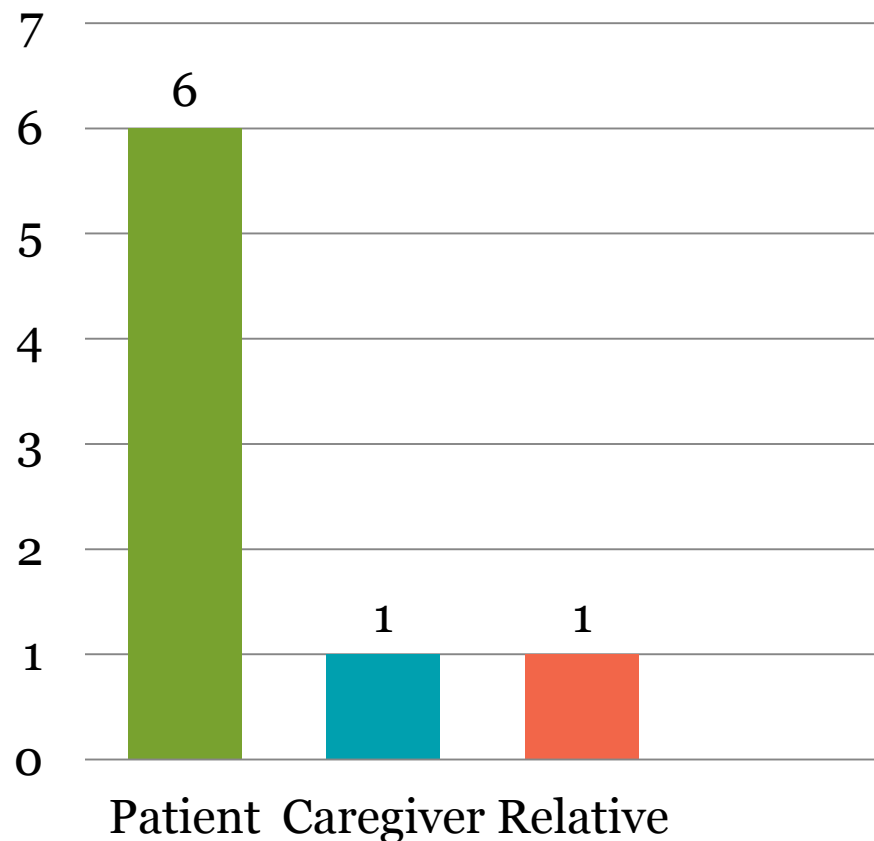
**18 responses**

# SUPPORT GROUP LEADER NETWORK SURVEY RESULTS

## Healthcare Professional Support Group Leaders (9 Responses)

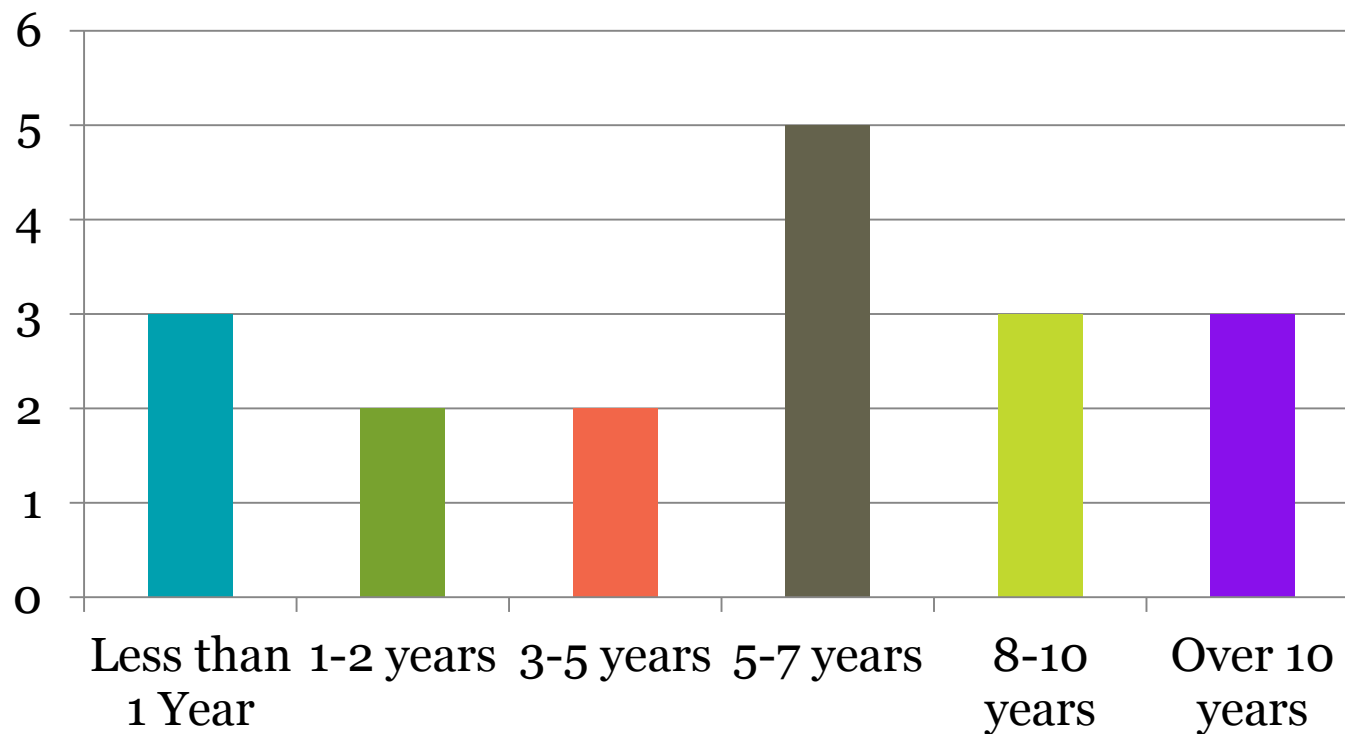


## Other Support Group Leaders



Other: Clinical Exercises Physiologist, DNP, CNA

## How long has your support group been active?



**Special shout out to the University of Washington Support Group which has been active for 25 years!**

# PFF Support Group Leader Network Enhancement & Expansion

- Provide more support to current members of the Support Group Leader Network
  - Develop a Curriculum Guide
  - Develop a Quarterly Training Program
- Provide more support for those looking to start a PF support group
  - Update PFF Support Group Leader Guide
  - Provide Quarterly webinars for potential new support group leaders
- Expand the Network
  - Outreach to areas that do not have a current group

**WE CAN'T DO IT ALONE!**

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The PFF needs your input and expertise to make this program a success!

We will be forming committees and working groups for each component of expansion and enhancement. If you are interested in helping with this endeavor, please let us know.



# Leanne Storch Support Group Fund

# REASONS YOU HAVEN'T APPLIED FOR THE LEANNE STORCH SUPPORT GROUP FUND

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- Don't have time to plan an event!
- My group has low overhead costs.
- Unsure of how to use the funds since I don't give speaker stipends.
- Need more details on the program.



**Goal: Develop three distinct tiers of funding**

- New Support Group Awards
- Existing Support Group Awards
- Patient Education Event Awards

Kathy Lindell, PhD, RN  
Simmons Center for ILD at  
University of Pittsburgh

Kirk Mathison, RN  
Calgary Pulmonary Fibrosis  
Support Group

# PFF DISEASE EDUCATION WEBINAR SERIES

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Wednesday, February 4<sup>th</sup>

“Occupational & Environmental PF”

Presented by: Mridu Gulati, MD, MPH

Wednesday, March 11<sup>th</sup>

“Pulmonary Hypertension & PF”

Presented by: Steven Nathan, MD

Wednesday, March 18<sup>th</sup>

“Ask a Doc”

The PFF Medical Team will answer your questions during an hour-long Q+A session.

All webinars are 12:00 p.m. to 1:00 p.m. CST.

PFF SUMMIT 2015

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# *Open Discussion*

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Thank you.