

SESSION II
DECEMBER 14, 2015

Pulmonary Fibrosis
FOUNDATION

PFF Support Group Leader Network Training Webinar:

Getting Your Support Group Started

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- Session I: *Available Online*
 - *Identifying Resources for Success*
- **Session II**
 - ***Getting Your Support Group Started***
- Session III (January)
 - *Maintaining and Growing the Group*

1. Benefits of Support Groups

- Research has shown that social support has a positive influence on health.
- Support groups can help members be a better educated patient by:
 - ✓ Learning about their disease & treatment
 - ✓ Learning to navigate the health care system more effectively
 - ✓ Learning to make better decisions about their healthcare
 - ✓ Taking charge of one's disease and set new goals
 - ✓ Changing health behaviors



1. Benefits of Support Groups

- Support groups can help members deal with psychosocial issues by:
 - ✓ Feeling supported by others who are going through the same thing
 - ✓ Meeting new friends
 - ✓ Maintaining a sense of normalcy
 - ✓ Sharing their story with others who understand
 - ✓ Helping others
 - ✓ Feeling less anxious
 - ✓ Improving coping skills
 - ✓ Feeling less isolated & hopeless



2. Guidelines, Best Practices, Disclaimers, Privacy

- ✓ Difference between hospital based and community support groups
- ✓ Check with your local hosting site to determine what privacy (HIPAA) guidelines might apply
 - Hospital vs outpatient setting vs private home
 - Emailing participants
 - Posting on social media
 - Sharing of any health information



2. Guidelines, Best Practices, Disclaimer, HIPAA

- ✓ Clarify 'disclaimer' – that any information provided is educational only and participants should always check with their health care providers before making any changes in their own treatment.
- ✓ What do you do in your group to respect the privacy of your members?



Photo credit: Joe Walsh Memorial SG in Denver, CO

3. Tips on Establishing Location, Day, Time

✓ Location:

- Medical setting: hospital, clinic, health center, pulmonary rehabilitation centers
- Non-medical: home, restaurant, community center

✓ Consider:

- Access to AV equipment, internet, food,
- Parking, wheelchair access, elevator availability
- Distance from parking to meeting location
- Good signage!
- Consistency: use the same location for every meeting

3. Tips on Establishing Location, Day, Time

✓ Time and Day Considerations

- Travel time, traffic, typically mid-day or early afternoon
- Consistency: “1st Monday of every month at noon”



*Photo credit: Piedmont Triad
SG in Greensboro, NC*

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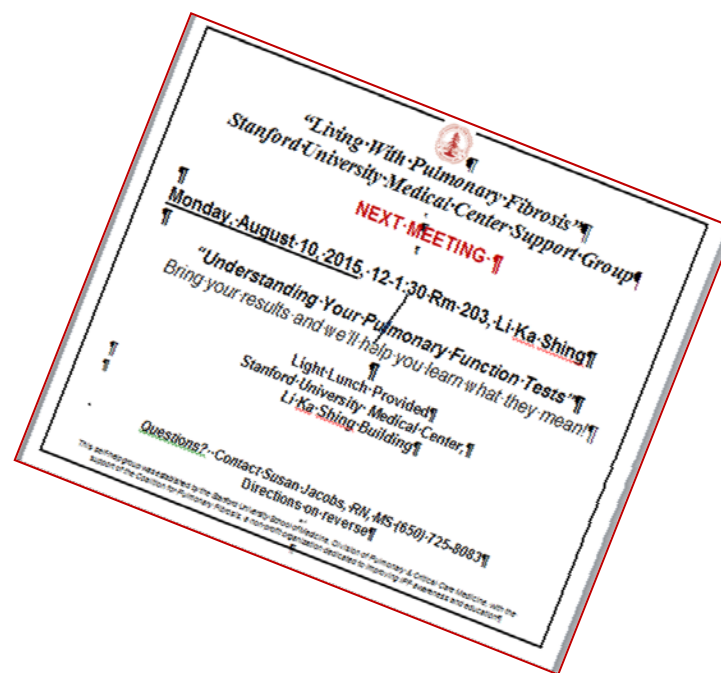
4. Getting the word out:

- ✓ PFF website: SG listings & Calendar of Events
- ✓ Social media, community advertising
- ✓ Hospital posting, health calendars, referring MDs, chest clinic handouts
- ✓ Senior centers
- ✓ Pulmonary rehab groups
- ✓ Website for the group
- ✓ Local city contacts, like a public library
- ✓ Chamber of Commerce



5. Prep/Set up, Sign-in & Checklist

- ✓ Make list of everything that you as the leader needs to bring to the meeting!
- ✓ Establish goal/plan for each meeting



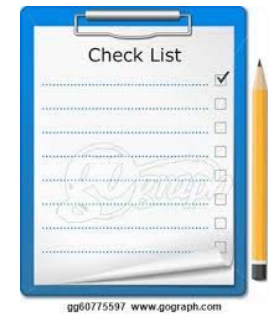
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Checklist

- ✓ Sign-in sheet
- ✓ Copies of speaker handouts and slides
- ✓ PFF handouts and materials for resource table
- ✓ Announcements from PFF and your own information regarding events, research studies, etc.
- ✓ Next meeting flyers
- ✓ Nametags
- ✓ Pens
- ✓ Clipboard
- ✓ Oximeter
- ✓ Throat lozenges
- ✓ Oxygen tanks & cannulas
- ✓ Contact numbers
- ✓ Pointer, thumb drive, computer if needed for speaker
- ✓ Thank you card for attendees to sign for special guest



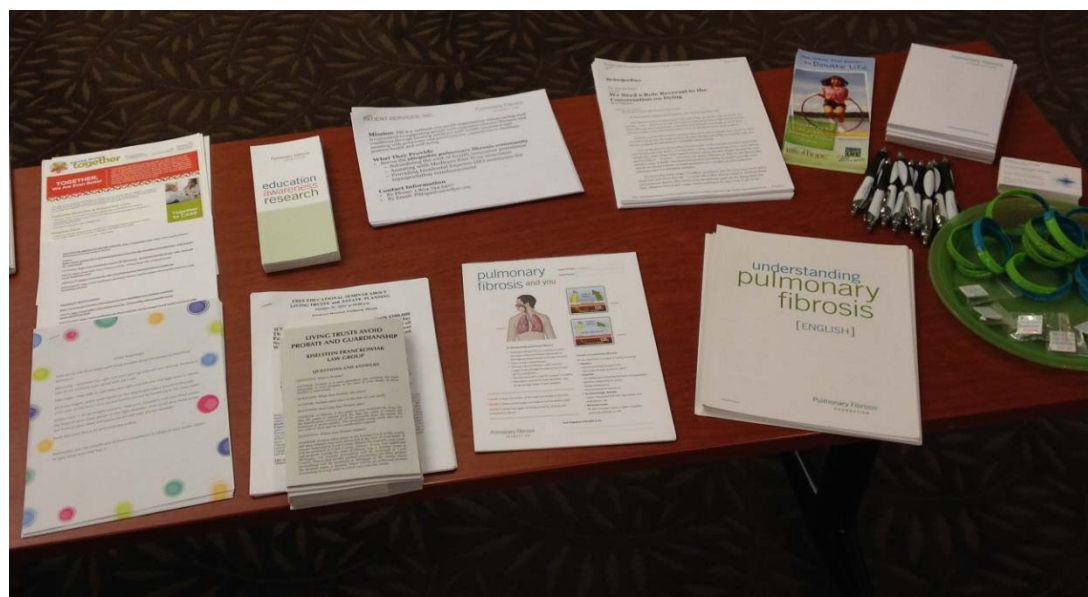
5. Prep/Set up, sign-in

- ✓ Identify assistant for meetings to help with:
 - Meeting notifications: helps with email lists, etc.
 - A “greeter”
 - Initial meeting check in: busiest time of meeting, assists with getting everybody to sign in, check their contact info, provide them handouts
 - Participant support: oxygen issues, handouts, wheelchair needs
 - Program planning: can collate participant input for future topics, etc.

SESSION II: GETTING STARTED

6. Resources, speaker, intros

- ✓ Have a designated 'Resource Table'
- ✓ Introduce yourself and clarify role of leader in the beginning



*Photo Credit:
Breakfast Club SG
in Elmhurst, IL*

6. Resources, speaker, intros

- ✓ Conduct a 'check in' at beginning of each meeting
 - Gets meeting started
 - Connects participants to one another
- ✓ Provide closure at the end of each meeting, dates of next meeting, summarize key points
- ✓ Always allow 'free time' after the wrap-up for visiting



*Photo credit:
Hampton Road SG
in Norfolk, VA*

SESSION II: GETTING STARTED SUMMARY

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1. Review guidelines, best practice
2. Find a location, get the word out
3. Review the logistics and preparation for each meeting
4. Enlist a helper!



*Photo credit:
Montgomery IPF
SG in Montgomery,
AL*

NEXT SESSION:
JANUARY 2016

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NEXT: Session III
Maintaining and
Growing the Group

1. Ongoing marketing & promotion
2. Special event planning
3. Regular re-assessment of group needs
4. Networking with other support group leaders

Thank you!

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