

Affiliating Your Educational Support Group with the Asthma and Allergy Foundation of America

Welcome!

We're glad you are interested in educational support groups. The Asthma and Allergy Foundation of America (AAFA), a private not-for-profit organization based in the Washington, D.C. Metro Area, believes that educational support groups are one of the most important ways to help people with asthma and allergies. Every day AAFA's nationwide network of educational support groups and chapters make a real difference in the lives of thousands of individuals. By joining us, you can help make that difference in your community.

An AAFA-affiliated educational support group reaches out with support and education to patients and their families. This sharing and learning, along with the physician care, offers the best in asthma and allergy management today. We hope you decide to join our circle of support.

<u>Affiliation Process</u>

Benefits of affiliating with AAFA include:

- The credibility of being associated with a national organization
- Technical assistance on educational support group setup, programs, events, fundraising, and member motivation
- Referrals to your educational support group through the 800 line, chapters, website, and all national staff
- Free educational materials and resources from AAFA and Kids With Food Allergies (KFA)
- Free subscription to Leaders Link, AAFA's support group leader/advisor newsletter

How do we affiliate with AAFA?

To affiliate with AAFA, your group needs:

- At least 5 members
- A leader or two co-leaders
- Physician(s) to serve as a medical advisor
- Complete the affiliation forms
- Submit semi-annual reports on the group's activities

To affiliate, you must complete the following **three** affiliation forms found on our website:

- 1. Affiliation Agreement
- 2. Medical Advisor Agreement
- 3. Educational Support Group Contact Information

Educational Support Group Medical Advisor

Role of the Medical Advisor

The responsibilities of the medical advisor include:

- Discuss all medical content featured at meetings (meeting topics, speakers, programs, and materials distributed) with the educational support group leader
- Approve all items written by the educational support group that include medical information and/or the medical advisor's name
- Refer patients and others to group meetings
- Serve as a liaison between the group and community contacts, including respiratory therapists, allied health professionals, nurses, pharmaceutical representatives, pharmacists, and home health care businesses
- Speak to the media as the need or opportunity arises

Selecting a Medical Advisor

At least one medical advisor per group is required who agrees to support the Asthma and Allergy Foundation of America's mission and has had specialized training in respiratory disease and/or allergies. A current copy of the medical advisor's curriculum vitae should be attached to the affiliation forms.

Many leaders discover that their personal physician is more than willing to serve as the medical advisor. If the leader's physician cannot assume this role, ask him or her to recommend another physician who has the interest and the time. Your local AAFA chapter, pharmacists, respiratory therapists, and nurses are also good sources for referral.

Your Medical Advisor Must:

- Hold one of the following credentials:
 - MD
 - PA
 - DO
 - APRN
- Complete and sign the Medical Advisor Agreement form
- Include a copy of their Curriculum Vitae with the Medical Advisor Agreement

Common Questions

Is an AAFA-affiliated educational support group tax-exempt?

AAFA's tax-exempt status does not extend to affiliated educational support groups. In areas where there is no chapter, or the chapter is unable to offer assistance, some educational support groups have secured their own not-for-profit status.

Can we affiliate with AAFA if we are also associated with other non-profit organizations? Yes!

Can non-AAFA materials be distributed at educational support group meetings?

Yes, though medical content must be reviewed and approved by your medical advisor. However, all group newsletters should include a disclaimer such as the following:

"Information contained in this publication should not be used as a substitute for responsible professional care to diagnose and treat specific symptoms and illness. Any reference to available products and procedures should not be construed as an endorsement nor are such references a representation as to the effectiveness or appropriateness of any such product or procedure. The Asthma and Allergy Foundation of America, including all parties to or associated with this publication, will not be held responsible for any action taken by readers."

How do I use a medical disclaimer?

Provide in writing with any materials you disseminate and explain during your meetings that any reference to products or procedures should not be construed as an endorsement; in addition, any information provided is never a substitute for professional medical care.

What is the disease focus for most AAFA-affiliated support groups?

Our support groups vary in size, focus, and structure. Some groups incorporate a combination of asthma, allergies, and food allergies; other groups choose to concentrate on a specific topic, such as asthma only. Audiences vary as well; we have groups aimed at pre-teens and teens, adults, parents, etc.

Basics of Starting an Educational Support Group

Congratulations on your interest in starting an educational support group with the Asthma and Allergy Foundation of America! What a great way to help others and help yourself at the same time.

Educational support groups bring people together through shared experiences. The community setting provides camaraderie, friendship – and of course, the vital support that helps members realize they are not alone. Groups meet to learn current information about asthma and allergies, offer each other emotional support, share valuable tips on managing asthma and allergies, and identify methods of reaching out to educate the community.

There is no single recipe for developing a group. Different individuals, issues, needs, and resources require different approaches, but the questions and answers below will provide you with a framework. They are suggestions for success!

Forming a Group

Who can start an educational support group?

Anyone who has a positive attitude, a sense of commitment, good people skills, and the ability to delegate will be a good leader! Some AAFA support groups are led by professionals while others are led by laypeople. Other groups are led by a team – a combination of professional and layperson that have "in the trenches" experience is ideal.

Who will join an educational support group?

Members will come from all facets of your community. Reach out within your networks to see who might be interested in joining the group. If you are a parent, you could try sending a message through your child's school to find other parents or children with asthma/allergies. Social media is another option for spreading information about your group and inviting others to join. Some groups have drawn members by posting their information in local media, community centers, and physician's offices.

Give physicians, allied health professionals, day care personnel, or teachers your written permission to provide your contact information to individuals who have similar health challenges. You can also make up your own informal business cards or mini-flyers that can easily be carried with you for spur-of-the-moment distribution.

Who will help with the group's activities?

It's up to you to energize and motivate your members to pitch in. Just because you started the group does not mean you have to do everything by yourself! Here are some tips:

- Delegate, delegate, delegate.
- Find out a potential volunteer's area of interest and expertise and match him/her with a group need.

- Ask for volunteers at the meeting and immediately pass around a clipboard with the job description and estimated hours needed to accomplish the task.
- Recognize individuals who help and give credit in your newsletter, meeting agenda, and at meetings.
- Ask for volunteer participation on many different levels. Contributions can range from a
 onetime donation of napkins/cups to working on a single special event like a Family
 Asthma Day or writing the group newsletter. Each situation provides the volunteer with
 an opportunity to feel good and to have a real investment in the success of the group.

Where do most groups meet?

Many groups meet at hospitals because the hospital locations are usually well-known and the medical setting lends itself nicely to the topics at hand. Other options for meeting places include community centers, schools, or religious centers (which will often rent space for community events). Depending on the size of the group, you can even meet at a member's home.

Wherever you meet, you will most likely need to reserve the rooms in advance, and make sure there is adequate lighting and safe parking before you decide on a definite meeting place. Remember to mark the route to the meeting room well and to inform the person at the front desk of the meeting location so he/she can inform attendees who are lost.

Some groups have taken more strides towards online meetings, using social media or email groups to communicate between members.

When do groups meet?

Some groups meet on a school calendar, starting in September and ending in May. The trend is toward fewer meetings per year. Quarterly meetings which offer seasonal asthma/allergy tips are popular and well attended because they are more of a special event. Mid-week evenings are the most popular time to hold meetings, but ask your members when is best for them.

How are groups funded?

If you are already located in an <u>AAFA chapter</u> area, contact the AAFA Chapter near you to receive assistance in starting your support group and to coordinate activities and fundraising efforts with your AAFA chapter.

Many groups are typically funded through private contributions at the beginning. Most do not collect dues, but some do place a basket at meetings to collect funds (or stamps) for copying and mailing. Maintain good records of expenses, donations, and materials owned by the group and hours donated by everyone, including you!

Medical advisors may be able to introduce you to pharmaceutical representatives who can donate printed resources, which are welcomed as long as they do not promote products and are reviewed by your medical advisor.

Local service organizations like the Lions, Sertoma, or Junior League may offer seed money to fledgling organizations. Companies based in your area may also award grants. Call and ask for specific information. The best news is that affiliation with AAFA is free!

How do you tell the community about your meetings?

After receiving permission, post flyers in your physicians' offices, hospitals, clinics, and pharmacies. In some areas, school nurses participate by distributing flyers to children who have inhalers, peak flow meters, or nebulizers at school.

Social media and sending messages across community list-servs and email groups will allow you to disseminate your message electronically and reach a greater number of people.

Call your local newspaper and ask if they will do a feature story on asthma and allergies with a "side-bar" about your new group. There is usually interest in seasonal stories, especially around May (Asthma and Allergy Awareness Month). Most newspapers will run a small free community service ad. Call radio stations and ask who to direct your text for your public service announcement to. Cable TV is also a good option for community service ads.

Meeting Tips

What types of topics are usually discussed at meetings?

Some groups start out by inviting a guest speaker and some start with an informal gathering. If you select a speaker, choose your medical advisor to focus on a topic that interests everyone. "Asthma and Allergy Medications: What's New and How Do They Affect You?" is a topic that is always popular and can be repeated once a year. Topics can be fairly specific – for example, with a focus on inhalers or epinephrine auto-injectors. Discussing the effect of asthma/allergies on families is another popular approach. Your medical advisor should approve all speakers and items set out on the resource table.

If you decide to start out more informally, discuss the priorities of the group. Are most attendees parents of toddlers with asthma...or children with food allergies...or adults with exercise-induced bronchospasm? The health concerns of those present will guide you toward the future.

Speaker tips: Confirm your speaker in writing, ask how he/she wants to be introduced, and make sure that directions to the meeting place are clear. Decide on a time limit in advance; approximately 45 minutes is ideal with time for questions and answers afterwards. Ask attendees to jot down questions during the presentation and then collect them for a question and answer session. This process helps the speaker and enables even shy members to have their needs addressed.

Remember to ask if the speaker will need a laptop or LCD projector. Are there handouts that need to be copied before the meeting?

And don't forget at the end – a warm "thank you" led by your applause is always appreciated!

What are some recommendations for the very first meeting?

- Post signs leading to the meeting room
- Assign a greeter who encourages attendees to sign in and wear a name tag
- When members sign in, ask for the usual contact information plus information on how they heard about the meeting and the age of the person(s) in their family with asthma or allergies
- Have an agenda on the resource table
- If possible, offer refreshments to encourage networking
- Ask for help on specific projects
- Provide information about your next meeting, if possible
- Thank everyone who took part in your successful meeting!

After the meeting, you can discuss with your members what was successful and what could use improvement. Remember to congratulate yourselves for all of your hard work – you are helping to build healthier lives through education and support!