PFF Support Group Leader Network Training Webinar:

Getting Your Support Group Started

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OVERVIEW OF WEBINAR SERIES

• 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
SESSION II: GETTING STARTED

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
SESSION II: GETTING STARTED

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*
SESSION II: GETTING STARTED

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
SESSION II: GETTING STARTED

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
SESSION II: GETTING STARTED

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
SESSION II: GETTING STARTED

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
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
SESSION II: GETTING STARTED

SUMMARY

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 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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