

# **Spondylitis Association of America (SAA)**

## **Things to Consider When Starting a SAA-Sponsored Spondylitis Educational Support Group**

Starting a SAA-sponsored educational spondylitis support group can be a fulfilling and rewarding challenge. As the facilitator or leader of the new group, you will be involved in coordinating and facilitating support group meetings. The role requires you to make arrangements for meeting dates and locations, plan agendas, line up guest speakers, design flyers/meeting notices and respond to patient telephone calls and emails.

Typically, we have found that people attending spondylitis meetings feel the most comfortable with a support group leader who has spondylitis. SAA also encourages all leaders to be very knowledgeable about spondylitis and the diseases that fit into this category. Therefore, we encourage spondylitis support group leaders to educate themselves as much as possible about the diseases that make up the forms of spondyloarthritis (ankylosing spondylitis, psoriatic arthritis, spondylitis associated with inflammatory bowel/Crohn's disease, and reactive arthritis/Reiter's syndrome, undifferentiated spondyloarthritis, juvenile spondyloarthritis) as well as diagnostic testing, therapies and current research. This is important as many groups often encounter people who are newly diagnosed or misinformed about their disease and the management of it.

### **Coordinating and Facilitating**

One of the things to consider when starting a spondylitis support group is deciding on a regular time and place to hold the meetings. Most people find that getting together every two months is sufficient to keep optimum interest and attendance. However, if enough interest is expressed, some groups meet monthly. SAA requires groups to meet a minimum of 4 times per year.

Right from the start, determine what your meeting schedule will be - for example, the fourth Thursday of the month, every two months, from 7-9 p.m. or the third Saturday of the month at 10 a.m. This will help when you are trying to secure a meeting room.

Many hospitals, medical centers, physicians' office buildings, churches, libraries and community centers provide rooms for support groups at little or no charge. Be prepared with your specific request and have information about spondylitis handy when calling to request a meeting space.

Consider the following: size of the room, proximity to a restroom, handicap accessibility, parking availability or fees, and how many major access roads are close to the building.

You will be surprised just how quickly you can secure a meeting room. It is best to find a meeting place and then stick to it.

## **Your First Meeting**

Your first meeting will help determine the direction for the group. This meeting should be simple and informal and should allow for new members to introduce themselves. Introduce yourself and share your story; invite others to share their stories but do not force anyone to talk before they feel comfortable. All information should be kept confidential within the group.

Emphasize the purpose of the group is to provide education in addition to emotional support. Education will be provided through materials provided from the SAA, but also through group members' experiences. Members should discuss what they would like to learn about. They will also need to determine how long and how often they would like to meet as a group.

To assist, SAA will provide a questionnaire that can be distributed to all new members of the group. This form requests basic contact information as well as feedback about suggested meeting topics and interest. Use this questionnaire to help determine future meeting agendas. Also, have these questionnaires on hand to distribute to new members as they attend meetings.

## **Think “Shared Leadership”**

As you establish your group, it's important to keep in mind the concept of “shared leadership”. Shared leadership promotes a sense of shared responsibility for the group; members will feel more connected to the group when they share in the responsibility for the work and the life of the group.

The group still needs an effective group leader, however shared leadership helps to lessen the burden of responsibility on the leader when members of the group take an active role in helping the group to keep going. Once you have gotten to know more about your group members, you may want begin delegating some of the responsibilities and get their help with securing speakers, promoting the group, responding to group inquiries, etc.

In the event you would need to step down as the leader of the group, shared leadership may also help make a transition to a new leader easier.

## **Planning Meeting Agendas**

Planning for your meetings is an important step in assuring the success of your group. Your goal is to have the group be as informative as possible, while providing a warm atmosphere in which members feel comfortable to share their experiences. However, unless you are a trained mental health professional, be diligent in keeping the group from evolving into a therapy session. Assigning and sticking to a specific meeting topic could help keep the group on track.

Popular topics include:

Self-help techniques  
Treatment options

Maneuvering the health care system  
Daily living tips

Physical therapy and exercise  
Pregnancy  
Current research  
Pain management  
Depression

Preparing for a doctor appointment  
Childrearing  
Stress reduction  
the challenge of getting enough sleep  
Employment issues

SAA has also created a Spondylitis Educational Support Group Resource Guide for spondylitis support group leaders in order to provide them with suggested guidelines, topics and materials to use during their group meetings. This guide contains information on 28 different subjects including information on how to promote your group, ideas for speakers, as well as educational materials on many different topics of interest to those living with spondylitis.

You may also print and copy any information from the SAA web site ([www.spondylitis.org](http://www.spondylitis.org)) to disseminate to the group. SAA will also provide you with copies of our educational brochures and other materials, and members can also obtain various resource materials from SAA.

It is crucial for the group leader to stay informed. One of the best ways to do this is to read *Spondylitis Plus* thoroughly – it is a very important source of accurate information. *Spondylitis Plus* may also provide you with ideas for topics to discuss with your group.

Occasionally, you might be able to schedule a guest speaker who will present information on a special topic of interest to the group's participants. Physicians, nurse practitioners, physical therapists, pharmacists, political representatives, health insurance professionals, attorneys knowledgeable about disability issues, and all other trained professionals who have an interest and knowledge about spondylitis can make for an excellent and engaging group meeting.

Lining up guest speakers may sound like a daunting task, but it can be as easy as picking up the phone. Your meetings are a great place for a speaker to introduce services to a large number of potential clients.

With that in mind, spondylitis support group meetings should be unbiased educational forums, not sales pitches for unproven product claims or product endorsements. You may want to avoid scheduling speakers whose sole intent is to sell a product or service. Likewise, it is critical to discourage individual members of your group from selling their own products and/or services to the group.

Remember to keep the focus of your group on proven information and support, and not on the selling of untested products, and/or services.

Lastly, try to end the meeting on an “upbeat” note so that people walk away feeling like they learned something. You want members to be excited and hopeful for upcoming meetings.

## **Recruitment of New Support Group Members**

SAA will assist spondylitis support group leaders with recruiting new members by sending electronic mail (email) notices to SAA constituents in the area. The leader is responsible for giving the SAA Programs Manager the pertinent information for meetings (e.g. meeting date, time and location) at least one week before the meeting notice should be distributed.

SAA has also created a Spondylitis Educational Support Group promotional brochure, which speaks to the benefits of becoming involved in a spondylitis support group. On the back of each brochure is space for a label, which can contain the leader's contact information. These brochures can be distributed to local rheumatologists, physical therapists and to local medical facilities where others with spondylitis may receive services.

See below for more suggestions on how to recruit new members within your community.

### **Things to Consider when Promoting Your Group**

Once you have established a meeting place and time, you will need a flyer in order to publicize meetings. Please talk with the SAA Programs Manager if you need assistance creating a flyer.

Many rheumatologists will post a well-designed support group notice in their reception area. They may also pass them along to patients as they conclude an appointment. You can encourage group members to bring flyers or the Support Group promotional brochure to their doctor(s) and distribute them to nearby medical offices. Remember to hand meeting notices to other health professionals who see patients with spondylitis, such as physical therapists, massage therapists and occupational therapists. Please note that some offices do not allow any posting or distribution of flyers.

Other useful resources include community bulletin boards in libraries, office buildings, hospitals and medical buildings, schools, town halls, and supermarkets. Look into submitting group information for free public service announcements on local access TV stations and radio. For free public service announcements in print media, contact local newspapers, hospital newsletters, Pennysavers, etc.

### **How to Keep It Going**

During your first meeting, have everyone complete a questionnaire so that you get to know individual experiences and needs right away. SAA will provide you with a sample questionnaire. Use the information on the questionnaire in order to stay in touch with the group's members. Keep the momentum going by continuing to promote the group.

Avoid using postcards when communicating with your group members to be sensitive to those who have privacy issues.

## **Responding to Patient Telephone Calls**

As the leader of a SAA-sponsored educational support group, you likely will be receiving phone calls and emails from spondylitis patients. This can be the most time consuming responsibility of managing a group.

Patients will call you for many reasons -- anything from driving directions to the meeting location to personal crisis situations. Many support group leaders seek help in handling these calls. After you get to know your group members, you may find one or two people who are willing and able to help you with this aspect of the role by either taking calls or answering emails for you.

In summary, a Spondylitis Educational Support Group Leader has many responsibilities. These include:

- Coordinating Meetings (including arranging for meeting location, determine date and time, etc. This includes notifying SAA Coordinator of meeting details for announcement)
- Facilitating Meetings (Setting the tone of the group, leading the meetings, model good listening, etc.)
- Planning Meeting Agendas (including determining meeting topic, arranging for speakers, preparing materials to be distributed)
- Recruitment of New Support Group Members
- Promoting the Group
- Responding to Group Member Telephone Calls and Emails
- Reporting to SAA (including sending copies of sign-in sheet after each meeting and completing semi-annual survey)

It may seem overwhelming at first, but keep in mind that once a core group is established, these responsibilities can be delegated to other members in the group.

Should you at any time feel overwhelmed by leading your spondylitis support group, contact SAA. We're here to help. You should never feel that you are going solo with your support group. Call (818) 981-1616 x227 so that we can assist you.

### **Is the role of support group leader right for you? You may want to ask yourself the following questions.**

1. Are you knowledgeable about the diseases that make up the forms of spondyloarthritis (ankylosing spondylitis, psoriatic arthritis, spondylitis of inflammatory bowel disease, reactive arthritis / Reiter's syndrome, undifferentiated spondyloarthritis, juvenile spondyloarthritis), diagnostic testing, therapies and current research?
2. Are you comfortable facilitating group discussions and speaking in public?
3. Do you live in an area where you could recruit/obtain speakers with an expertise in issues of interest to spondylitis patients?

4. Are you able to take phone calls and emails from local spondylitis patients who need support and understanding?
5. Are you able to organize and run at least four support group meetings a year?

If you have answered “yes” to these questions, you may be ready to start a spondylitis support group!

**Disclaimer:**

*These meetings should not take the place of professional medical care. Patients need to contact their treating physician before making any changes in their treatment. SAA does not endorse any medical treatments or services.*