

LIVING WITH SPONDYLITIS

What is Ankylosing Spondylitis (AS)?



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**Spondylitis
Association
of America™**

A FAMILY OF RELATED DISEASES

- ANKYLOSING SPONDYLITIS
- ENTEROPATHIC ARTHRITIS
- PSORIATIC ARTHRITIS
- REACTIVE ARTHRITIS
- UNDIFFERENTIATED SPONDYLOARTHRITIS

The Spondylitis Association of America (SAA) has produced this brochure to provide you with practical information about ankylosing spondylitis (AS).

Whether you have AS or someone close to you has received this diagnosis, the disorder and 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 your condition, backed by a sound knowledge base, will have a positive influence on its outcome. Thus, it is our hope that this pamphlet will make a solid

contribution to that effort and provide important tools in the quest for optimal health.

Information in this brochure cannot replace treatment provided by health care professionals. If you have questions as you read, you may want to consult further with your doctor.

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WHAT IS ANKYLOSING SPONDYLITIS (AS)?

AS is a rheumatic disease (arthritis) that primarily affects the spine. It is the main condition among a group of five called spondyloarthritis or spondylitis. Though AS primarily affects the spine, other parts of the body can be involved. That is why AS is called a systemic disease—meaning that it can affect the whole body.

All forms of spondyloarthritis (SpA), including AS, are chronic diseases. Hence, a person currently diagnosed with AS, given today's knowledge, will have it to some degree for the rest of his or her life. Although there is no cure for AS, there is much that can be done to help. In recent times, important advances have been made in understanding the condition and treating it much more effectively than in the past.

WHO GETS AS?

It has been estimated that up to 500,000 people in the U.S. have AS. It appears to be more common in men and uncommon in both genders in Americans of African descent. AS can occur as early as the teenage years, or as late as age 40 to 50, and more rarely in children, but it usually begins in people in their 20s or 30s.

For a long time, researchers suspected that AS had a hereditary component since about 20% of people with AS also have a family member with the disease. Then, in 1973, scientists found an association between the genetic marker HLA-B27 and AS. While the marker is found in 8-9% of the

Caucasian population, over 90% of patients with AS will have the HLA-B27 gene. Though this can be confusing to understand, what it really means is that HLA-B27 is a relatively common marker



Early Warning Signs

- Morning stiffness of the spine
- Duration of pain greater than six months
- Pain worsens gradually
- Under 40 years of age
- Some improvement with exercise

found in people who will never get AS, but that a high proportion of people with AS have the marker. Thus, identifying the marker is not, on its own, diagnostic.

Though HLA-B27 does not by itself cause AS, it is thought by most researchers that it may have a role in triggering the disease. One theory suggests that the presence of the gene in the human body may cause certain types of bacteria to thrive and to remain in the body a long time. This theory claims that the persistent presence of these bacteria may result in the type of inflammation that can lead to new bone formation; that is, bone formation where

it would not normally exist. Another theory is that HLA-B27 may interact with other proteins and alter the body's immune response. There is a great deal of work being conducted worldwide to explore these and other theories in regard to what causes AS. Many researchers believe that bacteria are an important component.

HOW DOES AS AFFECT A PERSON?

Inflammation plays a big role in AS. The hallmark of AS is enthesitis, which describes inflammation where ligaments insert into the bone. In the beginning stages of AS, this is where the inflammation starts. Research into the nature of inflammation has revealed that the inflammation itself can cause injury by releasing powerful chemicals, which include cytokines and proteolytic enzymes that actually damage the surrounding tissues. As the inflammation subsides, the lesions, which are injured areas, begin to heal by forming scar tissue. This scar tissue then replaces the destroyed cartilage or joint capsule. If this scar tissue is supplied by nerves, it may become very sensitive and an additional source of pain. Sometimes the scar tissue calcifies and turns into new bone formation, as indicated above, in areas of the body where none usually exists. This is the process that we want to try to prevent by means of exercise and medication.

WHAT IS "FUSING"?

New bone formation in AS is sometimes called fusing or stiffening. Fusing can occur in the spine and other joints, which include the hips and the knees, although not everyone will experience fusing

since the disease is highly individual and everyone is different. To prevent or minimize this process, there is much hope being placed in a new class of medications called TNF-a Blockers quite recently approved by the U.S. Food and Drug Administration that may have an important role in slowing down or halting the fusing process. Researchers also believe that within a few years there may be other breakthroughs and improved medical options for people with AS.

POTENTIAL COMPLICATIONS OF AS

About one-fourth to one-half of people with AS will experience arthritis in the joints of the arms and legs. About one-quarter of those with AS will get iritis or



uveitis, an inflammation of the eye that requires treatment by an ophthalmologist to prevent permanent eye damage. Osteoporosis is an important complication of AS, which if untreated can result in spinal fracture.

FATIGUE

Severe fatigue is a common complaint in AS. There are several known explanations for this. Fatigue can be a by-product of inflammation. If inflammation is extensive, then the body must use energy to deal with it. The release of cytokines during the inflammatory process can produce the sensation of fatigue and mild to moderate anemia. These effects, along with disturbed sleep due to uncontrolled

pain, may contribute to fatigue. It is important to tell your doctor if this describes your situation. There are medications that can help. In addition, a physical therapist can teach you to move with efficiency so that you may be better able to minimize fatigue and perhaps frustration in this regard.

OSTEOPOROSIS A HIGHLY PREVENTABLE CONDITION

There are several aspects of this disease only now becoming more widely appreciated in the medical community that have major implications for its treatment. As happens so often, this has occurred following the application of a new technology, in this case Magnetic Resonance Imaging (MRI). This technology has enabled us to better understand why patients with AS have a more fragile skeleton despite the overgrowth of bone that is so typical of this disease. This, in turn, has led to the introduction of additional therapeutic approaches for the disease.

Why do patients with AS have a more fragile skeleton? It is of some considerable interest that this was first noted almost a century ago when post-mortem analysis of spines was the only available approach to conducting research in this disease. Several pathologists remarked on the fact that cutting through the bones of patients with AS was like cutting through putty — the knife met no resistance whatsoever. These observations were largely forgotten and/or ignored until the modern era of advanced radiological imaging techniques and molecular immunology.

The introduction of MRI showed several interesting findings that readily helped to show just how different AS was from rheumatoid arthritis

(RA). Although AS patients understand that, like RA, this is an inflammatory disease of the joints, what is not well appreciated is that the major site of inflammation is in the bone next to the joint. We call this an osteitis, which means inflammation in bone. Very often, MRIs from AS patients show minimal inflammation in the joint but striking inflammation in the bone next to the joint. This is different from RA, where inflammation within the joint is the major feature of the disease. In addition, what is essentially unique for AS is that this inflammation in bone is also typically seen where ligaments and tendons attach to the bone.

A classic example would be the Achilles tendon attachment to the heel bone. Examples have been seen where the entire heel bone is inflamed. These patients often receive cortisone injections around the Achilles tendon with little benefit. This is not surprising since the major source of pain and inflammation is actually within the heel bone. Another example is the shoulder. This is a problem that is not well recognized by medical practitioners and often dismissed as “bursitis” or “tendonitis.” These patients also have inflammation within the bone where the shoulder tendons attach to the point of the shoulder. Cortisone injections around the tendon are unlikely to be of benefit for many patients because the major site of inflammation is within the bone. These same features are observed on MRIs in the spines of patients with AS. The major site of inflammation is within the bone of the vertebrae.

If this local inflammation in the vertebrae is not checked, it will ultimately cause severe loss of bone mineral, resulting in fragile bones. But there is also

a second way in which patients with AS can get fragile bones.

We now know that severe inflammation — wherever it exists — causes the release of certain chemicals into the blood that activate cells in bone that can literally dissolve bone mineral. These cells are called osteoclasts. They are normally present in bone but are only activated periodically when bone undergoes re-modeling in response to the stresses of various activities, e.g., sports. These cells secrete acid, which dissolves bone very efficiently. It is therefore understandable that the body keeps these cells under tight control — most effectively by secreting sex hormones, which typically shut these cells down. This is why menopause is a precarious period for the bones of women. The rapid decrease in sex hormone production results in the activation of osteoclasts — as if they are emerging from a period of hibernation. Women then become at high risk for osteoporosis. Long-standing inflammation also causes persistent activation of osteoclasts.

HOW DOES THIS OCCUR?

Inflammation, whether it occurs in the joints, the intestine or the lungs, causes the release of a variety of molecules into the blood. Some of these cause an elevation of body temperature, others cause fatigue, and still others cause persistent activation of osteoclasts. This is why RA is a major risk factor for osteoporosis and fractures of the spine, even though the inflammation of RA does not occur within the spine other than the neck. Similarly, chronic inflammation of the bowel — colitis — also results in osteoporosis and an increased risk

for fractures of the spine and hips. AS patients also release these same molecules into the blood that cause activation of the osteoclasts. So AS patients suffer from a double-whammy when it comes to the development of fragile bones. They have inflammation locally within the bones of the spine but also release molecules into the blood that cause activation of osteoclasts. This is one of the reasons why patients with AS are at much higher risk of developing fractures of the spine. To make matters worse, the AS spine is not that flexible and so is more likely to fracture if subjected to any significant impact.

IS THERE ANYTHING THAT CAN BE DONE ABOUT THIS?

The answer is — a great deal. First, patients must make sure that they stay active, not only to preserve strength and flexibility but also to preserve bone mineral. The cells that make bone mineral — osteoblasts — love weight-bearing exercise. But they can only make bone effectively if they are supplied with the proper nutrients. This means plenty of calcium, about 1500mg per day. A good rule of thumb is that a good helping of a dairy product, e.g., yogurt, cheese, a tall glass of skimmed milk, amounts to 300mg of elemental calcium a day. So does one tablet of extra-strength Tums. Beware of expensive calcium preparations that often fail to deliver on the required amount of elemental calcium. Read the label and make sure you know how much elemental calcium is in the product, because this is what really counts, and not the total grams of each tablet (which is what is often on the front label). Good nutrition also means 800 units of vitamin D per day. It is

surprising how many patients with AS are vitamin D deficient — about 20% according to the experts. Americans are not great milk drinkers, and if you are amongst them, then over-the-counter supplementation is important.

IS THERE A WAY OF TESTING WHETHER YOU ARE ALREADY AT INCREASED RISK OF HAVING A SPINAL FRACTURE?

This is normally done by having a bone density test — often confused with a bone scan. Bone density testing is widely available, and, according to many rheumatologists, everyone who has had AS for at least 10 years should have this done. If a fracture has already occurred, a bone density test should be done regardless of how long the AS has been present. This is the same approach to the assessment of osteoporosis for women of post-menopausal age. Is such screening currently being done for patients with AS? A recent survey of British rheumatologists showed that only a minority of AS patients had received bone density tests, and it is likely that the figures in North America would not be very different. Osteoporosis in AS patients is clearly not a well-recognized problem and requires more vigorous intervention.

ARE THERE ANY EFFECTIVE PHARMACEUTICALS FOR THIS PROBLEM?

Several agents have now been shown to be effective for the treatment of osteoporosis. These include agents belonging to a general class of drugs called bisphosphonates. They have been shown to be effective in most forms of osteoporosis and to be equally beneficial in men and women.

AS patients have a major opportunity to practice effective health care prevention, and osteoporosis is a readily preventable complication of AS.

Uncommon complications of AS

- Involvement of the aortic valve of the heart, resulting in aortic insufficiency caused by a leaky valve
- Blocks in the heart's conduction system
- Fibrosis of the lungs, especially the upper segments

Routine examination by a rheumatologist can detect complications before they become serious.

INTERVENTIONS AND TREATMENT

Along with exercise and good posture habits, nonsteroidal anti-inflammatory drugs (NSAIDs) are the cornerstone of treatment and work well for up to 50% of people with AS. If NSAIDs are not capable of

reducing your symptoms sufficiently for you to be able to function properly in your everyday life, your doctor may suggest that you try a TNF-a Blocker. These drugs can be remarkably effective in treating more moderate to severe AS, though not everyone needs them or will benefit from them.

*To find out more about these conditions and how they are treated, we invite you to read our booklet entitled *Spondyloarthritis, A Family of Related Diseases*, or you can visit our website at www.spondylitis.org.*

WHY EXERCISE IS SO CRITICAL IN AS



According to doctors and patients alike, exercise is amazingly effective in controlling pain. However, pain relief isn't the only reason to exercise. The arthritis associated with AS and related conditions may try to rob you of mobility and flexibility. Exercise is the

antidote to this, counter-acting the creeping control that the disease can impose on your life. With exercise a person is empowered, has less stiffness, more flexibility, better quality of sleep, weight control, a healthier heart and an improved sense of well-being. We are not suggesting that you get up and train for a marathon, just that you will feel better if you start a daily strengthening and stretching routine. Remember that it is your doctor's job to help control the pain, inflammation and stiffness so that you can maintain a healthy exercise program that will lead to better pain control for most people. Hence, it is important not to minimize your pain when seeking treatment from your physician.

*We invite you to read our pamphlet, *The Role of Exercise in Spondyloarthritis*, for more detailed information in regard to how regular exercise can help you.*

MAKE EXERCISE WORK FOR YOU



MORNING STRETCH.

If you are typically stiff in the morning this may be a good time to loosen up. You can do stretches to loosen up and save the range of motion exercises for later in the day after your stiffness lessens.

MAKE IT FUN.

If you don't like to exercise, be creative: exercise to your favorite music, or exercise with a friend.

START SLOWLY.

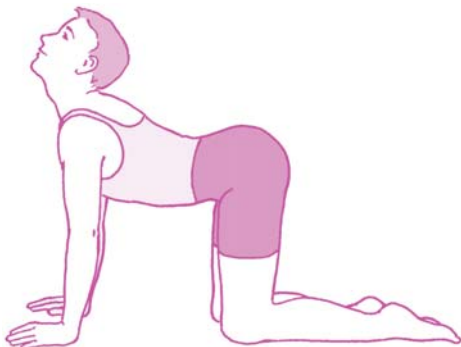
If you're afraid moving will hurt, start very, very slowly with gentle stretching and range of motion exercises.

MAKE TIME.

If you can't spare a big block of time all at once, try working in 15 minutes twice a day.

BE COMFORTABLE.

Wear comfortable clothing and try to relax by counting out loud. This helps with your breathing. Why is this important? Because, relaxed tissues stretch more easily.



All Exercise Illustrations: NASS Guidebook for Patients

EXERCISES

WARM UP

Only work within the limits of comfort

Vigorous marching on the spot for one minute with high stepping and arms punching upward for 20 seconds, forwards for 20 seconds and sideways for 20 seconds.

STRETCHING EXERCISES

Only work within the limits of comfort

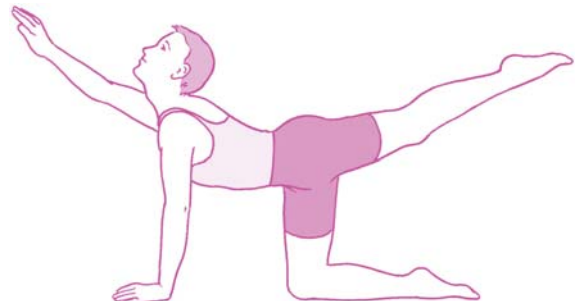
- 1 Kneel on all fours. Keeping your elbows straight throughout, tuck your head between your arms and arch your back as high as possible.



- 2 Lift your head and hollow your back as much as possible.



- 3 Keeping your head up, raise your right arm forwards as you raise your left leg backwards as high as possible. Hold for 5 seconds. Return to all fours and change to raising your left arm and right leg.



EXERCISES

EXERCISE AND POSTURE

Only work within the limits of comfort

Give someone close to you permission to nag. Often those around us notice bad habits, such as slouching, long before we do, ourselves. Agree on a code word and ask your friend to use it. Soon you won't need to be reminded.



1 Stretch up as tall as possible without lifting your heels. Hold this position. Raise your right arm forwards and upwards while keeping your elbow straight, your upper arm close to your ear and your thumb towards the wall. Lower and repeat with opposite arm.



DAILY POSTURE EXERCISE

Only work within the limits of comfort

Prone lying (laying on your stomach). Experts believe that this single activity alone can prevent postural deformity from developing into a forward stooped position. It will not prevent the fusing of the vertebrae which occurs later in severe forms of AS, but should fusing occur, this activity will ensure that an erect position is maintained. Make it part of your daily routine. The best time to do the prone lying down might be after a warm bath in the evening when your muscles are warm and relaxed. Consistency is key.

SURGICAL OPTIONS

In some people, when the arthritis associated with AS is severe, it can cause destruction of the joint cartilage. When this occurs, particularly in the knees and hips, surgical joint replacement with artificial joint components can be effective in alleviating pain and restoring function to the severely damaged joint.

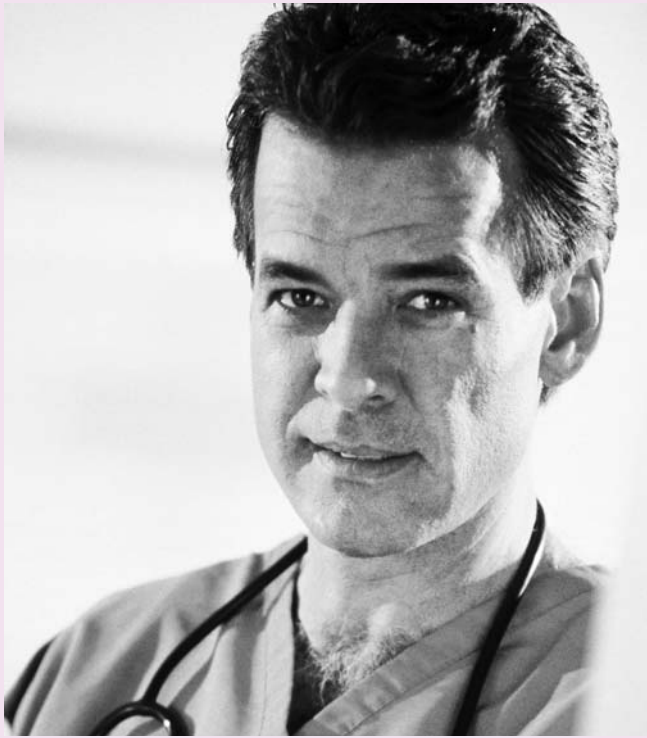
LUMBAR OSTEOTOMY

In more rare severe cases of AS, or sometimes when poorly managed or left untreated, AS can be associated with severe flexion deformity (severe downward curvature) of the spine, particularly in the neck. Surgical correction is possible, though this procedure is not without risk, principally in regard to potential spinal cord injury and paralysis. Hence, it should only be attempted by surgeons who have extensive experience with this procedure in people with AS.

WHAT IS THE ROLE OF THE RHEUMATOLOGIST

Rheumatologists are internists with additional specialized training in treating rheumatic diseases (arthritis). There are more than 100 rheumatic diseases. These include ankylosing spondylitis, rheumatoid arthritis and lupus.

The role of the rheumatologist is to make a diagnosis and to recommend a course of treatment. Toward this aim, the rheumatologist advocates for the patient. He or she educates the patient, the family, and the community. The rheumatologist



takes an active role in teaching not only medical information, but also techniques for preventing disability and appropriate coping mechanisms.

With so much information being made available almost daily in the field of rheumatology, it would be nearly impossible for all rheumatologists to be well-versed on all of the latest treatment approaches at all times. Hence, you will be better served if your physician has experience and even a special interest in AS and related diseases.

To help you, the SAA has developed a free booklet entitled ***Member-to-Member Recommended Directory of Rheumatologists***. The booklet is a listing of board-certified rheumatologists who have

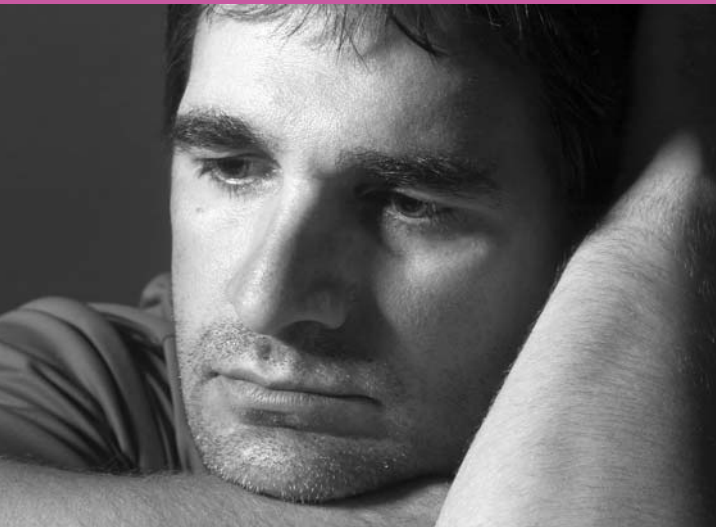
either been recommended by other patients or who have demonstrated a special interest in SpA and have asked to be included in the directory.

WHAT IS THE ROLE OF DIET IN AS?

In recent years, many specialized diets have gained popularity among people with arthritis. To date, there have been small studies to suggest that for some people diet may play a role in their arthritis symptoms. That said, currently there has been no study that has shown that there is anything akin to a universal dietary influence in arthritis—even though there may be exceptions to the rule that some people are affected in yet unaccountable ways by food they ingest.

If you think that you are affected either negatively or positively by certain foods, try keeping a food diary for a while to keep track of results. If you plan to do this, it might be helpful to also remember that in SpA, just like in many other forms of inflammatory arthritis, the symptoms can come and go without an apparent explanation. This situation can make it difficult to track such patterns over a short period of time.

With regard to healthy bones and diet, please read the “Osteoporosis” section of this brochure.



OTHER HELPFUL MEASURES

Much can be done to help, some of which can be incorporated into a person's lifestyle. Support groups for people with AS can offer shared experiences with others. For many, this can be an empowering experience. Research tells us that Mindful Meditation and Tai Chi, for example, can have a positive effect on pain and inflammation in rheumatic disease.

We do not want in any way to minimize the impact that your diagnosis on has had on your life, and we recognize the tremendous adjustments that you have made and are going to have to make in time to come. However, it is well recognized that when a person takes control of any chronic ailment, and has a healthy perspective, self-esteem is more likely to be high and quality of life is improved to include hope and optimism for the future.

We wish you all the very best success in carrying out your program for optimal health and hope that these educational materials will serve as a beginning guide to that process.



DEPRESSION—WHEN TO SEEK HELP?

Most people learn to live with the inconsistencies of having a life-long disease with its ups and downs, but if your distress is starting to interfere with your functioning on a daily basis, if you are really unhappy and are having difficulty tolerating the disease, it might be time to seek professional help.

Potential signs of clinical depression include:

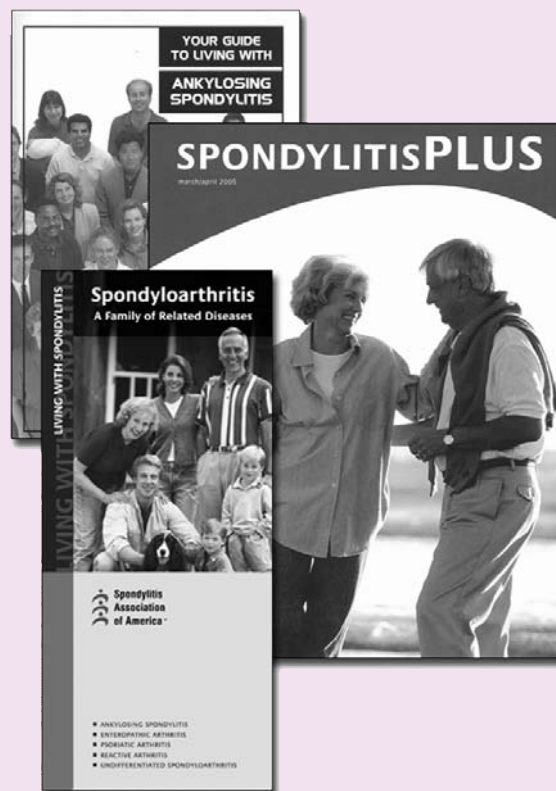
- Marked changes in sleeping patterns
- Ongoing fatigue and listlessness
- Changes in appetite—loss or over-eating
- Uncontrollable feelings of sadness, guilt, worthlessness or purposelessness
- Inability to concentrate
- Suicidal thoughts
- Problems with sexual function

Benefits of Membership

The Spondylitis Association of America was the first, and remains the largest, resource in the U.S. for people affected by spondylitis. For more than 20 years the SAA has dedicated all of its resources to funding programs and research that directly benefit the spondylitis community.

By joining the SAA you can improve your quality of life while helping hundreds of thousands of people throughout the nation. Join today and receive:

- A subscription to *Spondylitis Plus*, the only national magazine dedicated to your unique needs
- SAA's Member-to-Member Recommended Rheumatologist Directory
- Access to the "Members Only" section of www.spondylitis.org
- A complimentary copy of our guidebook, *Your Guide to Living with Ankylosing Spondylitis*.
- The satisfaction of knowing that you are part of an extraordinary community of patients, friends, family and health professionals who are all dedicated to finding the cure!



Your membership support makes you a partner in the national force to fight AS and related diseases and ensures that no one has to face these diseases alone. Thank You!

The Spondylitis Association of America acknowledges with great appreciation the expertise and guidance of the Medical and Scientific Advisory Board with regard to its programs and educational materials.

How do I become a member?
It's easy. Call toll free 800-777-8189 to speak with our friendly staff or join online at www.spondylitis.org