SPONDYLITIS PLUS
summer 2009

Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders

Are You Prepared For An Emergency Situation?

Integrated Biomechanical Influences On Ankylosing Spondylitis
In a fiscal climate that has caused many nonprofits to cut core programs and services, SAA is expanding its reach and doing more than ever before. In the following pages, you’ll read about a first-of-its-kind video training module to educate fire fighters and emergency medical technicians in the proper handling of spondylitis patients in an emergency situation. But that’s just one of the ambitious programs that your generous gifts make possible.

We’re also hard at work educating the patient population. We recently presented a Spondylitis Educational Seminar in Miami and there are an additional four seminars planned for the remainder of the year in cities around the country. These interactive, expert-led seminars are representative of our commitment to “bring SAA to you, wherever you may be.”

Still, we know we can’t visit every city, every year. So we’ve turned to emerging technologies to help us reach as many people as possible. More than 300 people registered to attend our first webinar, which was a critical success. Our second online seminar, addressing patients who are newly diagnosed, is scheduled for June. Plus, our library of podcasts is continuing to grow, with 10 audio presentations available in the member area of our website and more to come. Please see page 15 for a more complete list of SAA’s various upcoming events and educational resources.

Research, as always, remains a cornerstone of SAA’s mission. While the TASC study is continuing to uncover genetic clues to disease susceptibility, we remain open to exploring other potential avenues of research that might offer insight into the nature of spondylitis. The article on page 10 posits a novel hypothesis in regard to AS susceptibility.

On the awareness front, in late April, SAA Medical Board Member Dr. Millicent Stone and SAA Member Michael Smith (spenser23) appeared in a health segment on ABC News hosted by Dr. Jay Adlersberg, which aired in the Northeast US. The segment helped to raise awareness of the disease and point people toward resources to help them better manage their disease.

All of this important work is made possible through your generous support. Because of the dedication and commitment of our loyal members and friends, SAA is raising the bar and reaching greater heights than ever before. I can’t thank you enough for making this possible and I look forward to the important work to come.

Many thanks,

Laurie M. Savage
Executive Director
An Update

SAA recently received an update from Mike Parker, Lieutenant Colonel, United States Army (Retired), about the story we featured in the Spring 2009 Issue of Spondylitis Plus.

Good news! The VA has put out clear guidance on how to rate AS. This guidance clearly requires the disease to be rated under DC 5009-5002 if it is an active process.

The VA position is retroactive. They are not changing the rules; they are stating what should have always been. As such, veterans can use the recent VA advisory notice on proper AS rating procedures in their appeals. New applications should include an advisory notice with their claim to ensure the rating officer is aware of the issue and the requirement to rate active AS under DC 5009-5002.

I have more good news. I sat down with Brigadier General Jones and Colonel Cassidy, the commander and deputy commander of the United States Physical Disability Agency. They took a fresh look at SPC Hoffman’s case, in light of the recent VA notice on AS rating problems, and determined he did in fact have active ankylosing spondylitis and should have been rated under diagnostic codes 5009-5002. They will be writing an advisory opinion that will assist immensely as SPC Hoffman takes his case to an appeal board. Colonel Cassidy also stated they would be checking their database for past cases of ankylosing spondylitis and notifying those soldiers that they may have been improperly rated and that they should seek relief from an appeal board. They will also be talking to the Department of Defense and the other Services about the problem so they can self-correct as well.

MIKE PARKER

Editor’s Note: Congratulations and thanks again to Mike Parker for his service and dedication to helping his fellow service people in their efforts to obtain the benefits they have earned.

Running With AS

I’ve been living with AS for 35 years. I’ve been running in ultramarathons for the last few years, and once again this year I’ve been accepted into the Badwater Ultramarathon. This event will be held on July 13-14, and involves running a 135-mile course from Badwater in Death Valley over 3 mountain ranges to the portals of Mt. Whitney in the summer heat. It’s billed as the “World’s Toughest Footrace”. I ran in this race last year – needless to say it was very difficult but an honor to participate in. I hope to inspire others who have AS who are not physically able to do many daily activities, let alone run long distances.

I also wanted to share that last December a Japanese nun, who has led many peace walks through the world, suggested to me that I eliminate sugar from my diet to reduce the symptoms of AS. This includes molasses, honey, brown rice syrup, etc. Naturally occurring sugar, such as in fruit, is OK. I did as she suggested and have seen a big improvement since then. I’ve had only minor and less frequent flare-ups, and there are no side effects!

KERMIT CUFF from Mountain View, CA

Editor’s Note: Thank you, Kermit, for sharing your inspirational achievements and the information about a diet modification that has been helpful in reducing your AS symptoms.

LETTERS TO THE EDITOR

Dear Readers: We want to hear from you, whether it be informative, uplifting or a concern you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

Please send letters to:
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Letters to the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413
**Introducing...**

**ANKYLOSING SPONDYLITIS:** Managing Patients in an Emergency Setting, A Primer for First Responders

In 2006, prompted by you, our members, we conducted a two-year extensive search of the medical literature to find out to what degree first responders were aware of and trained in the special handling and care needs of the individual with AS in an emergency setting.

As a result of this research, it became clear that no such training existed -- the need was immediate.

**Setting the objectives and goals**

Working with SAA Expert Faculty of Advisors and in collaboration with the National Association of Emergency Medical Technicians (NAEMT), we quickly were able to identify several critical objectives of an effective continuing education program in AS. The primary goal of the program: to prevent further damage to the individual with AS in an emergency setting.

We set to work to develop a continuing education training video that will be housed on the NAEMT website for continuing education credits and be available to the more than 800,000 first responders in the U.S. That was in September of 2008.

**Randy’s story**

Today, the training video is finished and ready for distribution (to view the video, visit the For Physicians section of spondylitis.org). We would like to offer a special word of thanks to Randy Chism, the firefighter and paramedic through whose personal story we weave the educational components of this training program.

**Production highlights**

In December, Bill Morris, our contracted producer and his crew spent three entire days in Los Angeles and in San Diego taping “A Day in the Life” of Randy Chism. They came away with solid interviews and excellent visual material for the program. Stephanie, Bill’s production manager, also was treated to Randy’s “Firehouse Spaghetti” at the station -- and some sort of dice game at which she proved very adept, trouncing everyone in sight. (And she’s still welcome to return!) Both Randy and Bill have AS and so therefore this program is very dear to their hearts.

The SAA interview and the Fire Department/First Responder/Patient sequences came off without a hitch -- well, almost -- the weather cooperated for the whole three-day period, but the Marine/Navy jets and helicopters taking off and landing within sight of Dr. Vilke’s back yard provided a unique sight and sound challenge for our team. Jim Hall, our volunteer “patient” brought his own recent hospital in-patient experience to the program having gone through major surgical correction of extreme cervical and lumbar spine kyphosis. Drs. Supancich and Ray’s interviews fit the bill as did Dr. Vilke’s.

The two EMTs who treated SAA Board Chair Mike Supancich following his recent in home accident -- a terrible fall from collapsing ladder -- added an important element, underscoring the value of the phrase “Brittle Spine Disease” on the MedicAlert bracelet. As the paramedics put it, the mention of that particular phrase would catch their attention -- would catch anyone’s attention -- immediately, more so than just the words “Ankylosing Spondylitis”, and would consequently cause the caregivers to adjust their techniques accordingly.
Not to be confused with a diagnostic training program
This training is not intended to be diagnostic, but rather to prepare an emergency medical technician to do the right thing to prevent further injury once a person has self-reported, in some way, that he or she has AS. This point is key.

“Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders” provides the education and training needed to ensure that all emergency first responders, including emergency medical technicians, paramedics and fire and police safety personnel have an opportunity to learn the proper and safe techniques in the care and handling of individuals with spondylitis.

What is the problem?
AS is a systemic rheumatic disease that primarily affects the spine. It is estimated that at least 500,000 people in the United States have AS. As the disease progresses, in moderate to severe cases, the vertebrae of the spine can become fused into a single, solid bone incapable of flexion, extension or lateral movement. The fused spine of a person with AS is inherently fragile and as a result susceptible to fracture with resultant spinal cord injury. It has been reported in the medical literature that there is an estimated 35% to 58% mortality rate in people with AS following a spinal fracture, and additionally, that AS patients are at high risk for serious spinal injury and increased neurological complications even in the event of minor trauma.

How you can help
Are you prepared to help spread the word? If so, SAA can provide you with the tools to do so.

We have burned additional copies of the program on DVD to be distributed to SAA members’ local fire departments.

Please contact Melissa Velez Coelho, SAA’s Director of Program Services, at melissa.velez@spondylitis.org or 818-981-1616, ext. 227 to find out more. Thank you.
ARE YOU PREPARED For An Emergency Situation?

In an emergency, time and accuracy are of the essence. A study of emergency department admissions found that 13,200 cases per day are unnecessarily complicated by the lack of timely, accurate personal and medical information regarding the individual being admitted.

**Picture this:** you are being transported to the emergency room as the result of an accident. You are unconscious and unaccompanied. What is likely to be the single most important issue affecting the outcome of the care that you will receive? The answer: immediate access to your current personal and medical information.

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:

1) **Consider wearing medical identification “jewelry/tags”**. 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.”

2) **Consider carrying a medical information card in your wallet.**
   - **TIP:** The card could include vital personal medical information, such as what 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.

3) **Consider wearing a USB computer stick, like DataTag ® that contains your medical information.**
   - **TIP:** Contact SAA or visit our secure online store at www.spondylitis.org/store to find out about purchasing DataTag. DataTag is designed to store all of your emergency contact and medical information including MRIs, x-rays, medications, immunizations and even personal photographs on an ultra-slim 512MB USB Flash drive that can be carried on a necklace. DataTag features the universal emergency medical alert symbol on one side while the SAA logo and inscription “Brittle Spine Disease” appears on the other side.

4) **Consider keeping your medical records on file with multiple physicians.**
   - **TIP:** Be sure to review your medical records regularly to check for accuracy.

5) **Consider ICE.**
   - **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. Write the word “ICE” in permanent marker on your phone or place an ICE sticker on your mobile phone that indicates an ICE phone number is listed in the directory.
I am a Firefighter and Emergency Medical Technician (EMT) in Petaluma, CA and a person who has been living with AS for 25 years. When SAA asked me to participate in this training video, I was reluctant because I’ve never really spoken openly about my disease. But upon reflection, I realized that my fellow first-responders and EMTs know little or nothing about AS. If I could help educate them about this disease and how important it is to use alternative procedures in handling AS patients in an emergency medical situation, I knew that I couldn’t remain silent.

Thanks to the Spondylitis Association’s commitment to educating emergency first responders, for the first time, over 800,000 EMTs nationwide will learn about the disease and the proper handling of AS patients in an emergency situation …but it’s important that you become informed too!

I strongly encourage you to review the tips contained in this issue and then visit the For Physicians section of spondylitis.org where you can view the training video. The knowledge you gain can help you avoid further injury, paralysis or even death in the event of a medical emergency.

I hope you never have a medical emergency, but if you do, I hope the information provided in this training video and in this issue of *Spondylitis Plus* will empower you and give you peace of mind in knowing what to do to protect yourself.

Sincerely,

Randy Chism

Firefighter and Emergency Medical Technician
At SAA, our members and donors aren’t just the people who write us checks. They are the driving force behind the decisions we make every day about which programs to move forward with and how they are prioritized.

That’s why I hope you’re as excited as I am about the launch of the Emergency First Responder training platform you’ve just read about. After all, this is just one of the major projects undertaken by SAA at the behest of our members. You told us that medical emergencies held particular concern for you. You told us what you believed needed to be done. And we heard you. More importantly, we listened. And then, we acted.

As you read this, I hope that you recognize how much your support -- financial and otherwise -- directly contributed to this program’s success. It couldn’t have happened without you. Our more ambitious programs are often funded with restricted monies from corporations or foundations, but none would be possible if not for the membership contributions from individual supporters like you.

If you’re even half as excited as I am, that means you understand the far reaching implications of this important, first of its kind, program. By educating first responders, we have, together, taken the all-important first step in eliminating life-threatening mistakes by emergency personnel who are unfamiliar with the disease.

The completion of this phase of the effort is a success story. And one you have every right to be proud of. And now I’m hoping you’re willing to help us take the next logical step.

Educating first responders is key. But what happens when a patient is handed over to Emergency Room personnel?

It is important that we not rest on our laurels. In Phase II of this initiative, we’d like to institute educational training for in-hospital emergency care providers. To do this, we hope to develop a CME program whose audience will be in-hospital care providers, including ER physicians, ER nurses and ER Physicians’ Assistants.

We recently mailed our Spring Appeal letter asking for your support for this and other critical programs. I hope you responded generously. Whether you did or not, won’t you consider using the enclosed envelope to show your support for this project as well as SAA’s other important works? Any amount, or even a note of encouragement, will tell us that we’re on the right track and using your donated funds in a way you approve of.

Because that’s what we’re here for. Spearheading the programs you want to see.

As Membership Director, I, of course, want the enclosure envelope to be used to raise funds, but I also welcome your suggestions and opinions. This is YOUR organization. Whether or not you intend to make a donation right now, use the envelope to tell us what your priorities are. We’re listening. You are an active participant; a full partner, and your voice can and will be heard.

In closing, congratulate yourself on a job well done. The first responder training program is groundbreaking. But there’s still much more to do. I look forward to many future successes together and I hope to hear from you soon.

Diann Peterson
Director of Membership
Have You Been Putting Off Making A Will
Or Updating An Old One?

If so, you are not alone. Statistics show that more than half of all Americans do not have a valid will.

Your will is just one part of an effective estate plan – but a vitally important one. It is an essential step in planning for the future. Many people believe that a will is only for the wealthy but a will has little to do with the size of your estate and much more to do with your personal desires. If you are married or single, have children, own property, have business interests, securities or bank accounts, you need a will. A will ensures that your estate will be distributed according to your wishes. Through a will you will be able to:

- Determine the distribution of your property
- Make financial arrangements for your spouse, children or other family members
- Minimize expenses and estate taxes
- Leave a legacy to charitable organizations you care about

Also, having an out-of-date will can cause as much confusion and frustration for your family as not having one at all. Once prepared, your will should be updated regularly, especially if there has been a birth, marriage or divorce in the family, a change in the tax laws, a move to another state or any other significant change in your personal circumstances.

Without a will, the people and organizations you care most about may not benefit from your remaining assets. The state will intervene and your possessions will be distributed by the “will of the state” which may vastly differ from your intended wishes. Each state is different but not having a will can result in heavy taxes and legal expenses for your surviving family. That’s why a will is so important!

To make a will or update an existing one, you should consult an attorney or professional advisor who specializes in estate planning. Because having a will is so important, SAA is offering a booklet, How to Make a Will That Works. The booklet offers general information that may be helpful as you plan the long-term distribution of your property to family, friends, and charitable interests. Simply check the box requesting How to Make a Will That Works on the return envelope enclosed or contact Susan Jones, Director of Development and Planned Giving, at 800-777-8189, ext. 231 or susan.jones@spondylitis.org to get your free copy.
Integrated Biomechanical Influences On ANKYLOSING SPONDYLITIS

by Alfonse T. Masi & Laurie M. Savage | April 2009

The characteristic spinal deformities and lesions of AS occur at anatomical sites where ligaments, tendons, or joint capsules anchor or attach to bone (1-5). The epidemiological patterns of AS can offer essential clues to possible initiating pathways of the disease. The sex- and age-specific onset patterns of AS in the population are unique (6,7). The clinical condition develops about two or three times more frequently in males than females, and that M:F sex ratio increases with greater severity of skeletal lesions and deformities. Chronic low back pain and stiffness are the typical presenting symptoms of AS. These symptoms generally start from the later adolescent years to the 40s; however, juvenile onset AS (under age 16) occurs in about 15 percent of patients (6-8). Frequently, juvenile patients present with lower extremity arthritis before back symptoms (8). Foot problems, such as tarsitis (inflammation of the tarsus, the cluster of bones between the five long bones of the foot and the leg bones), often occur in children, while hip involvement is common in pre-teens and adolescents (7,8). Juvenile onset AS tends to predict a more progressive disease course (8).

AS and adolescent idiopathic scoliosis (AIS), a lateral curvature of the spine, were hypothesized to have counterevoking biomechanical predispositions (9). The theory was based on amounts of musculoligamentous (myofascial) tonicity, or stiffness of the spine, needed for its stabilization (9). Insufficient spinal myofascial stability has been incriminated in AIS (9), whereas excess spinal stiffness is proposed to increase the risk of developing AS (5-8). Myofascia is a network of strong connective tissue that wraps around muscle and connects to ligaments and tendons (5). Among individuals in the population, such extremes of axial myofascial tonicity, as proposed for AIS vs. AS, may be the opposite poles of this biomechanical body trait that varies in the population (polymorphism), like height or intelligence, presumably reflecting different genetic profiles (9).

Genetics increase AS disease risk

In the early 1970s, scientists discovered that AS has a strong genetic predisposition that associates with immune function. This genetic link occurs among the human leukocyte-associated (HLA) genes. People who inherit any one of the majority (but not all) of the over 40 HLA-B27 variations of this gene (isotypes) have a 40- to 100-times greater risk of developing AS than individuals without such isotypes (4-6, 10).

Unlike hemophilia or sickle cell disease, in which abnormal genes cause specific molecular pathology, the HLA-B27 genes do not cause AS, and may be described as susceptibility factors (10). Two forms of HLA-B27 do not increase the risk for AS (B*2706 and B*2709), for unknown reason (10). Among persons who do develop AS, over 90% of the influencing factors are genetically determined (heritability), rather than acquired or environmental components of risk. However, genetic influences do not have full expression to cause the disease. For example, even in HLA-B27-positive children of a parent with AS, the estimated penetrance (expression) is only about 30% or less (10).

New susceptibility genes with lesser AS risk, including ARTS1 (now ERAP1, endoplasmic reticulum aminopeptidase) and IL23R, have been identified (10). The ARTS1 (ERAP1) and HLA-B27 genes are believed to work together to determine the cell surface receptor molecular characteristics and levels that influence the body’s immune response. IL23R plays a role in the immune response to infection and is implicated in inflammatory bowel disease and psoriasis, which are both related to spondylitis. Identified genes explain roughly one third of the total inheritability of the disease (10). Scientists think increased immunological activation, particularly of innate pathways, is the pathological mechanism by which the various recognized susceptibility genes may predispose individuals to AS (4,7).

A broadened conceptual framework of AS is needed

At the 1970 Heberden Oration, one of the world’s premier rheumatologic pathologists, Prof. John Ball, proposed the term “inflammatory enthesopathy,” which received widespread attention (1). His autopsy study of advanced AS patients revealed multiple focal microscopic inflammatory lesions where ligaments attach to the spine (enthesopathy of the spine). Importantly, he subsequently indicated the possibility that mechanisms other than inflammatory enthesopathy, like trauma in a spine “susceptible to stress,” could give rise to syndesmophyte formation (2). However, that interpretation received little recognition or response in the scientific community (7).

Yet, the vital unanswered question remains as to the initiating and predisposing pathways or precipitating factors for developing AS (5,10). As in the past, the focal point of AS progression continues to be viewed as skeletal changes. Research has not yet critically addressed interactions of musculoligamentous (myofascial) components on the musculoskeletal system (5). Limited space, permits only brief mention of some integrated biomechanical influences on the unique manifestations of AS (5-9).
Research breakthroughs may be achieved by intensifying currently established immunogenetics and other pathways (3,4,10). Even so, a broadening of perspectives to include biomechanical systems analysis seems to be needed (5-9). The initiating mechanisms of AS are not yet discovered, nor do current concepts sufficiently explain its unique demographic patterns or characteristic localization of lesions (5). A broadened conceptual framework of this mysterious disease need not diminish the currently established core beliefs (3,4,10). Rather, novel theories can expand current concepts and stimulate research on new predictors of the development and sequential course of the disease (5-7). Once people who are susceptible to AS can be more accurately identified by their full range of risk factors and the initiating sequences of pathology are discovered, disease prevention can be approached and more specific therapy provided (3-5,10).

The proposed integrated biomechanical concepts are a work-in-progress (5-9). They need to be critically held up to the experiences of AS sufferers and testing by scientists (3,4,10). If the novel concepts have virtue, improved understanding and management of AS can be expected. If these new views are seriously faulty, addressing their errors will only improve understanding of the current concepts of AS.

Integrated biomechanical principles offer new insights on AS disease patterns (Table 1)

Excess biomechanical stress is a recognized mechanism of local tissue injury and immunological activation, mainly via innate, rather than adaptive pathways (3-5,7). Entheses are anatomically specialized sites to accept and transmit normal repetitive biomechanical stressing forces (3-5). Accordingly, a crucial question is whether or not excess integrated forces are imposed in AS? Assuming that such excess forces do occur, we need to ask why, how, when, where, and to what effect? While these questions cannot be definitively answered, inferences can be raised. A systems integration model of increased axial (spinal) myofascial forces in AS permits a probing interpretation of biomechanical influences in the disease.

Our proposed integrated concepts (5-9,11) expand upon accepted localized biomechanical mechanisms for enthesopathy lesions in AS (2-4), and deal with its other unique features (5). Table 1 outlines the integrated biomechanical principles that may be applied to AS (5). It assumes that excessive axial (spinal) myofascial stiffness predisposes a person to the disease (5-9,11). An understanding of these biomechanical principles can offer a new perspective in interpreting the incidence patterns of AS and the unique localization of its various lesions.

The biomechanical concept was clued by clinical observations of early disease patients who complained about prominent back stiffness and tightness—even without bothersome pain (5-7). Such patients still had essentially full range of motion, yet exhibited a slow (“straining”) forward bending, as if overcoming actual physical resistance, yet denying pain. An intrinsic musculoligamentous tightness and stiffness was then suspected to be an early physical component of AS, if not a predisposing factor (5-9). Many years later, after the theory had been considerably refined, it was discovered that in 1951 Dr. Jacques Forestier, an internationally acclaimed rheumatologist and spine specialist, described a similar observation in AS patients on lateral bending that he called the “bowstring sign.” Forestier indicated that the bowstring sign was a useful physical finding in diagnosing early AS (11).

### Table 1: Integrated Biomechanical Influences on Ankylosing Spondylitis (AS) Features*

| 1. | The body’s muscular and fascial (myofascial) networks are pre-tensed to resist gravity. |
| 2. | Body pre-tensing (stiffness) varies with age and sex and by the individual’s inheritance. |
| 3. | The inherent polymorphic degree of myofascial stiffness may be excessive in AS. |
| 4. | Excessive pre-tension decreases mobility and enhances enthesopathy. |
| 5. | Excessive pre-tension and enthesopathy concentrate forces and reduce transmission. |
| 6. | The body’s tensional integrity (“biotensegrity”) is an efficient design for energy and strength. |
| 7. | Chronically excessive biotensegrity can stress attachments and lead to syndesmophytes. |
| 8. | Splinting of myofascial anatomical chains creates compressional forces across the sacroiliac joints. |
| 9. | Hip joints can be compressed by the coupling of several musculoligamentous systems. |
| 10. | Spinal myofascial hypertonicity biomechanics can explain many typical features of AS. |

*Masi AT, Benjamin M, Vleeming A, 2007
Drs. Masi and John C. Hannon subsequently reviewed the vital role of human resting muscle tone (HRMT) (12). That effort signaled that individuals vary in such a morphological (structural) trait (9,12). HRMT occurs as part of the body’s tensitional integration (biotensegrity) system, which consists of tensional and compressional elements and provides our body with stability and flexibility (5,7,13,14).

Axial myofascial hypertonicity or excessive spinal stiffness in AS is now only documented objectively by the bowstring sign (11) and observations of increased palpable hardness of patients’ lower back muscles in a full resting prone position (5,7). Axial myofascial hypertonicity needs to be tested as a significant primary susceptibility mechanism in the onset and expression of AS. If confirmed, the biomechanical and biotensegrity principles can help explain the unique enthesopathy, SIJ, hip, and tarsitis lesions in this disease (5,8). Quantitative research is needed and planned to measure myofascial properties in AS patients compared to control subjects without back pain or other disorders.

Vignettes and Biomechanical Interpretations

Periodically, readers of the SAA news magazine inquire about possible precipitating factors related to AS. The vignettes and responses below answer some of those questions. These views are not intended to be definitive; rather, they offer interpretation of important questions that need to be scientifically studied.

Vignette 1. Over the years, people with AS have reported a higher proportion of serious self-identified juvenile or young adult athletes with AS compared to what would be normally expected in the general population. Is this true?

A Biomechanical View: Some juveniles and young adults have earlier constitutional or developmental maturation, strengthening and myofascial toning that can enhance athletic performance. If those young athletes are also genetically predisposed to AS, such otherwise advantageous constitution could further amplify axial myofascial tone to excessive amounts. To the contrary, low or generally insufficient musculoligamentous tone could modulate axial myofascial tone, which is suspected to predispose one to AS. Scientists need to vigorously define these physical associations in athletes.

Vignette 2. Many people with AS have correlated the onset of their symptoms with trauma, including motor vehicle accidents or some other sort of physical injury. Several SAA members have raised this cause-and-effect relationship. Does it exist?

A Biomechanical View: Susceptibility to injury following trauma is complicated and depends on multiple factors, including actual physical impacts, biomechanical morphology, and central nervous system coordination and reflexes. Individuals vary in degree of injury following similar types of trauma. A flexible body often has less physical reaction to stressful impact (e.g., children vs. adults). It is often stated in a car accident that a sober person incurs greater injury than an intoxicated person. The sober person is generally more aware of what is happening and tenses up. Another example is an elderly person who may fracture a hip on falling, even before actual impact.

This raises a question: Are AS patients more susceptible to injury, even before recognizing the first medical symptoms of the disease? One may suspect that AS patients have stiffer spines than people without the disease, preceding the onset of chronic pain, which would likely increase the risk of impact injuries. A scientific answer to this question, however, requires accurate measurement of axial myofascial properties in both AS and non-AS patients and their respective susceptibilities to similar injuries.

Does trauma simply reflect an alerting (i.e., first incident) event or is it a meaningful initiating factor in the development of AS? Currently, a conservative, tentative reply would be that the injury more likely first brought the condition to the individual’s notice, rather than caused the onset of disease. Again, scientific research is needed on this issue.

Further suggested research for future studies is outlined in Table 2. Preferably, these studies should be performed at the earliest detectable stages of AS. The objective would be to test the validity of the proposed hypothesis and to interpret its sequential influences in multifactor pathways (5,7).

In later or progressive stages, one may expect to find an expanded number of factors that contribute to the disease (4,5,7). Thus, a greater complexity of mechanisms is expected, as opposed to the initial predisposing and preclinical pathways. Better understanding of the initiating mechanisms of AS, however, is essential for more effective control and eventual prevention of this mysterious disease.

Dear readers: Questions or comments? We encourage you to give us feedback on this article. Please send your response to:

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Table 2: Areas of Controlled Research to Test Axial (Spinal) Myofascial Hypertonicity in AS

1. Noninvasively quantitate tension of spinal muscles at rest and with activity.
2. Noninvasively quantitate stiffness of spinal muscles at rest and with activity.
3. Quantitate paraspinal muscle hardness, as is done with tension-type headache.
4. Noninvasively quantitate sacroiliac joint stiffness under varied conditions.
5. Explore imaging (MRE and ultrasonography) to quantitate muscle tone.
6. Investigate bioenergetics of AS patients vs. control subjects under varied conditions.
7. Confirm or refute axial myofascial hypertonicity and study sequential risk pathways.

REFERENCES


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www.spondylitis.org
by Kath Donaldson

I am a physiotherapist and I have AS. I am very fortunate in that I am not badly affected by the condition. My lumbar spine and sacroiliac joints are almost fused but the movement in the rest of my spine, as long as I keep exercising, remains fairly good. I get very little pain as long as I keep moving and only need to take paracetamol (acetominophen) which I do most days.

I used to run the exercise classes for people with AS in Kendal (UK) and of course, exercising with the others in the class kept me mobile too. When we moved South 4 ½ years ago, I started going to the classes in the physiotherapy department at the nearby hospital. These were in the evening.

As some of the people who were in my Kendal class used to go to Pilates as well, I thought about going to those instead as the classes would be during the day.

Pilates is an exercise method designed to elongate, strengthen and restore the body to balance and is based on an anatomical understanding of the body’s muscular and skeletal systems.

We start each class by mobilization of all major joints and then practice the Pilates techniques of alignment, breathing and centering. We then go on to do mat exercises in lying and sitting, starting at beginner level but with the option of progressing as we move on. Instruction is given for progression for each exercise.

Pilates has exercises to strengthen the core stabilizing muscles in the abdomen, trunk and buttocks. The class also includes strengthening and stretching exercises for arms, legs, shoulders and buttocks.

I have now attended classes regularly for just over 3 years and I know the exercises help to maintain the movement in my spine. When we have a break such as over Christmas or during the summer, I do stiffen up very quickly.

When I started going to the classes I realized just how tight many of my muscle groups had gotten, particularly the hip flexors and hamstrings.

The only exercise I do not do is the frog stretch, i.e. both legs in flexion and abduction as it causes pain in my sacroiliac joints. I also cannot do rolling like a ball in flexion as I don’t have enough flexion so I just go side to side.

When we lived in the North, every so often I would go to a massage therapist for a good back message which I found very beneficial. After we moved I could only find holistic massage therapists which was not what I wanted. However, I have now found a sports massage therapist, who is excellent, and really sorts out the tightness in my back and shoulders. I was talking to him and he told me he had recently referred a patient to his GP as he was certain from his symptoms that he had AS. He was proved to be correct.

I would certainly recommend Pilates to anyone with AS if a physiotherapist run AS class was not available to them for any reason.

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TERMS USED

Extension based exercises are very important for AS patients as they involve exercising the muscles on the back of their bodies working to improve posture. Back extension means if you are lying face down, then lifting the trunk off the floor. Hip extensions would be standing on one leg and then taking the non-weight bearing leg backwards in a straight line. Shoulder extensors would be taking your arm back in a straight line. So extension is moving backwards away from your mid line.

Extensor muscles are those on the back of your body or limbs (except knee extensors) and they often produce a straightening effect on the joint or part of the body they are working.

Flexion of posture means a flexed posture where someone adopts a stooped or forward bending posture.

Rotation based exercises are those where you turn on your body’s axis, i.e. neck rotation is turning your head to the left or right trying to look over your shoulder. Trunk rotation is where you turn your body to the left or right from your waist.
SAA-Sponsored Educational Support Groups

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 email to: elin.aslanyan@spondylitis.org.

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- **Teen Athletes with AS** located in Orange County - contact WalkerRSM@aol.com
- **Support online from NY, NY** with Michael T. Smith, spenser23@aol.com

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