

support group  
leader  
guide

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We imagine a world without  
pulmonary fibrosis.

**DEDICATION**

With deepest gratitude to the members of the pulmonary fibrosis community past, present, and future. We thank you for sharing your journey.

## INTRODUCTION

# Thank you for your interest in establishing or further developing an existing pulmonary fibrosis (PF) support group in your area.

Support group leaders play a vital role in helping the Pulmonary Fibrosis Foundation (PFF) fulfill its mission to serve as the trusted resource for the PF community by raising awareness, providing disease education, and funding research.

We hope you find this Pulmonary Fibrosis Foundation Support Group Leader Guide helpful, whether you are planning your first PF support group meeting or developing new meetings for an established group. Within this Guide, you will find a variety of useful recommendations and resources to assist and inspire you in creating dynamic, informative meetings.

You are not alone. You can connect with other leaders to discuss your experiences starting and maintaining a support group. The PFF helps facilitate these connections through its Support Group Leader Network.

The PFF staff is available to assist you in planning support group meetings and answering questions. We can recommend topics for discussion, help secure speakers, promote your group, and provide educational materials for distribution at your meetings. Please contact the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or email [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org) for assistance.

Thank you for volunteering to take on the important role of support group leader and for providing a compassionate, open environment for PF patients, caregivers, and families to share information and support. Welcome to the Network!

Sincerely,



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## PART ONE:

# PF Support Group Basics

### THE PURPOSE OF THE PULMONARY FIBROSIS FOUNDATION

#### SUPPORT GROUP LEADER GUIDE

A fundamental goal of the Pulmonary Fibrosis Foundation (PFF) is to provide improved access and opportunities for individuals to learn about pulmonary fibrosis (PF) and how to live better with it. Through a support group, people affected by PF can learn, share common experiences, build their network of support, and take comfort in a community that understands the impact of the disease.

While managing a face-to-face PF support group is a big endeavor, support group leaders should not feel alone. The Pulmonary Fibrosis Foundation Support Group Leader Guide represents the collective wisdom of leaders, patients, caregivers, and health care professionals. It was created to provide both new and experienced leaders with the necessary tools to establish and maintain a successful group. We invite feedback and encourage you to share your expertise and experiences for future editions of this Guide. Contact the PFF Patient Communication Center at [844.TalkPFF](tel:844.TalkPFF) (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org). We hope you find the Guide both valuable and inspirational.

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**“The people in this group are wonderful. Sharing information, understanding that others know how I feel makes me feel not so alone.”**

**PF support group member / Pennsylvania**

## WHAT IS A PF SUPPORT GROUP?

A PF support group provides a setting where people affected by PF can come together to learn about the disease and available treatments, obtain tools to make better decisions regarding their care, express thoughts and feelings, and mutually support each other in living with PF.

**A successful PF support group can help those affected by the disease live productive, fulfilling lives.**

A PF support group is

- a place where people with a variety of fibrotic lung diseases, such as idiopathic pulmonary fibrosis (IPF), connective tissue disease-related interstitial lung disease (CTD-ILD), or hypersensitivity pneumonitis (HP) can learn and share;
- a group that meets face-to-face on a regular basis;
- member-focused, welcoming patients, caregivers, family, friends, and anyone affected by PF;
- a source of current and accurate information about PF;
- a place where privacy and confidentiality are respected;
- a safe and comfortable space in which anyone affected by PF can talk openly about the challenges of living with the disease;
- a forum to exchange ideas, compare experiences, and learn from others;
- a gathering where mutual emotional support and empowerment is encouraged and nurtured;
- an opportunity for people to develop relationships and friendships with others who are experiencing similar situations; and, most importantly,
- **a place where those affected by PF can find reassurance in the realization that they are not alone with this disease.**

**“The experience of illness is a profoundly social one.”**

**K.P. Davison, J.W. Pennebaker, S.S. Dickerson** / “Who talks?”

The social psychology of illness support groups.” *American Psychologist* Feb. 2000: 205-217.

**“Health professionals remain the central source of information for most Americans, but ‘peer-to-peer health care’ is a significant supplement.”**

**Susannah Fox** / “Peer-to-Peer Health Care.” Pew Research Center’s Internet & American Life Project 28 Feb. 2011.

**However, a PF support group is NOT a substitute for medical care.** Group members are responsible for their own well-being and should actively seek the best care available to them. Support groups supplement that care by providing emotional support and education.

Research has shown that social support has a positive influence on health. Support groups are among the best and most popular approaches for connecting and empowering because they can help individuals

- learn about their disease and treatment,
- feel supported by others who are going through the same thing,
- meet new friends,
- develop self-sufficiency,
- learn to navigate the health care system more effectively,
- learn to be a more engaged and knowledgeable patient,
- make better decisions about their health care,
- maintain a sense of normalcy,
- take charge of their disease and set new goals,
- share their stories with others who understand,
- help others,
- feel less anxious,
- change health behaviors,
- improve coping skills, and
- feel less isolated and more hopeful.

**“This disease  
is not just a physical thing –  
it’s an emotional thing.**

*We’re scared; we’re disappointed in the system; we’re angry. Who better to discuss this with than a person experiencing these same things? You begin to develop a trust, some comfort in not being alone, a sense that maybe, just maybe, because of some stories told in the room that day, maybe there is some hope after all. Not necessarily hope for a cure, but for a future. You now realize you have some input into how and what happens to you. We move forward with the help of others like ourselves who are looking for answers.*

**We are no longer alone.”**

**PF support group member / Colorado**

The PFF is committed to helping PF support groups provide safe, welcoming environments for patients and families affected by PF. The goals established for our PF support groups include providing medically accurate, up-to-date information and creating a supportive, compassionate environment for patients, caregivers, and families. While groups will evolve around the needs and wishes of members, there are basic rules and guidelines that should be followed.

### Support Group Ground Rules

- Maintain group confidentiality. What is said in a support group stays in the support group.
- Promote an environment of respect, positive regard, and caring for participants at all times to encourage understanding and sharing. Everyone is doing the best they can.
- Facilitate open communications and promote a safe forum to discuss frustrations, emotions, and concerns.
- Be sensitive to the feelings of others and consider the impact of your words on other members of the group.
- Focus attention on those speaking to promote a supportive environment.
- Acknowledge and respect the different points of view presented during meetings. Remember that members' viewpoints are formed by their own personal history and values and these should be respected at all times.
- Understand the value of sharing personal experiences with the group while being aware that other members may deal with similar issues quite differently.
- Be aware that not everyone in the group will carry the same diagnosis. Members' needs will vary, depending on individual diagnosis, symptoms, progression of disease, treatment options, and other issues. Members should be made to feel comfortable addressing these differences and asking the leader or speaker for clarification as needed.

### Disclaimers

- Encourage participants to consult their personal physicians or health care providers with any questions about their specific medical conditions. Information provided at meetings is not a substitute for professional medical advice.
- Inform members that they are responsible for their participation and for their behavior during a PF support group meeting.
- Remind participants that information shared in PF support group meetings does not necessarily reflect the viewpoint(s) of the PFF, the support group leader, or the institution where the group may be hosted.

# Rules and Regulations for Health Care Professionals

**Health care professionals who are support group leaders** must follow important rules and regulations. While some groups may be located at hospitals or have a health care professional involved in the management of the group, if the support group leader is not a health care professional, then these regulations do not apply.

## About HIPAA

Respecting member confidentiality is fundamental for any PF support group, **but health care professionals who lead PF support groups must also adhere to HIPAA standards.**

The Federal Health Insurance Portability and Accountability Act of 1996, commonly known as HIPAA, established standards for the privacy and security of people's health information. There are important implications for support group leaders who work in hospital or clinic settings.

- **Information learned from the medical record or in the health care setting (hospital, clinic, MD office, etc.) CANNOT be disclosed to members of the group.** This includes, but is not limited to, information about birthdays, addresses, email addresses, phone numbers, relatives, diagnosis, treatments, procedures, health status, and deaths.
- Support group leaders employed in hospital or clinical settings should also use caution when sending group emails or using social media to communicate with members. Group messages, such as meeting notices, should be sent as a blind copy, or "bcc," so members cannot view each other's email addresses. This is also a good practice for any non-health care professional group leader in order to respect everyone's privacy.
- **The question every support group leader who is a health care professional must ask is, "How did I learn this information?"** If you learned it from the medical record or from conversations at the hospital or clinic, it is confidential and cannot be disclosed or discussed with the group.
- This may create some frustration in the group, where one important goal is to build trust. This is the topic of many PFF Support Group Leader Network discussions to determine best practices.
- **Information learned strictly from group members CAN be disclosed and discussed, even by the health care professional support group leader.**
- Health information disclosed by a support group leader who is not a health care professional falls outside the definition of "individually identifiable health information" under HIPAA regulations and is not HIPAA-protected information.

Health care professional support group leaders can encourage outside contact among members, such as establishing a voluntary group email or "caring network" that leaves out the support group leader. This way, any personal and health information shared within this voluntary group can be brought to the full support group by the members themselves.

## Questions to Consider

- What day of the week will you hold your meetings? A consistent date is best, e.g., the first Monday of the month, etc.
- What time of day is best for your meetings? Lunchtime and early afternoons seem to work for some groups, while others prefer early evening.
- How often will you hold meetings? Will monthly or quarterly meetings work best for your group?
- How long will your meetings be (1, 1.5, or 2 hours)? Meetings usually last for 1-2 hours.
- Will you serve refreshments? Confirm that your meeting location does not have restrictions on serving refreshments or certain foods.
- Who will be responsible for refreshments? Rotating among the attendees usually works well, or you may find a sponsor willing to provide them.
- Will you collect donations to offset costs for copying, mailing, or refreshments?

## Choosing a Location

Before you can host your first support group, you need to determine a meeting location. Many support group leaders agree that the meeting place should be consistent, if possible. Hospitals, medical centers, rehabilitation centers, community centers, churches, schools, restaurants with private rooms, and libraries are a few places to consider.

Your location should be easily accessible to your members, keeping in mind that they may not be able to walk long distances, may utilize wheelchairs or electric carts, and may have to maneuver oxygen equipment. People with PF have difficulty walking up hills, stairs, and inclines. Parking should be available close to the facility. Members who use supplemental oxygen should be reminded to bring enough to cover travel time and the meeting.

You may wish to discuss options with the staff at your pulmonary physician's clinic, such as the registered nurse, respiratory therapist, or physical therapist. Having a health care professional involved in the leadership of your group will provide you and your group with better access to medically trained speakers. Additionally, associating your group with a medical professional or medical center provides your group with credibility within the community.

Audiovisual capabilities may prove useful, especially if you will be showing webinars from the PFF Disease Education Webinar Series. To access webinars, visit [pulmonaryfibrosis.org/webinars](https://pulmonaryfibrosis.org/webinars).

**“We kicked off our support group with a series of four mini-lectures given by faculty and staff from our medical center. We advertised it to our patients and our community – it really hooked people.”**

**PF support group leader / California**

## Getting the Word Out

To make your group successful and to grow and maintain membership, you will need to promote your group. There are a variety of ways to start the process and ensure that all PF patients, especially those recently diagnosed, receive information about your group.

- Contact local hospitals, pulmonary rehabilitation programs, pulmonary function test labs, home care oxygen vendors, and doctors' offices about your group and provide them with flyers and/or brochures with details about your meetings.
- Distribute flyers to other key places, such as churches, schools, clubs, shops, nursing homes, health departments, chambers of commerce, and libraries.
- Communicate meeting details with the PFF Programs staff each time you have a meeting so we can post the information to our website's calendar of events and promote your group.
- Promote the group via the PFF's Facebook page or create your own Facebook page for your support group.
- Search for online community calendars to post information about your group. Many newspapers, chambers of commerce, and other media outlets have online community calendars.

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**“When we started, we sent letters to over 120 physicians, hospitals, and pulmonary rehabilitation centers within a three-hour radius of Sacramento.**

In September 2002, we had our first meeting. I think we only had five people. We meet monthly. I open the meeting by welcoming new members and then go over the agenda. I have a guest speaker at each meeting covering all different types of topics. Sometimes we have a roundtable discussion and meetings are always open for questions. I have an information table with handouts, pamphlets, and copies of any information I can find. I have a sign-in sheet and name tags so everyone can learn each other's names. The members are in all stages of the disease – some in wheelchairs, some with oxygen – but whatever their needs, they still keep coming.”

**PF support group leader / California**

## MEETING FUNDAMENTALS

There are many ways to run a meeting. Here are some basic considerations, as well as suggestions and examples from support group leaders.

### Logistics

Decide how you want to address organizational details.

- Meeting notifications – How will they be done and who will handle them?
- Sign-in sheets and name tags – Who will bring them to meetings?
- Minutes – Will you keep minutes and who will write and distribute them?
- Educational/resource materials – You should have a resource table available at your meetings. The PFF Patient Communication Center can help you keep this stocked. To order materials, contact [844.TalkPFF \(844.825.5733\)](tel:844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).
- Basic meeting format and agenda – See suggestions on the following pages.
- Sharing responsibilities – Letting others take leadership roles helps them feel more committed and invested in the group. Maintaining the group email list, notifying members of meetings, being in charge of the sign-in sheets and name tags can all be delegated. Many support group leaders find having a co-leader advantageous. It will take a load off you, the leader.
- Birthday cards, sympathy cards, notifications of hospitalizations or death – PF support groups led by health care professionals have found that encouraging members to establish outside contact or to form a “caring network” outside the auspices of the hospital allows members to share more information about each other and to support each other more fully. Please see “About HIPAA” on page 8.

“I asked the staff if there was any way that we could get the names and addresses of our fellow patients who had become friends. The answer was that the hospital could not supply that but we could do it on our own, so I started collecting everyone’s names, addresses, phone numbers, e-mail addresses, and spouse/caregiver names. Each month, I update this list and send it out to everyone.

Many times, the leader will need a reminder or something sent out and I push my button and it goes. Also, if someone is sick or something special is happening, we can contact each other.

**This has been very rewarding to me.”**

**PF support group member / Pennsylvania**

## Opening the Meeting

- Always start on time, even if everyone has not arrived.
- Welcome the group.
- Ask everyone to sign the attendance sheet and wear a name tag.
- Introduce yourself.
- Introduce and welcome new members.
- Read the ground rules. If yours is a new group or whenever there are new members, explain the ground rules. It's also important to remind the group from time to time.
- Go around the room and have everyone give brief introductions, stating their names and a little about themselves. Be sure to ask each member to keep the introduction short (about 1-2 minutes) so you can devote as much time as possible to giving group members the opportunity to share their stories and ask questions.
- Attend to any old business.
- Briefly discuss any new business. Ask members if they have any new business or if they have any member updates.
- Introduce the program, topic, speaker, etc.

**“I can't emphasize enough the value of taking time at the beginning of the meeting**

**to go around the room and give members a chance to introduce themselves and briefly share their stories or simply state how they're doing today. This gives new members a chance to get to know and understand the group and gives old members a chance to get things off their minds.”**

**PF support group leader / California**

## During the Meeting

**Encourage members to talk about themselves.** A support group should be a place where members feel comfortable and safe talking about personal issues and experiences. When one member shares something with the group, it gives other members a chance to offer support, ideas, and assistance. It also encourages other members to discuss their thoughts, experiences, and feelings, which helps to build rapport within the group.

**Ask open-ended questions.** As the leader, start discussions with questions that can't be answered with a simple yes or no to encourage more sharing. "What is it like for you when you visit your grandchildren now?" or "What have you told your son about your health?" or "As a caregiver, how have you managed to take care of yourself?" Questions like these will spur more thoughtful responses and give other members something to react to.

**Encourage members to listen to each other.** Listening can be just as important as sharing. As the support group leader, make sure to set a good example by being an active listener. Use body language like leaning forward, making eye-contact, and nodding your head occasionally to show that you are attentive.

**Encourage members to offer support.** No one knows more about what a PF support group member is going through than other members, so give them a chance to offer their support. After a member shares with the group, you can help everyone respond by asking questions such as, "What do you think about what Ellen is going through?" or "How do you think we can best support Richard now?" or "Has anyone else had a similar experience or feeling?"

**Offer support.** Offering support simply means making statements that show your understanding, empathy, and concern. You can repeat or rephrase the member's concern to let them know you understand and can empathize. For example, if a member says, "I can't believe my daughter doesn't want to hear about my illness," you might say something like, "It must be really hard to not be able to discuss your illness with your family right now."

## Closing the Meeting

Most support groups meet for 1–2 hours. Generally, it's best to end the meeting on time.

- Briefly summarize the topics discussed during the meeting.
- Check to see if anyone in the group has anything to add.
- Remind members about the next meeting: date, time, location, topic.
- Request volunteers, if necessary, for the next meeting.
- Thank everyone for coming and encourage them to come again.

## KEEPING THE GROUP GOING

It's important to keep your PF support group vital, relevant, and meaningful to members.

- Keep recruiting. Groups can stagnate when membership remains the same all the time. Also, when members who leave are never replaced, it will be difficult for the group to survive. Have a plan for continued recruitment. See "Getting the Word Out" for some suggestions.
- A "Year in Review" can help remind group members of all they've accomplished throughout the year, such as what they've learned, who they've met, and what progress each individual has made in their PF journey.
- Because membership, group dynamics, and individual member needs change over time, it's important to re-survey the group each year to determine their preferences.
- Be creative. Groups benefit from a variety of activities and formats to keep them engaged and committed. Be sure to draw upon members' talents and skills for ideas.
- Stay connected with other PF support group leaders to get fresh ideas for topics, activities, tips for leading, etc. You can ask to be included in email notifications for other PF support groups and you can participate in PFF Support Group Leader Network meetings to share tips with other leaders.
- When planning meetings, include group members and encourage them to share experiences with practical, useful information, being mindful of the learning environment. These are all ways to keep group members engaged.
- Apply for the Leanne Storch Support Group Fund to develop your programming or host a special event.

Get support from other group leaders – you are not alone!

Finally, one of the most productive things you can do to prepare for meetings and constantly improve your skills as a PF support group leader is to talk to other support group leaders.

### WAYS TO CONNECT

- Meet with a support group leader at a local hospital who leads another disease-specific support group.
- As a PF support group leader, you are a member of the PFF Support Group Leader Network. Get involved by attending the quarterly teleconference to connect with other PF support group leaders.
- Watch the PFF Support Group Leader Network training webinars. These presentations offer valuable information and help leaders build on their skills.

PART TWO:

# Types of Meetings, Curriculum & Yearly Program

## TYPES OF MEETINGS

People attend support groups for both informational and emotional support. Some members prefer meetings to be educational, while others prefer meetings that focus on emotional support from other group members. Individuals will have different support needs as they progress through their PF journeys. A combination of meetings featuring guest speakers and general discussions will ensure that everyone's needs are met.

In Part Two of the Guide, we present suggested topics, resources, key points, and discussion questions to help all groups meet their members' needs.

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**“My favorite PF support group meeting is in June when the staff comes back from the ATS conference and shares all the research and new things coming up for PF.”**

**PF support group member / Pennsylvania**

# General Discussion / Open Forum Meetings

Emotional support is often best achieved within the group through general discussions or open forums.

Let members know in the meeting notification that the meeting will be a general discussion or open forum. This will give them time to formulate questions, topics, concerns, or ideas that they would like to bring to the meeting and discuss with other members. Alternatively, you could pose a question ahead of time for members to think about and bring their thoughts to the meeting.

To give some structure to this type of meeting, you might consider using a “check-in” format. A check-in is a simple way to build rapport and connections among members by giving them a chance to learn about each other as people rather than as patients and to build respect for each other’s interests, skills, and circumstances. It’s also a useful, widely utilized, and popular activity for ongoing groups as a way to build rapport between old and new members.

A check-in also helps members shift their attention away from the pressures of the outside world and be more fully present in the meeting. Some groups use it at the beginning of every meeting. Checking-in can also be the format for the entire meeting.

The idea is to hear from every member of the group without getting into a discussion about what any one member discusses. All attendees should be encouraged to check-in, but if some members do not wish to participate, they may pass.

If your group is not familiar with a check-in, explain the format.

- A check-in is a brief statement by each member in response to a question (see “Framing Questions” below).
- The idea is to hear from every member without getting into discussions about what any one member might share.
- Everyone is encouraged to check-in, but saying, “I pass,” is perfectly acceptable. No one should feel put on the spot. Reassure members that it is okay to just listen.
- If someone wants to follow up about something a member said, it can be done after everyone has spoken.

## FRAMING QUESTIONS

After explaining what a check-in is, the leader or a member can propose a “framing” question. Framing questions are generally positive questions that encourage a small amount of self-disclosure, but enable brief responses. Below are some examples.

- Tell us an interesting thing about you that others in the group might not know.
- What’s something you’re really proud of that you’d like to share with the group?
- What one thing do you hope to accomplish at today’s meeting?
- What did you do this summer?
- What do you hope to learn and contribute in this group?
- Name three things you’re looking forward to now.
- What brings you energy and joy these days?
- What upcoming plans do you have for this year?
- Name something you came across recently that gave you hope or inspiration.

## FRAMING QUESTIONS (cont.)

- What recent success have you experienced?
- How has this group helped you?
- In your PF journey, who has been the most helpful to you?
- Which of your symptoms have the most significant impact on your life?
- How have your condition and symptoms changed over time?
- What was your first/best/worst job?
- What ideas do you have to help raise awareness of PF?
- How did you (or will you) tell your family and friends about your diagnosis?
- How have you advocated for yourself on your PF journey?

The simplest way to conduct a check-in is to go in order around the room. A word of caution – **be sure to watch the time carefully so that everyone gets a chance to talk.**

Check-ins can take up the entire meeting, which is okay if that's what was planned. Otherwise, it will take time away from the planned agenda. You can ask a member to be the timekeeper.

The support group leader should also respond to the framing question. There are no hard and fast rules for check-in. Individual members, the group dynamic, and group size will all determine the particulars.

## Speaker Meetings

Some topics are best covered by speakers who are experts on a particular subject. These meetings tend to be more didactic or instructive. The topic should be one the group feels is important and of practical use. The meeting should be informal and include ample time for questions and discussion.

### PREPARING FOR SPEAKERS

- Ask the speaker for a title for the presentation, the correct spelling of the speaker's name and credentials, and whether you will need to provide AV equipment, a laptop, or other materials.
- Make sure the speaker has the correct location for the meeting and your contact information if they get lost.
- Provide a few key points or learning objectives for the meeting.
- Confirm the speaker.
- Test the AV equipment and laptop, if applicable, before the meeting.
- Thank the speaker with a note or a small gift or token.

**"I find that people like to talk about concrete things,**

**such as their medication regimens or oxygen equipment, and it takes some work sometimes to get them to talk about matters of the heart. I have a good repertoire of questions to ask to get a discussion going, but I'm not always successful. I'm learning to just go where the group wants to go."**

**PF support group leader / California**

## TOPICS / CURRICULUM

The PFF surveyed our current PF support group leaders and members to determine the most popular topics that are crucial and should be discussed each year. The committee added some additional topics and divided them into three main themes: Understanding PF and Treatments, Living with PF, and Planning. We've included suggested speakers and resources for each topic, along with key points that you can share with the speaker so he or she understands the goals of the presentation.

We've also included some sample questions to help generate discussion after the presentation.

This is by no means an exhaustive list, but is meant to give you ideas about meeting topics. If you have other favorite topics or ideas for meetings, we'd love to hear them. Send your suggestions to the PFF Patient Communication Center at [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org). Don't worry about repeating topics; sometimes people need to hear things several times.

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# Understanding Pulmonary Fibrosis and Treatments

## Understanding PF

A basic understanding of the disease process and course is vitally important to those living with the disease. There are many different types of interstitial lung diseases (ILD), each with different causes and treatments. They are diagnosed by taking a detailed history, high resolution CT scan, pulmonary function tests, and possibly a lung biopsy. An accurate diagnosis is important because of the different treatments and different disease course for each type of ILD. You can likely repeat this type of meeting several times.

### SUGGESTED SPEAKERS AND RESOURCES

- Local ILD pulmonologist or nurse
- PFF Ambassador who is a health care professional
- PFF Webinar

### KEY POINTS

- Provide an overview of PF that includes the physiology, ways it is diagnosed and treated, and what patients and caregivers can expect from the disease course.
- Discuss the various forms of PF and the importance of an accurate diagnosis.

### SUGGESTED DISCUSSION QUESTIONS

- What information did you receive from your physician about the disease?
- How did you learn more about PF after your diagnosis?
- What do you still want to know?

## Pharmacological (Drug) Treatments for PF

Each person living with PF has a unique experience with the disease, so treatment strategies are highly individualized. A discussion of available therapies could focus on the idiopathic pulmonary fibrosis (IPF)-specific therapies nintedanib and pirfenidone, or an overview of all therapies available for different types of PF.

### SUGGESTED SPEAKERS AND RESOURCES

- Local ILD pulmonologist or nurse
- Clinical nurse educator from a pharmaceutical company

### KEY POINTS

- Provide an overview of pharmacological treatment options.
- Discuss each medication and what type of PF it is used to treat.

### SUGGESTED DISCUSSION QUESTIONS

- What has been your experience with PF medications?
- Do you understand the purpose of your particular medication?

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PFF WEBINARS ARE AVAILABLE ONLINE AT:

[pulmonaryfibrosis.org/webinars](https://pulmonaryfibrosis.org/webinars)

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# Understanding Pulmonary Fibrosis and Treatments (cont.)

## Lung Transplantation

A lung transplant can be an option for some patients and is the only medical therapy available to help improve survival for PF. It's important to remember that while lung transplant recipients no longer have PF, they are said to trade one set of symptoms for another. A meeting on lung transplantation could include an expert discussing the process and answering questions, along with a shared personal experience from a lung transplant recipient.

### SUGGESTED SPEAKERS AND RESOURCES

- Transplant physician or nurse coordinator
- PFF Ambassador who is a lung transplant recipient
- PFF Webinar

### KEY POINTS

- Discuss the process for lung transplantation from the evaluation all the way through the post-surgical period.
- Explain how lungs become available and the lung allocation score.
- Describe post-transplant care, especially medications and rejection.

### SUGGESTED DISCUSSION QUESTIONS

- For someone who has had a transplant, what was the evaluation process like during the first visit to the transplant center? What were some lifestyle changes you had to make in order to be listed? How has your life been different after the transplant?
- What are some things that you have heard or read about lung transplants?
- How did you make the decision to have a lung transplant? What were you hesitant about?

## Gastroesophageal Reflux Disease

Gastroesophageal reflux disease (GERD) or acid reflux is common comorbidity of PF, meaning that many people living with PF also have GERD.

### SUGGESTED SPEAKERS AND RESOURCES

- Local ILD pulmonologist
- Gastroenterologist

### KEY POINTS

- Discuss what GERD is and why it's commonly associated with PF.
- Discuss what treatment options are available for members to discuss with their physicians.

### SUGGESTED DISCUSSION QUESTIONS

- Have you experienced symptoms of GERD? Did you notice it before or after your PF diagnosis?
- What treatment strategies have you tried, both pharmacological and non-pharmacological?

## Sleep and Interstitial Lung Disease

Sleep apnea or other issues with sleeping are also common in those living with PF. This presentation could include management strategies.

### SUGGESTED SPEAKERS AND RESOURCES

- Pulmonologist or nurse who specializes in sleep disorders

### KEY POINTS

- Discuss common sleep issues and why they are often associated with PF.
- Discuss management strategies for members to discuss with their physicians.

### SUGGESTED DISCUSSION QUESTIONS

- Has anyone experienced issues with sleeping? Were these present before or after your PF diagnosis?
- What management strategies have you tried?

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[pulmonaryfibrosis.org/webinars](https://pulmonaryfibrosis.org/webinars)

## Understanding Pulmonary Fibrosis and Treatments (cont.)

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### Pulmonary Hypertension

Pulmonary hypertension (PH) occurs when blood pressure within the lungs becomes abnormally elevated. PH can be a complication of PF, especially when there are low blood oxygen levels. It can be difficult to detect in people with PF because the symptoms can be similar.

#### SUGGESTED SPEAKERS AND RESOURCES

- Pulmonologist who specializes in PH
- Cardiologist who specializes in PH
- PFF Webinar

#### KEY POINTS

- Discuss what PH is and how it relates to PF.
- Discuss how PH can be diagnosed in people living with PF and management strategies.

#### SUGGESTED DISCUSSION QUESTIONS

- Have your physicians discussed PH with you? What have they told you?
- If you have a secondary diagnosis of PH, how does it affect you?

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### Understanding Pulmonary Function Tests

Pulmonary function tests (PFTs) are breathing tests that help determine how well the lungs are functioning. There are three parts to a full PFT: spirometry, lung volumes, and diffusion capacity. A six-minute walk test is often included in a full work-up as well. PFTs are an essential part of the PF journey during diagnosis and follow-up visits with the pulmonologist. It's essential for those living with PF to understand why these tests are important and what the results mean regarding disease progression, stability, or improvement. Support group members can bring copies of their PFT results to meetings for a more interactive discussion.

#### SUGGESTED SPEAKERS AND RESOURCES

- Medical director of a local PFT lab
- Respiratory therapist
- Pulmonologist
- PFF Webinar

#### KEY POINTS

- Describe each test, what it measures, and how the results are interpreted.
- Discuss why PFTs are repeated at regular intervals and what pulmonologists can determine from the results.
- Show examples of PFT results and discuss group members' examples.

#### SUGGESTED DISCUSSION QUESTIONS

- Has your doctor ever reviewed your PFTs with you?
- Do you keep track of your numbers from one visit to the next?

### Familial Pulmonary Fibrosis and Genetics

Approximately 10–15 percent of those with an “idiopathic” form of PF have a family member affected by the disease. This is referred to as familial pulmonary fibrosis (FPF). A number of genes and genetic variants associated with the development of PF have been identified, but there is still limited understanding as to the significance of these genetic abnormalities.

#### SUGGESTED SPEAKERS AND RESOURCES

- Genetic counselor
- Genetic researcher
- Pulmonologist
- PFF Webinar

#### KEY POINTS

- Explain what FPF is and discuss some of the identified genetic variants.
- Discuss what genetic counseling is and how it might be beneficial for some PF patients and families affected by this disease.

#### SUGGESTED DISCUSSION QUESTIONS

- Has anyone else in your family been affected by PF?
- Have you undergone genetic testing? What was that experience like for you?

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# Understanding Pulmonary Fibrosis and Treatments (cont.)

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## Hypoxemia and the Need for Supplemental Oxygen

PF can cause hypoxemia, meaning there is not enough oxygen in the bloodstream to keep the tissues and cells of the body healthy. Supplemental oxygen can help keep patients healthy. A discussion of oxygen use was the most popular topic suggestion from the survey we disseminated to all members of the PFF Support Group Leader Network. There is a separate meeting topic in “Living with PF” that explores equipment and how best to access oxygen.

### SUGGESTED SPEAKERS AND RESOURCES

- Pulmonologist or pulmonary nurse
- Nurse coordinator who helps patients obtain oxygen

### KEY POINTS

- Discuss supplemental oxygen and how to determine if someone needs it.
- Explain how to decide how much supplemental oxygen is needed and when (at rest, with activity, during sleep, at altitude).
- Provide information on how to use a pulse or finger oximeter to measure oxygen levels.
- Discuss myths about supplemental oxygen use, such as becoming “addicted” to oxygen.

### SUGGESTED DISCUSSION QUESTIONS

- What challenges have you encountered since you started using supplemental oxygen?
- How has the need for supplemental oxygen impacted your lifestyle?

## Connective Tissue Disease-Associated Interstitial Lung Disease

Connective tissue disease-associated interstitial lung disease (CTD-ILD) is a lung condition that affects some people with connective tissue disease such as rheumatoid arthritis, scleroderma, and dermatomyositis. Some people are diagnosed with a connective tissue disease first and develop ILD later, while for others the ILD is the first manifestation of the disease. Pulmonologists work very closely with rheumatologists to diagnose and treat CTD-ILD. In your support group, you may have several individuals with this diagnosis, so it is a worthwhile topic to cover.

### SUGGESTED SPEAKERS AND RESOURCES

- Rheumatologist
- Pulmonologist
- PFF Webinar

### KEY POINTS

- Discuss how CTD-ILD differs from IPF and other types of PF.
- Discuss the available treatment options and clinical trials for this type of PF

### SUGGESTED DISCUSSION QUESTIONS

- For those members with CTD-ILD, how is your disease managed?
- Was your connective tissue disease or ILD diagnosed first?

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# Living with Pulmonary Fibrosis

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## Supplemental Oxygen

Oxygen is a vital part of the treatment plan for all PF patients. It's important for patients, caregivers, and family members to understand the basics of oxygen use, including the types of oxygen available, how to use oxygen to maximize benefits, and how to travel with oxygen. Other important issues to discuss are how to access oxygen and what issues your members might encounter with their equipment and providers.

### SUGGESTED SPEAKERS AND RESOURCES

- Local oxygen supplier
- Pulmonologist or pulmonary nurse
- Nurse coordinator who helps patients obtain oxygen
- PFF Webinar

### KEY POINTS

- Discuss what supplemental oxygen is and why it's important for PF patients.
- Discuss types of equipment, accessories, and how to access oxygen.

### SUGGESTED DISCUSSION QUESTIONS

- What types of oxygen equipment have you tried?
- Do you have any tips or tricks to share with the group, especially about traveling with oxygen?
- How do you feel about wearing oxygen?

## Symptom Management

Managing PF symptoms is crucial to overall quality of life. The cough and shortness of breath are debilitating for many patients, so finding a speaker who can offer tips and tricks to help live better with PF is extremely important.

### SUGGESTED SPEAKERS AND RESOURCES

- Palliative care physician or nurse
- Pulmonologist or pulmonary nurse
- Occupational therapist or physical therapist for dealing with activities of daily living
- Integrative or alternative medicine personnel
- Pulmonary rehabilitation personnel

### KEY POINTS

- Discuss how to manage symptoms, especially cough, shortness of breath, and fatigue.
- Provide tips for performing daily activities (bathing, dressing, etc.) for those living with PF.

### SUGGESTED DISCUSSION QUESTIONS

- What do you do to help manage your symptoms at home?
- What triggers your cough? When do you cough most? What helps you manage your cough?
- When are you most short of breath? How do you manage it?
- How have these symptoms changed your life and your relationships?

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## Living with Pulmonary Fibrosis (cont.)

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### Nutrition

People living with chronic lung diseases like PF need to maintain a healthy Body Mass Index (BMI) by eating a healthy, balanced diet. Since disease symptoms and treatments can make it difficult to maintain a healthy lifestyle, a discussion on nutrition can be a valuable addition to any support group curriculum.

#### SUGGESTED SPEAKERS AND RESOURCES

- Dietitian or nutritionist
- Weight management program personnel at local hospital

#### KEY POINTS

- Explain how to determine your own BMI as well as an ideal BMI.
- Discuss how proper nutrition and managing weight can help with symptoms and keep people with PF healthier.
- Offer tips for managing weight when activity levels are lowered due to fatigue and shortness of breath or when appetite decreases as the disease progresses.
- Discuss the role of BMI in lung transplant candidacy.

#### SUGGESTED DISCUSSION QUESTIONS

- How are your PF treatments affecting your appetite and weight?
- How do you manage your loss of appetite?
- How have you lost weight successfully?

### Managing Anxiety, Stress, or Depression

There is a high prevalence of depression and anxiety in people living with PF and their partners. These appear to be related to increasing symptoms and decreased quality of life. Hosting a support group meeting addressing this issue may be difficult for some members, but ultimately will be a great support.

#### SUGGESTED SPEAKERS AND RESOURCES

- Social worker, therapist, or psychologist
- Integrative or alternative medicine personnel
- PFF Webinar

#### KEY POINTS

- Discuss the connection between chronic illness and stress.
- Talk about ways to manage stress, anxiety, and depression while offering concrete tips.

#### SUGGESTED DISCUSSION QUESTIONS

- Can you describe the stress and anxiety you feel as the result of having PF?
- What makes you the most anxious?
- What frustrates you the most about living with PF?

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## Living with Pulmonary Fibrosis (cont.)

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### Pulmonary Rehabilitation

A popular topic in our survey of support group leaders, pulmonary rehabilitation is another vital piece of the treatment plan for anyone living with PF. Pulmonary rehabilitation is an evidence-based, multidisciplinary, and comprehensive intervention for individuals with chronic respiratory disease, including PF. This program is designed to reduce symptoms and optimize functional status, which ultimately can increase participation in activities of daily living that were previously challenging.

#### SUGGESTED SPEAKERS AND RESOURCES

- Local pulmonary rehabilitation professional such as a nurse, respiratory therapist, or medical director of a pulmonary rehabilitation center

#### KEY POINTS

- Discuss what PF patients can expect from a pulmonary rehabilitation program and what a typical session might include.
- Explain how pulmonary rehabilitation can benefit those living with PF.
- Discuss how pulmonary rehabilitation is paid for via insurance and what a maintenance program involves.
- Provide tips for exercising at home and discuss the importance of exercise even when feeling fatigued and short of breath.

#### SUGGESTED DISCUSSION QUESTIONS

- Have you participated in a pulmonary rehabilitation program? How has it helped?
- Do you continue exercising at home? How?
- Do you continue to use the techniques you learned in pulmonary rehabilitation? Why or why not?

### Relationships and Illness

Chronic illness is experienced by the whole family and support system of someone living with a disease like PF and can affect these relationships. Spouses who are caregivers are much more likely to experience depression than spouses who are not caregivers. It's important for loved ones to communicate throughout the disease journey.

#### SUGGESTED SPEAKERS AND RESOURCES

- Social worker, therapist, or psychologist who specializes in family counseling

#### KEY POINTS

- Discuss how the patient's experience with PF can affect the whole family and offer tips on how to best manage issues.
- Open a dialogue within the support group so members feel comfortable sharing.

#### SUGGESTED DISCUSSION QUESTIONS

- How has PF affected your relationships?
- What has been important in helping you maintain your relationships?

## Living with Pulmonary Fibrosis (cont.)

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### Being a Caregiver

Caregivers are a vital part of the PF care team and need support as well. This might be a session where you separate the patients and caregivers in order to give everyone an opportunity to speak freely about their experiences.

#### SUGGESTED SPEAKERS AND RESOURCES

- Ask a caregiver in the group to discuss his or her experience.
- Invite a PFF Ambassador who is a caregiver to speak to the group.
- Provide a social worker, therapist, or psychologist to talk with the patients and caregivers separately about their experiences.

#### KEY POINTS

- Help all group members understand the PF journey from the caregiver perspective.
- Offer a space for patients and caregivers to speak freely about fears and anxieties without their partners in the room.

#### SUGGESTED DISCUSSION QUESTIONS

- For the caregiver: What is it like being a caregiver for your loved one? How has it changed your relationship? How has it changed you as a person? Where do you go for support?
- For the patient: How has your loved one's new role as caregiver changed you as a person? How has it changed your relationship?

### Palliative Care and Hospice

Palliative care and hospice are often difficult topics to address. Many support group leaders say meetings featuring these topics are often poorly attended, but those who do attend are grateful for the information. It's important for all group members to understand palliative care and hospice, how these services can be of benefit to everyone, and when it's appropriate to access these types of care.

#### SUGGESTED SPEAKERS AND RESOURCES

- Medical director from a local palliative care and hospice agency
- A palliative care and hospice nurse or physician
- PFF Webinar

#### KEY POINTS

- Discuss palliative care and hospice. Address the similarities and differences, as well as some of the myths associated with this type of care.
- Discuss how PF patients can access both types of care and when it is appropriate to do so in their PF journey.

#### SUGGESTED DISCUSSION QUESTIONS

- If you have ever been involved with palliative care or hospice, would you like to share your experience?
- Is anyone who has utilized hospice for a loved one willing to share his or her experience?
- What are some things you have heard about palliative care and hospice?

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## Living with Pulmonary Fibrosis (cont.)

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### Resources for PF

There are many resources available for people living with PF and their families. Going over these resources could help you identify what topics your support group members want to explore further.

#### SUGGESTED SPEAKERS AND RESOURCES

- Nurse from interstitial lung disease center
- PFF staff member
- Support group leader

#### KEY POINTS

- Discuss available local, national, and online resources. Focus on reputable resources and caution against “Googling” for information.
- Review resources and get feedback from your members about what resources they have accessed themselves.

#### SUGGESTED DISCUSSION QUESTIONS

- What types of resources did you look for when you were first diagnosed? What did you find?
- What resources have you found helpful?
- What kinds of resources do you look for now?
- What resources would you find helpful that are not readily available?

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### Alternative Medicine

There may be members of your support group who rely on alternative and complementary medicine treatments for their PF. While there is no scientific evidence that these methods are helpful in slowing disease progression, there may be some techniques that people living with PF have found helpful in improving their quality of life.

#### SUGGESTED SPEAKERS AND RESOURCES

- Integrative, alternative, and complementary medicine personnel

### Participating in a Research Study

Research is essential in the field of PF. It’s important to understand the different types of research you may be asked to participate in as a patient. This meeting topic could cover the different types of research and current studies that may be available to your support group members.

#### SUGGESTED SPEAKERS AND RESOURCES

- PF physician or nurse involved in research
- Clinical research coordinator
- Institutional Review Board or Committee on Human Research member at local hospital

#### KEY POINTS

- Discuss the different types of research studies in general and why each is important to PF.
- Discuss the phases of clinical research and provide examples of current studies for each, if possible.
- Explain how to find active trials and what it means to participate.

#### SUGGESTED DISCUSSION QUESTIONS

- Has anyone participated in a research study? Why did you volunteer? What was it like to participate? What were some of your thoughts and feelings during the study?
- For those who aren’t comfortable with the idea of participating in studies, what are your hesitations?

#### KEY POINTS

- Discuss the difference between alternative medicine, complementary medicine, and integrative medicine.
- Discuss techniques that might be helpful for PF patients and caregivers and how they can access services.

#### SUGGESTED DISCUSSION QUESTIONS

- What alternative medicine techniques have you tried?
- What have they done for you?

# Planning

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## Estate and Financial Planning

It's important to know how to plan for your future. Putting an official plan in place can ensure your wishes are carried out and help eliminate uncertainty over the administration of your estate.

### SUGGESTED SPEAKERS AND RESOURCES

- Certified financial planner or certified public accountant for financial issues
- Attorney who specializes in estate planning or elder law

### KEY POINTS

- Discuss the importance of estate planning and explain the legal terms and documents encountered during this process.
- Discuss the difference between financial and health care planning.

### SUGGESTED DISCUSSION QUESTIONS

- Has anyone in the group gone through the process of estate planning? Can you describe the process for the rest of the group?
- What concerns you most about developing a financial or health care plan?

## Advance Care Planning

Advance care planning involves making decisions now about the health care you want to receive if you become unable to speak for yourself. It's important for anyone with a chronic and life-limiting illness to understand the purpose of the many forms and documents they may encounter during this process.

### SUGGESTED SPEAKERS AND RESOURCES

- Attorney, especially one who specializes in elder law
- Palliative care and hospice personnel

### KEY POINTS

- Discuss the importance of advance care planning.
- Discuss the difference between all the forms and documents, such as a living will, durable power of attorney for health care, DNR, DNI, POLST, etc. Provide examples of the documents and what to do after they are filled out.
- Discuss how to have these important conversations with family members.

### SUGGESTED DISCUSSION QUESTIONS

- Can someone tell us about the process of advanced care planning? What was it like for you and your family?
- When did you start the process? What resources did you utilize?

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## Insurance and Financial Assistance

There are many local and national assistance programs available to people living with PF, including specific treatment assistance programs and Medicare. These can be challenging to understand, so finding a qualified speaker to discuss them is important for your support group members.

### SUGGESTED SPEAKERS AND RESOURCES

- Staff from local Area Agency on Aging
- Insurance counselor or Medicare representative
- Representative from financial assistance programs like Caring Voice Coalition, Patient Advocate Foundation, or Patient Services, Inc.

### KEY POINTS

- Discuss insurance options available and how individuals can find the programs they need.
- Explain available assistance programs and how to access them.

### SUGGESTED DISCUSSION QUESTIONS

- What difficulties have you had obtaining PF treatments?
- If you have experience with any of these assistance programs, what has your experience been like?

## YEARLY PROGRAM

To help you plan your PF support group's meeting agenda for the year, we've included some additional suggestions for meeting topics that could be of interest to your members, as well as a sample calendar. We've also noted a number of popular special events that many support groups hold annually to help strengthen the bond between members.

## Other Meeting Ideas

### **PFF AMBASSADOR PROGRAM**

Host a health care professional PFF Ambassador to share the "Understanding PF" slide deck and a PFF Ambassador who is a patient, caregiver, or lung transplant recipient to share the story of his or her journey with PF.

### **RESEARCH UPDATES**

For support groups with access to ILD researchers, have one of them present updates after attending meetings and conferences, such as the American Thoracic Society (ATS), European Respiratory Society (ERS), or the PFF Summit.

### **ENVIRONMENT AND ILD**

There are many occupational and environmental causes of PF. A pulmonologist who specializes in occupational and environmental medicine can talk to your group about the different known causes of PF. You can also show the PFF's Occupational and Environmental PF Webinar (available at [pulmonaryfibrosis.org/webinars](https://pulmonaryfibrosis.org/webinars)).

### **WHAT ARE STEM CELLS?**

Stem cells and stem cell treatments are a hot topic in medicine. The PFF published a statement in 2019 regarding the use of stem cell treatments for PF (to read the statement, visit [bit.ly/pffstemcell2019](https://bit.ly/pffstemcell2019)). You could discuss the statement with your group or invite a stem cell researcher to discuss active stem cell clinical trials for PF.

### **MEETINGS FOCUSED ON MEMBERS AND WHAT THEY LIKE TO DO**

Remember your support group members are not just patients and caregivers; they are people with interests and hobbies outside of living with PF. Sometimes it's great to focus on hobbies, such as gardening or crafting, that can get people's minds off living with their disease and focus on being themselves.

# Sample Calendar

**January** Understanding PF

**February** Supplemental Oxygen

**March** PF Treatments

**April** Palliative Care and Hospice/Advance Care Planning  
APRIL 16 IS NATIONAL HEALTHCARE DECISIONS DAY

**May** Pulmonary Rehabilitation

**June** Lung Transplant

**July** Symptom Management

**August** Focus on Research

**September** Host a PFF Ambassador  
SEPTEMBER IS PULMONARY FIBROSIS AWARENESS MONTH

**October** Understanding Pulmonary Function Tests

**November** Caregiving in PF  
NOVEMBER IS NATIONAL FAMILY CAREGIVERS MONTH

**December** Year in Review / Holiday Party / Planning for the  
Upcoming Year

## Special Events

Additionally, many PF support groups build a fundraiser, PF public awareness activity, or social event into their calendar year. These events serve many purposes, including strengthening the group's bond, providing a sense of purpose, building friendships, decreasing isolation, and simply having fun.

### POPULAR ACTIVITIES

- Holiday party or cookie exchange
- Picnic or barbecue at a member's house
- Sporting event outing, such as a baseball or football game
- River, lake, or bay cruise
- Special luncheon or dinner for caregivers
- Golf tournament
- PF walk
- Participation in Pulmonary Fibrosis Awareness Month activities (Learn more at [pulmonaryfibrosis.org/pfam](https://pulmonaryfibrosis.org/pfam).)

Be sure to let the PFF know about your special events and we will post them to our calendar of events on the PFF website. Contact the PFF Patient Communication Center at **844.TalkPFF** (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org).

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“Our annual golf outing is usually in August, as well as a walk. In October, from funds raised, the patients are invited on a river cruise for our meeting and lunch.

Doctors and staff are on board, so patients can talk on an informal basis .”

**PF support group member** / Pennsylvania