



Network of PEERS

Program Guidelines and Information for Mentees

When you have been newly diagnosed with AS or a related condition, its associated social, functional and economic consequences make disease management an important issue. It is especially important to take charge of the disease since the experts agree that taking an active role in managing spondylitis, backed by a sound knowledge base, will have a positive influence on its outcome. Being newly diagnosed with AS or a related disease can be a confusing experience.

SAA's Network of PEERS (**P**eople **E**ducated and **E**mpowered to **R**ise above **S**pondylitis) was developed to help people newly diagnosed with spondylitis feel less isolated, understand the importance of learning about managing the disease, and feel supported and encouraged to empower themselves to live life to the fullest.

Getting Started

In order to enroll in the program as a "Mentee", you must:

- Complete the Network of PEERS Mentee application.
- Have a newly diagnosed form of spondyloarthritis (e.g. less than 3 years); or be struggling with managing your disease and would like to talk to a peer who is managing their disease well.
- Participate in an informal interview process conducted by Programs staff.
- Agree to the guidelines put forth by SAA for enrollment in the program and sign a Network of PEERS Participant Agreement.

What to Expect

What is a Peer Mentor?

As a "Mentee", we are sure you are wondering what to expect. So what is a mentor and how can they help you?

SAA's Network of PEERS program defines a peer mentor as a member of the spondylitis community who has real-life knowledge and experience in managing their spondylitis. In general, we will consider someone for the role of "Mentor" if they have been diagnosed with spondylitis for more than 5 years and are effectively managing their disease. They are knowledgeable about resources for learning about spondylitis and living with

spondylitis, and would like to share their experiences with people who are newly diagnosed, or need support in managing their spondylitis.

A Mentor is someone who:

- Shares their experience of managing their spondylitis
- Provides practical day-to-day advice about living with spondylitis.
- Provides emotional support through empathy, and by listening to you when you need to talk.
- Provides a positive example of active self-management of spondylitis.

A Mentor is someone who is not:

- Part of your medical treatment team, and should not be seen as such. You are encouraged to routinely see your physicians and only seek medical advice from qualified health care professionals who know your medical history.

Mentors:

- Cannot and should not provide medical advice.
- Cannot solve family, social, work, school, financial, physical or other life problems for you.
- Cannot make decisions for you. Their role is to share their own experiences, solutions, and ways of managing their spondylitis. However, their personal approaches may not always be best for you.

Matching Peers

SAA Programs staff will collect application information and conduct informal interviews with both mentors and mentees to gather information about your experience with spondylitis. You will be matched with a peer based on the information you provide on your application, the type of spondyloarthritis you have been diagnosed with (e.g. ankylosing spondylitis, psoriatic arthritis, arthritis with inflammatory bowel disease, reactive arthritis or undifferentiated spondyloarthritis), the region of the country you are in related to time zone, your gender and other characteristics.

Once we have found a peer match, Programs staff will contact your potential mentor and provide them with some basic information about you. You will be notified that we have found a match for you. Your matched mentor will be expected to contact you to set up a time for your first conversation.

When Your Mentor Hasn't Contacted You

If for some reason, your mentor does not contact you, consider the following:

1. Do we have your correct contact information (email and phone numbers)? If you have changed contact information since you originally applied to be a participant in the program, please let SAA's Programs Coordinator know.
2. How much time has passed since you were notified we found a peer match? If it has been less than 2 weeks, please give it a little more time.
3. If its been over 2 weeks, contact SAA's Programs Coordinator and we will contact the mentor to find out what is causing the delay in response.
4. If the mentor does not respond to SAA's attempts to contact them within one week, we will consider them no longer interested in the program, and we will reassign you.

First Contact

At the first meeting you may want to discuss what you both hope to get out of the relationship and what kind of schedule you both have so you can set good times to get in touch. If you prefer, you may want to set scheduled times to communicate, but it is not necessary unless both you and your mentor feel it would be helpful. Remember, as you and your mentor get to know each other, the awkwardness you may feel at first will pass.

Let the relationship develop naturally. This may mean spending some of the initial conversations just getting to know each other and developing rapport. For some people it may take time to feel comfortable, while others will feel comfortable almost immediately.

Nurturing the Mentoring relationship

You should have a good feel after a few discussions as to whether the rapport is right for a mentoring relationship. You should bring trustworthiness and the ability to keep confidences to the mentoring relationship. Mentored relationships benefit when the mentee approaches the mentoring with openness, honesty, introspection, and realistic expectations.

The Programs Coordinator will check in with you within 30 days of your enrollment in the program to obtain feedback on your new peer relationship. If, after the first or second conversation with your mentor, you decide there is a personality clash or some other reason you cannot work with your assigned mentor, it is your responsibility to discuss your concerns with the Programs Coordinator. We will work to resolve the issue and will reassign you if necessary. If a situation arises where you no longer wish to participate in the program, it is your responsibility to inform SAA's Programs Coordinator.

Program Evaluation

After the initial 30-day review, you will be asked to complete a survey in order for SAA to collect data to evaluate the Network of PEERS program on a periodic basis, approximately every 4 months. These surveys are important to help SAA determine how it can better meet your needs and the needs of your mentor to strengthen and improve the program. We request that you complete these surveys in a timely manner.

Learning about Spondylitis

You have an important responsibility as a person newly diagnosed with spondylitis – learning as much as you can about this group of diseases. You will need to have a solid knowledge base in order to make informed decisions about your treatment plan with your rheumatologist. Educate yourself by visiting SAA’s website or requesting our educational brochures. Ask your rheumatologist questions that will help you understand your condition and the treatment involved. Be your own best advocate!

Setting Appropriate Boundaries

It is important to discuss and agree to the appropriate boundaries of mentoring between you and your assigned mentor early on in your mentoring relationship. Boundaries are the limits of your mentoring relationship. This should be established to avoid the possibility of misunderstandings and confusions. Consider the following guidelines:

- Mentoring is voluntary for both participants. Avoid unhealthy dependence. For example, mentors are not expected to be experts on spondylitis or be “on call” 24/7.
- Talk about your responsibilities, what you can and cannot do.
- Agree on frequency, duration and intervals of communications and how this will occur. If you are unable to make a planned time for communication, let your mentee know.
- Respect confidentiality. Talk with each other about what this means.
- If you are concerned about the boundaries in your mentoring relationship and are not able to resolve the situation, please contact SAA’s Programs Coordinator. We will try to resolve the issue.

Resources from SAA

The Spondylitis Association of America is your primary resource for information about spondylitis. SAA offers a toll-free information line (800-777-8189) to call for information about spondylitis and to request free educational brochures or to purchase the newest edition of [Straight Talk On Spondylitis](#), a book written specifically for the spondylitis patient.

Here are other SAA resources to help:

Information about Spondylitis and Patient Support – www.spondylitis.org

Become familiar with SAA's website and the wealth of information you can find there. In the "About Spondylitis" section, you can find information on ankylosing spondylitis and each of the related diseases, their symptoms, diagnosis, treatment, medications, the complications associated with spondylitis, as well as Frequently Asked Questions. In the "For Patients" section, you can find information about SAA Seminars and Events, Support Groups, Exercise and Tips, etc.

Social Service Referrals – SAA produces a Member Resource Directory, which include social service referrals to different agencies, including health care and prescription assistance. Members of SAA have direct access to this directory in the Members' area of the website.

SAA's Member to Member Recommended Rheumatologist Directory – This Directory includes a list of member recommended rheumatologists organized by state. Please note: these rheumatologists are not endorsed by SAA, and each member's experience is subjective. Members of SAA have direct access to this directory in the Members' area of the website.

Other Resources

American College of Rheumatology – www.rheumatology.org The American College of Rheumatology is an organization of and for physicians, health professionals, and scientists that advances rheumatology through programs of education, research, advocacy and support that foster excellence in the care of people with arthritis and rheumatic and musculoskeletal diseases.

On ACR's website, in the "Find a Member" section, you can find board-certified rheumatologists listed by city.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) – www.niams.nih.gov - A Division of the National Institutes of Health, NIAMS supports research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases. On the NIAMS website, you can find ways to request information about ankylosing spondylitis and its related diseases, ongoing research and clinical trials, etc.