

PHA's Support Group Leader Manual

About PHA

The Pulmonary Hypertension Association (PHA), established in 1991, is the world's largest, oldest patient advocacy organization whose mission is to improve and extend the lives of people affected by pulmonary hypertension. We envision a world without PH, empowered by hope.

Headquartered in Silver Spring, Md., PHA is an international organization with staff and volunteers working tirelessly through support, education and other programs to improve the lives of everyone affected by PH – patients, caregivers, medical providers and allied health professionals.

In 2016, PHA engaged its membership in a new strategic planning processes which helped PHA identify key focus areas:

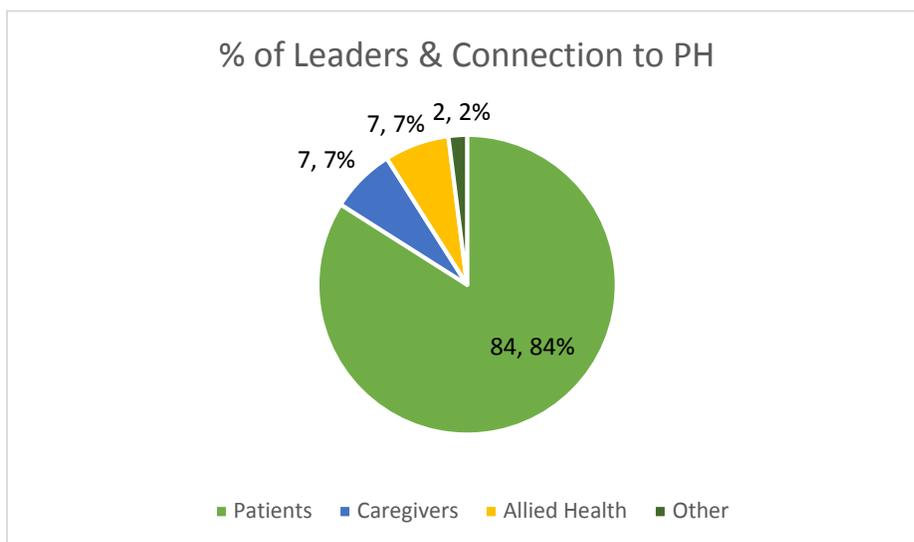
- Advocate for the PH Community
- Catalyze Research for a Cure
- Empower Patients and Caregivers
- Ensure Financial Resources to Achieve the Mission
- Promote Quality Patient Care

Support Groups

PHA provides training and resources to volunteers around the United States to create a network of support groups. Support groups are spaces open to anyone affected by PH – patient, caregiver, family member, health care provider – to empower, educate and inspire hope in one another.

Leaders

The volunteers who run support groups are called support group leaders. PHA proudly supports nearly 350 support group leaders. Anyone whose life has been affected by PH, and who agrees to PHA's volunteer terms and conditions, may lead a PHA support group and receive support from PHA. A 2016 survey of leaders showed the following distribution among constituent groups:



Becoming "Official"

Initial training to become a PHA support group leader is fairly simple. Volunteers will

- 1) Attend an initial training webinar scheduled with PHA staff.
- 2) Submit a signed leader agreement letter.

It's that easy!

Leader Agreement Letter

The Support Group Leader Agreement Letter explains the rules for being a support group leader, lists the ways PHA will support them in this work and formalizes the relationship between the volunteer and the association.

Leaders must acknowledge and agree to:

- Read and understand the Support Group Leader Manual, adhere to its policies and use it and other PHA resources explained during training to plan, advertise and run meetings
- Endeavor to hold four meetings each year; communicate with PHA if unable to do so
- Read and uphold the confidentiality statement provided by PHA
- Read and uphold the PHA mission, vision and key focus areas:

Our mission is to improve and extend the lives of those affected by pulmonary hypertension. Our vision is a world without PH, empowered by hope. To achieve our mission and ultimately realize our vision, PHA will advocate for the PH community, catalyze research for a cure, empower patients and caregivers, ensure financial resources to achieve the mission and promote quality patient care.

For every meeting, you agree to:

- Welcome anyone whose life is or has been affected by pulmonary hypertension, especially those living with pulmonary hypertension and those who care for them.
- Read PHA's confidentiality statement
- Never give medical advice and instruct support group members and attendees to seek medical advice from medical professionals.
- Promote PHA as the primary resource for information about pulmonary hypertension and support for those affected by it.
- Document the meeting after it is over using resources provided by PHA.
- Never use your role as a PHA representative to promote or fundraise on behalf of other PH organizations and other nonprofits. This includes during meetings and any other time you are wearing your support group leader "hat."

Leaders can complete this form online as well at the Support Group Leadership Institute – an online hub for leader resources and information accessible only to leaders on the PHA website.

What a Leader Is

As a support group leader, you may find yourself wearing many hats, among them

- Event planner
- Meeting host
- Club president
- Point of contact for newcomers
- Resource
- Liaison to PHA

PHA has resources to help you with each of these roles, but by far the best resource is the network of fellow leaders you can lean on for advice, guidance, ideas and support. You are not alone in your PH journey, and you are not alone in this effort to bring patients and families together. Access this network through the Support Group Leader Facebook Group or using the leader phone numbers and emails listed on the map of groups on the PHA website.

What a Leader is NOT

Some support group leaders are allied health or medical professionals, but most are not. Some leaders have professional backgrounds in mental health or meeting planning, but most do not. It's important for every leader to **establish clear boundaries and expectations** for themselves and their group. These might include

- I am **not** a PH specialist
- I am **not** a psychiatrist
- I am **not** an EMT
- I am **not** available at all hours (set your personal boundaries and expectations, whatever they may be)

Encourage attendees at your meetings to seek medical advice from their providers, get counseling from a professional if they need it and call 911 if there's an emergency. PHA does not have this expectation of you; don't have this expectation for yourself; don't allow your members to have this expectation of you, either.

Planning Meetings

Most of your time will be spent planning meetings.

As the leader, you get to decide all of the logistics about your meetings, like

- Where the meetings will be held
- When and how often you will meet
- If there will be a topic or speaker
- Whether or not you have food

There are a number of factors to consider for each of these questions, so let's take them one at a time.

Location

Where you have your meeting is an important question, and you will have to make a decision based on these considerations:

- Parking
- Handicap access
- Food service
- Central location
- Accessible by highway, public transportation, etc.

Nearly half of our current groups hold their meetings at a hospital or clinic, which has the benefit of being a location most attendees are already familiar with. Many others hold meetings at restaurants and get sponsors to pay for food. Weigh your options and make the best choice for yourself.

When and How Often

Timing is key with support groups, and our data suggest that Saturday afternoons are the most common.

But when to hold meetings, and how often, is a decision you should make with your group: Ask people what times work for them and how regularly they want to meet.

Topics and Speakers

Leaders need to balance support and education.

Try to make time at every meeting for each attendee to check in – to share how they have been doing since the last meeting. It never hurts to ask them about their health goals, and it's also important to ask about their life outside of PH – PH patients are not their disease; they are people with dreams, ideas, interests, families and so much else in their lives. Fun, lighthearted icebreaker questions are good to ask as well.

Education is also important. Remember: You are not expected to be an expert, *but* you can invite an expert to volunteer their time to speak to the group. Popular topics include

- PH diagnosis and treatment
- Clinical trials and research
- Coping with the emotional aspects of chronic illness (stress, depression, etc.)
- Diet, nutrition and exercise

For these and other topics, great speakers to invite are

- PH doctors
- PH nurses
- Pulmonary rehabilitation therapists
- Nutritionists and dietitians

For insurance-related topics, both the Social Security Administration and the Caring Voice Coalition have speakers' bureaus that may be able to help.

For more topics and speakers, contact PHA or other leaders.

Food

Food is an important part of meetings. Why? Food does three things:

1. Gives energy to attendees
2. Provides an opportunity for attendees to socialize
3. Draws people to meetings

PHA never expects for you to foot the bill. Volunteers are provided a list of pharmaceutical and specialty pharmacy company contacts which you can also access on the Support Group Leadership Institute.

Many of these companies have local representatives who will sponsor food – and often even a speaker! – at your support group meeting.

Dietary Needs

Do your best to select food or venues that meet attendees' dietary needs. Attendees need to be responsible for their own actions, but we must make it easy for them to meet their needs so they can focus more on the content of the meeting than the content of their plate.

Here are a few things to consider:

- Low-sodium for PH patients

- Food allergies, most commonly nuts
- Vegans and/or vegetarians
- People with gluten intolerance

A few little tricks make it possible to cater to all these needs:

1. You can meet all these needs with sandwiches and salads. Ask that salads, toppings, dressings, croutons, etc., be separate.
2. Ban chips from meetings and make that clear to sponsors.
3. Sandwich fillings will work for gluten-free dieters, and salads will work for them and vegans and vegetarians.
4. Identify any dishes with potentially allergic substances.
5. Salad and sandwich bars are popular and can be provided by many delis upon request.
6. Provide a list of guidelines and local sources to sponsors so everyone is on the same page.

Support Group Central Fund

In addition to putting you in touch with companies, PHA provides a special program just for leaders called the Support Group Central Fund. While it does have industry sponsors, the program is managed entirely by PHA and

- Provides up to \$15 per person per meeting, with no limit on the number of meetings
- Once per year, doubles the per-person cap for a “special meeting” (like a holiday party)
- Sends Party Packs of table cloths, paper plates and more to meetings that aren't in restaurants

The SGCF is a great program and it's easy to use. Contact PHA with any questions.

Advertising

Once you have your meeting planned, you have to tell people about it. PHA will provide the following advertising assistance:

- A flyer template (note: PHA will not create your flyer, just provide a template)
- Postcards or emails (PHA has an online form volunteers can complete to request postcards; the form has a “Part II” that allows you to request SGCF money for food, too)
- A PHA support group calendar entry, so anyone visiting the PHA website looking for a support group meeting will see yours coming up

There are a number of other advertising strategies you can do on your own, such as

- Ask your medical team and pharma reps to advertise your meeting to their patients
- Area newsletters or community calendars
- Public radio or television
- Some hospitals or clinic networks have directories of support groups yours can be added to

Running the Meeting

Presiding over a support group meeting may seem intimidating to some people, but, truly, the more space you give to attendees to talk and share, the better the meeting will be.

That said, it helps to provide structure. We recommend the following format:

- Introduce yourself, the group and its purpose
- Read – or ask a member to read – the confidentiality statement provided
- Share any updates, announcements and “housekeeping” (restroom location, etc.)
- Go over the agenda so everyone knows what to expect, and when

At that point, it is up to you whether to invite the speaker to begin their presentation, or for you to facilitate check-ins or simply invite everyone to eat and chat. Whatever you choose, it helps to always have an agenda and to stick to it.

Ongoing Training

PHA is a community of lifelong learners – from staff to doctors to volunteers.

1. We provide a monthly webinar on the second Tuesday of every month at 8 p.m. Eastern which covers a new topic each month.
2. We also seek out opportunities to bring leaders together in person, and we often host leader training sessions – called “summits” – in conjunction with larger PHA events like *PHA on the Road* and PHA’s International Conference.
3. *The Leader Letter* is a weekly e-newsletter with PHA updates and other relevant information for leaders, and it often includes tips and advice relevant to your work.

Networking

Connecting with other leaders is probably the very best resource PHA has to offer. The leader network is the best place to go for meeting ideas, troubleshooting issues that arise in your group and gaining support and even sympathy for the hard work you are doing for the PHA community. Every leader is

- invited to join a leaders-only Facebook group
- assigned a mentor
- provided a link to contact the Support Group Leader Advisory Board

In addition to these specific resources, we encourage new leaders to reach out to other leaders nearby (you can find groups and leader contact information on the PHA website). Go to other meetings if and when you can. Tell your group about other groups. Embrace an attitude that helping others will help your group, which ultimately helps the larger mission of PHA: to improve and extend the lives of people affected by pulmonary hypertension.

Retirement

Leaders retire from time to time for various reasons, and PHA understands.

If you decide to step down from leading your group, please contact PHA so we can update our records and thank you for your service.

Before you step down, please identify a new leader. Put them in touch with PHA for training and so that PHA can update records, review leader requirements, give them access to PHA resources and answer any questions.

In Closing

In 2016, PHA’s International Conference was held in Dallas. During a luncheon for support group leaders, with nearly 150 in attendance, we reflected on Texas being the Lone Star State, and how so many people in the PHA community begin their PH journeys feeling like “lone stars.” For many, it takes joining a support group to see that each individual light is part of a constellation, and that all together we are indeed a galaxy of hope.

Thank you for your efforts to bring together members of the PHA community. Let your light shine.

For further assistance, contact SupportGroups@PHAssociation.org or 240-485-0758.

APPENDIX I: Support Group Leader Meeting Checklist

Use this template to plan meetings. These are suggestions; you are not obligated to do everything listed.

Date, time and location

- I selected a date and time (or we have regular meeting times)
- I confirmed the meeting location (or we have a regular meeting location)
- The date, time and location work well for attendees (I will check in with them during the meeting)

Food

- There will be food at the meeting
- I have a sponsor
- I know where and when to get the food (or the meeting is at a restaurant)
- I know when and how the food will be served during the meeting

What kind of meeting

- I have chosen a topic for the meeting
- I have chosen a speaker for the meeting (or there is no speaker)
- I have the audio/visual equipment and other materials I need for the speaker and topic

Advertising

- I requested postcards from PHA
- I asked PHA to post the meeting on the support groups calendar
- I asked my doctors to help
- I posted an ad in community newsletters and local free media

Agenda & program

- I have a sign-in sheet for attendees so I can add to my list and PHA's list
- I have a copy of the Confidentiality Statement
- I have a copy of the PHA mission and vision
- I will observe a brief moment of silence for those we have lost
- I will share PHA and support group announcements
- I have an introduction prepared for the speaker or the meeting
- I know when my next meeting is going to be so I can tell everyone and they can plan ahead

Check-ins

- I checked in with everyone who came
- I asked if the meeting time and location were convenient
- I asked if they needed other resources from PHA
- I asked if they had topics they would like to cover at future meetings, or suggestions for speakers

Just in case

- I have PHA materials to give to attendees if they have questions I can't answer
- I know what to say if someone is monopolizing the conversation
- I know what to say if someone hasn't gotten a chance to speak

APPENDIX II: Thank You Letter and Letter of Welcome to New Group Members

Use this template to craft messages to guests who attend meetings to encourage them to come back.

Hello [name of new group member],

Thank you for joining our recent PH support group meeting on [date of last meeting]. [personal note – eg, **it was nice getting to meet you and your husband; thanks for coming all the way from Baltimore!**] The purpose of this group is patient and family support, as well as education to improve emotional and medical wellness.

And welcome to the [support group name] Support Group! We will notify you of upcoming meetings. We meet [how often/regular meeting time, eg, the first Wednesday of every month] and our next meeting is [date/time/location]. Please come and bring your caregivers, loved ones, coworkers – anyone in your life who could benefit from learning more about this disease.

I encourage you to also become an official member of the Pulmonary Hypertension Association (PHA), if you aren't one already. PHA is a national organization whose mission is to improve and extend the lives of anyone affected by PH. Membership connects you with resources and dues go toward programs and research. Email Membership@PHAssociation.org or call 310-565-3004 ext. 756 to join.

If you ever need to talk someone, don't hesitate to contact me. You can also call the PHA Patient-to-Patient Support Line anytime with volunteers available to talk: 800-748-7274. Let me know if you have any questions, comments or concerns.

Sincerely,

[leader name and contact info – include all leaders and co-leaders]

APPENDIX III: Invitation to Speaker

Use this template to draft notes to people you would like to invite to speak at meetings.

Hello [name of speaker],

I am [your name], leader of the [support group name] pulmonary hypertension support group which provides PH patients and caregivers an opportunity to support one another, and to learn important information for medical and emotional wellness.

I would like to invite you to join our meeting on [date] to speak on [topic]. [personal note – why them? Eg, "A fellow support group leader of mine, Venita Welcome, praised your presentation on nutrition at her Somerset group last year. I was hoping you could share that same presentation with my group here in Newark."]

Our normal meeting format is [explain normal meeting format; be specific – eg, "that we arrive at noon and spend the next half hour having an informal lunch. At 12:30, I will begin the official program with a Confidentiality Statement and some other announcements. Then we go around the circle saying our

name, our connection to PH and for how long, and answering an icebreaker question provided by me. At 1:00, I will introduce the speaker and you would have 30 minutes to present, followed by 30 minutes of Q&A and any other conversation before we wrap up at 2].

Please let me know by [set a deadline] if you can speak at our meeting on [date, again]. If you can, let me know if our normal format will work or if you have any questions or need any accommodations.

Thank you very much,

[leader and co-leaders name/s and contact info]

APPENDIX IV: Invitation to Sponsor

Use this template to send an invitation to someone to sponsor food and/or a speaker.

Hello **[name of speaker]**,

I am **[your name]**, leader of the **[support group name]** pulmonary hypertension support group which provides PH patients and caregivers an opportunity to support one another, and to learn important information for medical and emotional wellness.

Would you be able to sponsor our meeting on **[date]** to speak on **[topic]**. **[personal note – why them?** Eg, “A fellow support group leader of mine, Venita Welcome, praised your sponsorship of recent meetings for her Somerset group. I was hoping you could help us in a similar way by providing food and beverage for my group here in Newark.”]

[if you don't have a speaker/topic] If you are also able to provide a speaker for an educational topic, we would be so grateful. Support group members are especially interested in learning more about **[name topics – this is helpful so that they don't provide a speaker on a topic you've had recently or that your members are not interested in]**

[if you already have a speaker/topic] The theme of the meeting will be [topic], and [name speaker] will be attending to offer a presentation on the topic.

Please let me know by [set a deadline] if you can sponsor our meeting on [date, again].

Thank you very much,

[leader and co-leaders name/s and contact info]