



## ACTION PLAN

*to Manage Spondylitis*



*Learn About Spondylitis*



*Find Support*



*How To Get Involved*

**Spondylitis Association of America**

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## **Introduction**

*Whether you - or someone close to you - has been diagnosed with a form of spondyloarthritis, it is our hope that the information provided in this action plan will assist you in taking charge of the condition. It is imperative to take an active role in managing spondyloarthritis, as doing so will positively impact many aspects of life with this disease. Our goal is to provide you with a sound knowledge base with which to tackle the social, functional, and economic challenges often associated with spondyloarthritis.*

## STEP 1: Learn about Spondyloarthritis

It is important to learn as much as possible about spondyloarthritis – a family of closely related rheumatic diseases. SAA provides a variety of helpful resources to do just that.

[www.spondylitis.org](http://www.spondylitis.org)

Visit SAA's website, which is updated regularly with the latest news and information about spondyloarthritis treatment, medications, and research. In addition, information about SAA events and seminars, supportive programs and the online Message Board community can also be found here.

*Our website is organized as follows:*

**Home:** The home page highlights different sections of SAA's website.

**About Spondylitis:** In this section, you will find information about the six diseases included in the category of spondyloarthritis. Find information about the symptoms, diagnosis, treatment, medications, and alternative therapies for each of these diseases. In addition, this section hosts a number of sub-sections where you will find video and audio files from spondyloarthritis experts, as well as a plethora of educational materials and helpful resources, such as books, brochures, our rheumatologist directory, and the archive of our news magazine, [Spondylitis Plus](#).

**About SAA:** This section hosts a number of sub-sections, including:

***News:*** Each week, SAA provides news stories related to the research and treatment of spondyloarthritis. You will find the most recent news stories as well as an archive of older articles.

***Major Accomplishments:*** Here you will find a list of SAA's milestones with articles about these critical developments.

***Research:*** For over 30 years, the Spondylitis Association of America has encouraged and facilitated collaborations among prominent researchers as a means of accelerating advances in spondyloarthritis research, diagnosis, and treatment. This section provides the history of SAA's efforts and accomplishments in research as well as Current Research Studies and information on how you can get involved. We list spondyloarthritis research conducted by members of our Scientific and Medical Advisory Board as well as SPARTAN (Spondyloarthritis Research and Treatment Network), and include a Research Article Archive.

***Advocacy:*** SAA is the only nonprofit organization in the United States dedicating all of its resources to raise awareness, provide education, and promote research to ensure a better life for all spondyloarthritis patients. In this section, you will find details about

SAA's Advocacy Priorities and a list of SAA's advocacy accomplishments over the years.

[Community](#): SAA can help you get in touch with others and share information and support through our Connections Program. We have nationwide Support Groups, free online Message Boards, Seminars and Webinars, and an avenue to share and read patient stories in our Living with Spondylitis section.

[Donate](#), [Shop](#), or [Become a Member](#): If you share our commitment to ending spondyloarthritis and would like to join us in the fight, your financial contribution would be greatly appreciated and accomplish much.

You can *Donate* in your name or in honor of someone else, *Join SAA* as a Member and receive hard copy issues of our News Magazine, *Spondylitis Plus*, as well as *Shop* our online store for spondyloarthritis educational and awareness materials. We have e-books on diet and nutrition, an exercise DVD, awareness materials, and more.

SWIFT [www.spondykids.org](http://www.spondykids.org)

Spondylitis Web Info for Teens (SWIFT) is the first website of its kind for teens living with spondyloarthritis. SWIFT was developed with the help of teens and includes information about managing spondyloarthritis and its impact on school, sports and activities, and relationships. The site also offers tips and stories from teens living with spondyloarthritis.

### **Publications and Materials**

SAA produces a wide range of publications and materials with information specifically targeted to the spondyloarthritis community. These include:

- Educational Brochures – SAA publishes a number of different brochures, available for free. You can download them, or request hard copies to be mailed to you. [Find them here.](#)
- *Spondylitis Plus* – Our award-winning, advertisement-free, [quarterly news magazine](#) is distributed to SAA Members with information on the latest in spondyloarthritis treatments and research, issues related to managing spondyloarthritis, tips for daily living, and personal stories from people with spondyloarthritis. For a subscription to our magazine, [join SAA today.](#)
- *Straight Talk on Spondylitis* – This internationally recognized book, written specifically for the spondyloarthritis patient, contains information on therapies and treatments, a comprehensive list of medications, activities and exercise programs, and tips for coping with the psychological challenges of living with a chronic illness. Also included with the

book is a free pullout exercise poster to help you maintain an effective fitness program to ensure continued mobility and flexibility. [Find Straight Talk](#) and other educational products.

- *Back in Action* Exercise DVD – SAA’s popular exercise DVD includes demonstrations on a full range of flexibility, stretching, and strengthening exercises for the spondyloarthritis patient. [Find our Exercise DVD](#)

### **Educational Seminars & Webinars**

Each year SAA travels across the country to host free educational seminars in different metropolitan areas throughout the United States. All seminars include an experienced rheumatologist who provides an overview of spondyloarthritis along with current medications and other available treatments. Secondary speakers complement the program with presentations on other topics of interest including physical therapy, occupational therapy, pain management, and more. These seminars provide an opportunity for attendees to ask questions and meet other people from the area impacted by spondyloarthritis.

We also offer free online webinars which allow people to learn about specific spondyloarthritis-related topics in the comfort of their home. [Find out about upcoming SAA events and view recorded programs.](#)

## **STEP 2: Find Support**

SAA offers several different ways for patients and their families to connect with others in the spondyloarthritis community. Learn more about these programs:

### **National Educational Support Group Network**

SAA sponsors over 30 support groups stretching across the US from San Diego, CA to Boston, MA. These groups focus on education and support while providing a safe and friendly environment for people to discuss the day-to-day practical challenges of living with spondyloarthritis. SAA recruits and provides guidance to support group leaders through an interview screening process, trainings, and quarterly conference calls. Browse our [National Educational Support Group Network](#).

### **SAA Message Boards**

Spondylitis.org has an online community providing an opportunity for spondyloarthritis patients and their loved ones to start and contribute to discussions related to living with spondyloarthritis. [Visit our Message Boards.](#)

## **Social Media**

SAA is active on social media sites such as Facebook, Twitter, YouTube and Instagram. SAA provides updates and information through these online communities to further SAA's mission, and leads discussions to help connect spondyloarthritis patients. [Connect with SAA](#) on social media and join the online conversation!

## **Toll-Free Information Line**

Knowledgeable staff members answer SAA's toll free information line and provide information about spondyloarthritis, support programs, SAA events, and additional resources to thousands of callers each year. Talk to a real live person at 1-800-777-8189.

## **STEP 3: Become Your Own Healthcare Advocate**

You are your own best advocate. Being an empowered patient is the key to success as you navigate through the often-challenging healthcare system. We hope the information contained in this section will provide you with tools to make informed decisions about your healthcare needs.

### **When Should Someone See a Rheumatologist?**

You should see a rheumatologist when you suspect you may have arthritis. Rheumatologists are specialists trained to do the detective work necessary to discover the cause of swelling, stiffness, and pain. It is important to obtain a correct diagnosis early in the disease process so that the person can begin appropriate treatment since many musculoskeletal disorders respond best to treatment during the early stages of disease. Early diagnosis and treatment will be beneficial to those with spondyloarthritis since most of the functional loss associated with this disease group occurs during the first ten years.

Many people with spondyloarthritis need to be seen by a rheumatologist over an extended period of time rather than being cared for by their primary care physician. Rheumatic diseases often change or evolve over time; therefore, it is recommended that individuals with spondyloarthritis visit their rheumatologist at least once a year for a regular check-up.

Looking for a rheumatologist or have a great one to recommend? See [SAA's Rheumatologist Directory](#).



## Questions To Ask When Screening a New Rheumatologist:

- Approximately how long will I have to wait to get an appointment?
- Does the doctor see many patients with spondyloarthritis?
- Does the doctor accept my insurance? What is my co-payment or out-of-pocket cost for a visit? Is full payment required at the time of the appointment?
- Do you accept patient phone calls? If so, when is the best time to reach you?
- Is the doctor available by email?

## Before Your First Appointment

Build your own medical history by documenting:

- **Symptoms.** Document all symptoms regardless of their relation to your current issues. Ankylosing spondylitis and its related diseases are systemic diseases and may affect various parts of your body.
- **Previous Tests.** Document all previous tests you have had completed and collect the results from each.
- **Pain.** Write down how much pain you are in each day, where it hurts and how long it lasts, and any suspected pain triggers.
- **Past and Current Medications.** Document the drugs you have taken in the past to treat your symptoms, as well as the drugs you are currently prescribed. Mark which appeared to help and which did not alleviate symptoms. Be sure to include any over the counter medications, supplements or herbs you are using as well.
- **Your Goals.** Write down what you hope to accomplish while you are at the physician's office, including the top few questions you'd like to have answered, to help keep you focused.

## Your First Appointment

What should you take to your first appointment?

- Take your insurance cards and a photo I.D. so that the office personnel can begin to build a medical file.
- Bring along information about medicines, herbs, and supplements you take including:

- Name of the drug, herb, or supplement
- Dosage amounts
- Schedule
- Know the dates of pertinent visits to other doctors related to your current situation (i.e. orthopedic surgeons, internal medicine doctors.)
- Be able to describe your current symptoms and the date of onset. If you have prior x-rays related to spondyloarthritis, obtain the x-rays and/or reports so the information can be included in your medical records.
- Provide information about past surgeries (procedures, dates, and name of surgeons.)

### **Questions to Ask During Your First Appointment**

Consider asking your rheumatologist the following questions:

- (If you have not been diagnosed) Do my symptoms and medical history indicate spondyloarthritis? Which type?
- What treatment will be initially prescribed?
- What is the action of each medication prescribed? (I.e. is it a painkiller? Is it an anti-inflammatory drug?)
- Are there any side effects I should be aware of?
- When should I expect to notice an improvement of my symptoms?
- If this treatment plan does not work, what would be my next option?
- How will you monitor my progress or the possibility of adverse effects?
- Will I require routine blood tests?
- What other approaches should I consider? For example:
  - Exercise
  - Physical Therapy
  - Occupational Therapy
  - Dietary and Nutritional changes

- Weight Control
- Various Pain Management options
- Natural/Alternative Therapies
- Support and other coping strategies

## **Understanding Your Health Plan and What It Covers**

If you have health insurance, your health insurance policy is an agreement between you and your insurance company. The policy lists a package of medical benefits such as tests, drugs and treatment services. The insurance company agrees to cover the cost of certain benefits listed in your policy. These are called "covered services."

Managed care plans sign contracts with certain doctors and hospitals to care for their plan members. Your plan may refer to them as providers. This group of providers is often called the plan's *network*. Like you, they have agreed to follow the plan's rules.

Your doctor will try to be familiar with your insurance coverage so he or she can provide you with covered care, but there are so many different insurance plans that it's not always possible for your doctor to know the specific details of your plan. By understanding your insurance coverage, you can help your doctor recommend medical care that is covered in your plan.

- Read your insurance policy. It's better to know what your insurance company will pay for before you receive a service, get tested, or fill a prescription. Some kinds of care may have to be approved by your insurance company before your doctor can provide them.
- If you still have questions about your coverage, call your insurance company and ask a representative to explain it.
- Remember that your insurance company, not your doctor, makes decisions about what will be paid for and what will not.

## **Specialists**

Rheumatologists are considered specialists. Many managed care plans won't pay for you to see a specialist unless your primary care physician thinks it is necessary. If you see a specialist without a referral, you might have to pay more for the care you receive.

## **Other Services**

If your doctor decides that you need to go to the hospital, have surgery or have certain tests, your insurance company may refuse to pay for it unless it can approve the treatment beforehand.

## **What You Should Know About Medication Coverage**

Almost every managed care plan has a drug formulary. A formulary is a list of prescription medicines that your health plan has approved. If a drug isn't on the formulary, you'll probably have to pay more for it. Your insurance company can give you a list of drugs that are on the formulary. If necessary, show the list to your doctor when the doctor writes you a prescription. This list is reviewed and may be changed by the insurance company every few months, so be sure to check it often.

The drugs in a formulary are often listed in two or more groups, depending on how much of the cost you are expected to pay, referred to as your co-pay. A typical formulary might include various medications organized into different levels, often referred to as tiers.

## **Brand Name vs. Generic Medications**

When a drug company develops a new drug, it gives it a brand name. Brand names are the names you usually see in ads on TV and in magazines--names like Advil or Rheumatrex. For several years after the drug is developed, laws prevent other drug companies from copying it. When other companies start manufacturing and selling the drug, their versions are usually known by a different name -- the generic name. This is often the chemical name. For instance, the generic name for Advil is ibuprofen and the generic name for Rheumatrex is methotrexate. Generic drugs are regulated by the FDA and are required to meet the same guidelines as their brand-name counterparts. Furthermore, generics must be the same in several respects: the active ingredients (those ingredients that are responsible for the drug's effects), the dosage amount, and the way in which it is taken. The main differences between a brand-name drug and its generic counterpart are in the coloring, shape, and name, which are protected for the original company even beyond the years of the original patent. There may also be differences among the inactive ingredients (i.e. the 'vehicle' for the drug) from one brand to another, so if a person has a negative reaction to a drug (brand name or generic,) it may be worth talking with a health care provider and investigating a possible intolerance or allergy to one of the inactive ingredients, in addition to other possibilities.

## **Brand Name Biologics vs. “Biosimilar” Medications**

Biologics (such as *TNF inhibitors*) are made from living organisms using recombinant DNA technology. Over the past 20 years, several biologic medications have become available to treat spondyloarthritis. Most biologics are very large, complex molecules or mixtures of molecules. Unlike a non biologic medication, the living system used to produce biologics can be sensitive to minor changes in the process of manufacturing the medication. As with non-biologic medicines, the pharmaceutical companies have exclusive patents on their medications for a number of years. After the patent expires however, the FDA is able to consider approval of a 'biosimilar' medication based on the original. A biosimilar will be different from the original 'innovator' medication (and is expected to cost less) but will need to perform in a therapeutically equivalent manner to gain approval. On April 5<sup>th</sup>, 2016 the FDA approved Inflectra / CT-P13, a biosimilar version of the TNF inhibitor infliximab (Remicade) for use in all of infliximab's indications,

including ankylosing spondylitis and psoriatic arthritis. Discuss with your health care provider whether the innovator medication or a biosimilar would be right for you.

### **When Recommended Care is Not Covered**

Most of the things your doctor recommends will hopefully be covered by your plan, but some may not. When you have a test or treatment that isn't covered, or you get a prescription filled for a drug that isn't covered, your insurance company won't pay the bill. This is often called "denying the claim". You can still obtain the treatment your doctor recommended, but you will likely have to pay for it yourself.

### **Appealing a Health Plan Decision**

If your insurance company denies your claim, you have the right to challenge the decision. Before you decide to appeal, know your insurance company's appeal process. This should be discussed in your health insurance plan handbook. Also, ask your doctor for his or her opinion. If your doctor thinks it is right to make an appeal, he or she may be able to help you through the process. You have the right to both an internal appeal (appealing to the insurance company) as well as an external review (should your appeal be denied.)

### **Pre-existing Conditions**

A pre-existing condition is any condition - physical or mental - for which medical advice, diagnosis, care or treatment was recommended or received within a six-month period immediately preceding an individual's enrollment in a health plan. As of January 1, 2014 health insurance companies cannot refuse to cover you, nor can they charge you more because you have a pre-existing condition. They cannot limit benefits for that condition, nor refuse to cover treatment for your pre-existing condition. They also cannot charge more to cover women.

### **Health Insurance options include:**

**Group Health Plans:** These plans are usually sponsored by an employer, union or professional association and cover at least two employees.

**COBRA:** If you were covered by health insurance at work but are about to lose your job, you're typically entitled to coverage for up to 18 months under the federal Consolidated Omnibus Budget Reconciliation Act of 1985. Unfortunately, you are required to pay the full cost of this coverage, which can be quite expensive.

**High-deductible policies:** If you obtain this kind of a health insurance plan, you'll pay more of your medical costs out of pocket, but these policies do protect you against catastrophic medical bills. Having the coverage also entitles you to insurer-negotiated discounts with doctors and hospitals.

**High-risk pools:** These pools are no longer necessary the way they were prior to the passing of the Affordable Care Act, though some states do still offer and run them. More information on this [here](#).

**Medicaid:** This government-funded coverage is generally reserved for people with low income; each state has different guidelines and qualification criteria. [Could you be eligible for Medicaid?](#)

**Medicare:** This government-funded coverage is reserved for people age 65 or over, or for people under 65 with certain disabilities.

## Other Resources

### [Healthcare.gov](#)

Provides various resources such as a tool for helping visitors find available insurance options, and more.

### [Centers for Disease Control](#)

Provides information on state health departments as well as additional clinics and resources for the uninsured.

### [Kaiser Family Foundation](#)

Provides health news and information service on the Web and a series of specialized websites, including state health care information.

### [NeedyMeds Free/Low-Cost/Sliding Scale Medical Clinics](#)

Provides a searchable database of low cost clinics close to you.

## Where to Go For Assistance with Medical and Prescription Costs

Managing the costs associated with spondyloarthritis can be stressful, and for many a financial burden. Below is a list of assistance programs that can help with the cost of medications, co-pays, and other healthcare needs.

## **Patient assistance programs for HUMIRA (Adalimumab)**

### [HUMIRA Protection Plan](#)

(800) 4HUMIRA

From the site: *“With the HUMIRA Co-pay Savings Card, the majority of commercially insured HUMIRA patients are eligible to pay as little as \$5 a month for each HUMIRA prescription.”*

### [The AbbVie Patient Assistance Foundation](#)

(800) 222-6885

From the site: *“The AbbVie Patient Assistance Foundation provides AbbVie medicines at no cost to qualified patients who are experiencing financial difficulties and who generally do not have coverage available for these products through private insurance or government funded programs.”*

## **Patient assistance programs for ENBREL (Etanercept)**

### [Enbrel Support Card](#)

(888) 4ENBREL

From the site: *“The ENBREL Support™ card provides financial support to eligible\* commercially insured patients when presented to the pharmacy.”*

### [The Safety Net Foundation](#)

From the site: *“The Safety Net Foundation is a nonprofit patient assistance program that helps qualifying uninsured patients access Amgen medicines at no cost.”*

## **Patient assistance programs for REMICADE (Infliximab)**

### [Janssen CarePath and Other Savings Programs for REMICADE®](#)

(877) CarePath (877-227-3728)

From the site: *“Here you'll find the medication assistance programs available for REMICADE®. We have also listed most of the eligibility requirements.”*

## **Patient assistance programs for SIMPONI (Golimumab)**

### [Janssen CarePath and Other Savings Programs for SIMPONI®](#)

(877) CarePath (877-227-3728)

From the site: *“Here you'll find the medication assistance programs available for SIMPONI®. We have also listed most of the eligibility requirements.”*

## **Patient assistance programs for CIMZIA (Certolizumab Pegol)**

### [CIMZIA Co-Pay Savings Program](#)

(866) 4-CIMZIA

From the site: “Cost shouldn’t get in the way of your treatment. The good news is that CIMplicity<sup>®b</sup> and the CIMZIA \$0 Co-Pay Savings Program<sup>a</sup> may be able to help.”

## **Patient assistance programs for COSENTYX (Secukinumab)**

### [Cosentyx Connect Personal Support Program](#)

(844) COSENTYX

From the site: *The COSENTYX Connect Personal Support Program offers a range of helpful resources and tools available whenever you need them, 24-7.*”

## **Other Patient Assistance programs and Drug Discount Cards (May include additional discounts for biologics.)**

### **Drug Discount Card**

SAA has partnered with NeedyMeds to provide a Drug Discount Card for prescription medications. Anyone can use this card, but it cannot be combined with insurance, Medicare or Medicaid. [Download the Drug Discount Card.](#)

### [Good Days \(Formerly known as Chronic Disease Fund\)](#)

From the site: *“We help patients suffering from chronic medical conditions who have limited financial means get access to the medications they need. Our program helps qualified patients pay their insurance co-pays so they can get immediate access to prescription medications that will give them relief from pain and suffering.”*

### [GoodRx](#)

From the site: *“Use GoodRx's drug price search to compare prices (just like you do for travel or electronics on other sites) for your prescription at pharmacies near you. We don't sell the medications, we tell you where you can get the best deal on them.”*

### [HealthWell Foundation](#)

(800) 675-8416

From the site: *“A nonprofit, charitable organization that helps individuals afford prescription medications they are taking for specific illnesses. The Foundation provides financial assistance to eligible patients to cover certain out-of-pocket healthcare costs, including: prescription drug coinsurance, co-payments, and deductibles, health insurance premiums, and other selected out-of-pocket healthcare costs.”*



### [Merck Helps](#)

From the site: *“At Merck, we believe that no one should go without the medicines or vaccines they need. That is why the Company provides its medicines and adult vaccines for free or at discounts to people who do not have prescription drug or health insurance coverage and who, without our assistance, cannot afford their Merck medicine and vaccines.”*

### [NeedyMeds](#)

From the site: *“NeedyMeds is a source of information about assistance programs that help with the cost of medicine and other healthcare expenses.”* NeedyMeds also offers a searchable database of [Free/Low-Lost Medical Clinics](#).

### [Patient Access Network Foundation](#)

(866) 316-PANF (7263)

From the site: *“The Patient Access Network Foundation is a nonprofit 501(c)(3) organization dedicated to supporting the needs of patients that cannot access the treatments they need due to out-of-pocket healthcare costs.”*

### [Partnership for Prescription Assistance](#)

Toll Free (888) 4PPA-NOW

From the site: *“The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free.”* They also offer a searchable database of [Free/Low-Cost Clinics](#).

### [Patient Advocate Foundation Co-Pay Relief](#)

Toll Free (866) 512-3861

From the site: *“PAF Co-Pay Relief (CPR) provides direct financial assistance to qualified patients, assisting them with prescription drug co-payments their insurance requires relative to their diagnosis. CPR call counselors work directly with the patient as well as with the provider of care to obtain necessary medical, insurance and income information to advance the application in an expeditious manner.”*

### [Pfizer RxPathways](#)

From the site: *“Pfizer RxPathways is a comprehensive assistance program that provides eligible patients with a range of support services, including insurance counseling, co-pay assistance,\* and access to medicines for free or at a savings.”*

### [RxAssist Patient Assistance Program Center](#)

From the site: *“Patient assistance programs are run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medicine. RxAssist offers a comprehensive database of these patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need. All in one place.”*

### [RxHope](#)

(877) 979-4673

From the site: *"You can apply here for Patient Assistance Programs offered by hundreds of manufacturers, as well as find information on programs offered by State and Federal government and by pharmaceutical companies."*

### [Rx Outreach](#)

From the site: *"Rx Outreach is a patient assistance program (PAP) for people of all ages. The program makes prescription medicines affordable for uninsured and under-insured individuals and families."*

### [Together RX Access](#)

(800) 444-4106

From the site: *"The Together Rx Access™ Card was created as a public service by a group of some of the world's largest pharmaceutical companies, in order to provide savings on prescriptions to eligible residents of the US and Puerto Rico who have no prescription drug coverage."*

### [Xubex](#)

(866) 699-8239

From the site: *"We are a comprehensive pharmacy services company with the mission to be your leading source for affordable medications. We have helped tens-of-thousands of patients just like you save hundreds on their prescription medication cost through our Patient Assistance Program."*

## **Spondylitis and Emergencies**

Are you prepared for a medical emergency? In an emergency, making accurate personal and medical information available to the first responders and to the hospital staff are of the essence. A major concern being the potential fusing in the spine in those with ankylosing spondylitis, that makes them more susceptible to spinal fracture both after a trauma, and even in the course of being treated and moved by first responders.

Here are some tips to ensure that emergency medical providers will have the information they need to provide you with the safest and most effective care in an emergency situation, even if you are unconscious and can't communicate that you have AS.

### **Consider wearing medical identification "jewelry/tags" since emergency medical personnel are trained to look for these items.**

- TIP: "Brittle Spine Disease" and "Ankylosing Spondylitis" inscribed on the tag will alert the EMTs to your special situation.
- TIP: One paramedic has suggested inscribing the term: "Do not use standard spinal precautions."

### **Consider carrying a medical information card in your wallet.**

- TIP: The card could include vital personal medical information, such as any conditions, and any medications you take. This is especially important if you are taking medication that lowers your immunity.
- TIP: Carry the card in your wallet next to your driver's license and health insurance card. Be sure that it is legible to the average reader.

### **Consider including an ICE contact in your mobile phone.**

- TIP: List your ICE (In Case of Emergency) Contact in Your Mobile Phone. Emergency personnel are trained to recognize the acronym "ICE". Be sure that your ICE contact is aware of your medical needs.
- TIP: For smart phone users who lock their phones – You can set your Emergency Medical ID to have it be accessible from your locked screen, without needing your passcode.
  - For iPhone users: You will configure and enable this option through your "Health" app. Please see <https://support.apple.com/en-us/HT207021> for instructions.
  - For Android users: Most versions of Android do support lock screen apps such as this, though not all do. Please look into your particular phone to find this option.

**Watch SAA's Emergency First Responder training video:** "Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders." [Watch the video, and request copies](#) to distribute to local Fire Houses and Emergency Departments.

## STEP 4: Consider Getting Involved

Become an active part of our supportive community and make a difference through volunteering, being an advocate, participating in research, or making a financial contribution.

### Opportunities to Get Involved

- **Educate others about spondyloarthritis.** Send them to [spondylitis.org](http://spondylitis.org) where they'll find a host of information about AS and related diseases.
- **Distribute SAA's Emergency First Responder training DVD to your local Emergency Medical Personnel and Paramedics.** SAA developed a [training DVD for emergency first responders](#) to raise awareness about the special needs of spondyloarthritis patients in emergency situations.
- **Sign up for a Local Health Fair/Start a Fundraising Project.** SAA can provide educational materials to distribute at local health fairs, and help you start a fundraising project. Contact Sean Ewert, SAA's Development & Annual Giving Manager by email at [sean.ewert@spondylitis.org](mailto:sean.ewert@spondylitis.org), regarding both health fairs & volunteer fundraising.
- **Deliver SAA's Educational Brochures to your rheumatologist's office.** Contact Cynthia Rodriguez, SAA's Programs Coordinator at [programs@spondylitis.org](mailto:programs@spondylitis.org) to request brochures.
- **Raise Spondyloarthritis Awareness through Social Media.** Connect with us on [Facebook](#) and [Twitter](#), share images on [Instagram](#), and browse spondyloarthritis educational and support videos on our [YouTube Channel](#) (and share your own!)
- **Create your own awareness video or Public Service Announcement.** Post your videos on SAA's Social Media Channels, or send your videos to SAA and we'll post them on our site, as well as share them online. You can email them to Jason Blackwell at [jason.blackwell@spondylitis.org](mailto:jason.blackwell@spondylitis.org).
- **Offer support to someone else.** [Join/start a Support Group](#) in your area!
- **Get involved in Research.** Learn how to [participate in research studies](#).

## **Conclusion**

*If you, a family member or friend has been diagnosed with Ankylosing Spondylitis or a related disease, you have come to the right place. The Spondylitis Association of America is here to help you learn more about these conditions and to provide you with additional support and information.*

*We hope that this Action Plan has provided you with useful tools for taking charge of spondyloarthritis.*