



FOUNDATION FOR
SARCOIDOSIS RESEARCH

SARCOIDOSIS SUPPORT GROUP MANUAL

Developed by the FSR Sarcoidosis
Support Group Advisory Council

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www.stopsarcoidosis.org



FOUNDATION FOR
SARCOIDOSIS RESEARCH

HOW TO START A SARCOIDOSIS SUPPORT GROUP

INTRODUCTION

Congratulations on your decision to explore starting a Sarcoidosis Support Group. This chapter of the manual draws on the wisdom of experienced Support Group facilitators who are members of FSR's Sarcoidosis Support Group Advisory Council. (See *FSR Sarcoidosis Support Group Advisory Council contact list*.)

There are many different reasons for starting a group: to help people with sarcoidosis find others who really understand what they're feeling; to provide education for sarcoidosis patients and those who care about them; to give family members and friends of sarcoidosis patients a place to talk about how they're feeling. Some groups are formed to address one of these concerns, others invite anyone and everyone who's interested in sarcoidosis to come to meetings.

WHAT'S THE FIRST STEP?

You've already taken the first step by deciding to explore starting a Sarcoidosis Support Group.

Many Sarcoidosis Support Groups have been started by one person—either a patient or someone who loves a patient—who saw a need. Your passion for starting a Sarcoidosis Support Group may mean that you are the person to call a first meeting. If you choose to start a group by yourself, make sure you have the time and energy you will need to commit.

Another way to go is to identify one or two other people to join you in a core group which will share leadership and decision-making from the beginning. Whichever method you choose, be aware that your passion and energy are far more important tools than degrees and formal training.

You might also consider using professionals as advisors or consultants. Perhaps you know a doctor or other medical professional who might be called on in this capacity.

If you know of another Sarcoidosis Support Group within driving distance of your location, you might want to talk to their facilitator and/or ask to visit one of their meetings. You can also contact any of the members of the Sarcoidosis Support Group Advisory Committee or the FSR Office. (See *Contact Information*).

WHAT KIND OF GROUP WILL YOU START?

Support groups are generally divided into three kinds: educational, emotional support, or some combination of the two. You will want to talk with those who come to your first meeting about what they want. Also, you will want to decide if your group is open only to sarcoidosis patients or if you want to include their families and friends as well. There is no right or wrong decision, but what you decide may determine how you recruit members for the group and the activities you plan.

GROUP SIZE

The group should be large enough to offer support even when some group members are missing and small enough so members feel comfortable sharing their personal feelings and stories.

LOCATION

When searching for a location for your support group meetings, there are several things to keep in mind:

- Some groups choose to meet, at least initially, in the home of one of the group's members. This may not be feasible for your group or your group may quickly outgrow that kind of space. You will also want to consider your comfort level with having people who are (initially) strangers in your home.
- Look for a space large enough for the size of group you anticipate for your first meeting and one that allows room for growth as the size of your group increases.
- Make sure the space is accessible to people of all ability levels both in terms of ease of entry and in terms of location. If your group meets in a city, try to find a location that is close to public transportation. Make sure there is adequate free or low-cost parking and that the location is easy to find and centrally located.
- Select a location that is quiet, private and a comfortable temperature.
- If you are meeting in the evening, make sure the building you are meeting in is well-lit on the outside.
- Try to find free space to meet in. When you are inquiring about a meeting place, make sure you communicate the fact that your group is a voluntary non-profit organization that plans to provide a service to the public free of charge.
- Make sure the location doesn't trigger negative associations for potential group members. For instance, some folks may be uncomfortable meeting in a church or a hospital.
- Be sure the meeting space has chairs and tables for displays and other materials. Availability of a kitchen or at least a sink with running water is desirable for making coffee and other refreshments. You might also ask whether there is space available for you to store materials between meetings.
- Be sure there are adequate and accessible rest room facilities.
- A location with adjoining dining facilities or close to a restaurant or coffee shop can provide opportunities for people to socialize before or after the meetings.

- Some places to look for space include:
 - Churches and synagogues
 - A local YMCA/YWCA
 - Community centers and senior citizens centers
 - Rotary, Lions or Kiwanis meeting halls
 - Your local library, bank, town hall or college
 - Hospitals and clinics
- Be sure you are clear about your meeting times, frequency of your meetings and size of your group when you research meeting spaces.
- When you locate a space, you may want to draw up a simple contract and reserve the space for a year at a time to make sure your group is on their calendar.

MEETING TIMES

It will be easier for people to remember the group's meeting times if they are held on a regular day and time like the fourth Thursday of the month at 7:00 p.m. Choose a time for your first meeting that will allow for the most people to attend. At that meeting you may want to have a discussion about times that work best for the group and about how frequently the group would like to meet.

THE FIRST MEETING

- Make sure the leaders are clear on the agenda and goals for the meeting. These should be stated clearly to the group.
- Create a friendly atmosphere. Consider identifying someone to be a greeter. You might also want to provide simple refreshments before and after the meeting to give folks a chance to socialize.
- The group's leaders can share the experiences that led to their decision to form the group and invite others to share as well.
- Be sure there's a time for everyone to introduce themselves and tell their personal story if they want to. Remember, it may take several meetings for some people to feel comfortable sharing deeply.
- Make sure you get contact information for everyone who attends, including email addresses.
- One interesting activity for this first meeting might be to discuss a name for the group. Some groups identify themselves by their geographic location; others have chosen more descriptive names.
- Start and finish the meeting on time. If the advertised ending time is approaching and the discussion feels like it is at a critical point, the leader(s) can ask members how they feel about extending the time of the meeting. If this is done, it is good to put a limit on the extension.
- Before adjourning the meeting, decide on the time and place for the next gathering.

RECRUITING GROUP MEMBERS

Before your first meeting, spread the word as widely as possible. Some ways to do this include:

- Develop a flyer to place at churches, schools, organizations, hospitals, libraries, grocery stores and any other places with public bulletin boards in your community.
- Distribute flyers in doctor's offices, clinics, and hospitals including pulmonary clinics and rehabilitation centers.
- Send the information about your meeting to be posted on the FSR web site.
- Write a brief press release and send it to your local newspaper.
- If your newspaper lists community meetings, send a notice for publication.
- Send your local radio or TV stations a public service announcement.

LEADERSHIP

Generally speaking, groups are stronger if leadership is shared among the members.

While you may not want to discuss this at the first introductory meeting, be sure to bring it up early in the group's life. Shared leadership means more people feel ownership for the group and guards against anyone being burnt out.

You may want to structure in regular changes of leadership, but talk this over with the group and come to a decision that makes sense for your situation.

FINANCES

Be aware that there will be some expenses connected to your meetings. These might include refreshments, printing and mailings. You may want to ask members to contribute a small amount (\$1.00, for instance) at each meeting to offset these costs. This is everyone's group and it is not really fair for one or two people to shoulder all the expense.

You may also be able to find businesses in your area which will donate services like printing, supplies, or food for refreshments.

ONGOING COMMUNICATION

Set up an email group to allow communication between meetings and to post updates on future meetings. Be sure to update those without email by telephone.

CONFIDENTIALITY

Trust between members is the foundation for much of a support group's effectiveness. Generally this means, "What is heard in the group, stays in the group." Confidentiality can, however, mean different things to different people.

Here are a few questions the group might want to discuss:

- Can group members talk with each other outside the group about something they heard in the group?
- Can something from the group be discussed with others outside the group if the person's name is not used?
- Can spouses or roommates be told?
- Does the group member speaking have to ask for something to be kept confidential in each instance or is everything to be kept confidential?

The discussion about confidentiality is important for every Sarcoidosis Support Group to have, but it may be an especially delicate subject for groups formed in rural areas or small towns where everyone knows everyone else.

The important things are that you have the discussion and that everyone has an opportunity to be heard and that everyone understands and agrees to abide by the final decision of the group. It is also important that new members joining the group are informed of the group's decision.

SHOULD YOU SEEK 501(C)3 NOT FOR PROFIT STATUS?

Since most support groups are loose and informal with little money and few expenses, incorporation and 501(c)(3) tax exemption may be unnecessary. Many small volunteer service and advocacy groups exist with little or no money. They don't seek grants and their members or contributors don't care if their gifts are tax deductible.

Applying for 501(c)3 status can be a time-consuming process since it requires you to develop by-laws and fill out a lengthy application. You might want to wait until your group gets established before you consider this step. You don't need to incorporate to get an EIN (Employee Identification Number) from the Federal Government or to open a bank account. If you do open a bank account in the group's name, consider requiring two signatures on checks. One signer would probably be your group's Treasurer.

Even if you have some money or wish to seek an occasional grant, you may not need to establish a separate non-profit 501(c)(3) organization. There are ways, for instance, to partner with the Foundation for Sarcoidosis Research or another not for profit which already has 501(c)3 status and which could serve as your "fiscal sponsor," administering financial matters on your behalf.

Qualifying under Section 501(c)(3) offers significant benefits:

- Exemption from payment of federal income tax
- Exemption from payment of federal unemployment tax
- Reduced postal rates for bulk mailings
- Tax deductions to contributors for their donations

Tax exempt status under Section 501(c)(3) also imposes significant responsibilities:

- Limits the organization's purpose and activities
- Limits lobbying activities
- Prohibits political activities
- Prohibits excessive financial benefits to its directors and employees

- Requires tax returns
- Requires many records be open to public scrutiny
- Restricts certain distribution of assets if the organization is dissolved

Carefully weigh the benefits and costs of all your options before you commit the time and money to submit a 501(c)(3) application.



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HOW TO MAINTAIN A SARCOIDOSIS SUPPORT GROUP

Maintaining a support group requires as much effort as it does to start one. Support groups go through stages, much like the stages in a person's life, from initial organization through growth to maturity. As a group passes through these stages, different techniques and strategies can be used to maintain the original and central purpose of the group: support for sarcoidosis patients and those who care about them.

This chapter will provide you with some ideas about sharing responsibility, maintaining membership and keeping your meetings interesting and informative.

MAINTAINING GROUP MEMBERSHIP

When a group starts, members are usually very enthusiastic about attending meetings regularly and inviting their friends and family to come with them. As time goes on, membership may fluctuate or drop. There can be many reasons for this. Members who have sarcoidosis may go through periods when they are physically unable to attend your meetings. The time of year may also impact attendance. For instance, attendance may be lower in the summer time or close to holidays when people are traveling.

Some people may choose to attend only one meeting simply to reassure themselves that their situation is not unique and that the group is available if they need it. Others may have had unrealistic expectations and think that a support group will solve all their problems; when they find out this is not the case, they stop attending.

So, how do you keep the members you have and attract new ones?

How to Keep Members Coming Back

- Develop a contact list and notify members of meetings by phone, email or mail. Make sure your contact list is updated regularly.

- Use your contact list to develop a telephone tree and/or develop a buddy system so each person is paired with at least one other. You might pair people by age, the type of sarcoidosis they have, or family situation. Encourage people to contact each other between meetings to provide support.
- Coordinate transportation to your meetings if this is needed.
- Make sure your meetings are interesting and address topics the members have chosen.
- Involve people in leadership roles so they feel a sense of ownership.
- Build a family atmosphere. Consider organizing opportunities for socializing during the meeting and outside of meeting times. Plan some activities when the only reason for getting together is having fun. Some groups have potlucks or go to movies or concerts together. Depending on the type of group you have, you may want to include the whole family in events.

How to Attract and Welcome New Members

Nothing works as well as word-of-mouth publicity. Members who are benefiting from the support group are the best advertisement. Keep spreading the word. Develop a brochure or newsletter to distribute to members and prospective members. Continue to send meeting announcements to newspapers, churches, and community centers.

Sometimes when a group has been together for a while it is hard for a new person to feel like they fit in. Because you are a support group and members may see each other only at meetings, without really meaning to your group may seem like a closed club to new folks. Find ways to be intentional about making new people feel welcome. Remember, you only have one chance to make a first impression with new people.

- Assign members to act as greeters for meetings so that new members are made to feel welcome. Greeters should be people who are friendly and genuinely like meeting people.
- Ask everyone to wear a name tag.
- Consider pairing someone who has been attending meetings for a while with a new person. Ask them to share some of the history of the group with the new member and call them a few days after the meeting to see if they have questions or need more information.
- Make sure you include new members in socializing at the meeting and outside the meeting.
- Remember that people attending for the first time may be nervous and not know what to expect. They may not be ready to share deeply until they become more comfortable with the group. Be sensitive to this when inviting people to share.

REMEMBER TO SHARE

If you had the original vision for the support group and did the hard work of getting it started by yourself, it may be difficult for you to let go of some of the responsibility. Keep in mind that this is not your group—it belongs to everyone who walks into a meeting. Trying to do everything yourself is the quickest way to burn-out. (See *How to Avoid Leader Burn-Out*)

While many of us probably feel most invested in groups where our ideas and talents are sought out and appreciated, sharing responsibility and leadership is not always easy. Often it feels like things would go faster and be more efficient if one person made all the decisions. This may be true, but sharing strengthens a group because it provides opportunities for ownership and establishes an atmosphere of openness and a sense that we're all in this together.

Share Leadership for the Group

This is easiest to do if it happens from the beginning. Share tasks so that there are always at least two people who feel responsible for making sure things get done.

After you have had a few meetings, you might want to ask your members to fill out a form listing ways they would like to be involved in the group. Keep in mind that many of your group members probably have skills they are looking for ways to use since sarcoidosis may have limited their ability to use them in the work force.

Some groups appoint a council which makes decisions and shares responsibility for carrying out activities. Other groups set up committees or appoint a person or two to be in charge of specific areas.

Share Financial Responsibility

Running a support group doesn't have to be expensive, but every group has some costs. It isn't really fair for one person to have to foot the bill all the time. This can be tricky because most of us don't like asking others for money, especially when we know group members may not have much money to give. Here are some ways groups handle this:

- Put a basket out for donations at each meeting.
- Hand people stamped envelopes when they come in addressed to the leader/group treasurer so they can choose to put money in them and send them back or not.
- Ask for a small set amount at each meeting.
- Ask people outside of the group for donations to help offset the costs.
- Instead of purchasing refreshments, ask members to bring something to share or have a potluck.

KEEP YOUR MEETINGS INTERESTING

At one of your group's first meetings you probably asked members what topics they would be interested in hearing more about. Don't forget to re-visit this question after your group has met for a while. Some groups do this at their first meeting each year. You can brainstorm both ideas and speakers people would like to hear from

If you do ask someone to speak at a meeting, ask if an honorarium will be charged and offer to pay travel expenses and lodging if necessary. Often you'll find that speakers will waive these fees, but it is a courtesy to offer to pay them. After the speaker has accepted your invitation, send a letter outlining your expectations and understandings of what the speaker will provide for you. Make sure the speaker has all the information needed about the event: location, time, schedule, etc. If you would like to tape the speaker's presentation, make sure you get their permission in writing and be clear how you plan to distribute the tapes you make.

Don't forget why you are meeting—to support each other. Make sure there are adequate opportunities for members to share what is happening with them and get support either during the meeting itself or during the social time.

Have fun! People will keep coming back if they are invested and feel that they are a vital part of the group and the meetings.



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HOW TO AVOID LEADER BURN-OUT

INTRODUCTION

Leading a Sarcoidosis Support Group can be energizing and life-giving and provide group members and you, the leader, with the support needed to face life with sarcoidosis. There may come a time, however, when you will feel burned out. This chapter is designed to help you identify the signs of burn-out, how to deal with it if it happens to you and, more importantly, how to keep it from happening.

SOME SIGNS OF LEADER BURN-OUT

Most likely when you started the Sarcoidosis Support Group you were excited and full of passion. Actually getting a group started was hard work, but you saw a need and set out to meet it by providing a place where you and others touched by sarcoidosis could give and receive support.

But after a few months or years the meetings may not seem as exciting. You may even dread having to lead one more session or hear one more person's story about living with sarcoidosis. This feeling which may have crept up on you slowly has a name: *burn-out*.

Some of the signs of burn-out include a persistent lack of energy, satisfaction, enthusiasm, motivation, concentration, and humor. You may feel like you're overloaded and doing too much. You may resent the fact that even though you ask for help repeatedly, no one else in the group steps forward. Soon you may resent the people in your support group themselves.

According to VolunteerToday.com here are some questions you can ask yourself if you think you might be burned out:

- Has your enthusiasm for leading the group dropped considerably?
- Does leading the group feel like a heavy weight?
- Are you fretting and worrying about leading the group even when you are doing other things?
- Is there a feeling of emptiness in leading the group?
- Has the satisfaction gone?

- Do you think about quitting?
- Are you cranky with other group members?
- When was the last time you felt supported and/or enjoyed leading a group meeting?

SOME CAUSES OF LEADER BURN-OUT

Trying to do everything yourself is one of the most frequent causes of leader burn out. This is a support group for everyone involved, including you, the leader, so if you're not leaving the meeting feeling like you've been supported, something needs to change.

If you're the only one doing all the work, you're probably the one people come to most often with their problems. Whether they're a sarcoidosis patient with new symptoms, problems with a new medication, or trying to find a new doctor or a patient's family member trying to keep their spirits up, they may be calling you at all hours.

You may feel like you're the only one shouldering the financial responsibility for the group.

Your group may be experiencing difficult internal dynamics. All groups go through growing pains and sometimes this weighs particularly heavily on leaders. All groups have difficult people in them from time to time. Sometimes group members disagree with each other and expect the leader to act as a mediator or problem solver.

The sarcoidosis community is small and close-knit, so you'll likely have contact with groups and leaders from other parts of the country. This can provide you with an amazing means of personal support; however, sometimes internal politics and feelings of competition may arise.

Your own health problems may increase or you may face other difficulties in your personal life that make you or your family resent the time you give to leading the support group.

Unfortunately, some members of your group may get sicker as time goes by and some may die. Sarcoidosis Support Groups have experienced the death of leaders, group members, and family members of patients. Or you may hear of or know others who succumb to sarcoidosis from outside your group. As the leader you may struggle with finding ways to comfort the members of your group while you are grieving yourself.

HOW TO STOP BURN-OUT BEFORE IT HAPPENS

We can't say it too much: spreading the work around means everyone feels more invested in the group and guards against any one person feeling over-burdened.

Don't try to do everything yourself. Delegate.

Give people permission to step up and use their talents, gifts, and skills by asking for their help. Raise others up and give them an opportunity to feel the same satisfaction you do from leading the group. One Sarcoidosis Support Group leader calls this, "opening up your hands."

Keep people informed about what is needed to keep the group running smoothly. Involve everyone in the group in making a list of specific tasks to be done to keep the group going.

Develop clear job descriptions. You might want to consider forming a board for your support group that includes health care professionals or others who are not group members.

Develop a plan for rotating the role of leader and/or contact person for your group. That way no one person will have to shoulder the majority of the responsibilities forever.

Keep a manual including the job descriptions for volunteer responsibilities; a list of contacts for your meeting place, speakers, etc.; information on how to do specific tasks; and any policies your group has put in place. Make sure several people have copies of the manual so if something happens and one leader is unavailable, the group won't grind to a halt.

HOW TO DEAL WITH BURN-OUT AFTER IT HAPPENS

Don't be afraid to ask for help.

- Contact staff at the Foundation for Sarcoidosis Research for advice, resources, or just to talk. (See *Contact Information*)
- Call a member of the FSR Sarcoidosis Support Group Advisory Council, all experienced leaders of sarcoidosis support groups. It's likely one or more of them have dealt with the problems you're facing. (See *FSR Sarcoidosis Support Group Advisory Council contact list*)
- If your group has professional advisors, talk with them or with someone else you trust.

Share your feelings with your group—after all, it is a support group for you, too. Re-read the section above on ways to stop burn out before it happens and put those steps into place. Work with your group to prioritize the tasks and decide who will be responsible for each one.

Take care of yourself. Have some fun. Think realistically about how much time you have to give to the group.

Take a break if you need to. Do not be embarrassed or ashamed of taking some time off. Remember that your physical and mental health are more important than any group meeting.



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ORGANIZING A SUCCESSFUL EVENT

Sarcoidosis Support Groups around the country plan and carry out a variety of special events ranging from workshops with doctors and other health professionals to fund-raising golf outings. Each event is different, of course, but there are some things that need to be considered for any event. This chapter is designed to help you think through the steps necessary to ensure a successful event.

BRAINSTORM

It is important to involve all members of the support group from the beginning. Get together to brainstorm a list of ideas that will help you attract the audience you want to attend your event.

Remember, brainstorming means throwing out as many ideas as possible before you begin to evaluate which ones are best or feasible for your group to handle.

DEVELOP A TIME LINE

Working backward from the date of your event, develop a time line including tasks both big and small. There are few things more satisfying as an event draws closer than completing the tasks and crossing them off your list. A good rule of thumb is to begin planning at least six months before the event is to take place, longer if you're planning a bigger event. (See *Attachment #1*)

IDENTIFY AND ASSIGN TASKS

Once you have decided on an event, begin to develop a list of tasks that will need to be completed before you put on an event. (See *Attachment #2*)

Even though it may seem more convenient and simpler to do everything yourself, sharing responsibility builds investment and commitment to the event and the group. While you may be the over-all Event Coordinator, you might find it helpful to set up an Event Planning Committee which will be responsible for things like finding a venue, planning for food and hospitality, and contacting speakers. Identify specific people to coordinate these and other tasks including registration, audio-visual equipment, photography, compiling speakers' biographies, and publicity.

Ask those who coordinate each task to keep a written record of what they do so that at the end of the event you can put together a notebook of what worked and what didn't for the next time.

SELECT AN EVENT COORDINATOR

The Event Coordinator will be responsible for checking in with other committee members and volunteers to make sure they are following through on their commitments. Before you take on this role, be sure you are willing to be on call and that you enjoy detail and keeping lots of lists.

CHOOSE A LOCATION

The location you choose for your event will depend on a number of factors:

- How long will the event be?
- How many people do you anticipate will attend the event?
- Will you need spaces for workshops?
- Do you have funds to rent a space?

Once you decide what kind of space you need and can afford, ask the people in your support group to check with their families and friends to see if any of them work at locations that might provide you with free or lower cost space for your event.

The Internet is an amazing tool to use to search for venues, but make sure you physically visit the space before you commit to anything. Remember to check whether the space is handicapped accessible and easy to get to and if free or inexpensive parking is readily available.

If you are planning your first event, you may want to start small, with a half day event at a local church or hospital that will provide you with free space and allow you to bring in your own food.

If you are planning a bigger event and/or using a hotel or conference center, keep in mind that some venues require that you use their caterers and their security and clean up people. They often also charge extra for audio-visual equipment, tables, workshop rooms, etc. All of these items can add to the cost of an event.

If you're using a hotel and you know people will be coming from out of town for your event, ask the hotel if they can reserve a group of rooms for your registrants. Often if you fill all the rooms you've reserved, the hotel will give you a discount on the other costs of your event.

ALL ABOUT CONTRACTS

Having a contract with the vendors you will use is of great importance since contracts allow both parties to know exactly what they can expect and what is expected of them. If a vendor you work with doesn't have a contract, you can use the sample attached here to write up your own or purchase one at an office supply store. (See *Attachment #3*)

Whenever you enter into any transaction with a vendor, you should carefully review and understand the document you are signing. You should talk to the vendor if you are unclear on the terms of the contract. Don't sign the contract until you are clear about what the document says. If you don't understand the terms of the contract, find someone who can help you understand. This is very important since once you sign the contract it is legally binding and can be upheld in court.

GET THE WORD OUT

Use all the connections you have to get the word out about your event. Members of your group may work for media outlets or know people who do. Ask them to help develop a public relations plan to publicize your event.

Don't limit yourself to the obvious choices of television, radio and newspapers. Other places to advertise include: community service calendars, church bulletins, sarcoidosis chat rooms, the Foundation for Sarcoidosis Research web site (See *Contact Information*), doctors offices, hospital waiting rooms. Many communities have local cable access channels which are looking for events like yours to highlight. Someone in your group may have connections with a local radio or television station.

Here are links to two web sites where you can find information about how to put together press releases for various kinds of events and media:

The Community Media Workshop in Chicago at

http://www.newstips.org/interior.php?section=PR+Tips&main_id=141

The Substance Abuse and Mental Health Services Administration at

<http://www.toosmarttostart.samhsa.gov/html/tsts-impl/appendixG.aspx>

You may also want to try to place a feature article on one of your group members or the speaker you are inviting to your event in your local newspaper. This not only spreads the word about the event, it educates people about sarcoidosis.

Often people who are computer savvy like to produce brochures and flyers. Make sure the members of your group have a supply of these to pass out and put on community bulletin boards wherever they go.

Remember to document the event itself with photographs and video. You may want to partner with a local vocational high school or college that has a radio/tv production class to see if students might make a video of your speakers for a class project. **If a video does get made, remember there may be members of your group who will not want their pictures to be shown.**

MAKE A BUDGET

Early on, make a budget for the event. Try to think of everything you might spend money on, then look at your budget to see what pieces you might get donated from supporters or businesses in your area. For instance, hospitals and businesses are often willing to donate items for a goodie bag to be given to each participant. (See *Attachment #4*)

If you're planning to charge participants in your event, decide the minimum amount you feel you can ask given the number of people you anticipate will come to the event. You may also want to ask those who can afford it to contribute to a scholarship fund for those who are less able to pay the full registration cost.

CHOOSE YOUR SPEAKER

If you are planning an event where you will have a speaker, decide who you want to invite to speak based on the topics you want to cover. When you ask someone to come, ask if an honorarium will be charged and offer to pay travel expenses and lodging if necessary. Often you'll find that speakers will waive these fees, but it is a courtesy to offer to pay them.

After the speaker has accepted your invitation, send a letter outlining your expectations and understandings of what the speaker will provide for you. Make sure the speaker has all the information needed about the event: location, time, schedule, etc. If you would like to tape the speaker's presentation, make sure you get permission in writing and be clear how you plan to distribute the tapes you make.

OTHER

You'll want to have name tags for participants so they can get to know each other. Also, you might want to put together notebooks of materials on sarcoidosis to give to each registrant along with a goodie bag. The Foundation for Sarcoidosis Research will be happy to provide brochures for your event.

AFTER THE EVENT

Develop a short evaluation form for participants in the event and ask them to fill it out before they leave. An easy way to do this is to give them 5-10 minutes in the last session. When people take the evaluations home to complete they often forget to return them. Ask for feed-back on speakers, workshops, meeting location, the food and anything else you can think of.

Encourage members of the Event Planning Committee to fill out an evaluation form as well or to jot down their thoughts about the event and as soon as possible after the event meet with them and other key planners. Start with all the things that went well and list them for everyone to see. Then move to those areas you'd like to improve for your next event.

Event evaluations are important as they show you the areas that you did well in as well as the areas that need improvement. You might want to call the areas you need to improve in "learning experiences" to reflect your desire to give people nothing but the best when they attend any function you have. Don't be afraid to look at those areas that need improvement, as addressing your shortcomings will only make future events better.

Your work is not done at the end of the event. You might want to give your speakers a small gift of appreciation and definitely send them a thank you from your group. Keep a list of all those who have helped in any way as you go along and send them a thank you for their efforts.

By all means celebrate!! You've just done something amazing!

IF YOU'RE PLANNING A FUND RAISER

Many of the ideas in the previous sections of this chapter can be used when you're planning a fund raiser, but there are a few additional things to remember.

- Set a realistic, reachable goal of the amount of money you want to raise.
- If this is your group's first fund raiser, it might be easiest to start with something simpler like a bake sale or selling taffy apples.
- If you're planning an event like a Walk or Run
 - Find out if you need to take out liability insurance
 - Ask participants to sign a waiver
 - Make sure you have medical personnel available
 - Check to see if you need to reserve the place you plan to hold the Walk
 - Create a do-able route for the Walk
 - Develop pledge forms
 - Create alternatives for those who cannot walk
- Be clear about your purpose in raising money
 - Do you want to support research? If so, you might consider donating at least a portion of the proceeds of your event to the Foundation for Sarcoidosis Research.
 - Do you want to support a local sarcoidosis clinic? If so, ask them to work with you on publicity.
 - Are you raising funds for your support group? If so, make sure you come up with a clear statement of your needs.
- Try to schedule your event at a time when there are not a lot of other things happening in your community. For instance, you probably don't want to try to pull off an event the week before Christmas or the same week-end as the local fire fighters fund raising dance.
- Make sure you send thank you letters to everyone who makes a donation. If your group has tax-exempt status, indicate in the letter what portion of their donation is tax-deductible.
- Keep very careful records of donations you receive and your expenses.

A FEW TRIED AND TRUE FUND RAISING IDEAS

- **Golf Tournament**
- **Walk-a-Thon**
- **Gospel Music Fest**
- **Dinner & Music**
- **Fashion Show**
- **Spa Day**
- **Bake Sale**
- **Five K Run/Walk**
- **Selling Christmas wreaths**
- **Silent auction**

If your group is thinking about holding a fund raiser, call the Foundation for Sarcoidosis Research for ideas and assistance. (See *Contact Information*)

Attachment #1—Sample Time Line

EVENT PLANNING TIME LINE

As Early as Possible

- Brainstorm and choose an idea
- Determine your target audience and program goals
- Set date, time and place for event
- Develop a time line
- Find facility to be used
 - visit the site
 - determine the cost of rental
- If you're expecting out of town registrants, arrange to contract with a hotel for lower room rates
- Identify an overall Event Coordinator
- Form a committee for each task
- Identify and contact speakers/presenters
- Develop a preliminary schedule
 - include breaks, meals, set up, check in, clean up and travel time
- Develop a budget
- Confirm AV requirements and reserve all equipment needed
- Prepare and distribute registration forms
 - determine and include registration fee
 - include registration closing date
- Develop publicity plan and time line
- Investigate possible sources of donations
- Identify vendors you will use and get written estimates for their services

6 Weeks Before the Event

- Recruit necessary volunteers
 - registration
 - set up crew
 - food/refreshment set up and servers if necessary
 - clean up crew
 - AV and equipment
 - photographer/videographer
- Confirm site rental
- Confirm caterer and other vendors
- Confirm speaker and other presenters
- Review and finalize menus, room set ups, etc.

1-2 Weeks Before the Event

- Assemble check-in packets
 - agenda/schedule of events
 - evaluation forms
 - information about speakers/presenters
 - educational information about sarcoidosis
- Assemble goodie bags
- Confirm arrangements with all committees and people working at the event
- Pick up equipment as needed
- Create an accurate registration list
- Check in with speaker(s) to see if they have any last minute questions or needs

Day of Event

- Be prepared (for anything!!)
- Arrive early to set up and get organized
- Set up registration table
 - Have attendee list, properly alphabetized, with name tags

- Bring extra name tags
- If people will be paying a registration fee, bring change
- Have enough packets available so every participant gets one
- Handle questions/situations calmly
- Thank your resource people and give them honorariums as needed

After Event

- Planners meet to evaluate event (do this as soon as possible so the event is still fresh in everyone's mind)
- Send thank you's to everyone who helped
- Pay any outstanding bills
- Put together a note book containing information for those who will plan future events for your group.
- Make sure you follow up with everyone who attended the event so they know about your regular support group meetings. You may even want to call people who came to the event but do not currently attend your meetings to thank them for coming and ask if they have any questions about your group.

EVENT PLANNING BUDGET WORKSHEET FOR WALK-A-THON

PROGRAM NAME	DATE		
INCOME		Estimated	Actual
Registration Fees			
Other			
TOTALS			
EXPENSES			
Food			
Facility Rental			
Speaker Fees			
Transporation			
Equipment			
Printing			
Goodie Bags			
Publicity			
TOTALS			



FOUNDATION FOR
SARCOIDOSIS RESEARCH

If you are interested in more information about starting a support group, please contact a member of the FSR Sarcoidosis Support Group Advisory Council (see contact list).

FSR Staff

Katie Jensen Simms, Development Manager
312-341-0502
Katie@stopsarcoidosis.org

Kimmia Forouzesh, Communications Coordinator
312-341-0500
Kimmia@stopsarcoidosis.org

FSR Address

1820 W. Webster Ave
Suite 304
Chicago, IL 60614

Phone: 312-341-0500
Toll Free: 866-358-KISS (5477)

FSR Web Site: www.stopsarcoidosis.org

Support Group Listings: www.stopsarcoidosis.org/directory

FSR On-line Support Community:
<http://www.inspire.com/inspire/group/stop-sarcoidosis/>



FSR Sarcoidosis Support Group Advisory Council

Kristi Anderson

12619 S. Wilderness Way
Molalla, OR 97038
Phone: 541-905-2092
Email: AGHSarc@yahoo.com

Emma Carroll

Janine's Sarcoidosis Outreach Foundation &
Support Group
PO Box 1008
Alief, TX 77411
Phone: 832-248-6621
Email: Emma@jsof.org

Patricia Coleman

West TN Sarcoidosis Support Group
1670 McLemoresville Road
Huntingdon, TN 38344
Phone: 731-986-9832
Email: pat.coleman1954@yahoo.com

Sandra Conroy

National Sarcoidosis Resource Center
PO Box 1593
Piscataway, NJ 08855-1593
Phone: 732-699-0733
732-463-0497 (home)
732-718-0395 (cell)
73-463-0467 (fax)
Email: Sconroy846@aol.com

Brenda Harris

Let's Breathe Sarcoidosis Support Group
910 Countrywood Drive
Zion, IL 60099
Phone: 847-731-3110
Email: bharris354@aol.com

Shirley Holley

Denver Sarcoidosis Awareness Support Group
4351 Ireland Street
Denver, CO 80249
Phone: 303-375-9376
Email: shirley@denversarcoidosisawareness.org
Web Address: www.denversarcoidosisawareness.org

Ruth Jacobs

REACH—Sarcoidosis Network Foundation
11428 E. Artesia, Suite 10
Artesia, CA 90701
Phone: 562-809-8500 (office)
714-739-4023 (home)
Website: www.sarcoid-network.org
Email: reachsnf@msn.com

Yvonne James

Sarcoidosis Foundation of WV, Inc.
5156 Rainbow Drive
Charleston, WV 25313
Phone: 304-545-0922
Fax: 304-776-6707
Email: Yvonne@wvsarcoidosis.org
Email: Yvonnej3110@aol.com
Website: www.wvsarcoidosis.org

Ulysses Kirby

Chicago Southside Sarcoidosis Support Group
8634 S. Phillips
Chicago, IL 60617
Email: Kirbyma@yahoo.com

Dorthea McGuire

PO Box 1534
Bowie, MD 20717
Phone: 443-762-4282
Email: info@dortheamaquirefoundation.org

Alice Minyard

117 Lark Haven Dr.
Rainbow City, AL 35906
Phone: 256442-0463
Email: alifay1963@aol.com

Rodney Reese

5805 Grand Drive
Baton Rouge, LA 70712
Phone: 225-773-0985
Email: Sarcoidgbr@cox.net



FSR Sarcoidosis Support Group Advisory Council

Sharon Stewart

Sharon Stewart Sarcoidosis Foundation Support Group
149 McDonald Terrace
Childersburg, AL 35044
Phone: 256-346-3096
Cell: 256-391-7145
Email: sdstewart@bellsouth.net