

Welcome LFA Support Group Facilitator!

On behalf of the national Board of Directors, I am very pleased to have you working with the LFA as a support group facilitator!

This LFA Support Group Facilitator Manual will provide the necessary knowledge, forms, and tools you will need to successfully run an LFA Support Group. In order to provide the highest quality program, facilitators are also required to follow the *LFA Support Group Policies* and *LFA Support Group Guidelines* found in the Appendix of this manual.

I truly appreciate your time and commitment. Your efforts will have a significant and positive impact on people's lives as they learn to cope with lupus. In addition, you are fulfilling a vital component of the LFA mission: to provide a supportive and educational environment to the people living with lupus and to their families, caregivers, and loved ones.

*Thank you for making a difference in your community!*

Regards,



Sandra Raymond

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# About the Lupus Foundation of America, Inc.

## Mission Statement and Program Objectives

The Lupus Foundation of America, Inc. (LFA) is the foremost national nonprofit health organization dedicated to finding the causes and cure for lupus and providing support, services, and hope to all people affected by lupus.

The LFA energetically pursues its mission statement through five program objectives:

- Provides direct financial support to researchers through LFA's own national research program, *Bringing Down the Barriers*.
- Advocates for increased public and private sector support for research on lupus.
- Translates research findings into medically sound information and programs for people with lupus, their families, physicians, and other health professionals.
- Heightens public awareness of the impact of lupus.
- Supports individuals with lupus, and their families, caregivers and loved ones.

LFA has a national network of local chapters that provide programs and services to help people with lupus. These include:

### *Education Programs*

- Booklets and fact sheets on all aspects of living and coping with lupus.
- Print and electronic newsletters containing updates on lupus research, living with lupus, public policy issues, and local events and activities of interest to people with lupus.
- *Lupus Now*<sup>®</sup> magazine, the only national publication for people with lupus, their families, and caregivers that provides health and wellness features, lifestyle articles, research summaries, clinical updates, and more.
- Education programs to provide updates on developments in research, treatment, and coping with lupus.
- Website ([www.lupus.org](http://www.lupus.org)) which provides the latest information on living with lupus, message boards, Ask the Experts, breaking news, and links to other resources.

### *Support Services*

- Orientation seminars for people newly diagnosed with lupus.
- Support groups for people with special needs or who want help from others facing similar challenges.
- Health educators to answer questions and connect people with resources and other services, who can be reached at 800-558-0121 during normal business hours, EST.

## LFA Support Group Philosophy

People with lupus often feel alone with their disease and the everyday struggles that the disease brings to their lives, especially during times when the disease is active. *The philosophy of LFA support groups is to provide a warm and caring environment where people with lupus, their family members, caregivers, and loved ones can share their experiences, methods of coping, and insights into living with this chronic illness.* Knowing that others share this journey offers comfort and reassurance. LFA support groups encourage and accept people as they are (not by trying to change them through therapeutic or other means of intervention) and provide a comfortable learning environment to help them develop the best coping strategies to reduce stress that often accompanies living with this chronic illness.

### A Support Group IS:

- A self-help group. It is usually organized by people who share a particular challenge or life situation. LFA support groups are open to people with lupus, their family members, caregivers, and loved ones who gather periodically to share common concerns.
- A place for people with lupus to be themselves and come to terms with a diagnosis of lupus and the way their disease affects them as individuals.
- A source of information, which includes LFA educational materials and community resources.
- A place to confidentially share, learn, and help others. Group members discover a place where they can receive information that is accurate and up-to-date, as well as come to terms with living with chronic illness.

### A Support Group is NOT:

- *A professional counseling or therapy group.* If the facilitator perceives that a person needs more help than that a support group can provide, the facilitator can talk to that person privately and suggest that he or she contact his or her health care provider about any health issues that may need to be addressed. The facilitator must **not** provide individual referrals.
- A substitute for medical treatment or health counseling. *The facilitator must **not** give medical advice.*
- A replacement for family and friends, or other close relationships. However, participating in a support group may help lighten the burden of living with lupus and allow relationships outside of the group to be less stressful.
- For everybody. The idea of a support group may make some people uncomfortable. Some people prefer different types of support at different times in their lives,

depending on a variety of factors. One may not want to share his or her health problems with others, and listening to other people's problems may be too stressful. A newly diagnosed individual may not be ready to attend a support group.

- A cure. It won't make lupus go away, but it can help people with feelings of helplessness and address their fears.

## Goals of an LFA Support Group

- Provide an accepting and safe learning environment so that support group members are able to express their feelings and concerns and develop appropriate skills to cope with chronic illness.
- Provide comfort and reassurance to those who feel alone in their disease.
- Provide current and accurate information about lupus and related issues.
- Help group members come to terms with the fear of living with lupus and gain confidence in learning to cope.
- Encourage group members to share their health issues, including any change or worsening of symptoms and disease management concerns, with their doctors and other members of their health care team.
- Assist group members, through guided and effective group interaction, in adjusting to changes in lifestyle that can help them cope and better manage living with lupus.
- Provide a positive social support system where a peer support network can develop.

## Value of a Support Group

### *Sharing*

People with lupus may not be able to share with family and friends just how difficult it can be to live with the day-to-day struggles of a chronic illness such as lupus. Sharing their stories and experiences, openly and honestly with others “who have been there,” can help decrease a sense of isolation and helplessness, and promote a renewed sense of well-being. Many lifestyle adjustments are often necessary to live successfully with lupus. The exchange of information in a support group can help members process this change.

### *Peer Support and Friendship*

Most people with lupus experience any number of lifestyle adjustments. Most people who come to a support group are in the process of trying to understand their diagnosis and are looking for emotional support. Members can support and help one another in coping with the up and down cycle of the disease and its unpredictable nature. Through peer support and friendship, group members can find the courage to begin creating a “new normal” — a life that

has changed due to chronic illness, but is still fulfilling and rewarding. Peer support and friendships enable members to give help as well as receive help.

### *Information and Education*

Successfully managing lupus starts with awareness, and awareness starts with having current, accurate, and experience-based information. Through guided discussions, group members can become more aware of their particular symptoms and how lupus is affecting them. They can become more conscious of what they need to do to prevent flares and how to take care of themselves to be as healthy as possible. They can become more aware of the tension and stress that often accompany chronic illness, as well as coping strategies and techniques to reduce that stress.

A support group is a good place to get accurate, up-to-date information about lupus, the disease process, the symptoms, disease management, forms of treatment, and research. A support group can also be a good place to learn about related issues of disability income, accessibility, employment concerns, stress management, community health resources, etc. Appropriate, professional guest speakers may be invited to the meetings as approved by the LFA or Chapter to talk about these or other related issues as they pertain to the needs of support group members.

## **Why Support Groups Work**

- No one knows better than someone “who has been there” how the understanding and empathy inherent in support groups can provide a sense of relief to members.
- Support group members can help others develop new insights about living with a chronic illness such as lupus.
- Support group members can help each other understand that coping is not a single behavior, but a collection of many strategies and behaviors that develop over time.
- Support groups allow members to accept their diagnoses in a way that makes sense to them.
- Support groups allow members to take small steps which make adjusting to living with a chronic illness easier. Small, steady changes with validation from peers can help make adjusting to a life with chronic illness easier.

## LFA Support Group Facilitator Criteria

LFA Support Group Facilitator Training ensures participant understanding of how to effectively and successfully run an LFA Support Group and reinforces that facilitators must comply with *LFA Support Group Policies* and *LFA Support Group Guidelines*. Support Group facilitators have an opportunity to touch the lives of people with lupus and make a meaningful difference in their own lives.

LFA Support Group facilitators should have a true desire to help people with lupus and their families, in addition to having a basic understanding of lupus and how it can affect the body. The LFA has many educational resources in a variety of topic areas and formats that facilitators should read to learn about the complexities of lupus. The LFA appreciates its Support Group facilitators and their efforts in working to help others adjust to a life changed by lupus.

### *Facilitators need to:*

1. Submit a *Support Group Facilitator Application*. (See Appendix.)
2. Be interviewed and selected by the LFA or Chapter.
3. Attend LFA Support Group Facilitator Training. Thereafter, participation in “refresher” sessions is strongly encouraged.
4. Sign the *Support Group Facilitator Agreement*. (See Appendix.)
5. Understand and be compliant with *LFA Support Group Policies* and *LFA Support Group Guidelines*. (See Appendix.)
6. Commit to a one-year term of service as a facilitator.
7. Actively seek a trained co-facilitator for the support group.
8. Stay in close contact with the LFA or Chapter, as required.



## An Effective Facilitator

A support group needs a facilitator who has a different role than support group members. A facilitator's job is to be aware of how group members are working together to assure that the group can accomplish its goals. An effective facilitator guides group interaction according to guidelines set forth in this manual and balances individual needs with group needs. While it may be challenging at times, it can also be very rewarding.

The support group facilitator is responsible for guiding and protecting the support group process. Therefore, effective support group facilitators will often need to set limits, including time limits, and introduce topics for discussion or education programs. For example, limits should be placed on facilitator dependency. The facilitator must set limits on member access to the facilitator's personal time.

The *Seven Step Facilitator Process* provides a general framework for the support group process. A good understanding of the *Seven Step Facilitator Process* will help the facilitator run an effective support group.

### The Seven Step Facilitator Process

#### 1. Setting Climate

- Setting the climate involves allowing people to feel as though they can participate comfortably and communicate easily.
- The facilitator's job is to establish a safe climate for the healthy exchange of information. A facilitator who respects all members for their integrity and worth will create an atmosphere of friendliness and cooperation, informality and freedom.
- Another equally important part of setting the climate is to help the group to communicate effectively. The facilitator maintains an informal and friendly atmosphere in which full participation and cooperation can be achieved.
- The facilitator initiates discussion and stimulates participation.
- The facilitator works to ensure that opinions of all group members are heard and understood, even if not all participants agree.

#### 2. Mutual Planning

- Everyone plays a role in the decisions of the group. Groups work better when the planning is shared among members.
- The support group facilitator should set the precedent of sharing tasks and primary responsibilities to get group members involved in helping the group stay organized. In the short run it may seem easier for the facilitator to do most of the tasks, but such a pattern is very easily set and quite hard to break; the facilitator then becomes the "best

person to do it” at the cost of member joint ownership. Sharing tasks and responsibilities can help members connect with each other.

### 3. Assessing Needs

- The facilitator takes special responsibility for being sensitive to the need for definition or clarification of goals and purposes.
- Assessing needs is an important step that allows individuals to feel as though their needs are important and that their needs will be met.
- Many support groups spend the first few sessions simply discussing common concerns and giving members a chance to get to know one another. This is the time in which support group facilitators can assess the needs of the group.
- Once the group needs are assessed, an agenda or meeting schedule can be outlined which includes discussion or program topics that will address these needs.

### 4. Forming Objectives

- The support group facilitator helps group members form objectives to help achieve their goals individually and as a group. However, there must be some common ground in the support group; otherwise, individuals may not get what they are looking for.
- It is up to the facilitator to assure that each member’s needs are assessed and understood by the group. The group must then come to some sort of an agreement on what the common objectives of the group will be—and those objectives need to take into account everyone’s needs.

### 5. Designing

- The facilitator helps the group determine its course of action and conduct. In other words, the facilitator helps the group to reflect on its problems and assessed needs to determine what procedures might provide the best outcomes, such as open discussion, role playing, professional speakers, or a special time for socializing.
- Though the facilitator should never be in the position of making decisions for others, he or she should feel free to raise questions and make suggestions. The facilitator should not allow her/himself to be put in the position of making decisions for others.

### 6. Implementing

- The facilitator cultivates a sense of shared responsibility for the implementation of the group. The facilitator should encourage members to contribute their skills and talents. However, the facilitator has the primary responsibility to carry out the necessary tasks to successfully get a support group “up and running.”

- A co-facilitator is encouraged and can help the facilitator with many tasks and functions. The co-facilitator should help arrange and run support group meetings a few times to ensure the continuity of the support group when the facilitator is not available.
- Once the group is established, the Support Group facilitator, based on input from group members, may ask individual people to help with specific tasks and projects.

## 7. Evaluation

- The facilitator has a special responsibility to coach the group in becoming aware of the processes as well as the content of its work, and to evaluate these processes objectively so that the group can improve on them.
- The facilitator helps the members of the group to learn from their experience. By developing the habit of looking not only at what they are doing, but also how they are doing it, members of a group can improve their ways of working together.
- The evaluation process will involve several factors such as attendance, participation, staying on track, group feelings and respect, accomplishment of goals, attitudes toward the group facilitator, and members' attitudes at the conclusion of a meeting.
- Facilitators are getting results when:
  - Individuals feel they belong to the group.
  - Members improve their ability to function and feel better about living with lupus.
  - Members have developed strategies to cope better with a chronic illness.

## Qualities of an Effective LFA Support Group Facilitator

In addition to concrete skills, there are a number of important qualities that can help the facilitator lead an effective support group. Throughout the process of starting and running a support group, hard work will help the facilitator strengthen these qualities and even develop new qualities as the group also grows and develops.

- *Integrity, Self Knowledge, and Awareness:* First and foremost, facilitators who share the same life situation as the group (facilitators who also have lupus) need to evaluate where they are with their illness, and separate their own illness from their role as facilitators. Facilitators also need to be aware of their own values and attitudes that they may bring to the support group and recognize that these values may differ from those of others in the support group.
- *Commitment:* The facilitator must have a strong sense of the LFA and its mission, and believe in and be committed to the LFA support group philosophy.
- *Creativity:* The facilitator should be able to create and maintain an atmosphere for sharing, support, and education. The facilitator needs to use creativity to keep meetings interesting and worthwhile.
- *Patience:* Facilitators need to be comfortable with group silence. Facilitators need to allow group members to take the time that they need for appropriate group interaction and processing.
- *Understanding:* The facilitator needs to understand and be sensitive to the fact that lupus affects people differently, and people react to the diagnosis and living with lupus differently. Understanding and empathy (not sympathy) can help enable the group to improve relationships that enhance group processes.

## Facilitator Responsibilities

- Complete the application process, complete LFA Support Group Training, and sign the Support Group Facilitator Agreement.
- Responsibly educate himself/herself about the LFA and its mission and have a general knowledge of and understanding about lupus.
- Work continually with the LFA or Chapter to plan and organize a support group for those affected by lupus.
- Prepare for and implement a support group according to *LFA Support Group Policies* and *LFA Support Group Guidelines*. (See Appendix.)
- Understand the purpose of a support group and be willing to protect the purpose and goals of a lupus support group, and the integrity of the group.
- Guide the group in identifying its goals and keeping the group focused on those goals and tasks in order to enable effective sharing and learning.
- Maintain the value of a support group by facilitating appropriate sharing, peer support, and friendship, and providing accurate and up-to-date information.
- Serve as a good role model and practice positive coping skills.

## Facilitator Skills

A skilled facilitator will have a good sense of direction and a clear perception of immediate, as well as long-range, support group goals. Positive leadership helps the support group to develop and function more effectively. A Support Group facilitator needs to develop strong leadership skills in order to implement and guide the support group process – in order for the group to provide the best support possible to people living with lupus, their families, caregivers, and loved ones. While it can be very difficult at times, it can also be very rewarding when individuals, and the group as a whole, succeed in accomplishing their goals and are able to make effective lifestyle changes to live better with a chronic illness. The following skills are important and can help to ensure a more productive group process.

### 1. Organization

- A skilled facilitator needs to have the ability to organize a safe, warm, and caring support group environment.
- A well run support group requires sound planning, structure, and a sense of direction to help move the group forward.
- A good organizer is able to help the group sort out what is important and meaningful to group members so they can form and clarify their own goals to live better with chronic illness.
- A good organizer has the ability to maintain focus on the essence of ideas and periodically pull together the related parts of group discussions, helping group members organize thoughts and ideas to improve group interactions and build synergy.
- A good organizer does not make all of the decisions all of the time, but knows when to share and delegate responsibilities that are in the best interest of the group.

### 2. Effective communication

- Effective communication can be described as sharing information, providing feedback among group members, and having meaningful interaction that provides effective understanding of group discussions.
- Personal styles, personalities, emotions, cultural differences, and circumstances of a given situation can all influence communication. Self-awareness is an important factor in helping people to communicate with others.
- Effective communication is achieved when the facilitator and group members are able to articulate thoughts effectively. However, expressing and articulating thoughts clearly can be very difficult in a support group setting where people are dealing with emotions and various symptoms of their illness.

- Taking the time to listen and reflect on the content of what is being said – being a good listener.
- Finding purpose and intent in what is being said.
- Demonstrating that you are listening through eye contact, head nodding, etc.
- Obtain clarification by repeating the content or by asking a follow-up question that starts with “Are you saying...?”
- Pay attention to what isn’t being verbalized, such as body language.
- Being patient and giving the speaker time to say all that he or she needs to say.
- Some ineffective communication skills are:
  - Not listening
  - Not making eye contact
  - Appearing bored or distracted
  - Interrupting the speaker
  - Taking away from the speaker’s message with side talk
  - Not responding to, or ignoring the speaker
  - Minimizing or dismissing the ideas and/or problems of the speaker

### 3. Intervention

Facilitator intervention is a critical skill that guides group interaction and the entire support group process. For example, a facilitator may interrupt group discussion in order to change a behavior or keep discussion focused and on track to improve group functioning. Very specific interventions will be addressed in the next section. A skilled facilitator knows when to interrupt the support group process in order to protect the purpose and goals of the group.

- Appropriate intervention may be necessary to address conflicts or problem behaviors that threaten the effectiveness of the group.
- Appropriate interventions can help to broaden or limit participation, and move the group forward.
- Appropriate interventions can help the group process stay organized.
- Appropriate interventions help the group members to participate more effectively in group discussions and move toward more effective outcomes.

### 4. Processing

People come to a support group meeting to achieve something, so awareness of the group’s work is a very important part of every group meeting. A skilled facilitator has the ability to help

the group examine their shared thoughts, ideas, and experiences. People come to a support group with various experiences that they share with each other. Group processing, the reflection and interpretation of group interaction, generates feedback, awareness, and new learning. The facilitator moves the process along through good organization and communication, appropriate interventions, and problem solving.

- People come to a lupus support group and recreate their “living with lupus experiences” through interacting openly and honestly with each other.
- During the meeting, group members listen, interpret, and generalize what they hear from each other and provide feedback.
- Through group processing members learn that they are not alone and they find comfort in learning that others have had similar difficulties and are able to offer new insights about coping. They have the opportunity to apply new learning that makes sense to them.
- Through applied new learning, group members will bring back new experiences to the group.

## 5. Problem Solving and Decision Making

A skilled facilitator has the ability to help the support group members develop techniques and strategies to solve problems and make good decisions. The idea is to recognize problems, decide how to deal with problems in the group in the best way possible and move forward. Sometimes it is difficult to determine a problematic situation, but if something doesn't feel right, it should probably be addressed. Important steps in problem solving and making good decisions include:

- Observing a behavior or a particular need that is problematic.
  - *Ask yourself: Is there something that is making the group uncomfortable or keeping the group from moving forward?*
- Clarifying the problem with the group. Ask members to describe what they think is the real problem.
  - *Ask the group: What should be happening and what should not be happening?*
- Formulating possible solutions and assessing value of possible solutions.
  - *Ask yourself: What are some possible solutions and how will they improve the situation?*
- Choosing the most valuable solution and putting it into action.
  - *Ask yourself: What solution will benefit the most members of the group?*
- Getting feedback from group members and evaluating the effectiveness of the action taken to address the problem.
  - *Ask yourself: Were the outcomes of the action effective?*



## Planning and Organizing an LFA Support Group

Once you and the LFA or Chapter decide that you should start a support group, you have met the facilitator criteria, and you understand the *LFA Support Group Policies* and *LFA Support Group Guidelines*, the next step is to work with the LFA or Chapter to plan and organize a support group and get it “up and running.” In addition to helping you plan and organize a group, the LFA or Chapter may also be helpful in identifying a core group of people (two or three others) interested in helping you start a support group.

### How Support Groups Get Started

Every support group has its own story about how it began. The group that you are starting will also have its own unique beginning. A person with lupus, caregiver, or health care professional who sees the need for a group and is willing and able to take on the responsibility can plan, organize, and implement a support group. Some scenarios include:

- Someone with lupus contacts the LFA or Chapter looking for a support group, but learns that there are none in the area. He or she then expresses an interest in starting a group. (This is the most common situation.)
- A family member or caregiver understands that connecting with others in the same life situation may lighten the burden of the illness for those who have the disease as well as their family members.
- A health professional, such as a social worker, nurse, or mental health professional, realizes that a lupus support group would be beneficial in the community and contacts the LFA or Chapter for information about starting a support group for persons affected by lupus.
- Someone has a friend with lupus. But in order to give support, he or she needs to have some understanding about lupus and how the illness can affect people, and how to cope with lupus. *A friend who understands lupus can lend valuable support.*

## A Few Things to Consider

- Starting an LFA Support Group takes time and energy, but the benefits are worth the investment. If you have lupus, it is important to be aware of how your illness is affecting you and whether taking on the responsibility of a support group might add to the stress of your illness. On the other hand, working on developing an effective support group and helping others can be a great learning experience and very rewarding.
- Starting a support group requires a reasonable amount of planning, organizing, and preparing for each meeting. Please keep in mind the following:
  - Starting and developing a support group is an ongoing commitment.
  - Keeping a support group “up and running” is not a one person job. Working with a co-facilitator to help meet the demands of organizing and running an effective support group can make the experience more enjoyable and prevent burnout. Effectively delegating tasks is important.
  - Starting a support group can have many positive effects and can change your life. In fact, you may find yourself becoming a “lupus advocate” in your community.

## Meeting Location, Time, and Frequency

### *Location*

It is important to pick a location that will serve the greatest number of people. For example, should the group be more centrally located, or outside of a metropolitan area? Participants should not have to travel far to a support group, and the location and facility should be convenient for participants. The LFA or Chapter may have some good location suggestions based on their membership database. The LFA or Chapter must review and approve the meeting location of a support group.

### *A Safe Place*

Usually a meeting room can be found for use free of charge, but may require a contractual agreement for liability purposes. Meeting spaces may sometimes require a fee, and that must be approved by the LFA or Chapter. It is essential that the LFA or Chapter be involved in any contracts that occur and must co-sign along with the facilitator. Meetings should take place in convenient and public locations (not in private homes) that provide a comfortable and safe environment and necessary physical accommodations. Some places where support group meetings may be held include:

- Hospital meeting rooms
- YMCA or YWCA
- Senior centers
- Public libraries
- Rehabilitation centers
- A community room at a local mall
- Local LFA Chapter meeting rooms
- Churches, synagogues, or other places of worship (note that this is simply a location for a meeting and the support group is not affiliated with any religious beliefs)

Be sure to visit a potential meeting place before deciding to use it. The location must be accessible to those with disabilities as defined by the Americans with Disabilities Act. Contact the meeting facility approximately one week in advance of each meeting to confirm the meeting space.

Here are some things to consider when looking at a potential meeting place:

- Is the parking lot close to the entrance? Do people have to pay to park?
- Are the building entrances, exits, bathrooms, and meeting space easily accessible, handicapped-accessible, and well lit? Is there an elevator if needed?

- How large is the room? Will it accommodate wheelchairs? Will the room ensure privacy of the group?
- Is the room quiet, or will the noise from other building activities and the surrounding area be disturbing?
- Is the room adequately ventilated, heated, and/or air-conditioned for year-round comfort?
- Are you able to alter the lighting for people with light sensitivity?
- Can you gain access to the building and meeting room outside of conventional business hours to set up before the meeting?
- Are there any security issues?
- Is there a closet where the group can store supplies and literature? Can you bring in refreshments?
- Are there chairs and a table already in the room, or will you have to set up chairs and a table for every meeting? Can the room be set up for guest speakers? Is audiovisual equipment available to the group?
- Would the facility be willing to help your group to advertise its presence there?
- Is there a requirement for liability insurance?

### *Time*

The facilitator should be aware of his or her availability as well as the availability of potential support group members. The facilitator can ask participants at the first meeting about convenient meeting times. The day of the week and the time of day are important factors and should be consistent so people can plan ahead and make necessary arrangements. The day and the time of support group meetings should reflect what is best for the majority of group members. Here are some things to consider:

- Certain routines and commitments such as work, school, and/or childcare may preclude daytime participation for some members, especially during the work week.
- Night-time meetings require additional considerations for safety and public transportation issues. There may be more transportation options during daytime hours. It may be helpful to check public transportation schedules in the area.
- Older individuals with lupus might prefer a daytime meeting in order to avoid driving at night.
- When looking at weekends it is important to consider the religious differences within the group, especially when it comes to Sabbath observances.
- A support group meeting normally lasts between an hour and an hour and a half.

- Typically, support groups will meet from an hour to two hours. A group that meets for an hour and a half (no more than two hours) is reasonable and allows/respects group process and it respects individual time and commitment. However, support group facilitators should suggest a reasonable amount of time for group meetings and give group members the opportunity to determine a time frame that is reasonable and agreeable to the group as a whole.

### *Frequency*

How often a support group meets is an important consideration. Most support groups meet monthly. Monthly meetings are far enough apart so that they are not too stressful, yet close enough together to allow people to get to know each other and provide consistency. Some groups may meet more often if there are special circumstances and group members are seeking extra support. The frequency of support group meetings should be agreeable to all members of the group. Well-attended support groups have consistent meeting times and publish a yearly or at least a six-month schedule of meeting times and topics.

### **Type of Meeting and Format**

LFA support groups are open to people with lupus, their family members, caregivers, and loved ones only. They can be ongoing or meet for a set period of time. Participants will change from time to time and people will come to the group with various needs. When new members come to the support group meeting, they will add new perspectives; therefore, relationships within the group may change. Typically, support groups have fewer than 20 members. However, a group with six to eight (no more than ten) members is a good size for the purpose of the group and for a more focused discussion within a particular time limit.

Facilitators are responsible for structuring and guiding the group format. Although meeting formats may vary from time to time depending on the needs and composition of the group, the initial and ongoing format for a support group is often similar to the following, where the facilitator:

- Starts the meeting on time.
- Opens the meeting by introducing her/himself and extending a warm welcome to group members.
- Provides a brief orientation to the support group (e.g. the group's purpose, how it functions, the facilitator's role, meeting format, etc.)
- Asks participants to introduce themselves and briefly share their situations and what they would like to accomplish by participating in the support group. If this is not the first meeting, the facilitator may ask participants to share how they have been feeling since the last meeting.
- Guides the group in establishing and complying with ground rules, or revising as needed.

- Introduces the discussion topic and guides group discussion, making sure that everyone has the opportunity to share information and contribute to the discussion.
- Summarizes group interaction before the meeting comes to a close. This is a good time to ask members to briefly share what they got out of the meeting.
- Reminds members of the next meeting and asks if the discussion topic for the next meeting is still agreeable
- Thanks everyone for coming and closes the meeting on time.

## Meeting Topics

All meetings, even open discussion meetings, should have a topic to help the group focus. In the beginning, the group meeting topic might be “Getting Acquainted” or “Sharing your Lupus Story.” As the group grows, a variety of topics can help meet the needs of group members. *It is important to allow group members to help determine meeting structure and topics.* The following topics can be used for open discussion, or they can be addressed by a guest speaker. A possible guest speaker could be a rheumatologist or other medical specialist, a rheumatology nurse, a registered nutritionist, a physical therapist, a pharmacist, or a licensed mental health professional, depending on the topic.

The *Support Group Meeting Planner* helps facilitators plan for the year of support group meetings, topics, and guest speakers (See Appendix). As the support group progresses and its needs change, topics may have to be adjusted accordingly. We encourage you to share the planner with the LFA or Chapter upon completion and throughout the year.

### *Some suggested topics:*

#### Understanding Lupus

- What is lupus?
- What are the different forms of lupus?
- Common symptoms of lupus
- How can lupus affect the body?
- What causes lupus?
- Risks for developing lupus
- What is a lupus flare?

#### Diagnosing Lupus

- Why does a diagnosis of lupus take so long?
- How is lupus diagnosed?
- What do diagnostic tests mean?

### Treating Lupus

- What are the various categories of drugs used to treat lupus?
- The best approaches to taking medications
- Are complementary and alternative medicines safe?
- Successfully managing lupus in partnership with your doctor and health care team
- Preparing for a visit with your health care provider

### Living with Lupus

- Emotional reactions to living with lupus
- Depression
- Living with memory loss and “lupus fog”
- Living with chronic pain (pain-management)
- How can people with lupus deal with extreme fatigue?
- Photosensitivity and skin care
- Diet and nutrition for people with lupus
- Benefits of exercise and movement
- Lupus and intimacy

### Coping with Lupus

- Explaining lupus to family and friends
- Lupus on the job
- Lifestyle changes
- How has lupus changed your life?
- Stress management
- How is the support group helping you?
- Strengths gained from coping with lupus

## Support Group Promotion

Building awareness about your group is critical in order to generate interest and attract members to develop the group. Publicity should begin at least four to six weeks prior to the group meeting to:

- Provide information about the purpose of the support group and whom it may benefit. Building trust in support groups begins with the very first contact, whether it is through news releases or articles, a one-to-one personal contact, the telephone, or a group meeting. Every contact with a potential member should be characterized by a nonjudgmental attitude, empathy, understanding, and concern.
- Reach out to the community to let people newly diagnosed with lupus and other potential new members know that the support group exists and how they can join the group.
- Remind established members of upcoming meetings and expand the membership of future group meetings.

### *How to Promote Your Support Group*

Maintaining the integrity of the LFA brand is critical when conducting any kind of public awareness or promotion. The public relies on the LFA as the most credible and trusted authority for information on lupus. In order to continue to meet that expectation, promotional materials must be high-quality, accurate, and consistent with the LFA's colors and brand. To assist Chapters and support group facilitators in promoting their support group, the following tools have been developed consistent with the LFA's brand (and can be found in the Appendix of this manual):

- Flyer
- Postcard
- Print Advertisement
- Calendar Notice

The LFA or Chapter can provide the facilitator with these materials in electronic form. The Chapter logo may be added and the time, date, and location may be customized.

Below are some suggested strategies and tips to help you get started promoting your support group within your community.

### *Media*

Getting your support group listed in community newspapers, local radio event calendars, and other media outlets is a great way to increase visibility for your support group and attract a new



audience. Most newspapers, for example, have a calendar and events editor responsible for the community calendar. You can contact media outlets and ask them for the appropriate contacts.

Editors should be emailed or faxed the calendar notice with all of the relevant details including date, time, location, and any guest speakers for the upcoming support group meeting.

### *Advertising*

The print advertisement provided is currently sized to ¼ page. Each newspaper has its own size and format specifications and the ad will need to be modified to meet its requirements. Do not discount advertising just because there is a cost associated. Some weekly community newspapers have affordable rates. Targeting your advertising is instrumental in successfully recruiting participants. Identify publications that target the specific community where your support group is located. Announcements in publications focused on minorities and women are a great way to reach your target audience.

### *Community Outreach*

There are a number of organizations and places within your community that you can work with and ask for support in publicizing your support group. You can ask these groups to post flyers, publish the information on their website, or include it in their electronic or printed newsletters.

Recommended organizations and places include:

- Hospitals and community clinics
- Local health departments
- Rheumatologists' and physicians' offices
- Churches, synagogues, or other places of worship
- Libraries
- Pharmacies
- Coffee shops
- Other community based health and advocacy organizations including NAACP, La Raza, Urban League, local medical associations, and local community health coalitions.

We also encourage you to do some homework and to research organizations online! Many communities have health coalitions and organizations unique to that community.

### *Events*

Distribute flyers or postcards at local events such as a Walk for Lupus Now<sup>®</sup>, health fairs, and community festivals. Summer is a great time to find out what events and festivals are going on in your community and where you might be able to promote your support group.

### *Mailings*

A 4 X 6 postcard has been provided for Chapters and support group facilitators to mail their constituents. Do not forget to mail the postcard to previous attendees.

### *Online/Website*

- Post support group meeting information in LFA Chapter E-newsletters and websites.
- Chapters with a Facebook or Twitter account are encouraged to use these tools as a way to promote their support groups.
- Chapters and support group facilitators should also ask constituents, friends, family, etc. to help spread the word about the support group through email or Facebook.

Support group facilitators should contact the LFA or Chapter with any questions regarding the materials provided, or how to further promote support group meetings.

# The Support Group Meeting

## Before the Meeting

A facilitator can help the meeting get off to a good start by being prepared. Adequate preparation before the meeting can help you, as the facilitator, to feel more relaxed and confident about getting the meeting started. A good sense of organization and direction can help group members feel at ease, especially if this is the first meeting. Think about what you want to accomplish and how you might achieve your goals.

Have a good understanding of the meeting topic. Develop a few questions that reflect this topic to use in initiating group discussion. Look at your questions and prioritize them. Are the questions clear? How might they help keep the discussion focused? Use open-ended questions that will draw out thoughts and feelings rather than questions leading to a simple yes or no response.

For a new group, the topic might be *Understanding Lupus, Adjusting to a Diagnosis of Lupus, or How Lupus Affects You*. Some helpful questions to initiate open discussion include:

- Trying to reach a diagnosis of lupus isn't always easy. What were some of the challenges that you faced?
- At the time of your diagnosis, how did you feel?
- How do you feel now?
- How is lupus affecting you?
- What has been the reaction of your family?

For a more established group, the topic might be *Living with Lupus* or *Successfully Living with Lupus*. You can reflect on the group's experiences and ideas and share LFA educational materials. Some helpful questions to initiate discussion may include:

- How has living with lupus changed important things in your life?
- What are some of your strengths gained from coping with lupus?
- How have our group meetings been helpful?
- In past group meetings we have talked about the reactions of family and friends to your diagnosis. Have the reactions of family and friends changed over time?

### *Preparation for a Guest Speaker*

The Facilitator must get preapproval from the LFA or Chapter on all guest speakers at support group meetings. Guest speakers must be relevant to the topic of discussion and provide education to support group members, but **must not directly recruit volunteers for clinical trials, sell a product, or offer therapy**. A facilitator should submit the *Guest Speaker Request Form* at least four weeks in advance of the proposed presentation. (See Appendix.) If you have arranged for a guest speaker, you will have some additional tasks to do before the support group meeting.

- Call the speaker to remind him or her about the meeting, the time, and location.
- Ask the speaker if he or she needs directions and if there is anything that you can do to help make the experience more enjoyable.
- Let the speaker know approximately how many people will be attending and the amount of time that has been arranged for the presentation. Speakers will usually take questions at the end of their presentations, so you can ask how he or she would like to handle questions and answers at the end of the presentation, and plan accordingly.
- Make arrangements for audio/visual equipment as needed and make sure that it is in place before the meeting. You will want to test the equipment before the meeting starts.
- Ask the speaker for information that you can use to properly introduce the speaker. This may include a resume or CV that you can then provide copies of to the support group members.

### *Just Before the Meeting*

Creating a safe, warm, and caring environment starts before the meeting. Members need to feel comfortable in order to participate effectively. The following tasks are important to make sure the meeting is set up to start on time. The facilitator can ask the co-facilitator(s) or other group members to help.

- The facilitator should arrive at the meeting place well before the meeting is scheduled to make sure that the room is open, clean, and well lit, and that the temperature is comfortable.
- If the room is inside a large building, for example, you will need to post a sign at the main entrance directing people to the meeting room. Or, as a welcoming gesture, a volunteer can greet people at the main entrance and guide them to the meeting room.
- Seating in the room (usually in a circle) should be arranged so that members can maintain eye contact at all times, which provides a sense of connection from the start.

- *Support Group Meeting Sign-in Sheet* and *Support Group New Member Registration Forms* should be easily accessible and appropriate education materials neatly arranged on a table for dissemination. (See Appendix.)
- Light refreshments can make the environment feel more social and help people relax. Refreshments should be set up before the meeting so the meeting can start on time.
- As the meeting is about to begin, double-check any security issues.

### *Registration and Sign-in Process*

Facilitators are asked to follow the registration and sign-in process to enable accurate communication with support group members and to ensure complete reporting of outreach. This process is important in keeping personal information confidential. No personal information is shared with outside parties unless the participant chooses to do so.

The following forms are used in this process: (See Appendix.)

- *Meeting Sign-in Sheet* – signed by every attendee at each meeting, collected, and secured by the facilitator in his or her personal records for the duration of the support group. It will not be collected by the LFA or the Chapter.
- *New Member Registration Form* – given to each new member to complete at his/her first meeting, collected, and secured by the facilitator in his/her personal records. These forms will be attached to the *Support Group Meeting Report*.
- *Support Group Meeting Report* – completed by the facilitator at the end of each meeting to capture important outreach data, and submitted to LFA or Chapter upon request.

Given that society is increasingly more concerned about privacy issues, in particular as they relate to an individual's health, the LFA is taking a much more conservative approach when dealing with support group meeting sign-in. While organizations such as the LFA are not currently impacted by the Health Insurance Portability and Accountability Act (HIPAA) regulations, in the interest of individuals with lupus who are involved in support groups, the LFA places protecting a person's personal information at the center of our support group attendance strategy.

Confidentiality is a must for all support groups in order to create a safe and welcoming environment. Below are a few important things to consider about confidentiality.

- Group members may choose to exchange names and phone numbers among themselves. It should be made clear that no one is required to do so and that any exchange of information shall not be given to outsiders. This policy may be especially important to newcomers who have not shared their diagnosis with others (e.g., friends, employers, etc.).
- A support group is not a place for pharmaceutical representatives, company representatives, or the media. Someone seeking a lupus story or a particular project, for example, needs to be referred to the LFA or Chapter for information. Allowing

someone who is not part of the group to attend a support group meeting compromises the caring and trusting environment of the support group. It is the responsibility of the facilitator to protect the group environment.

- Individual personal problems, such as divorce or financial difficulties, for example, should not be the focus of group discussion. Personal problems of members must not be discussed outside of the group. Group members shall not provide personal advice to other group members, but information about appropriate community resources may be helpful.
- The names and phone numbers of support group facilitators are sometimes included in meeting notices and media releases. It is possible that a facilitator may receive a call from a sales or marketing person asking for names and addresses of group members, or asking if he or she may attend a group meeting. The support group is not a place for sales and marketing, and the names and addresses of group members are confidential and may not be provided, no matter what product or service is being marketed. The facilitator can ask that information about a particular product or service be sent to the LFA or Chapter. It is the policy of the LFA not to make recommendations concerning medications or products concerning the treatment of lupus.
- A facilitator may not speak to a support group member's family or friend without the support group member being present.

## Opening the Meeting

Over time, and as group members continue to participate in the support group, they will usually develop a secure set of expectations regarding the opening, running, and closing of group meetings. Familiar expectations can help group members feel more at ease. The following tasks will help open a support group meeting in an orderly manner.

### *Welcome and Facilitator Introduction*

Every meeting should start on time. It is important to respect everyone's time. As the group facilitator, you should introduce yourself, extend a warm welcome to the group, and share what your role is as a facilitator. The way a facilitator opens the support group meeting can be an indicator of how well the rest of the meeting will proceed. This is a good time to ask if everyone was able to sign the *Support Group Meeting Sign-In Sheet* and if new members were able to fill out the *Support Group New Member Registration Form* and to address any other housekeeping issues, as well as any other announcements that LFA or the Chapter has asked the facilitator to relay to the support group members. It is also a good time to ask if everyone is comfortable; if not, find out if there is anything that would help to make the group more comfortable before getting started.

### *Group Introductions*

Going around the room, allow each person to introduce him or herself. If this is the first meeting, members may want to share if they are newly diagnosed or how long they have been living with lupus or caring for someone with lupus. They can volunteer to share what brought them to the support group and what they hope to gain from the group. If this is not the first meeting, the facilitator may ask members to share briefly how they have been doing since the last meeting. Group introductions help people get settled in and become engaged. Remember that each member will interact at his or her own pace, and the facilitator should be accommodating towards people who may not want to share personal information right away.

Facilitators should also be accommodating toward new members to help them have a positive experience. Remember to acknowledge new members and be aware that they may need a clear understanding of group expectations. Consider asking an established member to offer additional attention and support to the new member. New members need to feel valued and they may need a little time to orient to the group. Before moving on, ask new members if they have any questions about the group.

Learning the names of group members is important. Address a group member by her name instead of “the lady on the right....” If the group is large, using name tags can be helpful.

### *Support Group Purpose and Goals*

Take a minute or two to remind the group about the purpose of the support group, what a support group is and is not. Briefly share the goals and the value of a support group with the members. The group is a place for people affected by lupus to come and be themselves and come to terms with their diagnosis and the way lupus is affecting them as individuals. The group is a place to share and learn from each other about the best coping strategies to reduce the tension and stress that often accompanies living with lupus.

### *Ground Rules*

An effective support group needs to have established ground rules. Generally, if members have the opportunity to participate in determining ground rules that are specific to their group, they will respectfully assume ownership for the rules that guide the effectiveness of their group. Group members should be reminded of the ground rules at the beginning of each meeting.

Confidentiality must be understood and agreeable to group members. One of the most important ground rules is that what is said and expressed within the group should not leave the group. Additionally, any information which might individually identify a group member should never be discussed outside of the group. In order to maintain a safe and caring environment, it is essential that the *LFA Support Group Policies* on privacy are followed. Group members should be reminded about the confidentiality policy at the beginning of every group meeting. The facilitator should ask to be informed about any breaches in confidentiality.

### *Additional Important Ground Rules*

- Group members will respect and listen carefully to all members, accept feelings, not engage in side conversations, and not be judgmental.
- Group members are here to express their own experiences, rather than those of someone else who is not present.
- *Emotions are a healthy part of coping.* Group members are encouraged to reveal as much or as little as they wish about their illness; it is acceptable to share both positive and negative feelings within the group.
- Avoid extensive advice-giving; group members should focus on sharing and support. **No one may offer or formally recommend medical or treatment advice.**
- If another person has expressed a need or concern, allow the group to support them before expressing your own need or concern.
- It is important that each member's differing needs and values are respected and the group remains a safe place where people can be themselves and come to terms with their illness in their own way.

After providing ground rules, the facilitator should introduce the discussion topic and initiate discussion using prepared questions. This is a good time to ask group members one thing they would like to accomplish during the meeting, given the topic.

## **During the Meeting**

### *Facilitator Awareness of Group Processing and Experiential Learning*

Support and group processing is about support group members listening to what is being said and interpreting and reflecting on what they hear. The idea is for members to consider what is being shared and how it might pertain to them, apply this new learning and then bring back their learned experiences to the group. In other words, effective group processing can help members become more aware of how their illness is affecting them and how they can apply new learning outside of the group to reduce the tension and stress that often accompanies living with lupus. It encourages them to come back to the group to, once again, share how they have handled problems based on what they have accomplished in the support group.

Open discussion at group meetings has a particular purpose. The exchange of information is really an active approach to finding “best coping strategies” to live with a chronic illness, such as lupus. The exchange of information through guided open discussion can provide various perspectives to living with lupus. Open discussion also helps people to actively deal with their emotions, thus allowing a creative learning process to develop.

During the meeting, help the group chart its course and accomplish its goals by helping the group stay focused and complete mutually agreed upon tasks. It is the facilitator's responsibility to create and maintain an emotionally safe environment, that is, an environment that accepts



people as they are and provides understanding, support, friendship, and shared learning. What happens during a support group meeting will determine the effectiveness and value of a support group.

### *Group Development through Support and Group Processing*

The stages of group development, known as *Forming*, *Storming*, *Norming*, and *Performing*, were proposed and published by Dr. Bruce Tuckman many years ago. He determined that specific phases, or developmental sequences, were necessary for a group of people to become a functioning team that could accomplish important goals. Tuckman's model became the basis for other models of team development. Whatever terms are used by experts to describe the development of groups, the basic concepts of awareness and acceptance of group goals, peer support, and effective group interactions are important to the success of the support group. Dr. Tuckman's group phase concepts as applied to lupus support groups are explained in detail.

#### *Forming: Coming together and forming a support group*

- Initially, group members simply come together as individuals and begin to get to know each other and begin to talk about the purpose and goals of the support group.
- Members may not be clear about what is expected and they may have some concerns about whether or not they fit in. Group members are usually looking for information.
- Group members will usually decide how safe the group is before they decide how much of themselves they will disclose and how much of their lupus experiences they will share. They slowly get to know each other by sharing similarities and differences about their diagnoses and living with lupus.
- There may be awkward moments as members try to determine a comfort level before they are willing to take risks and share personal information.
- Members will usually look to the facilitator for a sense of direction or approval.
- In general, group members are busy gathering information and forming impressions.

#### *Storming: A period of unrest*

- Group members may question goals. There may be disagreement about how the group functions.
- In general, members usually share their individual thoughts and feelings more openly and there may be disagreements.
- There may be resistance to group discussion and activities; competition and conflict are also common. The facilitator may be aware of differences in personalities and personal values.
- There may be individual struggles about wanting to get more involved, but still some reservation about how much to share with the group.

- A period of unrest in group development will be challenging and the group may lose focus on its goals; however, storming is necessary to the growth of the group. The facilitator will need to take the time and patience to resolve conflict, to help the group be mindful of support group goals, and to carefully guide group interaction in order to move forward.

*Norming: Working together*

- This is a time in which group members are more focused on building cohesion and developing mutual respect.
- The group settles down, focuses on its goals, and works to resolve differences.
- Relationships are valued. Members help each other to cope with living with chronic illness through peer support and more constructive sharing.

*Performing: Accomplishing goals, individually and as a group*

- Group members work to accomplish their goals more effectively and identify with the group as a whole.
- The group functions more smoothly, the group environment is positive, and group interactions are productive.

*Effective Facilitation: Helping the Group Move Forward*

*Some helpful tips*

- Facilitators are responsible for supporting the strengths of individual members and maintaining an atmosphere in which members support each other.
- People usually will assume different roles within groups. Facilitators should allow members as many constructive roles as possible. For example, some group members may be better than others at helping with group conflict.
- Facilitators warmly encourage everyone to participate, giving recognition for contribution and demonstrating acceptance and openness to ideas of others. However, not all members will be ready to participate, and that's okay.
- Facilitators guide the sharing of information and keep the group focused and on track.
- Facilitators guide members in understanding their differences, search for common elements in conflict, and use problem solving techniques to try and reconcile disagreements. What may be helpful to one member may not be helpful to another member. The facilitator needs to help members respect differences.
- Facilitators ease tensions within the group by making sure that the support group maintains a safe and comfortable environment and that open discussion is appropriate. Suggesting a break at the right time can provide an enjoyable time for members to

connect further with each other. Encourage a sense of humor but de-emphasize inappropriate humor and clowning around.

- Facilitators listen and serve as interested audiences for all members, are receptive to everyone's ideas, and help other group members to be receptive to everyone's ideas.
- Facilitators accept and support openness of all group members, reinforcing appropriate risk taking and encouraging respect of individuality.
- Facilitators demonstrate good communication skills to help ensure that each group member understands what other members are saying. If someone has trouble making a point or communicating an idea, take a moment to help the group member clarify the point. The facilitator may ask other group members if they can help restate the issue. If restating the issue creates conflict, spell out the points of disagreement so the whole group can help settle the difference.
- The facilitator and group members **must not diagnose, recommend treatment, or recommend a specific health care provider**. There are many details about a person's medical history that may not be shared with the group.
- To ensure effective communication, the facilitator must:
  - Use open-ended questions to initiate and guide discussion to help the group process move along. Closed-ended questions can be answered with a simple yes or no. Open-ended questions encourage members to express their thoughts and feelings, and stimulate an exchange of information. For example, "What is everyone's reaction to..." instead of "Does everyone agree?"
  - Maintain eye contact with participants. By simply looking at someone and smiling, you help that person participate, even if the member hasn't said anything for a while.
  - Be aware of group energy and individual relationships. Glance around the room frequently to check expressions and body language. Be aware of members who are inattentive or appear uncomfortable, and figure out the best way to engage them.
  - Let one person talk at a time. If someone does not get to finish a point, go back to that person. If someone tries to contribute, but can't get into the conversation, give that person the chance to contribute to the discussion using the appropriate interventions.
  - Listen so that you can give feedback, extend support, and call attention to similar or conflicting points of view.
  - Let members speak first. Any questions directed to you should be redirected back to the group. For example, "What do the rest of you think?"
  - Discourage monopolizing of discussions.
  - Be able to recognize behaviors that block communication.

### *Challenging Behaviors You Might Encounter*

- One or two members doing most of the talking.
- One or two members competing to see who has the greatest story.
- Someone trying to get the group to be overly sympathetic to his/her situation.
- Disrupting the work of the group by inappropriately joking around.
- Seeking attention by excessive talking, loud talking, talking over others, extreme ideas, or unusual behavior.
- Wandering from the topic of discussion, whispering to others, or acting indifferent or passive to group interactions.
- Criticizing or blaming others, or showing hostility toward the group.
- Introducing personal experiences unrelated to the discussion topic.
- Attempting to get others to accept one's personal values and beliefs, and rejecting other's ideas without consideration.

### *Facilitator Interventions*

Interventions by the facilitator may be necessary to correct the course of the group process to improve individual or group behavior. This will strengthen group interaction and functioning, and will help the group stay on track and move forward.

Usually it is the support group facilitator who intervenes, but when group members intervene appropriately, it indicates group development. For example, a member of the group may make an observation, ask a question, or ask for redirection. Or a group member may offer information that helps the group evaluate itself. An intervention may be as simple as taking a minute or two to reflect, or it can be more involved. Intervention can include asking the right questions, providing constructive feedback, validating feelings, or providing information.

An intervention is *valid* when it:

- Protects the purpose of the support group.
- Brings awareness to a situation that may impact the effectiveness of the group.
- Helps the group self-examine support group goals.
- Helps address conflict.
- Helps the group process move forward.
- Encourages all members to participate and express thoughts and feelings appropriately.

An intervention is *invalid* when it:

- Is not relevant to the situation at hand.
- Is used for the purpose of sounding superior and showing one's expertise to the group.

- Does not enhance the group process.
- Encourages behaviors that move the group away from constructive interaction.

### *When to Intervene*

As the facilitator, you need to intervene when you sense that group interaction and group processing is at risk. When you feel the need to intervene, take a minute or two to reflect, stay calm and focused on the situation at hand, and intervene.

### Some General Guidelines

Even for the most prepared and seasoned support group facilitator, mistakes are inevitable. Taking risks, however, is necessary and will enhance your ability to be an effective facilitator and stimulate group development. Being an effective facilitator is not about how many or how few mistakes are made, but is about how much and how fast one learns. *Effective facilitators need to practice their intervention skills.*

- Practice “permission based” interventions. For example, “May I offer an alternative?” or “May I offer a few suggestions?”
- When responding to negativity, be selective and offer constructive interventions.
- An intervention needs to be clearly stated and sincere.
- An intervention should move an individual or the group forward.
- Keep interventions brief and to the point.
- Focus on behaviors, and not individual personalities.
- Intervention is not about sounding superior or threatening. Rather, using a calm, friendly tone of voice, offer comfort and reassurance.

### Sample Interventions

The facilitator must make sure that each person has a chance to speak and is heard. Some people speak more slowly, or more softly, than others. It is okay for the Support Group facilitator to assist, but not to speak for that person. Sample interventions are included in the Appendix.

### *Assessing your intervention skills*

As a facilitator, evaluating how you intervene and how you facilitate support group meetings should be ongoing. Using the following questions, it may be very helpful to maintain a journal for a while until you are comfortable with your facilitation and intervention skills.

- How did you feel right after you intervened?
- What were the consequences of your intervention? What happened? What should not have happened?

- What would have made the intervention more effective?

*What should a facilitator avoid?*

- Overemotional identification with difficult experiences of members and/or inappropriate expressions of sympathy around them.
- A patronizing manner.
- The temptation to give ready answers, to lecture, to convince, to persuade, or to withhold.
- The need to be right or to be omnipotent as an authority.
- The need to excessively reassure members that they are achieving.
- Functioning solely as a parliamentarian, or dominating the group.
- Pushing her or his personal agenda.
- Sharing too much or competing information about her or his personal experiences.
- Siding with various group members.
- Offering inappropriate information, such as treatment advice or non-LFA approved materials.

## Closing a Meeting

- **Close on time.** A good rule is the 15 minute reminder rule. Let the group know that the meeting is approaching the last 15 minutes and that you would like to use that time to summarize the content of the meeting and call attention to any unanswered questions.
- **The group should help bring the meeting to a close.** For example, the facilitator can suggest going around the room and asking members for their closing remarks. The facilitator might ask members to share how the meeting was for them, what was most helpful to them, or recommendations for the next meeting.
- **Ask the group if the topic that was discussed needs more attention and further discussion at the next meeting.** Are there any loose ends that need to be taken up at the next meeting? No one should leave the group feeling as if their needs were ignored.
- **Remind members about LFA printed materials.** Every group meeting should have an information table with LFA materials.
- **Remind members about the date and time of the next meeting.** Encourage group members to tell their physicians about the support group and others who may be interested in the group.
- **Make sure that everyone in attendance is accounted for** on the *Support Group Meeting Sign-In Sheet*; this will be important for evaluation and reporting. Members may exchange contact information with each other, but they may not provide names of members to anyone outside of the group without the member's permission. Confidentiality is a MUST.
- **Thank everyone for coming** to the group and for sharing and supporting each other. Make an effort to connect with anyone in the group who did not share openly.
- **After the meeting, the facilitator should reflect on how the meeting went, perhaps with the co-facilitator.** You may wish to utilize a journal again to answer the following questions:
  - Did people seem comfortable?
  - Did everyone get a chance to participate?
  - Were the proposed topics adequately covered?
  - What, if anything, needs to be done differently at the next meeting to enhance group interaction, allowing the meeting to be more effective?

## Meeting the Challenge

One challenge in starting and sustaining a support group is bringing together enough people affected by lupus who are willing to share the “ups and downs” of their illness, and who are committed to attending the support group long enough to experience and benefit from effective relationships and support group development. The success of a support group also depends on whether or not members are achieving their goals and experiencing helpful new learning. And, most certainly, the success of a support group is determined by how well the facilitator anticipates and copes with all of the challenges that come with organizing, implementing, and facilitating a support group.

## Group Attendance

There are many reasons why people may stop attending a support group. It is not unusual for some members to come and go depending on their circumstances. Facilitators should keep in touch with support group members in between meetings to bring them information or to touch base to remind them that a meeting is coming up. However, below are some factors that may influence the ebb and flow of support group attendance.

- One or two sessions might be enough for some individuals.
- They may be physically unable to attend a support group because of the way lupus is affecting them.
- They may not want to be known as a person with lupus.
- They may feel that the need for a support group is a sign of weakness.
- Their new identity as a person with lupus can be emotionally overwhelming.
- Cultural beliefs and values may not support participation in a support group.
- They may experience anger, disbelief, or denial upon being diagnosed with a chronic illness.
- They prefer to deal with their illness privately.
- They prefer sharing information about their illness, and about how the illness is affecting them, with family and friends.
- Support groups are not for everyone.
- Support group goals did not meet their expectations.
- They found that some group members made them uncomfortable.
- Some people with lupus come to a group hoping to change it to fit their needs and are disappointed.



- After attending a few meetings, a participant may become overwhelmed and may need some time to reflect on his or her situation before coming back to the group.
- Issues that consistently disrupt group interaction, such as severe depression, anxiety, or other mental health issues can add more stress and tension for people already dealing with the stress that often accompanies living with lupus.
- A change in health status (improved health or deteriorating health) or other circumstances.
- They may have received what they wanted from the group and have no further need to attend.
- Lack of meeting organization and poor facilitation of the support group can keep people from coming back.

## Assessment and Evaluation

It is important to assess and evaluate the effectiveness of your support group and facilitation skills on a regular basis. This ensures that all LFA Support Groups consistently deliver high value to people with lupus, their families, caregivers, and loved ones.

On an annual basis, facilitators will distribute the *Support Group Assessment Form* to members to solicit their anonymous feedback on group dynamics and topics. The facilitator will then submit these assessments to the LFA or Chapter upon request. (See Appendix.) Collectively, the facilitator and LFA or Chapter will review the feedback and determine any appropriate responses and modifications.

On an annual basis, the LFA or Chapter may formally evaluate a support group facilitator utilizing the *Facilitator Evaluation Form*. This also creates an opportunity for the LFA, Chapter, and facilitator to reflect and report on effectiveness as well as goals for the coming year. (See Appendix.)

## When Support Groups Work Well

An effective LFA Support Group facilitator is instrumental in delivering on LFA's mission to support those affected by lupus. Becoming a skilled facilitator starts with your facilitation training. However, as you learn more about working with the lupus community and guiding constructive support group meetings you will help your members to grow and achieve positive coping skills. Everything you have learned in this manual enables you to demonstrate best practices for facilitating effective group interaction that helps members become more aware of how the illness affects them, lifestyle changes that can help them stay as healthy as possible, and behaviors and techniques that make living with lupus easier.

## Quick Reference Index

This Quick Reference Index identifies some helpful reminders about best practices in facilitating an LFA Support Group. New LFA support group facilitators may find this quick reference index particularly helpful.

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# Appendix: Tools and Forms

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## LFA SUPPORT GROUP POLICIES

The following LFA Support Group Policies support the mission and core values of the LFA. They are written for both LFA nationally managed Community Support Groups (hereby referred to as “LFA”) and LFA Chapter sponsored support groups. Policies are listed by category.

The purpose of Lupus Foundation of America Support Groups is to provide current and reliable lupus information and to assist group members to adjust to a life with lupus. Lupus support groups are open to those with lupus, their family members, caregivers and loved ones and shall be implemented by a facilitator who has been trained by the LFA.

Chapters shall use these LFA Support Group Policies governing the formation and operation of support groups and may create additional policies that help govern support groups within each Chapter area.

### Operations

- Support groups are approved and established as a direct service by either the LFA National Office or LFA Chapters.
- The LFA and Chapters may terminate a support group as deemed appropriate.
- Each support group shall have at least one LFA National trained facilitator. In addition, an LFA trained co-facilitator is strongly encouraged. Anyone interested in becoming a support group facilitator must comply with the following process:
  - The applicant must complete an LFA or Chapter Support Group *Facilitator Application*.
  - The LFA or Chapter must screen and interview applicants.
  - If the initial application is approved, the applicant must complete LFA Support Group Facilitator Training.
  - Following LFA Support Group Facilitator Training, the facilitator receives a Certificate of Completion.
  - Following receipt of the LFA Facilitator Training Certificate, the LFA or Chapter shall determine final approval of the facilitator’s support group and meeting location.
  - The applicant then must sign an LFA or Chapter *Facilitator Agreement*.
- The facilitator must agree to conduct a support group for at least one year.

- The facilitator must agree to facilitate a minimum of eight support group meetings per year.
- The LFA or Chapter is responsible for assigning facilitators to support groups.
- The LFA or Chapter must approve any and all guest speakers at support group meetings.
  - Guest speakers must be relevant to the topic of discussion and provide education to support group members.
  - Guest speakers may provide education but must not directly recruit volunteers for clinical trials.
- All meeting locations must be accessible to those with disabilities as defined by the Americans with Disabilities Act.
- Any agreement required to obtain meeting space, such as proof of insurance, must be pre-approved and signed by LFA or Chapters.

*Policy on reporting*

- The LFA and Chapters shall require quarterly activity reporting from each facilitator on attendance, topic of discussion, type of support group, and any guest speakers.

*Policy on finances*

- Any projected support group expenses such as room rentals, educational materials, and/or speaker fees fall under the responsibility of the LFA or Chapter. The facilitator must obtain prior approval for these expenses.

**Privacy**

- The LFA protects the privacy and confidentiality of people who participate in support groups.
  - Each new attendee must sign an LFA-provided *New Member Registration Form* that includes privacy and confidentiality information.
  - LFA, the Chapter, the support group facilitator, or support group members shall not share support group member information with outside organizations, companies, the media, or individuals.
- If LFA or Chapters offer telephone or online support, LFA and Chapters must abide by the LFA's Privacy Policy to protect the confidentiality of support group members.

## **Medications/Treatments/Products**

- LFA trained support group facilitators do not make referrals to physicians or other health professionals, and do not make recommendations concerning medications and products for the treatment of lupus. The facilitator may not offer medical or treatment advice. The facilitator may refer support group members to the LFA or Chapter for a list of health professionals in their area.
  - The LFA does not endorse products or services. Support group facilitators or members may not market or sell products or services within the support group, and support groups must be protected from the sales and marketing of products or services by outside groups. Speakers must not promote products or services.

## **Fundraising**

- The purpose of a support group meeting is to provide a supportive and educational environment to people living with lupus as well as their loved ones and caregivers, not to raise funds. If individual support group members wish to participate in LFA or Chapter sponsored fundraising activities, they can elect to do so. Any other fundraising efforts must be pre-approved and funds will be managed by the LFA or Chapter.

## **Promotion**

- Facilitators can promote their support groups for the purpose of attracting members and keeping them informed. Only the templates provided in Support Group Manual may be used for promoting your support group. These materials include a postcard, flyer, calendar notice, and advertisement. Any additional promotional materials must be pre-approved by the LFA or LFA Chapter.
- All promotional materials and strategies must adhere to the LFA's current policies for use of the LFA logo and website.



## LFA SUPPORT GROUP GUIDELINES

The following LFA Support Group Guidelines provide guidance in following Support Group Policies. They are written for both LFA nationally managed Community Support Groups (hereby referred to as “LFA”) and LFA Chapter sponsored Support Groups. Guidelines are listed by category.

LFA Support Groups are intended for people with lupus, their families, caregivers and loved ones. LFA Support Groups are not open to the general public.

The LFA Support Group facilitator should make every effort to ensure that potential attendees are not working on behalf of the media, corporations or pharmaceutical companies, or other outside parties who may not attend support group meetings.

LFA and its support group facilitators do not endorse products or services.

### Operations

#### *Guidelines on creating and terminating a support group*

- A support group should be created by the LFA as a response to a community need, rather than the request of any one particular individual. The decision as to who will lead the group is at the sole discretion of the LFA. Location and meeting times of the group should be approved in advance by the LFA.
- The LFA or Chapter secures and approves the meeting location based on established criteria, such as handicapped accessibility, safety, etc.
- The LFA may decide to disband or move the location of a support group for a variety of reasons, including:
  - attendance issues
  - resignation of the facilitator
  - difficulties in accessing meeting location
  - the combining of two support groups
- The LFA or Chapter may terminate a facilitator based on outcomes such as poor performance or non-compliance with LFA Support Group Policies.



### *Guidelines on the selection of a facilitator*

- The LFA or Chapter should ensure that anyone interested in becoming a facilitator is screened and interviewed and completes all necessary paperwork before being considered.
- The LFA or Chapter requires a facilitator to undergo LFA standardized training to conduct a lupus support group.
- It is recommended that facilitators exhibit empathy towards people with lupus gained through personal or professional experiences, and have experience in one of the following:
  - peer to peer support
  - group facilitation
  - counseling
  - social work
  - another health related profession
- If a new facilitator is not already knowledgeable about lupus, the LFA or Chapter should provide lupus education including recommended reading.
- Following LFA training and LFA or Chapter approval, The LFA or Chapter requires that the facilitator understands and signs a written agreement indicating commitment to facilitator responsibilities and compliance with LFA or Chapter policies to include:
  - Facilitating a support group for at least one year.
  - Facilitating a minimum of eight support group meetings per year.
- The LFA or Chapter determines final approval of the facilitator following a signed *Facilitator Agreement*, and decides when and where to place a facilitator.
- The LFA or Chapter provides facilitators ongoing education and updated information on lupus with LFA approved content.

### *Guidelines on reporting and evaluation*

- While quarterly reporting is required of all support group facilitators, the LFA or Chapter may request more frequent reporting on attendance, topic of discussion, type of support group, and any guest speakers.
- Facilitators should inform support group members that any and all information collected is solely for the purpose of the LFA or Chapter and will be kept confidential.
- It is strongly recommended that the LFA and Chapters request at least one annual evaluation of each facilitator and support group. The LFA has provided an *Evaluation Form* as a template.

- Chapters may choose to use the data gathered from these evaluations to report to their funders and/or constituents on the effectiveness of their support group program, as well as to provide constructive feedback to the facilitators to help ensure the quality of the group.

#### *Guideline on finances*

- Facilitators must obtain prior approval of any requested expenditures and use of funds designated for the LFA or Chapter Support Group Program.

### **Privacy**

#### *Guidelines on protecting privacy of support group members*

- The LFA or Chapter support group members should sign a *New Member Registration Form* that provides privacy and confidentiality information.
  - If a member chooses, his/her information may be placed in a database which is used to send LFA or chapter communications such as e-newsletters. However, the member will always have the opportunity to opt out of receiving such communications.
- The facilitator should ensure that the support group is open to only people with lupus, their families, caregivers, and loved ones.

### **Medications/Treatments/Products**

#### *Guidelines on providing referrals*

- Members do discuss diagnosis, treatment, and living with lupus topics within the support group meeting where physicians or other health professionals are mentioned. However, the facilitator should indicate that they do not make a recommendation for or referral to a specific physician.
- Members may discuss medications during support group meetings. The facilitator should inform support group members that such discussion is not a recommendation or endorsement.
- The facilitator may not offer medical or treatment advice. The facilitator should inform members that only their physicians or healthcare teams can offer such advice.

#### *Guidelines on speaker selection and content*

- The facilitator should discuss and obtain agreement from the speaker that the purpose of the talk is solely for education and may not involve marketing a product or service. In addition, the speaker may not directly recruit members to volunteer for clinical trials.
  - For example, a nurse educator from a biotechnology, pharmaceutical, or other organization may be a speaker for an event or request to speak to a group about

lupus or treatments related to lupus. Not only is planned content to be reviewed and approved by the LFA, but he or she may only provide direct education information on the topic as a whole and not promote a product or service directly.

- If the speaker has an FDA-approved treatment for lupus he or she may only discuss the treatment in context of all treatments used for lupus.
- Speakers can answer questions from support group members about products, services, or clinical trials, but should keep their remarks general and based on providing education and awareness.

### **Fundraising**

- Support group members may want to individually support the LFA or Chapter and can do so; however, the fundraising activity should not be discussed within the support group meeting.
  - Some members may decide to raise funds for a Walk for Lupus Now. They may do so, but there should be no expectation for all members to participate, and member information should be kept confidential.
  - Members may not solicit or raise funds for the operations of LFA Support Groups. However, if support group members wish to contribute to the sustainability of LFA or Chapter Support Groups, they may designate their gifts accordingly.

### **Promotion**

- Online or virtual support groups are not considered best practice or recommended at this time. Some Chapters have tried them with limited success. The LFA needs to fully evaluate their effectiveness, and develop a separate program and format that would provide the same support and information as in a regular support group.
- LFA Chapters with a Facebook page may post messages about their support group. However, it is not recommended that a separate page or account is created just for the support group.
- Before the facilitator distributes promotional materials, final copies should be provided to the LFA or Chapter.



## LFA SUPPORT GROUP ASSESSMENT FORM

This assessment gives support group members the opportunity to provide feedback on the facilitator as well as the overall Support Group.

Name of Support Group \_\_\_\_\_ Date \_\_\_\_\_

Approximately how many times in the past 12 months did you attend support group meetings?\_\_

	1	2	3	4
Please indicate the extent to which you agree with the following statements.	Strongly agree	Agree	Disagree	Strongly disagree
My experience in this support group overall is satisfactory.				
The support group is an accepting, safe, and caring environment.				
Members are able to comfortably express their feelings and concerns about the way lupus affects them.				
Support group members seem connected and listen to each other with understanding.				
Open discussion topics are relevant to lupus and helpful.				
I have learned that I am not alone in my disease. Group interactions and peer support have helped me become more aware of coping strategies to reduce stress and live better with lupus.				
The support group provides updated materials from the LFA that are helpful.				
I have gained new insights and a broader perspective about living and coping with lupus.				
The support group facilitator starts group meetings on time and reminds members about support group goals and important ground rules, especially confidentiality.				
The support group facilitator has good leadership skills and has a good sense of support group goals.				
The support group facilitator is attentive to group needs and supports all group				

	1	2	3	4
Please indicate the extent to which you agree with the following statements.	Strongly agree	Agree	Disagree	Strongly disagree
members.				
The support group facilitator encourages all group members to participate in open discussions and the decision-making process.				
The facilitator is able to help guide group discussions and keep discussions on track, and help members process shared thoughts, ideas, and experiences.				
The facilitator is able to effectively help the group with conflict.				
The facilitator is a good listener.				
The group facilitator and group members do not provide medical advice.				
The facilitator is able to help group members summarize points of discussion towards the end of the meeting and then closes the meeting on time.				
As a member of this support group, I am accomplishing my goals.				
I appreciate this support group as a safe and non-threatening place for lupus information and constructive sharing.				

*Optional:*

Describe/share any particular concerns that you have about the support group.

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Describe/share how the support group has been particularly helpful to you.

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## LFA SUPPORT GROUP FACILITATOR APPLICATION

### Personal Information

Name

Address

City, State, Zip Code

Daytime Phone

Evening Phone

Email

May we contact you at work?

Yes

No

### Professional Information

Job Title

Organization

Education

**Why would you like to become an LFA Support Group facilitator?**

**Are you willing to assume the responsibility of Support Group Facilitator for at least one year?**

Yes

No

**Are you willing to commit to facilitating a minimum of eight meetings per calendar year?**

Yes

No

**Are you willing to work collaboratively with the LFA or Chapter which will include being supervised, submitting group reports, etc. during the time your group is operating?**

Yes

No

**The LFA strongly encourages all support groups to have a co-facilitator. Are you willing to work with a co-facilitator?**

Yes

No

**Do you have any co-facilitators in mind at this time?** Yes  No

If yes, please provide their contact information below. (Use additional sheet if more than one.)

Name

Address

City, State, Zip Code

Daytime Phone

Email address

**Are you interested in facilitating any specific type of support group (such as online, pediatric, etc.)?**  
 Yes  No

If so, please state which kind:

**Have you ever been convicted of a felony or misdemeanor which resulted in imprisonment within the last seven years?**  
 Yes  No   
*(A conviction will not necessarily result in the denial of a facilitator opportunity)*

If yes, please explain:

**Personal References**  
 Give or attach separate sheet of three individuals (not relatives) who can provide a reference.

Name: \_\_\_\_\_  
 Relationship: \_\_\_\_\_  
 Phone Number: \_\_\_\_\_  
 Email Address: \_\_\_\_\_

Name: \_\_\_\_\_  
 Relationship: \_\_\_\_\_  
 Phone Number: \_\_\_\_\_  
 Email Address: \_\_\_\_\_

Name: \_\_\_\_\_  
 Relationship: \_\_\_\_\_  
 Phone Number: \_\_\_\_\_  
 Email Address: \_\_\_\_\_

**Personal Statement**

Please describe your background and experience (educational, professional, or volunteer) that will help you be an effective Lupus Support Group Facilitator, such as knowledge of group facilitation, health education, or work with people who have chronic, autoimmune diseases, etc.

Please write a brief statement describing your personal attributes and communication style that you feel will help make you successful as a Support Group Facilitator.

**Agreement and Signature**

By submitting this application, I affirm that the facts set forth in it are true and complete. I understand that false or misleading information given in my application or interview(s) may result in termination of the facilitator relationship. I also understand that I am required to abide by all rules and regulations of the LFA.

Applicant Signature: \_\_\_\_\_ Date: \_\_\_\_\_

LFA Chapter CEO or LFA Network

Development Signature: \_\_\_\_\_ Date: \_\_\_\_\_

For office use only			
Received by:		Reviewed by:	
Next steps:			





## SUPPORT GROUP FACILITATOR AGREEMENT

This document is provided following the LFA Support Group Facilitator Training as a written agreement for the formation and operation of a Lupus Foundation of America, Inc. Support Group between the LFA or LFA Chapter and the Facilitator, \_\_\_\_\_. (*first and last name of facilitator*)

### The Support Group Facilitator:

1. Has completed sanctioned LFA Support Group Facilitator Training.
2. Will facilitate an LFA Support Group in \_\_\_\_\_. (*territory, town or city*)
3. Has read and agrees to abide by all LFA Support Group Policies and Guidelines, in particular, the confidentiality of group members, not disseminating medical advice, not fundraising, etc.
4. Will participate in an LFA-Refresher course (as offered) to review key parts of initial training as well as to participate in ongoing professional dialogue with LFA colleagues and/or other professionals.
5. Will notify the LFA or Chapter regarding all matters deemed to be improper or potentially legally injurious to the LFA.

### The LFA or Chapter:

1. Will provide direction, consultation, and programmatic support as requested by the facilitator.
2. May make changes to this agreement which shall be in writing and agreed to by the facilitator.
3. May evaluate this agreement annually. It will be renewed if both parties agree to do so.
4. Has the right to remove the facilitator and/or terminate a Support Group as deemed appropriate. The facilitator agrees to abide by this decision, return all materials, etc, and cease operation of the Support Group program. The LFA or the Chapter will communicate termination to Support Group members.

---

As a Support Group Facilitator and representative of the Lupus Foundation of America, Inc., I have read, understand, and agree to the above conditions and will conduct Support Group activities in an appropriate and professional manner and according to LFA Support Group Policies and Guidelines as set forth in the LFA Support Group Manual.

Support Group Facilitator: \_\_\_\_\_ Date: \_\_\_\_\_

LFA or Chapter Representative: \_\_\_\_\_ Date: \_\_\_\_\_

Title: \_\_\_\_\_



## LFA SUPPORT GROUP FACILITATOR EVALUATION FORM

This form allows the LFA or LFA Chapter to evaluate the Support Group facilitator. This is also an opportunity for the Support Group facilitator to provide feedback on the LFA Support Group Program. The Yes/No questions should be filled out by the LFA or LFA Chapter. After completion, the supervisor and facilitator should discuss the answers and then use the open-ended questions to prompt a dialogue about the support group program. The supervisor will document all discussion and keep the evaluation on file.

	Yes	No	Comments
The facilitator is knowledgeable about lupus and has attended any refresher courses offered by the LFA or LFA Chapter. The facilitator keeps Support Group members updated on latest lupus information the chapter has previously provided.			
Meetings are held in a safe, convenient, public location on a regular basis.			
All guest speakers are preapproved by the LFA or the Chapter, and support group meeting topics are appropriate.			
The facilitator always respects the confidentiality of members and open discussion. The facilitator does not share member information with outside organizations, companies, the media, or non-members.			
The facilitator does not offer medical or treatment advice and does not make referrals to physicians or other health professionals. Nor does the facilitator make recommendations concerning medications and products for the treatment of lupus.			
The facilitator, in collaboration with the LFA or LFA Chapter, is effective in promoting the support group, resulting in a steady or increasing attendance.			
The facilitator timely submits all reports including the New Member Registrations, Meeting Summary Reports, and Annual Support Group Evaluations.			
The facilitator follows all other LFA Support Group Policies and Guidelines.			

What accomplishments has the facilitator experienced during this past year in facilitating his/her support group? \_\_\_\_\_

\_\_\_\_\_

What aspects of the support group and/or facilitation might be goals for growth and development for next year?

\_\_\_\_\_

What other LFA volunteer activities has the facilitator been involved in?

\_\_\_\_\_

What additional direction, consultation, or programmatic support does the facilitator wish the LFA or LFA Chapter would provide to aide in the group's success?

\_\_\_\_\_

What specific topics or areas of professional growth would the facilitator like covered in potential future facilitator refresher courses?

\_\_\_\_\_

Additional Comments:

\_\_\_\_\_

Name and Location of Support Group: \_\_\_\_\_

Facilitator Name: \_\_\_\_\_ Facilitator Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Supervisor Name: \_\_\_\_\_ Supervisor Signature: \_\_\_\_\_ Date: \_\_\_\_\_



## LFA SUPPORT GROUP GUEST SPEAKER REQUEST FORM

Please fill out and submit to the LFA or Chapter at least four weeks in advance of the proposed guest speaker's presentation.

Support Group	
Support Group Facilitator	
Speaker and Professional Title	
Speaker's Organization	
Address	
City, State, Zip	
Phone	
Email	
Title of Presentation	
Will this speaker be presenting at your regularly scheduled meeting?	Yes <input type="checkbox"/> No <input type="checkbox"/>
If not, please state the date, time and location	
<b>How did you find this speaker?</b>	
<b>Please provide a description of any extra help you will need for the meeting and speaker including educational materials and flyers. The LFA or Chapter will subsequently contact you to discuss how they can help you prepare for the meeting.</b>	

LFA or Chapter Staff Signature: \_\_\_\_\_ Title: \_\_\_\_\_  
 Date of Approval: \_\_\_\_\_



## LFA SUPPORT GROUP MEETING PLANNER

Utilize this planner to help map out your topics and speakers for the year and consult with the LFA or Chapter.

**Fiscal Year:** \_\_\_\_\_

**Support Group:** \_\_\_\_\_

**Facilitator:** \_\_\_\_\_

Month /Date	Topic	Video or Guest Speaker
January		
February		
March		
April		
May		
June		
July		
August		
September		
October		
November		
December		



## LFA SUPPORT GROUP MEETING REPORT

Facilitators should fill out this form shortly after each meeting and submit according to the instruction of the LFA or LFA Chapter. Please be sure to attach all New Member Registration Forms when turning in this report.

Support Group Name:

Facilitator Name:

Meeting Date:

Please circle the type of support group held:

General Women Men Teens Caregivers Online  
Teleconference Other (please identify: \_\_\_\_\_)

Number of attendees:

Please provide a brief summary of topics discussed:  
*(do not include member names or confidential information shared among group members)*

Additional comments and/or follow-up action needed:



## LFA SUPPORT GROUP MEETING SIGN-IN SHEET

New and returning members should sign-in here. This sign-in sheet is confidential and for record-keeping purposes only. The LFA or Chapter will never share your name or information with outside parties.

Facilitator: \_\_\_\_\_

Location: \_\_\_\_\_ Date: \_\_\_\_\_

**Member First and Last Name (please print)**

1.

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22.

23.

24.

25.



## LFA SUPPORT GROUP NEW MEMBER REGISTRATION FORM

If you have never attended an LFA Support Group, please fill out the following registration form and give to the Support Group facilitator.

The Lupus Foundation of America and Chapter affiliates provide support groups for two reasons:

1. *To assist and support group members in developing skills in coping and living with a chronic illness*
2. *To foster open discussion of how lupus affects our lives and assist members in developing self-management skills.*

A support group is not designed to provide professional psychotherapy or counseling. Lupus Foundation of America (LFA) Support Group facilitators have a desire to help others. All facilitators have received special LFA training by a professional in how to provide support in a nonthreatening environment. Some are trained professionals. Although this is **not** a therapy group, out of respect for participants, **confidentiality is a must**. All information and dialogue is confidential and shall not be discussed or revealed outside the group.

The opinions and statements expressed by the group members or its facilitator do not necessarily reflect the opinions or positions of the Lupus Foundation of America or its affiliated Chapters.

LFA, the Chapter, the support group facilitator, nor support group members shall share support group member information with outside organizations, companies, the media, or individuals. Member contact information will only be used to notify an individual of any changes to future support group meeting times and location unless members choose to join the LFA or LFA Chapter mailing and e-newsletter distribution list.

Name of Support Group: \_\_\_\_\_

New Member Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_

Yes    No  
   

I wish to be added to the LFA or LFA Chapter mailing list to receive the latest communications and helpful information about upcoming events, programs, services, lupus research, volunteer opportunities, etc.

By signing below, I acknowledge that I have read all of the information above and agree to abide by the confidentiality and privacy rules of LFA Support Groups.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_





## LFA SUPPORT GROUP FACILITATOR INTERVENTION TOOL

Interventions by the facilitator may be necessary to correct the course of the group process to improve individual or group behavior. Here are some suggested interventions.

### **Paraphrasing to emphasize important points**

“Mary, you seem comfortable with the idea based on your experience, but I sense that some of you have some concerns about...”

“What I hear you saying is that we need to discuss this issue further at our next meeting.”

### **Calling awareness to the overall tone of the group**

“The group today has expressed a lot of anger. Do we need to take some time to gain a better understanding of everyone’s feelings?”

“The group seems quieter today than usual. Would anyone care to elaborate?”

### **Calling awareness to a specific undesired behavior or situation**

“Several people are asking questions at the same time. Everyone’s question is important. May we address them one at a time, starting with Mary?” (Permission based)

“The group seems to have strayed from our discussion topic. May we get back to sharing how everyone feels about...?”

### **Expression of feelings**

“I’m confused as to where our discussion is heading.”

“I’m feeling uncomfortable about where our discussion is going.”

### **Observations**

“I noticed that everyone participated today and shared some deep and personal feelings about living with their illness. How did it feel to share your experiences?”

“Mary, I appreciate your story, but now everyone seems quiet. Can we take a few minutes to reflect and talk about how everyone is feeling? Is that okay with you, Mary?”

### **Processing**

“Can we go around the room and share our thoughts and ideas, given the situation?”

“How is everyone being affected by their illness? How have your needs changed since your diagnosis?”

## **Encouraging group discussion and problem solving**

“What does everyone think about the problem as stated? Have we clearly defined the problem?”

“Would everyone like to share how they have addressed the issue of ...?”

“Would anyone care to offer suggestions about what we need to discuss at our next meeting?”

“Now that some of you have shared your thoughts and feelings, would others like to add to the discussion? How is the rest of the group feeling about...?”

“What else do we need to address before the end of our meeting?”

“Thank you, Mary, for sharing your experience. Has anyone had a similar experience?”

“You have made several good points, and I am wondering if someone else might like to share their comments?”

“Your thoughts are interesting, but I wonder if you would hold your comments for a few minutes until everyone has had an opportunity to describe their experience?”

## **Focusing and summarizing group discussion**

“Can we take a look at where we are now in relation to our goal for this discussion?”

“Why don’t we review important points and the progress we have made thus far in this discussion. My understanding is that...What do the rest of you think?”

“Your comment is interesting; can you help me better understand your point of view?”

## **Moving the group forward**

“I wonder if we have spent enough time on this aspect of the problem; should we talk more about...?”

“Have we gone into this part of the problem far enough so that we might now shift our attention and consider this other area?”

“Does anyone have anything further to share regarding...? If not, can we move on to ...?”

“We have spent a lot of time on this topic and if no one has any further concerns at this time, would it be in the group’s best interest to address...”

## **Making a decision**

“I feel that everyone is in agreement on these points. Are there any further comments?”

“Does everyone agree that this is the best solution and that it will benefit the group?”

“Do we need further clarification about the problem before the group makes a decision?”

## **Lending continuity**

“Since we did not have enough time to discuss how everyone feels about...at our last meeting, can we take a few moments to review what we covered at our last meeting and what needs further discussion?”

“Would someone care to suggest points that need further discussion before we move on?”

## Helping the group evaluate itself

"I wonder if any of you feel that we are stuck on this point?"

"Should we take a look at our goals to see how we are progressing?"

"Does anyone have any suggestions as to how we can make our group meetings more meaningful?"

"Would the group like to share how our support group meetings are helpful?"

"What have we accomplished in our discussion up to this point?"

## Additional sample questions

"I'm concerned that we've taken the conversation away from Mary. Can we get back to Mary's question?"

"Can you share how your situation is affecting you right now? You seem encouraged about the progress you've made."

"I'm confused. Can we take a few minutes to sort out everything that has been shared?"

"Is there anything that we should deal with before we end? Is there anything that can't wait until our next meeting?"

"Would anyone like to respond by talking about a similar situation they've had?"

"What choices do we have when that is the case?"

"I'm concerned about ... what does everyone else think?"

"If that is your choice, would you be willing to share how you think that it will be helpful to you?"

"Life seems especially difficult for you now. Is there something the group can do to help you?"

"What do you do to take care of yourself?"

"How does everyone feel about...?"

"It seems like we're trying to fix Mary's problem. Mary, what would be helpful to you right now?"

"You mentioned several things. Is there one thing in particular that you would like to focus on with the group?"



## LFA SUPPORT GROUP MEETING CALENDAR NOTICE TEMPLATE

Dear Editor (or Public Service Director),

We wanted to let you know about this upcoming support group for people living with lupus in < CITY> for the community calendar. Please let me know if you have any questions, or would like any additional information.

Best,  
<NAME>

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### **Lupus Support Group Provides Valuable Information on Coping and Living with Lupus**

*People with lupus, their family members, caregivers, and loved ones can share their experiences, methods of coping, and insights into living with chronic illness.*

\*\*\*FOR IMMEDIATE RELEASE\*\*\*

**When:** <Date and time>

*i.e. The group meets the 3<sup>rd</sup> Tuesday of each month beginning June 21, 2011*

**Where:** <Location>

**RSVP:** Space is limited. Advanced registration is recommended. To register, call <Phone> or email <Email address>

**Who:** The Lupus Foundation of America, <Chapter Name> is a proud member of the LFA National Network, which is comprised of chapters, field offices, support groups, and community representatives. The LFA and its National Network are focused on improving quality of life for people with lupus through programs of **research, education, and advocacy**.

**What:** The **Lupus Foundation of America (LFA)** support groups are intended to provide a warm and caring environment where people with lupus, family members, caregivers, and loved ones can share their experiences, methods of coping, and insights into living with chronic illness. The support group also provides current and accurate information about lupus and related issues and information about appropriate community resources.

LFA Contact Person: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**The Lupus Foundation of America, Inc. is the foremost national nonprofit health organization dedicated to finding the causes and cure for lupus and providing support, services, and hope to all people affected by lupus.**

# LFA SUPPORT GROUP MEETING NOTICE FLYER TEMPLATE



LUPUS FOUNDATION OF AMERICA

## Lupus Support Group LIVING & COPING WITH LUPUS

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*MEETING NOTICE*



**Lupus Foundation of America, Chapter Name**

**DATE**

**LOCATION**

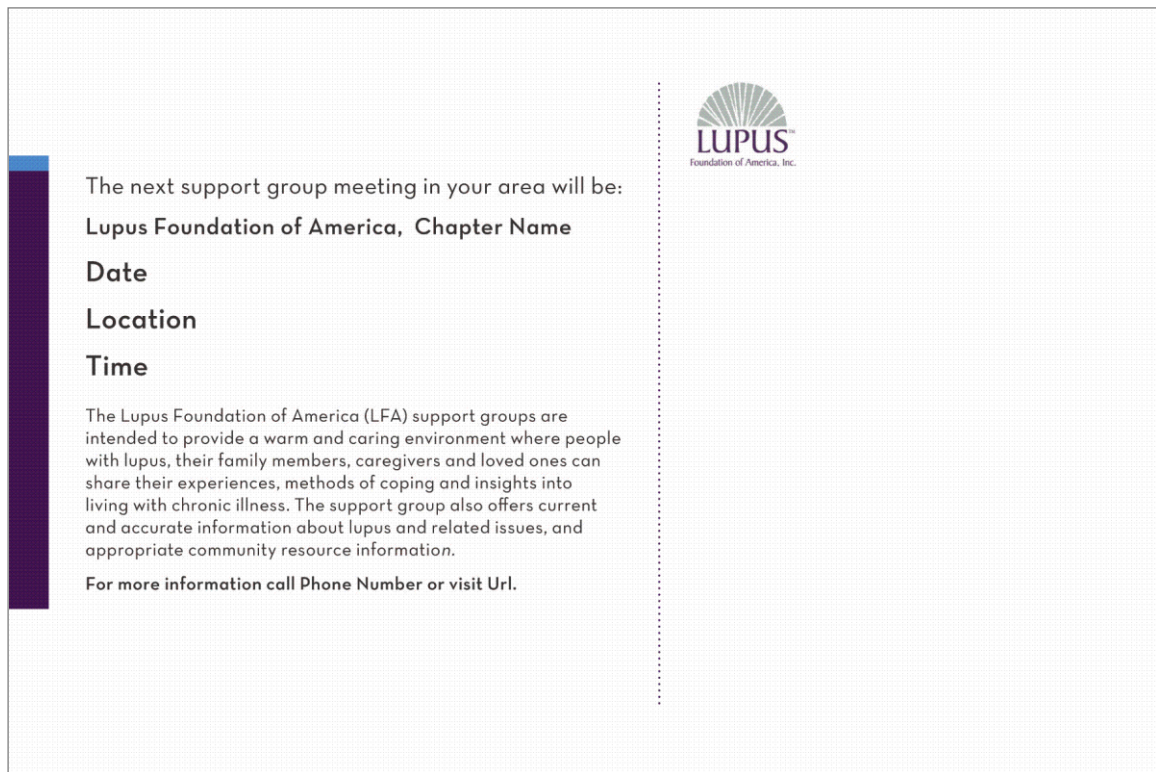
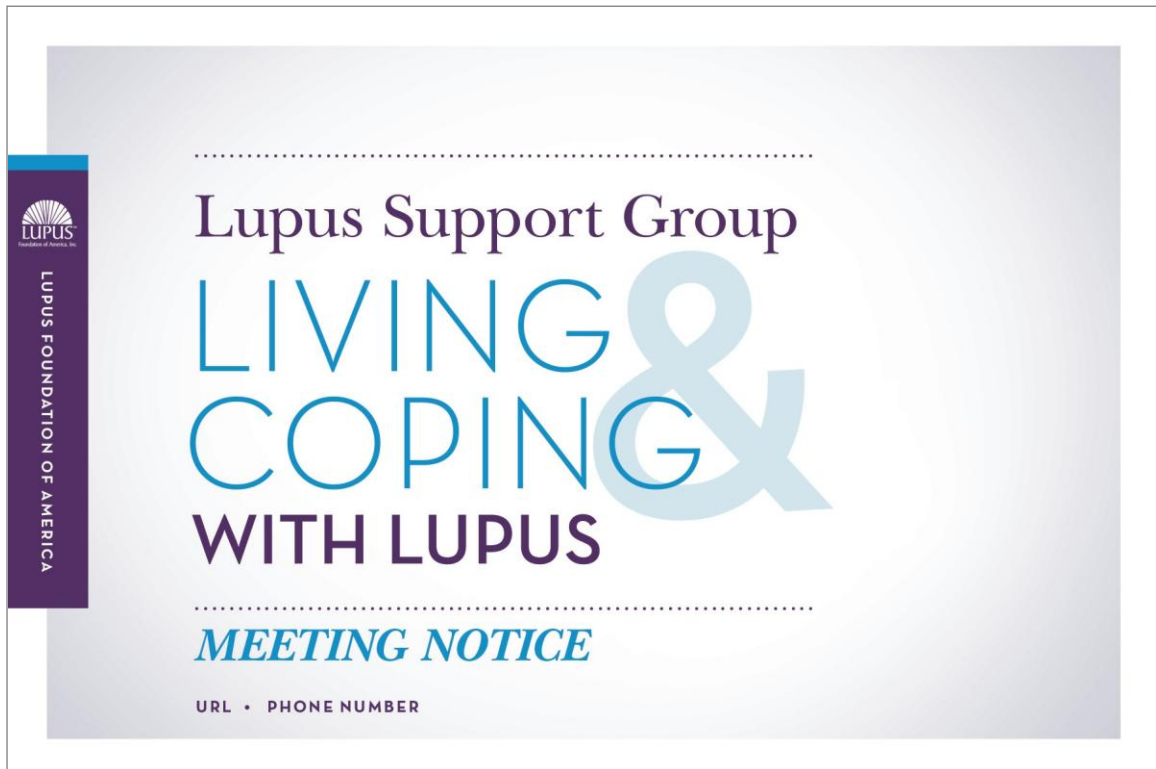
**TIME**

The Lupus Foundation of America (LFA) support groups are intended to provide a warm and caring environment where people with lupus, their family members, caregivers and loved ones can share their experiences, methods of coping and insights into living with chronic illness. The support group also offers current and accurate information about lupus and related issues, and appropriate community resource information.


**For more information call Phone Number or visit Url.**

LUPUS FOUNDATION OF AMERICA • URL • PHONE NUMBER

## LFA SUPPORT GROUP MEETING NOTICE POSTCARD TEMPLATE



# LFA SUPPORT GROUP MEETING NOTICE PRINT AD TEMPLATE

**LUPUS FOUNDATION OF AMERICA**


## Lupus Support Group

# LIVING & COPING WITH LUPUS

.....

### *MEETING NOTICE*



Lupus Foundation of America, Chapter Name

Date

Location

Time

The Lupus Foundation of America (LFA) support groups are intended to provide a warm and caring environment where people with lupus, their family members, caregivers and loved ones can share their experiences, methods of coping and insights into living with chronic illness. The support group also offers current and accurate information about lupus and related issues, and appropriate community resource information.

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