



SPONDYLITIS
ASSOCIATION
OF AMERICA

spondylitis

plus

MAY
JUNE
2004



A Dance with Life

A.S. didn't stop her from
reaching new heights

TO PARTICIPATE IN IMPORTANT RESEARCH, SEE BACK PAGE



Building on the successes of recent years, SAA now has a tremendous opportunity to grow in service to the entire country. Can you help us reach that goal? Can you help us increase our capacity for national leadership?

Because one of the essential factors in our success is an effective and dynamic Board of Directors, we are aiming to expand our volunteer Board nationally.

and marketing. We attempt to have a diversity of geography, age, ethnicity, and talents among our board members.

The SAA Board of Directors meets four times a year, most frequently in Los Angeles, SAA's headquarters. There are specific responsibilities and expectations that accompany board membership, including supporting the Spondylitis Association's fundraising efforts through personal giving in accordance with one's means, as well as soliciting others.

Over the next several months, we are seeking to fill available director positions. If you are interested or know of someone who would meet these qualifications, please send a resume and/or biography and a letter outlining how you believe you could contribute to the board, to Brian MacKenzie, Chair of the Board Development Task Force, at brianmackenzie@spondylitis.org. We would be glad to send additional information on board responsibilities and membership, if desired.

On behalf of the Spondylitis Association of America's Board of Directors, staff and its volunteers, thank you for supporting the important work of SAA.



TOM WEST
SAA President

In our role as the leading non-profit organization funding education, research and support for people with ankylosing spondylitis, SAA has accomplished great things over the past 20 years. We have initiated vital research that promises to uncover the cause, produce more effective treatments, and eventually, lead to the cure. Our Board has led the way by voicing our mission and setting our goals.

We are seeking qualified and committed candidates who possess leadership ability, a passionate belief and engagement in the work of our organization, interest in fundraising, ability to network in the community, and the willingness to give of their wealth, wisdom, and /or work.

A wide range of people with interest in and knowledge of spondyloarthritis is appropriate for board membership. We are looking for those with skills or experience in one or more of the following areas, especially as they relate to nonprofit organizations: strategic planning, organizational development, public policy, philanthropy,

SPONDYLITIS ASSOCIATION OF AMERICA

A volunteer, non-profit 501(c)(3) organization

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SAA MISSION

To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.

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SPONDYLITIS PLUS

Published six times a year
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readers' forum

More about those zzzz...

I always read the magazine because you do such a great job. I wanted to comment on the effects of sleep deprivation. I am a trauma surgeon so I am up at night a lot, and I can assure you that sleep deprivation affects my symptoms. One night with only a few hours of sleep is usually okay, but two nights always causes me to flare up no matter how good I'm feeling prior to that. I've taken to using Indocin when I am on for the weekend. Unfortunately, the last few times I have ended up flaring my iritis, so I'm starting ketorolac eye drops. Hopefully that will help.

Something about the sleep deprivation really activates my immune system.

MIKE IVY, MD
Guilford, CT

Still me – but with an extra dose of caution..

I was diagnosed one year ago! I was playing slow pitch softball and fell. After I fell, the pain in my hips and lower back was so bad I could hardly walk. I decided to go to a chiropractor, which was really stupid. Then I went to a family doctor in my small hometown. Neither of them did an x-ray or blood test. All they did was give me a steroid pack and told me to do range of motion exercises.

I decided to see a real doctor! The doctor I have now did many tests and did a full exam



before he told me I had AS. The doctor I have has dealt with AS many times, so I am confident in him. Now, with the exercise and meds, I live the same as I did before, just more cautious. I am married with four children. With them in my life I will never let anything get in my way of living a happy life.

JULIE ALZATE
via e-mail

If it all ended tomorrow...

I am hoping my remarkable initial success with this Remicade continues. I have had 3 infusions so far. Since I had my last infusion several days ago, I will now have to see if the efficiency lasts until my next scheduled infusion.

If it all ended tomorrow, and the effects of the drug were to wear off, I'd still be thankful for the weeks of pain-free living I have experienced. I had forgotten what it was like to feel "normal" and not be always conscious of my AS and the associated pain, stiffness and Iritis. It certainly brings hope to people afflicted with AS, that medical science is making progress and that one day there will be a cure.

Unfortunately, the cost of the 4 vials used per infusion is over \$3,000. I understand the wholesale cost per vial is somewhere in the vicinity of \$625. If one has no insurance or isn't Bill Gates, the out-of-pocket expense one would incur is close to \$20k/yr. Sad if it comes down to the haves and have-nots.

CRAIG YOUNG
Fredrick, MD

Kudos to to a knowledgeable rheumatologist.

As a healthy lady at age 35, two years ago, I had never even heard of ankylosing spondylitis much less understood it for the first year or so. Thanks to a persistent general practitioner, a knowledgeable rheumatologist and some patience on my part, we figured it out and began treatment. What I have come to understand about my disease is, not a lot of people understand it (doctors included), it can be very aggressive, and, as the patient, your lifestyle and perception of your abilities have to change to cope with the limitations that will continually be put on your body and mind.

Your association has taught me that I am not alone. Your articles are most helpful and your website has captured my attention.

Thank you for all your efforts and I look forward to future communications from you.

Keep up the good work!

PATTY DENDY
Horton, AL

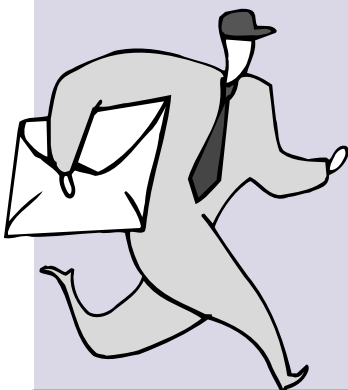
LETTERS TO THE EDITOR

We want to hear from you, whether it be informative, uplifting, or a gripe you need to express.

Include your full name, address and phone number.

Please keep comments short and concise. However, we do reserve the right to edit for space.

Send letters to: Laurie.Savage@spondylitis.org
Letters to Editor/SAA
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Sherman Oaks, CA 91403



DATA IN ON IMPORTANT STUDY

Study examines issue of HLA-B27 negative to HLA-B27 positive patients with AS

IN 2000, THE ANKYLOSING SPONDYLITIS INTERNATIONAL Federation in collaboration with Dr. Juergen Braun, a highly respected German rheumatologist and researcher, initiated an important study involving patients in Germany and Austria. The aims of this study, achieved through a self-reported questionnaire, were to:

- Determine the age range of initial symptoms and the age at diagnosis (delay)
- Investigate possible triggers of disease onset
- Determine the side-effects of nonsteroidal anti-inflammatory drugs (NSAIDS) in a real-world situation
- Determine the presence or absence of HLA-B27 in AS patients

The conclusions of the study, which were published in the refereed (peer reviewed) journal *Rheumatology International*, provided important data on B27 negative AS patients. It was able to confirm earlier reports that indicated that B27 negative patients with AS have a significantly older average age when the disease first manifests, in addition to a less frequent prevalence of acute anterior uveitis (inflammation of the eye) when compared to B27 positive patients with AS.

Summary of conclusions from the study data:

- The average age when AS first manifests is significantly higher in B27 patients. In fact, 60% of B27 positive patients and 45% of B27 negative patients were at least 25 years old when they experienced their first symptoms of AS
- The age of disease onset has a significantly wider range in B27 patients
- The frequency of juvenile onset (before age 16) is nearly the same in B27 negative and B27 positive patients
- The frequency of late disease onset (after 40 years of age) is significantly higher in B27 negative patients
- The average delay between first symptoms and diagnosis in Germany and Austria is significantly longer for B27 negative patients
- Acute anterior uveitis is significantly more frequent in B27 positive patients
- The association with another disease from the family of spondyloarthritis, such as inflammatory bowel disease and psoriatic arthritis, is more frequent in B27 negative patients

The number of people who responded to the questionnaire within the two-month deadline was 1,044 in Germany and 67 in Austria. Among the 1,089 patients, nine were excluded from the study because they did not indicate a physician-confirmed diagnosis of AS.

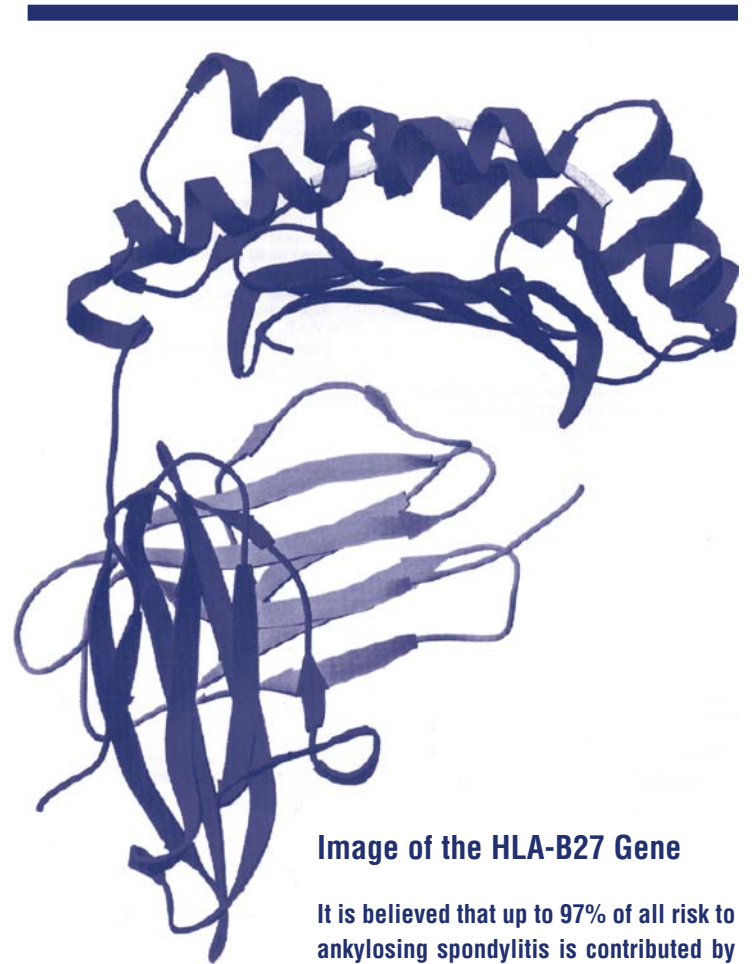


Image of the HLA-B27 Gene

It is believed that up to 97% of all risk to ankylosing spondylitis is contributed by hereditary factors

We would like to thank ASIF for conducting this important study and for providing the data to ASIF member societies, which includes SAA.

Rheumatology International, volume 23 (2003) pages 61-66
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research

Gene isolated in Crohn's by Canadian Group

USING DNA SAMPLING from family groups, researchers at the University of Toronto have isolated a gene that potentially predisposes people to Crohn's disease. The finding appear online in Nature Genetic:

Nature Genetics <http://www.nature.com/ng/> keyword search "Crohn's."

The gene isolated by the researchers produces a protein that sits on the cell surface and regulates how substances enter or exit the cell. According to the study, in the majority of people with Crohn's disease, this protein functions improperly and allows toxins easier access to the cell.

According to Dr Katherine Siminovitch, Professor of Medicine, whose team made the discovery, the ability to test for this protein malfunction will help physicians distinguish between Crohn's and ulcerative colitis, the other recognized major form of inflammatory bowel disease. The malfunction is not present in ulcerative colitis – thus potentially making it possible to distinguish between the two diseases.

Dr Siminovitch and her team are currently working on the development of a chemical that would have the potential to alter the protein and restore its normal function.

Knowing what you don't know

HOW AWARE ARE PATIENTS regarding the possible adverse effects or treatment alternatives to the anti-inflammatory medications they are taking? A recent study conducted by Yale University examined whether or not the use of anti-inflammatory drugs is

so widespread as to reflect a lack of informed choice by patients taking the drugs. 100 patients with osteoarthritis completed a questionnaire to assess their awareness of drug toxicity. It was found that over half (54%) of the patients surveyed were unaware of any adverse effects related to NSAIDs, and 4 out of 5 were unaware of the toxicity of nontraditional NSAIDs, COX-2 inhibitors. When given a choice between COX-2 inhibitors and traditional NSAIDs, or a third less effective, albeit safer, alternative, 100% of patients switched to the safer, less effective option.

Conclusion: Thus, the study concludes suggesting that "the widespread use of NSAIDs may reflect lack of informed choices among patients." *Interscience, 5/04*

Puffing accelerates the disease

A RECENT STUDY initiated by the VA Palo Alto Health Care System set out to find out how smoking cigarettes impacts the health of functioning ability of people with AS. They observed a group of 48 patients, 24 each who smoked and 24 who did not smoke.



Conclusion: The researchers found that smoking cigarettes is associated with a more rapid progress of disease as well as higher impairment of functional ability when assessed using validated functional scoring tests. *Rheumatology International, 5/04*

health

Medicare's new drug plan

THE MEDICARE PRESCRIPTION Drug Improvement and Modernization Act of 2003 offers new prescription drug and wellness care benefits in addition to increased assistance to people in low income brackets.

When does it take effect? The new wellness or preventive benefits which now include a no-charge one-time wellness exam and screening for diabetes and heart disease begins January 2005.

How do the prescription drug benefits work? Expect to pay a monthly premium of \$35. Then each year, you will pay the initial \$250 in drug costs. From the next \$2,000 in drug costs, Medicare will pick up 75%, which means that you will have to pay the remaining 25% (\$500). After that, you will be responsible for paying all expenses until your out-of-pocket costs total \$3,600. After that, Medicare will pay 95% of all costs.

What about the new prescription drug discount cards? Beginning in June, anyone on Medicare will be able to purchase a discount card. It will cost about \$30. People with low income in 2003 and no other drug coverage could be eligible for a \$600 credit on the card.

How do I choose the best card for my situation? Later this year, you will be able to compare discount cards on the Medicare web site at www.medicare.gov

How much can I expect to save? Expect to save from 10% to 25% on prescription drugs.

Do I have to change my Medicare coverage? No, but you should compare your current plan with the new benefit to find out which is best for you.

To learn more visit Medicare online at www.medicare.gov or call 1-800-MEDICARE

Understanding NonSteroidal Anti-Inflammatory Drugs

Millions benefit – but there are sometimes risks associated with long-term usage

The forerunner of today's nonsteroidal anti-inflammatory drugs (NSAIDs) dates back to the fifth century BC, when the pain relieving properties of the willow bark were used in childbirth. Fast forward to the nineteenth century AD, when from this knowledge emerged the compound to become known as ASA or Aspirin®. Since then, in the United States alone, more than 35 NSAID compounds have been brought to market.

For those with spondyloarthritis, NSAIDs continue to be the cornerstone of treatment; they allow many people to maintain a productive and full life by helping to alleviate some of the more prominent symptoms of the disease. By reducing pain, inflammation and stiffness, they encourage the other mainstays of treatment – good posture management, regular breathing exercises and daily stretching and strengthening – these in turn help preserve strong muscles and optimal range of motion.

What are the concerns?

Yet, this very important category of medicines, which ranges from the familiar Aspirin® to the newest class of NSAIDs, the coxibs (COX-2 inhibitors), is full of paradoxes that pose significant challenges to the physician and patient alike. Although they are the most commonly used medications for spondyloarthritis, high doses often are needed to maintain relief. Since they reduce the production of gastric mucus, they can cause localized irritation. Some formulas are sold over the counter, while others are only available through prescription. In addition,



physicians sometimes are faced with the choice between prescribing the lower cost, older NSAIDs and the considerably more expensive variety with a potentially safer profile.

What can be done to help?

NSAIDs are important drugs in the treatment of spondyloarthritis. However, it is critical to be aware of potential adverse effects associated with their long-term usage, and of the medications available that can help reduce these adverse effects.

The following medications can be helpful in preventing some of the more serious side effects of long-term NSAID use:

- Antacids or H2 blockers such as cimetidine, to neutralize or prevent the production of gastric acid
- Carafate®, to coat the stomach
- Cytotec®, to restore the lost gastric mucus

Conclusion

NSAIDs come in different strengths and formulas. Some may work better for you than others. Your physician can help you find the dose and medication that works best for you. No single NSAID is guaranteed to work. Should you experience inadequate relief from NSAIDs, your health care provider can tell you about other options, since the U.S. Food and Drug Administration recently approved a new class of medication for moderate to severe ankylosing spondylitis.

NSAID Safety Issues

It's important to know the safety issues as stated from the America College of Rheumatology

Cardiovascular Complications

The weight of current evidence suggests that patients taking either traditional NSAIDs or selective COX-2 inhibitors (coxibs), who are at risk for cardiovascular disease, should be offered anti-platelet agents (Aspirin®) where there is not contra-indication for their use.

Congestive Heart Failure (CHF)

According to recent studies, it has been suggested that NSAIDs should be used with caution in people with CHF, in addition to those with kidney impairment and diabetes.

H. Pylori Testing

The relationship between peptic ulcer disease and infection with helicobacter pylori (H. Pylori) and NSAID use continues to be debated. According to two studies from Denmark and Hong Kong, patients infected with H. Pylori who use NSAIDs have almost twice the risk of developing bleeding ulcers than those who are uninfected with the bacteria.

Aseptic Meningitis

Aseptic meningitis is a recognized, if rare, adverse reaction that can occur with traditional NSAID use. In recent years, there have been reported cases of this disease associated with the use of COX-2 inhibitors.

Aspirin-sensitive Asthma

Aspirin-sensitive asthma is an important concern. Since the introduction of COX-2 inhibitors, it has been suggested, with appropriate caution, that these NSAIDs may provide a viable option for those with Aspirin-sensitive airway symptoms.

Journal of Allergy Clinical Immunology 2001; 108:47

Arthritis Rheumatology 2001;44:S372;S230;S266

New England Journal of Medicine 2001;345:1809

Lancet 2002;359:9

KNOW YOUR SCORE

In 1970, a scoring system was devised to assess the risk of bleeding in people considering long-term use of NSAIDs. The system was designed by a team of researchers at Stanford University School of Medicine and dubbed the Stanford Calculator of Risk for Events (SCORE). The results of this simple patient questionnaire are widely used to identify who might benefit from the newer, potentially safer NSAIDs called coxibs.

Online printable form:
<http://www.mplan.com/pdf/score.pdf>



Your blood pressure could be affected by NSAIDs

HEALTH HINTS FROM THE FDA

Risk factors that can increase your risk for stomach bleeding include:

- If you are over 60 years of age
- Taking prescription blood thinners
- Have previous stomach ulcers
- Other bleeding problems

Risk factors for kidney damage may increase in:

- People who are over 60 years of age
- People who have high blood pressure, heart disease or pre-existing kidney disease
- People who are taking a diuretic (water pill)

THE FATIGUE FACTOR

WHAT WORKS,
WHAT DOESN'T



“How bad is your fatigue today?” You’ve most likely answered that question dozens of times, along with the pain and stiffness questions. But how to describe the fatigue of spondyloarthritis to the uninitiated? We recently talked to some of the visitors to the SAA electronic message board at www.spondylitis.org about this question, and here is what we heard. Many thanks to all who participated in this discussion.

What does it feel like?

“Some days it feels like wanting to blend into the sofa, so that none of my family members will notice that I am there and ask or expect me to do anything.” – **Christie, Huntington Beach, CA**

“I liken it to wearing a jacket containing 40 pound weights in each pocket, while slogging through a vat of molasses with suction cups glued to the bottom of your shoes.” – **Michael, New York, NY**

“No amount of sleep will reduce the fatigue that makes me feel like I’m walking around all day with one of those lead aprons that they use at the dentist’s office for x-ray protection. It

feels like when you experienced a BAD case of the flu – pre AS.” – **Tim, Phoenix, AZ**

“It’s nothing like when you have overworked your garden or put in too many hours on the job. It’s a totally different type of fatigue. You don’t have energy to take a shower. You are just too tired to stand up. It takes all of your energy to breathe and you feel as if your life is slowly leaving you.” – **Gypsy, Farmville, NC**

“I lie in bed at night and will myself to move because it hurts so much to actually do it. In addition, when I “wake up” in the morning, if I actually managed to get some sleep, I feel like I haven’t even been in bed. It’s such an over-

whelming sense of exhaustion. Arms and legs feel like lead – and there is a sense of failure – even though you know this is not the case.”

– **Crystal, Cleveland, OH**

“For me, fatigue is as bad as the pain. My body does not function when fatigued. Nothing can make it better – sometimes it wears off only to return a week or a day or two later. It’s as if I am being drained of all life.” – **Gypsy**

“Prior to starting a TNF-blocker, I had the worst fatigue. Partly because I couldn’t get a full night of deep sleep due to pain. I never felt refreshed in the morning. My mind was dulled. I couldn’t concentrate. I was irritable. It affected my work. By noon, I was exhausted. It affected my work performance. When I got home, I was too tired to even communicate with my children. They were teenagers and they suffered, too. Forget dating. I became reclusive. It wasn’t until my doctor put me on a TNF-blocker that I realized

how very bad it had become. Then, it was like day and night!” – **Bernie, Pensacola, FL**

What helps?

“I set myself a goal of one or two things that I want to get done each day. They aren’t unreasonable goals so I am able to accomplish them. I am therefore happy with the results and with myself for accomplishing something. And if I get an extra errand or task taken care of, I reward myself with a special coffee or an ice-cream cone and then become one with the sofa.” – **Christie**

“I try to get at least 8 hours of sleep and eat healthily. I have learned to recognize when depression sets in and to seek professional help ASAP, since I know that fatigue, depression and pain all go hand-in-hand. Exercise helps. Even though it’s tough to do when tired and actually the last thing I want to do, I know that it helps. Most importantly of all, I try to remember to pace my activities – which translates to not being too hard on myself while trying to live up to my own and other people’s expectations.” – **Bernie**

“TNF-blockers help. About 15 minutes after finishing the first infusion, I noticed that my usual blanket of fatigue had lifted and had been replaced with a surge of energy.” – **Michael**

“Personally, when AS is active nothing seems to help. Finding a solution to the inflammation and maintaining a regimen to keep AS in check (everyone’s different) is the best solution for me (exercise, diet, medication).” – **Tim, Phoenix, AZ**

“What helps, other than sheer will-power and the Grace of God – I am still trying to discover.” – **Tania, Denver, CO**

“Since I discovered the “spoon theory” I found it to be a highly useful conceptualization to help me and those among my family/friends who are receptive, to cope with and adjust to my disease.” – **Karla, Kent, OH**

The “spoon theory” developed by Christine Miserandin, who has lupus, likens having a chronic illness to having a finite number of spoons, which represent daily activities, and

once the spoons are all used up, then it’s all over for that day!

– <http://www.butyoudontlooksick.com/spoons.htm>

“Like most people with AS, I just keep putting one foot in front of the other, and keep on doing the best I can – hoping that tomorrow will be better.” – **Crystal**

“Lying down, taking a nap or warm bath can help, as can eating a snack.. Coffee helps for a short duration. Hydrocodone and my recliner have become my two best friends. Pacing myself and preserving my energy for what is most important at the time helps a lot. But the best thing is to achieve as much pain relief as possible because if I have less pain, I can fight the back harder.” – **Randy, Portland, OR**

What doesn't help?

“People who tell me that it’s all in my head. Physicians who have no clue and who don’t take me seriously.” – **Bernie**

“Someone telling me to take a nap so that I can ‘snap’ out of it.” – **Christie**

“People who suggest that we are making it all up and overstating how bad we feel—even some doctors. I just wish that those physicians who don’t treat us with the respect we deserve

could live for just 24 hours ‘in our shoes’ and perhaps, that way, their level of compassion would improve dramatically.” – **Crystal**

“People who telephone on weekend afternoons when I am napping or attempting to nap.”

– **Michael**

“Napping, resting or remaining immobile for an extended period of time because it results in more pain when I get up.” – **Tania, Denver, CO**

“Stress..anything that takes me out of the regimen I have in place for living with AS.” – **Tim**

What family and friends can do to help?

“Be supportive even if it means just being there to listen when we need to talk. Be understanding when we say we’re just too tired when we don’t want to do something. Helping out with things we can’t do – cooking, housework, etc. Sometimes just asking if there is anything you can do to help us out means a lot.” – **Bernie**

“Be more understanding when I bite off your head due to feeling grouchy through lack of sleep. Stay out of my way when I am on a fatigue-inspired rant...other than that, love, support and devotion are enough.” – **Michael**

“Be understanding and supportive rather than judgmental and critical. We do not ask for AS.” – **Tim**

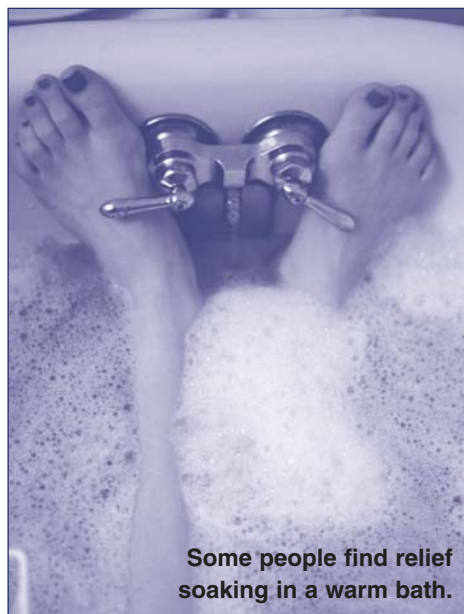
“Please don’t try to fix things and problem solve. Been there; done that. Just listen.”

– **Sally, Seattle, WA**

“When I tell you that I feel like I have the flu 24/7 and 365 days a year – only worse – try not to be scared. – **Jimmy, San Francisco, CA**

And the final word from **Terry Stephens** in Michigan to all of you reading this:

“Faced with all this, I remain completely positive that every thing will work out in the long haul. Keep your chin up. Walk tall. And know that you are walking with friends who know how it feels.”



Some people find relief soaking in a warm bath.

Juvenile-Onset Spondyloarthritis

DIAGNOSIS CAN SOMETIMES BE CONFUSING WITH EPISODIC SYMPTOMS

What is it?

Juvenile-onset spondyloarthritis (JSpA) is the medical term for a group of childhood rheumatic diseases that cause arthritis before the age of 16. The arthritis can cause pain and inflammation in the joints, pelvis, hips and spine, and sometimes elsewhere in the body, such as in the eyes, skin and bowels. Fatigue and lethargy can also occur. The good news is that there is much that can be done to help. To that end, it is very important to have a correct diagnosis made as quickly as possible. This is the role of the pediatric rheumatologist, who is a physician with special training in rheumatic diseases (arthritis) in children. In order to make a diagnosis, he or she will evaluate your child's history of symptoms,

perform a complete physical exam and do laboratory tests, and then be able to decide upon a course of treatment that will sometimes involve bringing in other medical experts. These can include an eye doctor (ophthalmologist), bowel doctor (gastroenterologist) and sometimes a skin doctor (dermatologist).

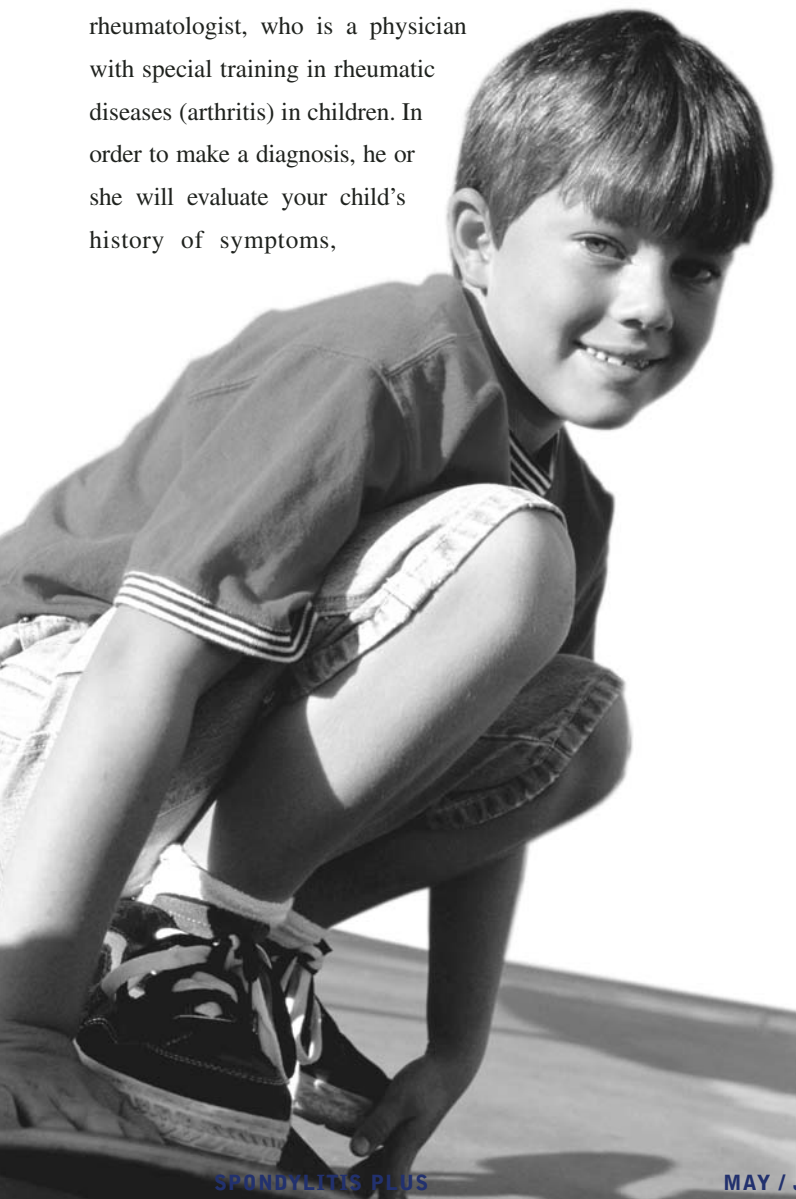
What are its symptoms?

The diagnosis of JSpA can be confusing because the symptoms are sometimes episodic and unpredictable – seeming to come and go without obvious cause over a long period of time. The main symptoms include arthritic pain, especially around or under the heel or toes, around the knee and in the lower back. Children may also experience fever, rash, colitis or Crohn's disease (inflammation of the bowels or intestines) and iritis (inflammation involving the eye). Rare complications may affect the heart, kidneys or nerves in the spine.

The severity of symptoms varies among patients. Some children may experience a mild, short-term disease; others experience a severe, long-term and often disabling condition. At the beginning of the disease, children often have large joints, like knees and ankles, affected whereas in adults the spine is more likely to be involved. The hips are also more commonly affected in children with JSpA.

How is it treated?

While there is no cure for JSpA, there are many therapies that can be used successfully to control the disease and possibly prevent further damage in areas of inflammation. A combination of drug treatment, physical therapy and rehabilitation is used to increase mobility and reduce pain and discomfort. Therapy is also used as a measure to control and reduce future damage and symptoms. Most recently, a new class of medicines called TNF-blockers or biologics have shown tremendous promise in treating adults with SpA; however, as there are no studies of these treatments in children with JSpA, there are no recommendations to date. Although studies in children will need to be



spondylitis 101

done, TNF blockers are already used for other types of childhood arthritis and therefore are likely to be relatively safe and effective in JSpA.

How will this affect my child's day-to-day life?

Even in its mild forms, JSpA can affect your child's normal daily routines. It is important to keep the child's daily life as normal as possible to prevent any undue emotional stress. Together with the doctor, inform your child's teachers and school of the condition, and make them aware of any special needs your child might have, such as seating and the need to stretch. Whenever possible, your child should participate in physical activities and sports. Remaining active will help your child stay involved with his or her peers and lead a normal life. Before returning to a physical activity, make teachers and coaches aware of any limitations the child may have. Low-impact sports are more favorable than sports that produce high joint stress. However, it is not necessary to remove your child from high-impact sports. The potential damage from the sport is much less than the psychological impact that a lack of involvement can have on your child.

Attitude is important

A positive attitude can be difficult to maintain when dealing with a chronic illness. JSpA can be overwhelming and take a toll not only physically, but emotionally as well. A child will often react as he or she sees her parents coping. It is important to keep in mind that a good attitude is everything. A parent with strong coping techniques will be able to pass a positive attitude -- and outlook -- on to a child. Some families will find that psychological support is needed to help cope with the hardships that this disease can produce.

What does the future hold?

Because an exact cause of JSpA has not been determined, a cure has not been found. Treatment should continue for as long as the symptoms persist. The length and scope of the disease varies in each patient. It is difficult to predict a long-term outcome for this disease,

especially in its early stages. The goal of therapy is to help your child have a normal life. As research and therapies continue to develop, your child can look forward to the advancements medicine is making.



RESOURCES

What is Juvenile Spondyloarthritis?
<http://www.spondylitis.org/about/whatisjuvenile.aspx>

LEARN MORE
Order "Juvenile Ankylosing Spondylitis"
<http://spondylitis.org/store/>

GET HELP
Find support for siblings of children
who are chronically ill
<http://www.asiblingsite.com/>

Acknowledgement:
Many thanks to Dr. Robert Colbert for his assistance in writing this article. The SAA is currently updating its Juvenile Spondylitis pamphlet under the guidance of Dr. Robert Warren and Dr. Colbert. The pamphlet will be available in the latter part of 2004.



questions + answers

Navigating Government Waters

Finding your way through government programs can sometimes be like navigating choppy seas – you know you’ll make it to the end but it’s rough going. To help make the legal journey calmer for you, Social Security expert **Rich Feingold** steers you in the right direction:

Can I be working and still apply for Social Security disability benefits?

ANSWER: Yes, but it depends upon how much you are earning. For the year 2004, if you are working and earning \$810 or more per month gross income (for non-blind persons), you are considered to be engaging in “substantial gainful activity,” Social Security’s phrase for working.

Social Security says that I must have a “severe” impairment in order to qualify for disability benefits. What exactly do they mean by that?

ANSWER: At step two of the “sequential evaluation process,” Social Security requires the presence of a “severe” impairment or impairments. In order for an impairment to be considered “severe,” it must at least minimally limit your physical or mental ability to do basic work activities, which include the following: 1) Physical functions such as walking, standing, sitting, lifting, pushing, pulling, reaching, carrying, or handling; 2) Capacities for seeing, hearing, and speaking; 3) Understanding, carrying out, and remembering simple instructions; 4) Use of judgment; 5) Responding appropriately to supervision, co-workers and usual work situations; and 6) Dealing with changes in a routine work setting. (Ed. Note - See the May/June 2003 issue of Spondylitis Plus, for a fuller explanation of Social Security’s five-step sequential evaluation process.)

I understand that in determining whether or not I am disabled because

Setting your sights on the Social Security Disability Program



of Ankylosing Spondylitis, the Social Security Administration will look at whether or not I can “ambulate effectively.” What does that really mean?

ANSWER: Social Security will particularly focus on your ability to walk, or “ambulate effectively,” at step three of their analysis, although any limitations in your ability to walk will be considered throughout its determination process. At step three of their “sequential evaluation process,” Social Security determines whether or not your impairment(s) meet or equal in severity one of their medical Listings. The medical Listing for Ankylosing Spondylitis and other spondyloarthropathies specifically considers the ability to “ambulate effectively.”

Social Security’s regulations define inability to ambulate effectively as “...an extreme limitation of the ability to walk; i.e., an impairment(s) that interferes very seriously with the individual’s ability to independently initiate, sustain, or complete activities.” To be able to ambulate effectively, you have to be able to walk well enough to carry out your activities of daily living. Examples of an inability to ambulate effectively are: having trouble walking even a block at a reasonable pace on rough or uneven surfaces; inability to use standard public transportation; inability to carry out routine ambulatory activities, such as shopping and banking; and the inability to climb a few steps at a reasonable pace with the use of a single hand rail. By the way, just because you can walk

questions + answers

independently at your home without a cane or other assistive device does not, in and of itself, mean that you have the ability to “ambulate effectively.”

How important is it that I, or my representative, obtain the opinion of my treating specialist about whether or not I would qualify for Social Security disability benefits because of my Ankylosing Spondylitis?

ANSWER: It is very important, because the findings and opinions of your treating specialist are given special consideration if they support and are consistent with your clinical and diagnostic medical records. This again emphasizes the importance of ongoing medical care with the appropriate specialists and that you fully inform your doctor about all your physical and mental symptoms.

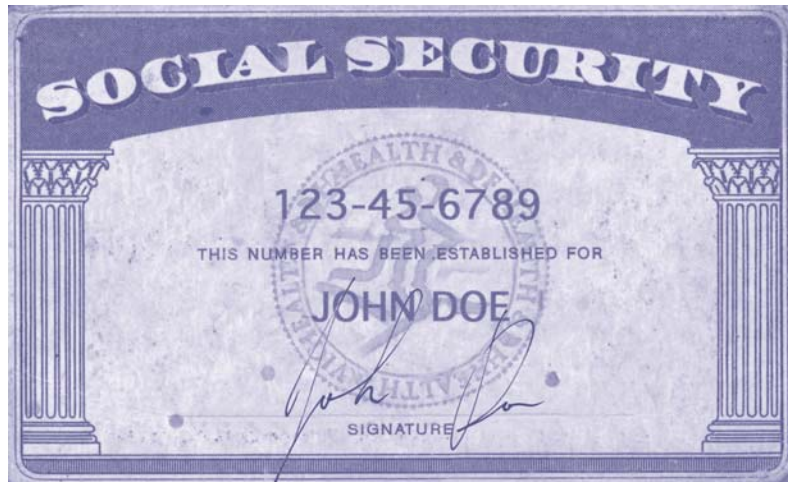
How does Social Security decide how much importance to give to your treating physician's opinion?

ANSWER: Social Security will consider a number of factors in deciding how much importance to give your treating doctor's opinion regarding the nature and severity of your impairments. Some of the factors include the length of the treating relationship and the frequency of examinations, whether your doctor is a specialist and how consistent the doctor's opinions are with the medical records.

I have been experiencing terrible pain that varies in intensity, but is always there at some level. Will Social Security consider my pain complaints?

ANSWER: Pain symptoms are particularly important in cases involving Ankylosing Spondylitis because pain is such a common and debilitating symptom. How your pain affects your ability to function must be consistent with the objective medical evidence

and other evidence in your case. Objective evidence refers to the clinical and laboratory findings such as range of motion testing, MRIs and x-rays. Some of the factors that Social Security considers relevant to pain symptoms include: 1) your daily activities; 2) the location, duration, frequency, and intensity of your pain; 3) things that bring on the pain or make it worse, for example, movement, sitting, standing or walking; 4) the type, dosage, effectiveness, and side effects of any medication you take or have taken to lessen your pain; 5) treatment, other than medication, for the relief of your pain; 6) other things you have done to relieve pain



such as lying flat on your back, standing for 15 to 20 minutes every hour, ice or heat, etc.; and 7) any other factors concerning your functional limitations and restrictions due to pain.

Will Social Security consider the mental effect of pain and other symptoms on my mental state?

ANSWER: Yes, Social Security must consider all of your impairments and their limiting effects. For example, in a recent Ruling regarding another condition involving pain, Social Security acknowledged that chronic pain and many of the medications prescribed to treat it may affect your ability to maintain attention and concentration, as well as adversely affect your cognition, mood, and behavior, and may even reduce motor reaction times. It

acknowledged that these factors can interfere or prevent you from sustaining work activity over time. Therefore, Social Security must carefully consider chronic pain and the use of pain medication in determining to what extent pain affects your ability to work. Your credibility is important to their making this determination.

How does Social Security evaluate my credibility?

ANSWER: Social Security considers many factors in evaluating whether or not your complaints about pain or other symptoms are credible. Key evidence that Social Security considers includes: the medical signs and laboratory findings; the diagnosis, prognosis, and other medical opinions provided by your treating or examining physicians or psychologists and other medical sources; and medical and other statements and reports about your medical history, treatment and response, prior work record and efforts to work and daily activities. The consistency of your statements to your doctors and others will also influence Social Security's determination of your credibility.

ABOUT OUR EXPERT

Richard I. Feingold is an attorney in Chicago who has been practicing in this area of law since 1986. He represents claimants nationwide and is a sustaining member of the National Organization of Social Security Claimants' Representatives (NOSSCR) and a member of the Chicago Bar Association's Social Security Committee. He can be reached at Jeffrey A. Rabin & Associates, Ltd., 640 Pearson Street, Suite 640, Des Plaines, IL 60016. Telephone 1-888-LAW-0600 or 1-847-2990008. Email: rich@rabinsslaw.com.



athletes against a.s.

JUST KEEP MOVING!

Dancer Melba Morris didn't let her diagnosis with AS keep her feet on the ground

IN THE ANIMATED MOVIE "Finding Nemo," the main character is a little blue fish whose survival mantra is "just keep swimming." Melba Morris, dancer and ballet teacher extraordinaire, has a similar motto when she reminds us to "just keep moving" in the fight against the challenges of ankylosing spondylitis (AS).

Ms. Morris, who encouraged us to call her Melba on the very hot and sunny day in Los Angeles when we visited her studio, moved from New York to California in 1971. Dancing all her life and diagnosed with AS in the mid '80s, with the initial symptoms masquerading as a simple stiff neck, Melba knew after those first few weeks that something definitely was very wrong. A couple of weeks turned into a month, and when she finally went to see her primary care doctor, his initial diagnosis was arthritis. He referred her to a rheumatologist, who made a fairly quick and surprising diagnosis of AS.

After this, the disease began to travel through her body and she said, "I felt like I had rusted like the Tin Man from the Wizard of Oz; even my hair hurt!" She tried to exercise, but the only thing that seemed to work was stretching in a hot tub.

As well as the physical effects of this disease, the mental impact also took its toll. Melba said it "was day after day of pain wearing you down" and she felt that, "if it is going to be like this for the rest of my life, it is time to check out." But she didn't "check out," because her doctor gave her the hope for a better tomorrow. None of the



PHOTO: BETH RANSOM

Melba Morris and her husband, Roger Morris, met during the run of a dance show 35 years ago, and have been married ever since. They are both featured on the cover from that show.

medication she was taking worked until she began corticosteroids. Although as a side effect she "blew up like a balloon," she said, "That was the only time in my life I didn't care what I looked like because I felt good." She also remembers her dance instructor Luigi telling her to never stop moving. That has been her savior in the battle against AS. With the help of medication and physical therapy she did start feeling better, and she returned to dancing and teaching dance. She performed in her last show when she was in her 40s with Moiseyev, a Russian ballet company. She also opened her own dance studio 15 years ago that has kept her busy doing what she loves, dancing. She teaches 13 classes a week, along with using dance movement as a form of physical therapy with some individuals.

Her advice to other athletes is that no matter what disease you have, there will be pain and suffering, but you must get a handle on the pain. She feels that pain level is related to your active life. Find work you enjoy and if not work, find pleasure in a different activity.



WHO WE ARE
A committee of professional and amateur athletes with spondylitis who encourage others to pursue their athletic aspirations.

CONTACT US
The next Athletes Against AS story will appear in the Sept/Oct 2004 issue of Spondylitis Plus. If you have a question for one of our athletes, please send it to us:

beth.ransom@spondylitis.org
Beth Ransom c/o SAA
PO Box 5872,
Sherman Oaks, CA 91413

Find something you like to do and keep active. Don't force yourself to do painful things. Know your limits and the limits of your body.

Melba is now a member of "Curves," a women's circuit-training club, where they encourage you to do what you can and not push yourself beyond your limits. She recommends that you get yourself going each morning with a top-down warm-up. Start with your neck and work your way down to your toes, using range of motion exercises to stretching each muscle as you go. If you have a physical therapist, have them show you proper stretches for you. Also you should try to adapt the sport you love so you can participate. She feels that the mistake many AS patients make is to just give up! Her advice is to "*Just Keep Moving.*"

online poll

You can find this New Instant Poll on our web site at www.spondylitis.org. We'd like to hear about your experiences. Thank you in advance for your participation.

If you are a member of the SAA, what prompted you to join?

- My doctor's suggestion
- To gain full access to web site
- To receive this magazine
- To help with advocacy
- To support SAA research efforts
- For philanthropic reasons
- Other

RESULTS OF PREVIOUS POLL

Has your spondyloarthritis been treated with a TNF-a Blocker?

- 50% No, my doctor has not prescribed**
- 25% Yes, Enbrel®**
- 11% Yes, Remicade®**
- 6% No, but I am pending approval**
- 5% Yes, more than one of these meds**
- 3% Yes, Humira**

SNAPSHOT

“...to empower those affected to live life to the fullest.”

This essential component of SAA's mission cannot be repeated too often. In addition to providing a place for those living with AS and related diseases to share their experience, hope and strength, our regional support group leaders provide inspiring examples of the importance of maintaining a positive attitude.

Listen to Ken Prather describe some of what takes place in the Indiana and Ohio-based “Reaching for Joy” groups:

“Bob has had AS for 32 years, and when I met him, he was deeply depressed. He now drives over 120 miles to every one of our meetings to help others deal with their depression by providing positive energy.”

“Rachel, a 17-year-old girl and the valedictorian of her class, is researching the



**Ken Prather,
Ft. Wayne, IN**

relationship between DNA and AS. She is going to college to major in the medical field; her goal in life: to find a cure for AS.”

“Judy, dealing with AS for almost 20 years, recently had a hip replacement. She just got a new job working with the disabled at a local university. At Judy's request, we made an anonymous donation to one of her patients, afflicted with cancer and undergoing chemo, to help with her expenses. What a compassionate soul!”

Ken concludes his message by saying that the accomplishments of these people would not be possible without the love and support of SAA. To Ken and the other vital members of our support group system, the feeling is indeed mutual!

support group leaders

The people listed below are a vital part of our support system. They have volunteered to lead support groups across the US because they want to help. If you'd like to find out more about support groups and online meetings, pick up the phone or send an e-mail to:

Glendale, AZ (John Kornfeind)	(623) 937-1484.....	jmmkorn@cox.net
Los Angeles, CA (Barbara Crofut)	(562) 421-9698	lcrofutgr@netzero.net
(Frances Tomich).....	(562) 429-9685.....	N/A
Richmond, CA (Ken Lee)	N/A	KWLee234@aol.com
San Diego, CA (Mike Supancich)	(760) 438-2962	turbo996@sbcglobal.net
Stamford, CT (Pamela Fore)	(203) 322-3710	pamfore@optonline.net
Chicago, IL (Michelle DeLong).....	(773) 463-3256	ChicagoAS@comcast.net
Fort Wayne, IN (Ken Prather)	(260) 637-1705	pratherken@yahoo.com
Indianapolis, IN (Ken Prather).....	(260) 637-1705	pratherken@yahoo.com
Lawrence, KS (Karrie Shogren)	(785) 832-8738	shogren@ku.edu
Boston, MA (Mitch Goldman).....	(617) 964-2811.....	grarch@comcast.net
Marlboro, NJ (Howard Feingold)	(908) 415-2250	saa_nj@yahoo.com
Portland, OR (Rob Williams).....	(503) 329-8523	RideOutAS@hotmail.com
Philadelphia, PA (Howard Tevelson)	(215) 844-6075	hotbyht@yahoo.com
Houston, TX (Richard Powell).....	(409) 883-7822	rwpowell@gt.rr.com
Springfield, VA (Roger Stead)	(703) 569-8270	rogerstead@aol.com
Mountlake Terr., WA (James O'Connell).....	(425) 744-1631.....	oconnjj@u.washington.edu

If you are an active member and would like to start a group of your own, request a “Support Group Starter Kit” at 800-777-8189 xt. 227 or info@spondylitis.org

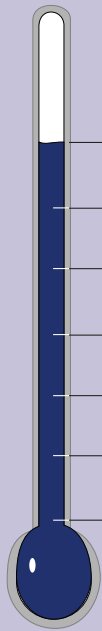
**Online Support:
Michael Smith – Spenser23@aol.com**

Medical and Scientific ADVISORY BOARD

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RESEARCH GOAL

400 sibling pairs for study



317 SIB-PAIRS
Spring 2004

301 SIB-PAIRS
Winter 2003

250 SIB-PAIRS
Fall 2003

200 SIB-PAIRS
Spring 2002

152 SIB-PAIRS
Fall 2000

118 SIB-PAIRS
Spring 2000

103 SIB-PAIRS
Fall 1999

75 SIB-PAIRS
Summer 1999

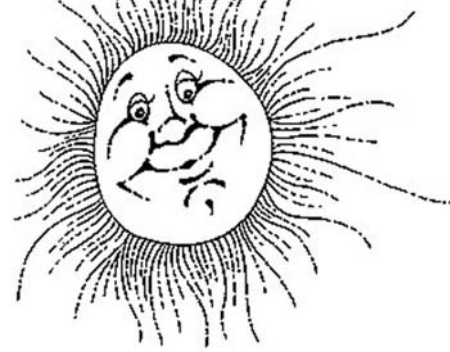
Do you and a Brother or Sister have ANKYLOSING SPONDYLITIS?

If so, you can help an important research effort to identify the genetic causes of A.S.

If you and a brother or sister both have ankylosing spondylitis, please contact us at the following research center:

Spondylitis Association of America
(Clinical Coordinating Center)
info@asresearch.org
1-800-777-8189

Strict confidentiality is maintained at all times



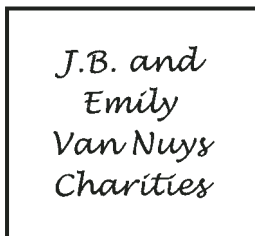
Get ready for summer fun.

SAA's **Water Workout** video (VHS) is packed with special exercises to get you moving, and ready for summer.

Call 800-777-8189

or access our secure server at www.spondylitis.org to purchase via credit card.

Many thanks to these friends for sponsoring, in part, this bi-monthly publication:



ARE YOU WILLING TO HELP RESEARCHERS

find the genes that determine the severity of Ankylosing Spondylitis? If so, you may be interested in participating in our study. To participate you need to be at least 18 years of age or older and have been diagnosed with Ankylosing Spondylitis.

Who is conducting the study?

The study is sponsored by the National Institutes of Health (NIH). The doctors conducting this study are Dr. Michael Weisman at Cedars-Sinai Medical Center in Los Angeles, Dr. John Davis at the University of California, San Francisco, Dr. John Reveille at the University of Texas at Houston, and Dr. Michael Ward at the National Institutes of Health in Bethesda, MD.

How can I find out more?

Please contact one of the following Study Coordinators for more information:

- Southern California: Erin Skrok, 310-423-3032, email: skroke@cshs.org
- Northern California: Jenny Novack, 415-502-1886, jnovack@medicine.ucsf.edu
- Houston Area: Laura Diekman, 713-500-6852, laura.diekman@uth.tmc.edu
- Washington DC Area: Lori Guthrie, 301-435-8434, guthriel@mail.nih.gov

Save the Date



SPONDYLITIS Educational Seminar

SATURDAY
October 16, 2004

AFTERNOON PROGRAM
IN SAN ANTONIO, TX
(location pending)

Save the date for this important, free event. Plan to bring family and friends to share information with others, and to speak with the experts.

ADDITIONAL INFORMATION
FORTHCOMING IN JULY, 2004

Spondylitis Association of America
PO Box 5872
Sherman Oaks, CA 91413

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LOG ON: The digits that appear above your name on the mailing label (to the right) is your SAA membership ID number for access to the member section of our web site.

WWW.SPONDYLITIS.ORG