

SESSION I
OCTOBER 7, 2015

Pulmonary Fibrosis
FOUNDATION

PFF Support Group Leader Network Training Webinar:

Identifying Resources for Success

Susan Jacobs, Carol Bair, Cindi Brannum

- **Session I**
 - *Identifying Resources for Success*
- Session II (November)
 - *Getting Your Support Group Started*
- Session III (December)
 - *Maintaining and Growing the Group*

Part One: Preparing as the Leader

PART ONE: PREPARING AS THE LEADER

- ✓ Connect with the PFF to identify resources specific to support groups
 - pcc@pulmonaryfibrosis.org to find out about starting a group
 - PFF Support Group Leader Network (SGLN) to learn about available teleconferences, newsletters, etc...
- ✓ Review the PFF Support Group Leader Guide

Pulmonary Fibrosis FOUNDATION



Pulmonary Fibrosis
FOUNDATION

support group leader guide

[ENGLISH] The mission of the Pulmonary Fibrosis Foundation (PFF) is to help find a cure for idiopathic pulmonary fibrosis, advocate for the pulmonary fibrosis community, promote disease awareness, and provide a compassionate environment for patients and their families.

This Support Group Leader Guide is provided by the Pulmonary Fibrosis Foundation as a public service to our patient community.
© 2013 PULMONARY FIBROSIS FOUNDATION. ALL RIGHTS RESERVED.

PART ONE: PREPARING AS THE LEADER

- ✓ Apply for Leanne Storch Support Group Fund (LSSGF) as needed
 - 1) www.pulmonaryfibrosis.org/medical-community/leanne-storch
 - 2) Applications due 12/1/15 for this year
 - 3) \$500 grant available for new group, \$750 grant available to develop an existing group
 - 4) Review LSSGF Guidelines for use of funding information



Part Two:
Obtain the Skill Set &
Education to deal with...

PART TWO: OBTAIN THE SKILL SET & EDUCATION TO DEAL WITH...

✓ Adult Learners:

- learn best when motivated to acquire new knowledge
- are practical in their approach to learning
- want to feel they are in control of their own learning
- want to learn as quickly, cheaply and easily as possible
- learn by doing
- learn by relating new information to past experiences
- have significant experience that can be beneficial to the leader and to the group
- learn best in an informal situation
- want to be treated like adults



PART TWO: OBTAIN THE SKILL SET & EDUCATION TO DEAL WITH...

Managing the group dynamic

1. Review the references in the SG Leader Guide
2. Make efforts to include all participants in discussions
3. Tactfully and respectfully control those that dominate discussions or draw the discussion off topic:

“That is a very good question Mr. X and I would be happy to answer that after our meeting, but let’s hear from others who haven’t spoke yet about this issue”



PART TWO:
OBTAIN THE SKILL SET & EDUCATION
TO DEAL WITH...

✓ **Leading discussions**

- 1) 'Checking in' is a great way to start meetings. Go around the room and have each participant take a minute to either introduce themselves as a new member, and/or tell the group how they are doing.
- 1) This can provide a portion of the meeting time for the more emotional supportive aspects of living with PF even when you have a speaker coming. It often becomes the entire meeting!

PART TWO: OBTAIN THE SKILL SET & EDUCATION TO DEAL WITH...

✓ Leading discussions

- 1) Use “active listening” skills including repeating the question back to the participant: *“I hear you saying how difficult it is to try and not feel like a burden to your family; do others have the same feelings? And what works for you?”*
- 2) Open discussions lend themselves to more exploratory and problem-solving and sharing.
- 3) Guest speakers usually create an atmosphere more for education/information versus support

Part Three: Resources for Speakers & Topics

PART 3: RESOURCES FOR SPEAKERS & TOPICS

✓ *Physicians, Nurse,*

- 1) What is Interstitial Lung Disease? (Diagnosis, testing...)
- 2) Current research related to PF
- 3) Managing Cough, Shortness of Breath, Fatigue
- 4) When to call the doctor
- 5) What is an Acute Exacerbation?



✓ *Lung Transplant patient, Nurse Specialist, or Transplant Surgeon*

- 1) Criteria for lung transplantation
- 2) Life after Lung Transplant

PART 3: RESOURCES FOR SPEAKERS & TOPICS

- ✓ *Pulmonary Rehabilitation Personnel*
 - 1) What is PR? What are the benefits? Where are programs located?
 - 2) Home exercise prescription options

- ✓ *Respiratory Care Practitioners, Pulmonary Function Technicians*

- ✓ *Oxygen vendors*
 - 1) Available portable systems, general precautions
 - 2) Reimbursement issues
 - 3) Oxygen testing needed



PART 3: RESOURCES FOR SPEAKERS & TOPICS

- ✓ *Physical Therapist, Occupational Therapist*
 - 1) Exercise as fall prevention, home exercise, joint mobility
 - 2) Organizing activities of daily living to minimize breathlessness, use of adaptive living aids

- ✓ *Dietitian*
 - 1) Weight loss/gain
 - 2) Healthy eating, reading labels, 'My Plate', portion size, economic shopping

- ✓ *Social Workers*
 - 1) Support for families and caregivers
 - 2) Identification of financial and caregiving resources

PART 3: RESOURCES FOR SPEAKERS & TOPICS

✓ *Pharmacists*

- 1) Side effects of Immunosuppressant Medications
- 2) Over-the-Counter Supplements

✓ *Alternative Medicine Specialists*

- 1) Acupuncture
- 2) Herbal Supplements
- 3) Harmonica Playing

PART 3: RESOURCES FOR SPEAKERS & TOPICS

- ✓ *Advanced Care Directive personnel*
 - 1) Physician Order for Life-Sustaining Treatment (POLST) forms
 - 2) Advanced Directives
 - 3) Durable Power of Attorney

- ✓ *Home Care, Palliative and Hospice care*
 - 1) The Difference between Palliative and Hospice Care

- ✓ *Spiritual Care*

PART 3: RESOURCES FOR SPEAKERS & TOPICS

- ✓ *Travel agency personnel especially pulmonary Cruises/outings*
- ✓ *PFF Ambassador Program*
- ✓ *Representative from other foundations like Scleroderma Foundation, Pulmonary Hypertension Association and Rare Lung Consortium*
- ✓ *Medical Librarian*
 - 1) How to search for medical information on line
 - 2) How to know which sites are accurate?

Part Four: Considerations for Choosing a Location

PART FOUR: CONSIDERATIONS FOR CHOOSING A LOCATION

- ✓ Travel/parking distance and costs, elevator
- ✓ Temperature
- ✓ Honorarium for speaker, if needed
- ✓ Refreshments
- ✓ Handouts, copying
- ✓ Wheelchair assist, back up oxygen, oximeter
- ✓ Audio Visual equipment (screen, laptop)



SUMMARY

- ✓ Prepare as the leader!
 - ✓ Review the Support Group Leader Guide & talk to the PFF
- ✓ Apply for funding
- ✓ Find a location
- ✓ Identify speakers and topics



NEXT SESSION:
NOVEMBER 2015

Pulmonary Fibrosis
FOUNDATION

NEXT: Session II

Getting Your Support Group Started

1. General guidelines
2. Tips on location, time
3. Getting the word out
4. Set up, meeting logistics



Thank you!

Sponsored with the generous support of

