

If you are thinking about starting a support group and becoming a support group leader, make sure you have read <u>FARE's criteria and application process</u> to become a FARE-Recognized support group first. Then use this checklist as a guide. After reviewing this checklist, find additional advice in the *Support Group Planning Manual* below.

Who will lead this group?

- An individual affected by food allergies (e.g., a parent of a child with food allergy or an adult with food allergy)
- A professional (e.g., an allergist/mental health counselor)
- □ A mix of both!
- A rotating group of individuals affected by food allergies

Will you charge for membership?

- □ I will charge *a* small fee to support costs for professional involvement, food/drink, etc.
- \Box This group will be free.

What type of meetings will your support group offer?

- In-person
- □ Virtual/online
- □ A mix of both

How often will you meet?

- Once a week
- □ Every other week
- Monthly
- Quarterly

On which day(s)?

Where will you meet?

- Local hospital
- □ Local religious establishment
- $\hfill\square$ Private room at a coffee shop, library, etc.
- Virtual/online
- Other

List some important rules for your group:

With what content will you fill your meetings?

- An introduction/"ice-breaker," where members can:
 - a.) Share their connections to food allergies
 - b.) Share experiences
 - c.) Introduce themselves
- □ An educational experience consisting of:
 - a.) A guest speaker (professional)
 - b.) A guest speaker (within group)
 - c.) Discussion of a book
 - d.) Discussion of an article
 - e.) A theme (e.g., how to ensure your child's safety at school)
- The leader(s) will predetermine a topic for each meeting.
- We will allow the conversation to dictate the topics.
- A period for informal socializing.

What are topics you will discuss?

- Dining out with a food allergy
- □ Allergy-friendly recipes
- □ Navigating the school system
- Talking to other parents about your child
- Carrying epinephrine
- Day-to-day anxieties
- □ Challenges/success stories
- Creating a section 504 plan
- Other:

How will you advertise this group to find members?

- Website
- Facebook
- Word of mouth
- Posters on bulletin boards in common public places
- Social media posts
- Other:

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Getting Started

FARE-Recognized Support Groups and Support Group Leaders provide a valuable resource to the millions of families across the country managing the diagnosis of a food allergy. Your interest in starting a support group is the first step in helping both your family and your community to feel safe, included, and supported.

Who will lead this group?

This is the first major decision you will make! An individual who has experience in managing a food allergy (whether the allergy is his/her own or his/her child's) is the first option. This would require a substantial time commitment, but it also allows the individual to dictate the content, layout and meeting times of the group.

Another option could be a professionally led support group. For example, a local allergist could step up to this role. It may be difficult to find someone willing to volunteer his/her time, so looking for someone with a personal connection to food allergy is advisable.

Lastly, multiple people can assume the role of "leader" together. Some support groups implement a dynamic consisting of a President, Vice President, Treasurer, and Secretary. Of course, you can assign roles as needed for your specific group. This is a wonderful way to collaborate and delegate responsibility. However, this requires equal buy-in and commitment from those involved.

Will you charge for membership?

Some support groups charge a small "membership fee" that supports such costs as compensating a guest speaker, paying for meeting space, or purchasing refreshments for meetings. Others make membership free so there is no barrier to participation. This decision is really based on your own group's needs. Do you have someone you need to pay for his/her services? Do you have anyone willing to donate drinks/snacks for the meetings? Does the space you meet in cost money to reserve? These are questions you should ask yourself when deciding upon a fee.

How often will you meet?

To be identified as a FARE-Recognized Support Group, your group must meet at least once every three months. This can be in-person, via video or via teleconference. However, many groups meet more frequently. Will you meet weekly, every other week, or every month? It is best to establish dates and times early to ensure members can set aside this time in advance. When deciding upon a meeting time, consider the demographics and responsibilities of your group. Do most people work? Do most people stay at home? Oftentimes, meeting times outside of "9 to 5" are most convenient. Perhaps, you can poll your members for their availability with a free <u>Doodle poll</u>.

Where will you meet?

Make some phone calls to your local hospital, churches, temples, coffee shops, libraries, etc. Ideally, you will secure a private space without a fee for your meeting. Sometimes, hospitals may even provide complementary beverages for your group. If you do opt to hold your meeting in a public place, make sure the area you are in is private, quiet and conducive to good conversation.

When sharing this location with others, be sure to thoroughly explain how to get there. For example, which building of the hospital? What is the room number? Which entrance is most convenient? Is there a reception desk? It is better to be overly descriptive, as opposed to having new members getting lost and then showing up late.

What are the rules for your support group?

Jot down some informal rules before you hold your first meeting. Then, a verbal presentation or a physical handout will help set the tone for your group. See Appendix A for details. Do you want to create a culture of confidentiality? Do you want cellphones to be silenced? Do you want one member to speak at a time or will you allow side conversations? Are members allowed to come and go, or will you require attendance throughout the meeting? You can ask members to share their input on your suggestions, and you may decide to add or subtract from your list of rules as the group evolves.

Support Group Content

Now, you have the big questions answered. The next question is... "Well, what are we going to talk about?" Some support groups are very casual and allow the conversation to dictate the topic. After brief introductions, they work off each other's stories to fill the meeting time. Other groups are more organized. Some support group leaders predetermine a topic for each meeting, notifying their members ahead of time. This allows for adequate preparation and may (hopefully!) pique interest. Below, we will discuss possible content options for your support group.

A brief introduction

At least at the start of the first meeting, it may be beneficial to encourage members to introduce themselves, for example, by giving their name, connection to food allergies, type(s) of allergy, date(s) of diagnosis, and how they hope to benefit from participating in the support group. This does not have to happen at each meeting, but it is good practice to have new members introduce themselves.

An educational experience

During some meetings, you may opt for an educational component. For example, you could recruit a guest speaker to present to your group. This could be a professional with expertise in the field, like an allergist or a mental health expert. Or, this could be a member of the group with above-average experience in a certain domain. Perhaps, one group member is a dietitian with tips regarding cross-contact and communication with restaurants. Once you get to know your members, you'll have a better sense if anyone has content like this to offer.

Additionally, you could assign some "homework" with the hopes of spurring conversation at the next meeting. For example, a book, an article or a webinar could all be great ways to get the community engaged. Of course, you should make sure your source is trusted and up-to-date before assigning it. FARE's website is a wonderful place to obtain resources like this. See Appendix B for a sample "homework" assignment and the corresponding guided discussion. Make sure the sources are accessible for all, both in terms of time and money. For example, refrain from assigning a 200-page book that costs \$19.99. You may have read it and loved it, but you do not want costs or time demands to deter people from attending.

Theme ideas

Maybe you are struggling to find a guest speaker and do not wish to burden people with support group homework. Other leaders simply make their members aware of the upcoming meeting's theme and leave it at that. This allows members to brainstorm before the meeting on topics of discussion, questions of interest, and experiences to share. The following topics provide some ideas:

- Dining out with a food allergy
- Allergy-friendly recipes
- Navigating the school system
- Talking to other parents about your child
- Carrying epinephrine
- Day-to-day anxieties
- Challenges/success stories
- Creating a section 504 plan

A time for informal conversation

Some support groups allow 10-15 minutes for informal conversation, food and drink. This helps facilitate bonding among group members, ensures focus later, and ultimately leads to fewer distractions.

Creating an Agenda

Now, regardless of which content you decide to include in your meeting, it is VERY helpful to create an agenda for your members. Of course, this is not mandatory, but it will help the meeting flow on time. The agenda can be sent out as early or late as you wish. At the same time, if you are asking everyone to read an article, it would not be a good idea to send the agenda on the day of the meeting. If you are opting to discuss, say, "talking to other parents about your child," it may be acceptable to send the agenda closer to the meeting date, since this requires little to no preparation. Ideally, your members will come to expect when they are to receive an agenda from you. For example, if you meet every Thursday, perhaps you can habitually send the agenda to your members on Monday.

Communicating with your support group

How will your members receive the meeting agenda? This question raises the topic of communicating with your support group. There are a few options here, and your choices can reflect both your level of comfort with certain technologies and the size of your support group.

A **group email** is both easy to navigate and convenient. This will require you to obtain the email addresses of your members, accurately type them into your computer, and send emails to the entire group when necessary. Most people are comfortable using their email account, so this is one of the most popular options.

Additionally, you could create a *private, visible Facebook group* that includes only your members. This setting allows anyone to search and find the page but restricts who can join and view content. This option requires all members to have an active Facebook account.

If neither of these options sound doable, applications like *GroupMe* provide a simple way to communicate. This works on every device and pushes notifications like a text message. However, cell phone numbers are protected, and members can join only by invitation. This facilitates more back-and-forth conversation than the other communication tools would.

There is no best way to communicate with your support group. At the first meeting, it's a good idea to ask what the members prefer: "Does everyone here regularly check their email?" "Does everyone here have a Facebook account?" "Has anyone here heard of GroupMe?" Making a democratic decision is best, because this is one of the most important aspects of your group.

What will I send my members?

Now, back to the agenda. It is important to not overuse the communication avenue that you adopt. Sharing agendas and meeting reminders in a timely manner is a good place to start your communications. For example, one agenda email can be sent on Monday (see Appendix C), followed by a reminder email sent on Thursday for a meeting held Thursday night. With time, you can gauge the group to see if more communication would be welcomed or bothersome.

Marketing Your Support Group

Finally, after the logistics have been worked out and the meetings have been planned, it is time to start spreading the word about your support group. Will you rely on word of mouth? Will you have a website? Will you create posters? Will you post on social media? Once you have become a FARE-Recognized Support Group, you will have access to a recorded webinar on **marketing your support** group. It discusses best practices for using marketing tools such as newsletters, web sites, blogs, and virtual meetings to reach your target audiences online.

Messaging

In general, it is best to pick a logo, a few similar colors, and a single font and then stick with them. Consistency is key with branding your messages. You want your group to be recognizable, your aesthetic to be pleasing, and your tone to be clear. It is always recommended to use your own pictures. However, if you need more, the following websites provide free stock photos: <u>Unsplash</u>, <u>Pexels</u>, <u>Reshot</u> and <u>Foodiesfeed</u>. To create your own graphics, the following websites may be helpful: <u>Canva</u>, <u>Piktochart</u>, <u>PicMonkey</u> and <u>Stencil</u>.

Word of mouth

The power of word of mouth is not to be underestimated. Make sure you strongly encourage members to bring their friends. More likely than not, they know someone who could benefit from attending!

Website

Creating a website is a wonderful marketing tool. Here, you can post events, content of interest, support group information and more. It is important to make sure your website has a responsive design, which means it can be viewed easily on most devices. Also, including a call to action (like join, donate or subscribe) is useful. The following platforms can help you easily create your own, free URL: <u>Squarespace, WordPress, Wix, Weebly, Blogger</u>.

Posters

Aesthetically appealing posters placed strategically can do wonders for advertising your support group. <u>Canva</u> is a free website that can help you produce an eye-catching poster (see Appendix D). Or, have your child design it. Either way, be sure to have contact information and meeting information easily viewable.

Doctor's offices, schools, churches, temples and local sports complexes are all great places to put your posters. Keep in mind that some organizations may require poster approval before poster placement. Be sure to check with administrators first.

Social media

Social media can help spread the word regarding your support group. Whether you use Facebook, Reddit, Instagram, Snapchat, Twitter, or another platform, the more people you reach, the better. A good rule of thumb is to choose one or two platforms and then use them well. Ideally, you should keep your posts brief. Also, make sure your settings allow for public viewing. This will help you reach people outside of your network. A recommendation would be to create one public Facebook page (for advertising purposes) and then one private, visible Facebook page (for official group members). Once you have become a FARE-Recognized Support Group, you will have access to a recorded webinar on **using social media for your support group**. It discusses best practices for using the different platforms.

Benefits of Leading a FARE-Recognized Support Group

Leading a FARE-Recognized Support Group offers several special benefits. Support group leaders may take part in the following as part of community leadership:

- Public listing in our Support Group Directory
- Access to our closed Support Group Leader Facebook Group for peer-to-peer communication
 and resources
- Access to FARE's monthly Support Group Bulletin with the latest news and information
- Opportunity to apply for annual funding for your group through FARE's Stipend Program and Community Outreach Award Program
- Discount registration rates for the FARE conferences
- Digital recognition for your group with FARE's Support Group Web Badge (updated annually)

Good Luck!

Remember, this will not happen overnight. Developing your local support group will take time and effort. However, your hard work will pay off: community leaders like you help to improve the daily lives of people with food allergies and their families. Please feel free to contact education@foodallergy.org with any specific questions.

Appendix A

Sample Support Group Rules

"Hi everyone! I wanted to start off today's meeting with a quick reminder about the group's rules. Remember, feel free to speak up if you feel as though you may have another rule to add.

- 1.) Confidentiality
- 2.) Cell phones silenced & no texting (except for emergencies)
- 3.) One person speaks at a time
- 4.) Feel free to come and go as you please
- 5.) Try not to monopolize the conversation
- 6.) No judgements

Does anyone have anything else to add? Thanks for continuing to respect these rules."

Appendix B

Sample "Homework" with Guided Discussion

From: Support Group Leader

To: Members

Subject: "Homework" for Thursday

Hi all,

I hope everyone had a wonderful weekend! In preparation for Thursday's meeting, I would love if everyone watched minutes 12-24 of this <u>webinar recording</u> regarding "The Microbiome and Food Allergies". Of course, feel free to watch the entire video! FARE presented it on 6/24/2020.

On Thursday, we will be walk through the following questions:

1.) What is the microbiome?

- 2.) Does it impact food allergy risk?
- 3.) Can we change the microbiome?
- 4.) Can changing the microbiome change food tolerance?
- 5.) What does this mean for me/my child?

Can't wait to hear what you all have to say! See you Thursday.

Appendix C

Sample Meeting Agenda Email

From: Support Group Leader To: Members Subject: Thursday 6/25 Meeting Agenda Hi all, I hope everyone had a wonderful weekend! Here is the agenda for Thursday's meeting on 6/25. Hope to see you there! FARE Support Group Room 34B at Jones Branch Hospital 7:00 - 7:15 Informal chatter, refreshments 7:15 - 7:30 Introductions (name & connection to food allergies) 7:30 - 8:00 Guest Speaker: Dr. John Smith - IgE Testing 8:00 - 8:15 0&A 8:15 - 8:30 Debrief Reminders: Next meeting is on 7/2/2020 at 7:00 pm.

Appendix D

Sample Marketing Poster

Made with Canva.



JOIN OUR FOOD ALLERGY SUPPORT GROUP

WHEN: Every Thursday at 7:00PM WHERE: Room 34B, Fake Hospital

JOIN OUR FACEBOOK GROUP: "FARE Support Group - Faketown Chapter"

Email supportgroupleader@email.com for more information :)