

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 Washington, DC, 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.

Affiliating Group Materials

Each affiliating group receives the following FREE materials

1. *Starting Strong - Staying Strong*: A Resource Manual for Educational Support Groups and a 20 minute CD –
2. Copies of AAFA's Resource Catalog
3. A "Sample Pac" – a selection of products including peak flow meters, spacers, demo-inhalers and written information. (Contents depend on availability)
4. * FEAST groups receive 15 Epi-Pen Trainers
5. * Adolescent/Teen groups receive 25 copies of *Teens Talk to Teens* brochure
6. * Adolescent/Teen groups receive a free interactive game on CD ROM called *Quest For The Code*

Affiliating groups receive a "Library Pac" for \$50. A Library Pac contains a variety of materials (books, brochures, etc.) selected by AAFA National based on your type of group and on the availability of resources.

Benefits of Affiliating with AAFA Include:

1. The credibility of being associated with a national organization.
2. Technical assistance on educational support group setup, programs, events, fund-raising, and member motivation.
3. A Resource Manual, entitled, "Starting Strong-Staying Strong" and companion CD.
4. A Library Pac – books for starting your own lending library – available to groups paying the \$50 affiliation fee.
5. A Sample Pac containing a variety of free sample products as they become available.
6. Referral to your educational support group through the 800 line, chapters, website and all national staff.
7. Adolescent/Teen Group members will receive a bi-monthly newsletter called *AAIRwaves*, for ages 9-17 and an interactive game on CD ROM, *Quest For The Code*.
8. A certificate of affiliation with the Asthma and Allergy Foundation of America.
9. Free publicity for your group on our up-to-date website at www.aafa.org.

"This is a GREAT Opportunity!"

How do we affiliate with AAFA?

To affiliate with AAFA, your group needs:

- At least 10 members
- A leader or two co-leaders
- Physician(s) to serve as a Medical Advisor

Complete the attached affiliation form and return to the address below. There is no charge to affiliate your Education Support Group with AAFA. To receive the Library Pac, please enclose with your application a processing fee of \$50. Checks should be made out to the Asthma and Allergy Foundation of America and mailed to:

**Asthma and Allergy Foundation of America
1233 20th Street NW, Suite 402
Washington, DC 20036**

Your educational support group will be notified of acceptance within 30 days.

If you have any additional questions, feel free to write or call:

AAFA National Office
Educational Support Groups
1233 20th Street NW, Suite 402
Washington, DC 20036
Phone 202.466.7643 x 230
Fax 202.466.8940
E-mail supportgroups@aafa.org

Educational Support Group Medical Advisor

Role of the Medical Advisor

The responsibilities of the Medical Advisor include:

- Discussing and approving all meeting topics, speakers, programs, and materials distributed at meetings.
- Approving all items distributed by the educational support group, which include medical information and/or the Medical Advisor's name.
- Referring patients and others to group meetings.
- Serving as a liaison between the group and community contacts, including respiratory therapists, allied health professionals, pharmaceutical representatives, pharmacists, home health care businesses, etc.
- Speaking to the media as the need or opportunity arises.

Selecting a Medical Advisor

At least one Medical Advisor per group who supports 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 form.

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 and Unproven Techniques

Based upon the numerous scientifically controlled studies in peer review, professional journals and official positions taken by the American Academy of Allergy, Asthma and Immunology, the American College of Allergy, Asthma and Immunology, and the AAFA Board of Directors considers the following techniques in diagnosing and treating asthma and allergies to be examples of unproven and controversial methods:

- Urine autoinjection
- Cytotoxicity
- Subcutaneous provocation testing and treatment
- Sublingual provocation testing and treatment
- Low-dose allergen immunotherapy based upon skin titration (Rinkel Method)

Leaders of all groups are reminded to not give medical advice at any time.

AAFA affiliated educational support groups may not have Medical Advisors who emphasize and/or promote the utilization of controversial and unproven techniques in diagnosing and treating asthma and allergies.

Responsibilities of Affiliated Educational Support Groups

After acceptance by AAFA, educational support groups are responsible for:

1. Ensuring that only qualified professionals present medical information. **No educational support group leader or member may give any medical advice at any time.**
2. Soliciting and receiving approval by the Medical Advisor on speakers, meeting topics and any written materials containing medical information or including the advisor's name.
3. Honoring the confidentiality desires of individuals who attend meetings.
4. Advising members that a technique is scientifically unproven if such a technique is discussed or references are made at a meeting.
5. Completing an Educational Support Group Update Form annually. The form includes information on programs, meetings, speakers, and activities during the past year. Details about important and creative events may be highlighted in the ESG section of AAFA's website. You will receive a blank form to complete and return.
6. Sending newsletters, meeting announcements, etc. to the AAFA National Office and your local AAFA chapter.

Call 1-800-7-ASTHMA or visit us at www.aafa.org to find the chapter closest to you. We strongly encourage you to contact your chapter right away, and to work closely with them. You may be eligible for:

- Help in setting up, publicizing and running your educational support group.
- Additional opportunities to raise money for your group.
- Help in finding a Medical Advisor.

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 the American Lung Association or other non-profit organizations?

Yes!

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

Yes, with review by and permission of 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.”

Basics of Starting an Educational Support Group

Congratulations! You're interested 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!

As an AAFA group leader you will be a part of our “circle of support” which receives free assistance on coordinating your group, newsletters, referrals from the AAFA National office and 800 line, plus special mailings throughout the year. Since you will be on the cutting edge of asthma and allergy progress, the health of individuals you care about will improve while you are building valuable leadership skills.

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!



Before that very first meeting you need the answers to the following important questions:

Is there a need for an educational support group in your community?

Call AAFA at 1.800.7ASTHMA and ask if there is an AAFA Chapter near you. If so, the staff will offer you invaluable assistance and resources. If not, talk to your physicians and ask them about the current educational support group status in your area. They can also guide you to other professionals who will provide you with the background of any past support group endeavors. They may be interested in helping - remember to keep a notebook or file of all contacts.

Call the education and respiratory care departments of the closest hospital, school nurses, home health businesses and pharmacists to check on existing groups. While you are doing your homework to make sure you are not re-inventing the wheel, you are also developing valuable contacts.

Investigate other types of health outreach in your community and note the names of leaders. Diabetes and epilepsy groups are two great places to start. Arrange to meet with them and ask for tips on publicity, media contacts, fundraising and networking opportunities. Information they share can save you months of trial and error.

What is an AAFA educational support group?

A group of individuals who have gathered together to:

- Learn current information about asthma and allergies
- Offer each other emotional support
- Share valuable tips on the day to day management of asthma and allergies
- Identify methods of reaching out to educate the community.

To affiliate with AAFA a group must:

- Have a medical advisor who meets the criteria in the affiliation form
- Meet at least four times a year
- Submit annual reports
- Have at least ten members.

What kind of groups does AAFA have?

In addition to “General” groups, there are currently four specialized types of groups:

- Parents of children with asthma/allergies
- Pre-teens and teens
- Adults with allergies/asthma
- FEAST - Food Education Allergy Support Team for families with food allergies

Who can start an AAFA 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! Approximately 50% of AAFA groups are led by professionals while the other half are led by lay people. Some groups are led by a team — a combination of a professional and a layperson that have “in the trench” experience is ideal. Dual leadership is a great way to “grow” the group more quickly, avoid burnout and...have more fun!

Leaders of all groups are reminded to not give medical advice at any time.

And who will join and, most importantly, help?

Members will come from all facets of your community. It’s up to you to energize and motivate them to pitch in. Just because you have started a self-help group does not mean you do it all yourself. Here are some tips:

- ☑ Delegate, delegate, delegate. Sometimes the ball is dropped at a crucial moment, but remember that the world will not come to an end if things do not go exactly as planned and delegation is the *only* way your group will grow.
- ☑ 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.
- ☑ Remember to describe WIIFM, “*What’s in it for me?*”
- ☑ Recognize individuals who help and give credit in your newsletter, meeting agenda and at meetings. Ask them to stand as you acknowledge them at the meeting so others can join you in saying, “Thanks!” No one has ever been thanked too much so never overlook an opportunity to honor someone for their contribution.
- ☑ 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 organization.

Where do most groups meet?

Most groups meet at hospitals because most individuals know where they are. Also the medical setting gives your group added credibility. If you work outside the hospital you may need to ask one of your professional contacts at the hospital to reserve the room for you. If you meet at night (which most group do) 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.

When do groups meet?

Many 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. Tuesday, Wednesday or Thursday evenings are most popular, but ask your members what evening is best for them.

How are groups funded?

Groups are typically funded through private contributions at the beginning. Most groups do not collect dues, but some do place a basket at a meeting 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!

Ask your medical advisor to introduce you to pharmaceutical representatives who may help with refreshments, copying and helping sponsor celebrities. These reps may also donate printed resources, which are welcomed as long as they are not product promotional 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 and all of the technical assistance you need is available at no cost.

How do you tell the community about your meeting?

After receiving permission, post flyers in 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.

Call the 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 also 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.

These ideas will get you started! For additional ideas or if you have any other comments or questions please contact:

Asthma and Allergy Foundation of America
1233 20th Street, NW, Suite 402
Washington, DC 20036
Phone: 202-466-7643
Fax: 202-466-8940
E-mail: supportgroups@aafa.org

Now read on for helpful hints for your first meeting.....

The First Meeting - Building the Group

What should the first meeting be about?

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 should be repeated once a year. Other popular meetings are *Tools of the Trade: Spacers, Peak Flow Meters* and *The Domino Effect: Families Coping with Asthma/Allergies*. 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 she or he 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. Collecting attendees' questions that are jotted down during the presentation helps the speaker and enables even shy members to have their needs addressed.

Remember to ask if the speaker will need a slide, overhead or LCD projector. Are there handouts that need to be copied before the meeting? A warm "thank you" led by your applause is always appreciated!

Before and during the 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 mailing information and phone number plus information on how they heard about the meeting and the age of the person(s) in their family with asthma.
- ☑ Have an agenda on the resource table
- ☑ Have demonstration items for the presenter to use to illustrate a point - AAFA supplies these in the free Sample Pac for AAFA-affiliated groups
- ☑ Offer refreshments to encourage networking
- ☑ Ask for help on specific projects
- ☑ Provide information about your next meeting, if possible
- ☑ And thank everyone who took part in your successful meeting!

After the meeting:

- ☑ Discuss what was great and what could have been better.
- ☑ **Congratulate yourselves - you helped build healthier lives through education and support!**

Starting an Asthma and Allergy Foundation of America Educational Support Group

It's a frequent comment. "I *think* I want to start a group, but I'm not sure how to find anyone who will be interested." You *know* they are out there, but how do you find them?

You also know that networking gives you "from the trench" hints, guidance on food products that are difficult to locate and even the opportunity to develop a babysitting co-op — key items that make daily asthma or allergy management achievable.

Here are tips for those of you who want to gather individuals to form a core group — the nucleus of what will ultimately be a dynamic organization that offers cutting-edge allergy and asthma information plus emotional support to your community.

- ☑ Talk to your physicians, teachers and day care personnel about your goal of gathering individuals who want to learn together and support each other. Is there a bulletin board? Ask for permission to place a flyer on the board. The words will change depending on the focus of the group and how much contact information you want to include, but here is an example:

**Mother of food allergic child
would like to network with other parents.**

I am interested in learning, sharing and educating others!

Please contact:
Sherri Wheeler
phone number
e-mail address

- ☑ When you are contacted by an interested parent, get together for coffee or tea. Great plans can be made over a bagel! Remember the "Tupperware party principle." Ask everyone you plan to meet if they would like to bring a friend.
- ☑ Give physicians, allied health professionals, day care personnel and teachers your written permission to provide your contact information to individuals who have similar health challenges. Ask that this permission be posted somewhere highly visible so that it is a frequent reminder. Give verbal reminders of your outreach goals, too.
- ☑ Make up your own informal business cards or mini-flyers that can easily be carried in your purse or wallet for spur-of-the-minute distribution. You may be standing in line at the post office with a future dedicated AAFA support group member!



**EDUCATIONAL SUPPORT GROUP
AFFILIATION FORM**

Group Name: _____

CITY, STATE: _____

AREA(S) SERVED: _____ State
 County
 Metro Area

GROUP TYPE: (PLEASE CHECK ONE OF THE FOLLOWING IN EACH CATEGORY)

AUDIENCE: YOUTH (ONLY) ADULT (ONLY) PARENT (ONLY) ALL AGES

FOCUS: ASTHMA (ONLY) FOOD ALLERGY (ONLY) ASTHMA & FOOD ALLERGY
COMBINED

**PLEASE PROVIDE YOUR GROUP'S CONTACT INFORMATION THE WAY YOU WOULD LIKE IT AVAILABLE
ON THE AAFA WEBSITE SEARCHABLE DATABASE:**

COORDINATOR(S): _____

MEETING LOCATION: _____

CONTACT NUMBER: _____

FAX NUMBER: _____

E-MAIL: _____

PLEASE PROVIDE EACH COORDINATOR AND MEDICAL ADVISOR CONTACT INFORMATION

(Lead Coordinator)

NAME: _____

ADDRESS: _____

PHONE NUMBER: (_____) - _____ - _____

EMAIL: _____

(Co-Coordinator)

NAME: _____

ADDRESS: _____

PHONE NUMBER: (_____) - _____ - _____

EMAIL: _____

(PRIMARY MEDICAL ADVISOR)

NAME: _____
MEDICAL SPECIALTY _____
ADDRESS: _____
PHONE NUMBER: _____
FAX NUMBER: _____
EMAIL: _____

(SECONDARY MEDICAL ADVISOR)

NAME: _____
MEDICAL SPECIALTY _____
ADDRESS: _____
PHONE NUMBER: _____
FAX NUMBER: _____
EMAIL: _____

I have read "Affiliating Your Educational Support Group with the Asthma and Allergy Foundation of America." I agree that _____

(Name of educational support group)

will abide by the responsibilities as listed in that document. In addition, I will notify AAFA in writing within 30 days if there is a change in group leadership or address, or a change of the Medical Advisor.

Signature of Group Leader

Date

- Enclosed is a check for \$50 for AAFA Library Pac, or
- Free affiliation without AAFA's Library Pac.

**PLEASE SEND TO:
ASTHMA AND ALLERGY FOUNDATION OF AMERICA
1233 20TH STREET NW, SUITE 402
WASHINGTON, D.C. 20036**

IF YOU HAVE QUESTIONS, CONTACT:
ASTHMA AND ALLERGY FOUNDATION OF AMERICA
(EASTERN TIME)
PHONE: 202-466-7643 x230
FAX: 202-466-8940
EMAIL: SUPPORTGROUPS@AAFA.ORG

**Asthma and Allergy Foundation of America
Affiliation Form**

Founding Members

(At least 10 members are needed to affiliate with AAFA.)

Please print names and addresses.

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

AAFA does not sell or share mailing lists. This information will be kept confidential.



**EDUCATIONAL SUPPORT GROUP
MEDICAL ADVISOR
AFFILIATION FORM**

Thank you for agreeing to be Medical Advisor to the

(Name of Educational Support Group)

an asthma/allergy educational support group in the process of affiliating with the Asthma and Allergy Foundation of America (AAFA).

Every day AAFA's nationwide network of educational support groups and chapters make a real difference in the lives of thousands of individuals with asthma and allergies. By working with your local educational support group, you will help ensure that the education it provides is appropriate, accurate and timely.

The role of a Medical Advisor in an AAFA - affiliated educational support group is to:

- Discuss and approve all meeting topics, speakers, programs and materials distributed at meetings.
- Approve all items written by the educational support group, which 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, pharmaceutical representatives, pharmacists, home health care businesses, etc.
- Speak to the media as the need or opportunity arises.

At least one Medical Advisor per group is required who supports 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 form.

Based upon the numerous scientifically-controlled studies in peer review, professional journals and official positions taken by the American Academy of Allergy, Asthma and Immunology, the American College of Allergy, Asthma and Immunology, the AAFA Board of Directors considers the following techniques in diagnosing and treating asthma and allergies to be examples of unproven and controversial methods:

- Urine autoinjection
- Cytotoxicity
- Subcutaneous provocation testing and treatment
- Sublingual provocation testing and treatment
- Low-dose allergen immunotherapy based upon skin titration (Rinkel Method)

AAFA-affiliated educational support groups may not have Medical Advisors who emphasize and/or promote the utilization of controversial and unproven techniques in diagnosing and treating asthma and allergies.

I have read the above information, and agree to be Medical Advisor to the _____ Educational Support Group.

Signature of Primary Medical Advisor

Date

Signature of Secondary Medical Advisor

Date

Please attach a copy of each physician's curriculum vitae to this form.

AAFA ADMINISTRATIVE USE ONLY

BASIC AFFILIATION
SAMPLE PAC
LIBRARY PAC
MED. ADV. LETTER

MED. ADV. CERTIF.
WELCOME LETTER
CERTIFICATE
DATE RECEIVED
DATE SHIPPED

