The Heart In Ankylosing Spondylitis

Blood Work in Ankylosing Spondylitis: Diagnosis

Spondylitis PLUS
Winter 2012

Special 28 Page, Full Color Issue!
Dear Readers,

As we think about the past year and how we have been impacted in spondyloarthritis (SpA), it would seem that the above quote gives much pause for thought.

So, where are we today compared to yesterday? Where are we going tomorrow? The medical literature informs us that much more is known today in SpA compared to just a few years ago. Published prevalence data from a Centers for Disease Control and Prevention national study, in part sponsored by the SAA, reports that 2.7 million adults in the U.S. are affected by some form of SpA. Now, you may ask, how does that help? Well, there are multiple potential benefits to having this information. One - now that higher prevalence numbers are known, it is more likely that we’ll see new treatments developed specifically for SpA rather than having to wait for the “trickle down” approval of drugs initially developed for other better known diseases like rheumatoid arthritis, for example. Other good news—advancements from the SAA-seeded TASC genetic study are leading to earlier diagnosis and improved treatments. That said, some of you may remark that you really have not seen much improvement in your experience and that some of these advances may not have helped you directly. True. We are aware of this and regret the fact that these advancements did not come sooner. However, all of these new findings suggest a brighter future for our younger generation, who may be impacted. Indeed, recently an important study proposed that with early diagnosis and proper treatment, the disease process actually may be slowed or even stopped.

In the upcoming year, SAA is collaborating with the American College of Rheumatology to develop standardized treatment guidelines in spondyloarthritis. In addition, our research clinicians in North America, in collaboration with the Veterans’ Administration, will be completing phase one of the SAA-seeded and privately funded Patient Registry to improve our understanding of spondyloarthritis, the efficacy and side effects of treatments and the natural progression of the disease over time.

These are good things to celebrate. My team and I, plus all of our dedicated volunteers, wish each and every one of you optimum health and happiness in 2013. We celebrate all of us, serving all of you. Thank you for your support and confidence in our work.

Sincerely,

Laurie M. Savage
Executive Director

“Give thy mind more to what thou has than to what thou hast not”
-Marcus Aurelius Antoninus
Online News & A Laptop Tip
First, thanks so much for your recent article about Inflammatory Back Pain (IBP) [See editor’s note below]. I really appreciated learning about the differences between IBP and mechanical trouble. The IBP symptoms match my experience perfectly.

Secondly, I have a tip to share related to IBP to pass along to fellow members.

I stand up most of the time at my laptop instead of sitting; however, a recent flare-up of inflammation around the neck vertebrae made looking down at the monitor very painful. So, I purchased a second monitor that I have on a stand at face-height, which prevents having to look down at the monitor. This way, I still have the keyboard at the right height for my elbows and wrists, while having a second monitor straight ahead. I can still use the laptop periodically when seated and have the right height when standing. (Standing has always helped to reduce other problems for me that I experience when sitting for too long. Varying standing and sitting is helpful for me—approximately 80% standing and 20% sitting during a regular day.)

Thanks very much,
~SUSAN

Editor’s note: Thanks much for the tip, Susan, and for your kind words. The IBP article Susan is referencing was published in our News Section online at spondylitis.org/press.

Compliments On The Summer 2012 Issue
“i meant to tell you all how amazing the last Spondylitis Plus was. I think that’s the best one yet! Love what you do and thank you so much for doing it!”
~DIANE (via Facebook)

“One of the best issues ever! Congrats!”
~MICHAEL (via Facebook)

Editor’s note: Glad you enjoyed the issue as well as the new look of our News Magazine. It sounds like we are on the right track. If you have questions, comments or a suggestion for an article, please email or mail using the contact information below. If you prefer, you can also suggest topics on Facebook at facebook.com/spondylitis or tweet us: @spondylitis

LETTERS TO THE EDITOR
Question, comment or concern? We want to hear from you!

Please send letters to:
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Please note that we reserve the right to edit for space and clarity.
Location, Location, Location: Enthesal T Cells Set Up Shop at the Intersection of IL-23 and Spondyloarthritis

by Robert A. Colbert, MD, PhD Chief, Pediatric Translational Research Branch NIAMS/NIH/DHHS

For decades, rheumatologists have puzzled over why some people develop arthritis in their wrists and fingers, while in others it affects primarily the spine and places where tendons and ligaments attach to bones (known as entheses). Why does arthritis lead to severe bone and joint destruction in some, while in others bone damage is followed by overly aggressive bone formation causing joints and vertebral bodies to fuse? These dramatic differences in the appearance of disease (phenotype) are striking when one compares spondyloarthritis (SpA), particularly ankylosing spondylitis (AS), to rheumatoid arthritis (RA).
In the last decade, there has been major progress in discovering genes that predispose to arthritis. Almost two-dozen genes along with HLA-B27 have been implicated in susceptibility to AS, and for RA the list is even longer. Interestingly, there is virtually no overlap between AS susceptibility genes and those implicated in RA, while there is overlap between AS, psoriasis/psoriatic arthritis, and inflammatory bowel disease. This is not surprising since many individuals with AS also have psoriasis or inflammatory bowel disease. We say these diseases have overlapping clinical features or phenotype. We don’t fully understand how the predisposing genes work together to cause arthritis, and why the pattern of arthritis is different in different people.

“In the last decade, there has been major progress in discovering genes that predispose to arthritis.”

Animal models have taught us a great deal about how HLA-B27 might trigger inflammation as an early step in the development of AS, and we are gaining a better understanding of the cytokines that send instant messages from cell to cell to direct the immune response. One of the cytokines that has been implicated in AS is called interleukin-23 (IL-23). It is produced in greater amounts by certain cells from individuals with AS, and in some studies has been found at increased levels in the blood. In rat cells, abnormally folded forms of HLA-B27 can generate cellular stress that has been linked to increased production of IL-23, suggesting one way that HLA-B27 might contribute to disease. IL-23 exerts its actions on cells that have a specific receptor (cleverly named the IL-23 receptor or IL23R), and natural variations in the IL23R gene have been associated with susceptibility to AS, psoriasis, and inflammatory bowel disease. So this road appears to be well traveled in several forms of spondyloarthritis. However, how this leads to the spondyloarthritis phenotype – enthesitis, spinal arthritis, and aberrant bone formation – remains unclear.

A recent study published in the journal *Nature Medicine* sheds light on this important question. Long recognized as an important site for inflammation and related symptoms (pain, tenderness, and sometimes swelling), what happens at entheses may be the key to understanding the AS phenotype. The researchers who performed this study made two very important observations. The first was that simply raising the level of IL-23 in mice caused enthesitis including spinal inflammation. Careful study of the entheses under the microscope at the earliest stage of inflammation showed the expected inflammatory cells such as macrophages and neutrophils in and around the entheses, but not in the joint itself or the thin layer of cells (synovium) that lines the joint. This is important because other types of arthritis such as RA start with inflammation in the synovium.

Remarkably, inflammation caused by IL-23 was followed shortly by new bone formation adjacent to the entheses. The second observation that was completely unexpected was that there were special kinds of T cells sitting in the entheses waiting to be activated by IL-23. These T cells were discovered using a special technique where the researchers genetically engineered a mouse so that every cell that could respond to IL-23 turned green – actually fluorescent green – by expressing what is called green fluorescent protein or GFP, attached to the IL-23 receptor. In this way, cells that express IL23R are also fluorescent green and easy to find with a special microscope. When the researchers looked in the mouse, GFP-expressing cells were found not only where immune responses are normally generated, but also in peripheral and spinal entheses. The IL23R-green cells were present even in healthy mice that had not been exposed to extra IL-23 or any other agents that activate the immune system. Quite remarkably, they were also found in specific regions of the heart where the aorta comes out, suggesting that they might be involved in the development of aortic valve inflammation that occurs in some individuals with spondyloarthritis and can lead to valve damage. When the GFP-expressing enthesal T cells were further examined they were found to make a number of inflammatory cytokines when treated with IL-23, including IL-17 and IL-22. IL-17 is well known to mediate some of the pro-inflammatory effects of IL-23. Of even greater interest, they found that IL-22 was
These new findings have many implications and like most good research studies, they raise additional questions. First, it has long been thought that the entheses and spine were affected in ankylosing spondylitis because of a different kind of T cell that would be aimed specifically at HLA-B27 as part of the adaptive or memory immune response. Results from rats expressing HLA-B27 have caused this theory to be questioned, and this new study confirms that the road to enthesitis does not require immune recognition of HLA-B27. Second, and more importantly to the many individuals who suffer from the symptoms of enthesitis along the spine or in the extremities, this type of inflammation might be treated by inhibiting IL-23. However, it is important to remember that many people already benefit from biologics that target tumor necrosis factor (TNF), which could be part of this inflammatory cascade. Thus it will be important to learn in future studies whether blocking IL-23 is beneficial in spondyloarthritis, and eventually whether it is more effective than TNF blockade. This study also raises the possibility that targeting IL-22 will help slow the progression of spinal disease and the bone formation that can eventually cause ankylosis. As a
pediatric rheumatologist I am often puzzled by the observation that in children with spondyloarthritis, the hips and enthese in the legs and feet are affected, while the back and spine are often spared, at least until later in the course of the disease. Considering these new findings, it is intriguing to speculate that the location of the entheseal T cells might change with growth and development, which could account for the age-related differences in symptoms. One important question not addressed by this study is what causes the overproduction of IL-23? Moreover, since IL-23 has been implicated in a number of inflammatory diseases, why aren’t enthesis and spinal involvement more common? Perhaps the answer is once again, location, location, location! Just like the entheseal T cells may be situated at the crossroads of IL-23 and spondyloarthritis, perhaps the biomechanical forces generated at enthese provide a stimulus for IL-23 production in genetically susceptible individuals. Stay tuned.

Glossary

**Cytokines** Small protein molecules such as interleukins or interferons that are made and secreted by cells. Cytokines can act locally or circulate through the blood and communicate messages to other cells.

**Enthesis** Area where tendons and ligaments attach to bone.

**Enthesitis** Inflammation of the enthese. Common sites of enthesitis in SpA include the pelvis, spine, heel, and knee.

**Macrophage** A type of white blood cell that can ingest material including bacteria, and produce pro-inflammatory cytokines.

**Neutrophil** A type of white blood cell, also known as a granulocyte, that circulates in the bloodstream and is one of the first responders to tissue damage including infection, and helps to eliminate invading organisms.

**Synovium** A cellular membrane located between the joint capsule and the joint cavity.

**T Cells** A type of white blood cell or lymphocyte that matures in the thymus and can secrete cytokines and other mediators of the immune response.
THE FACES of Ankylosing Spondylitis

Faces of Ankylosing Spondylitis is a website dedicated entirely to the stories of those with AS. As of this writing, over 590 stories have been published on the site, and more are being added regularly. Men, women, and children from numerous countries and continents have shared their stories and photos, and we would like to share a few excerpts here, with our gratitude to all. You can read all of the stories on the Faces of AS Site.

Face # 1: Kevin Andrews

Excerpts from Kevin’s story -
“I am Kevin. I am 57 years old and I live in England. My problems started about 50 years ago at a time when even less was known about this disease, and if you had pains they were growing pains or imagination.”

“As you can see from my photos I am a classic case of Ankylosing Spondylitis. It’s not a pretty sight I know, but this is me. I can’t change the way I look. I used to try to hide it - avoid mirrors and shop windows and refuse to have my photo taken, but recently realized, ‘What’s the point? Everyone else can see me. Hiding from myself is not changing the way I look to other people and is just making me miserable.”

“If I didn’t have Ankylosing Spondylitis I would not be me as I am now; my whole life would have been different. I wouldn’t have my wonderful daughters and grandchildren, I wouldn’t have met Joanne, my very supportive wife, and I wouldn’t have met all the wonderful friends I have who, like me, have Ankylosing Spondylitis.”

Face # 593: Lisa Russouw

An excerpt from Lisa’s story -
“At some point, I stood up straight on the inside and I got angry. I went off the prescription meds. I started to make myself move and I took every step with determination not to let this disease win. I did everything- changed diet, underwent sessions of prayer with many people, I started to jog on the treadmill through the pain. I didn’t care. I spoke to the pain like it was a robber who illegally came to take my life, and I told it I was going to tell it what to do not the other way around. I knew I sounded like I had lost it, but I didn’t I was aggressively responding to this in the only way that worked for me.”

Face # 580: Jennifer Aiello

“My name is Jennifer Aiello. I live in Maryville, Tennessee. I was diagnosed with AS in April 2012. Today I am 47 years old and was in pain beginning in my teenage years. With many doctors and many misdiagnosed theories, it was a case of iritis that set the wheels in motion to do other tests. Finally, a rheumatologist listened to me and took the necessary steps to treat me. I have been on Sulfasalazine and Humira since April 2012, and on May 14th, I woke up for the first time pain free! I continue to stretch and stay active. But can’t help feeling deprived of many things for many years due to pain. Live on, starting now!”
The woman behind Faces of AS: SAA member, Cookie Hopper, is pictured here on the left, after her Remicade infusion.

The woman on the right is Genie Hayward, who has been Cookie’s infusion nurse since her diagnosis in 2002 and is, in Cookie’s words, “my rock and supporter in this long journey.”

“Our goal is to have ONE THOUSAND faces... There is strength in numbers.” ~Cookie

What inspired you to create Faces of AS?

“There was a time that my struggles with Ankylosing Spondylitis and other difficulties had brought me to the brink of despair, and I had made the decision to take my life. My husband’s intervention changed the course my life would take.

A number of years later, I came across someone with AS who was feeling the same way that I had about life; not long after we learned that he had died. I remember how desperate and alone I had felt, and didn’t want anyone to ever feel that way. I wanted to do something to bring people with AS together on a personal and emotional level. I didn’t start Faces of Ankylosing Spondylitis to raise awareness, or funds; I didn’t start it to become a health activist, or even to find a cure for AS. I started Faces of AS for that desperate frightened person in all of us when we learn we have this disease.

I wasn’t sure how to do this and then one day a gentleman from the UK named Kevin Andrews shared his pictures with me, and I knew what had to be done. We had to show the world the reality we deal with, and be honest about our lives. So I decided to start asking people to share their stories about their lives with AS. I never wanted anyone to feel that the only hope they had was to take their life. I wanted to show that with support from one another, we can not only survive but thrive in our lives with AS. I wanted to do something that would make my life of pain and suffering have meaning, I didn’t want it to be for nothing.

How do you feel about the project’s success so far?

“I am blown away by the reception that Faces of AS has received and by the response of the spondylitis community. We are almost at 600 stories at this time, and over a quarter of a million views on the site. It is so amazing and unbelievable to me. Each day, I am grateful that people were willing to come together and bare their souls to make a difference for others. For me personally, the true triumph is when people tell me that they are getting together and meeting each other. That they know that from this day forward when times are unbearable they only have to reach out to one of the others on this site, and they will have the emotional support that is needed to survive this disease; they know they are not a support group but a family.

Where do you see Faces of AS going? Any future plans or dreams for the project you’d like to share?

“I am hoping that one day each of the Ankylosing Spondylitis Societies across the world will include a link to the Faces of AS on their site, to make it global and bring us together to work toward finding a cure. I am also hoping that in the future I will be able to set up a fund that will help people with their personal and medical needs. Those are my ultimate goals for Faces.”

~You can find Faces of AS on SAA’s website at: Spondylitis.org/faces

“It was important for me to do this, not for myself, but for each one of the Faces on this site and those who are still unknown.” ~Cookie

*Cookie Hopper is Face # 62. We chose not to truncate her story to allow for printing here, but rather invite you to visit the website, and read her story in full.

Faces of Ankylosing Spondylitis: http://thefacesofankylosingspondylitis.com
S.M.A.R.T. is a safe, secure and convenient way to put more of your money to work advancing the spondylitis community’s shared mission. Just specify a monthly amount and SAA will automatically deduct the contribution from your credit or debit card. At the end of the year, we’ll send you a summary of your giving and a tax receipt. Your dependable monthly gift of $100, $50, $25, $15 or even $10 will boost the impact of your SAA membership gift many times over.

Sign up today and get a free gift. Holding 14 ounces of your favorite beverage, this heavy, oversized mug features a large ear shaped handle and boasts the SAA logo on each side. A great way to get the word out about a cause that’s close to your heart!

To sign up for the S.M.A.R.T. Givers Program, go to www.spondylitis.org/smart or contact Helene Hart at 800-777-8189, ext. 229 • or at hhart@spondylitis.org
Q: Can you describe the following blood tests and what they look for? Also, how do they relate to the diagnosis of AS?

ESR - erythrocyte sedimentation rate: this is a blood test for inflammation. Unfortunately, it is not high in all AS patients and even when it is high, it can be from other causes. Other causes of an elevation in the ESR include anemia, infection and cancer. That is not to say that if you have an elevation in your ESR in AS, you need to worry about infection or cancer.

How the test works: as the test implies, we calculate the rate of sedimentation of the red blood cell (or how fast it falls in a test tube). If there is a lot of inflammation, there is often a molecule called fibrinogen and this makes the red blood cells fall faster thereby increasing the rate!

One more pearl about the ESR: it goes up normally as we age and in women. Therefore I would not use the quoted common reference range of 0 to 10 or 15mm/hr. There is a rule of thumb you can use to approximate what is an acceptable ESR for age and gender. Age (+10 for a woman)/2. In other words, a 40 year old woman should not have an ESR > 25mm/hr.

CRP - C-reactive protein: this is another blood marker of inflammation. Different laboratories use different tests and different reference ranges so don’t worry if the number changes a lot from lab to lab. Look at the reference range. Also remember other causes of an elevation in the CRP include infection and the high sensitive CRP has been associated with cardiovascular disease.

Many researchers believe the CRP may be better than the ESR in AS. My experience is that sometimes one is elevated and not the other (without clear predictability), sometimes both and often neither. I generally follow both as a measure for disease activity in patients.

HLA-B27- this is a genetic test. In other words, it doesn’t change over time and you cannot become positive. In general, once it is tested, it should not need to be retested. HLA-B27 is positive in 80-90% of AS patients. This is especially true in caucasians and less true in some other ethnic groups, especially African Americans. It is often ordered in the diagnostic stage of disease and may help your doctor decide whether the probability of AS is higher or lower. It is not a diagnostic test however for 2 reasons. 1) Not everyone with AS has the gene (though most people do). 2) In the United States population, 7.5% of white people carry the gene, yet less than 5% of them develop AS. It is lower in other ethnic groups, except in some Native American patients, when it can be much higher.
Other HLA B27 pearls:

- AS rarely recurs in families in the absence of HLA-B27
- If you have AS and are HLA-B27 positive, the probability that your child develops AS is 20%
- If you don’t have HLA-B27, the age at onset of disease appears to be 10 years later

Q: What are rheumatoid factor and antinuclear antibodies? Do these have any association with AS?

Neither of these tests are associated with AS and should not be ordered if the provider is thinking about AS only and not rheumatoid arthritis or connective tissue disease. In general these diseases do not co-exist. Rheumatoid Factor (RF) is an antibody test found in Rheumatoid Arthritis, but also in other diseases (both rheumatologic (i.e. Sjogren’s syndrome) and non-rheumatologic (i.e. Hepatitis C) diseases). The Anti-nuclear antibody (ANA) is an antibody test seen in lupus, but also in other rheumatologic (i.e. Systemic sclerosis) and non-rheumatologic (autoimmune thyroiditis) diseases. Neither of these tests are expected to be positive in AS. Unfortunately, there are a lot of providers that do not understand the differences and order a panel of rheumatologic tests that may include all of the above. There are also labs that allow for “panels” of tests to be done. In the future, we are moving towards better quality healthcare including appropriate laboratory testing.

Q: Are there any other blood tests that may be used to help diagnose AS or that you personally have felt helpful in diagnosis?

No (not yet).

Q: In Dr. Muhammad Asim Khan’s book, “Ankylosing Spondylitis: The Facts”, he states that, “...less than 70% of people with AS have a raised ESR value, even when there is active inflammation.” Can you briefly discuss why this may be?

It is not clear why AS patients don’t always have as much inflammation in the blood as those with diseases like rheumatoid arthritis do. One reason may be that the inflammation is local to the sacroiliac joints and spine and therefore the blood measurement is not picking up this more remote process.

Q: Is there any one blood test that can definitively diagnose AS on its own? (Note: We have had numerous members contact us under the assumption that the HLA-B27 test is actually diagnostic).

No. There is no one blood test that gives a diagnosis of AS to a patient. The diagnosis is made based on several factors:

1. A history of inflammatory back/buttock pain
2. In late AS, the physical examination may be helpful, but early in disease it often is not
3. Elevation in the ESR and /or CRP If the HLA-B27 is positive. Keep in mind the points above about this test
4. X-ray or MRI if the x-ray is negative

This does not mean you need all of these features, but your doctor will take these “pieces of the puzzle” and use something called “clinical reasoning” to decide whether you do or do not have AS.

Lianne Gensler is the Director of the Ankylosing Spondylitis Clinic at UCSF in San Francisco, CA. She is an Assistant Professor of Medicine in the division of Rheumatology and sees patients in addition to teaching and performing research in Spondyloarthritis.
One of the most common - yet impactful - complications of ankylosing spondylitis (AS) is fatigue. As detailed in SAA’s book, “Straight Talk On Spondylitis,” fatigue can be caused by many things related to spondylitis such as loss of sleep because of physical discomfort. But it can also be a by-product of the disease itself.

Spondylitis causes inflammation. When inflammation is present, your body must use energy to deal with it. The release of cytokines during the process of inflammation can produce the sensation of fatigue as well as mild to moderate anemia. Anemia may also contribute to a feeling of tiredness. Treating the inflammation caused by ankylosing spondylitis can assist in decreasing fatigue and anemia.

A study examining fatigue in AS and published in the journal Musculoskeletal Care states that in those who participated in the study, “Fatigue impacted on social life, relationships and work.” The authors of the study concluded that, “Future practice should include a comprehensive fatigue assessment and the development of treatment programmes” to help those affected self-manage their fatigue.

Speaking with your physician / rheumatologist is a first step in order to find the exact cause of the fatigue (e.g. lack of sleep, inflammation, anemia, another cause or a combination thereof). That said, most medications used for AS are aimed at helping with inflammation including NSAIDs (non steroidal anti-inflammatories) and the TNF-a Inhibitor / biologic medications. Proper exercise can also help with fatigue. In the case of anemia, where the body does not produce enough red blood cells, certain diet changes such as supplements may also be helpful.

As the study points out, “fatigue has a negative impact on quality of life in people with AS.”

References:
Fatigue in Ankylosing Spondylitis: Causes, Consequences and Self-Management; Wendy Farren MSc1,*, Lynne Goodacre PhD2, Mark Stigant PhD3 - Article first published online: 24 JUL 2012 - DOI: 10.1002/msc.1029
Straight Talk On Spondylitis; Spondylitis Association of America - © Copyright 2008
“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

“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

“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 overwhelming 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

“Oh how I can relate. It was great though to find a doctor who really gets it and doesn’t want to blame all my symptoms on depression!”

—Kristy

“Fatigue is definitely an issue. Last summer I had Fifth Disease and felt extremely cruddy and fatigued for a couple of months. Fifth and AS is not a good combination. That was scary because it took a long time to find out that there was a light at the end of that lethargic tunnel.”

—Richard
Fatigue can affect all of us. I’ve got three children, ages 9, 6 & 3, a business with 5 locations and have AS. I can totally empathize. As physical therapists we work with conditioning, as well as strength, flexibility, proprioception, etc. And conditioning can go a long way toward decreasing fatigue in the long run.

In normal cardiovascular training or conditioning, a rule of thumb is to ascertain the individual’s capacity for exercise, either their true capacity through a Bruce Protocol or some similar test, or their theoretical maximum heart rate and then shoot for 60%-80% of that maximum. A generally accepted formula for the theoretical maximum heart rate, though not as accurate as we would like, is Max HR=220-age. Then estimate 60% of that as a target for training and conditioning. (40 year old person’s target for exercise: 220-40*.6=108 beats per minute (bpm))

So ideally, a 40 year old person would engage in an activity that caused their heart rate to exceed 108 bpm, but not go too much beyond that for safety purposes. Of course, you’ll need to be able to check your heart rate. Here is a quick how to guide: http://www.wikihow.com/Check-Your-Pulse.

The key here is consistency. Consistency matters much more than intensity. And by consistency, I mean doing something 3-4 times each week for at least 10-20 minutes. Ideally it would be every day. It can be as simple as walking to lunch or as involved as going to the pool. It can even be broken up throughout the day, such as parking at the far end of the lot, taking the stairs (if they don’t hurt), sitting down & standing up 10-20 times in a row. Short bouts of exercise have been shown to result in improved aerobic capacity. An example I use in talks for SAA is brushing your teeth. You wouldn’t expect to brush and floss for 45 minutes on Saturday and have everything be okay. Exercise is the same way – it takes a little bit every day, consistently, over time, to see an effect.

The key here is consistency. Consistency matters much more than intensity.

With AS or related conditions, the problem becomes a bit more complicated. How do you change your level of conditioning, and thus your fatigue state, when movement and activity hurts? A big key is finding something that doesn’t hurt, or at least doesn’t leave you in pain or debilitated for days after activity. Really, any movement can help to elevate your heart rate. Below are a few ideas for activities. You will have to experiment and try different things to find activities that don’t aggravate you too much or cause your condition to flare up. And be patient. Normal training effect, in other words, when you start to see results, takes at least 6-8 weeks. So be consistent, start moving a little more, and you’ll start feeling better and have more energy in a few weeks.

Possible Activities: Walking, Cycling, Swimming, Jogging, Stationary Bike, Stairs, Ping Pong, Volleyball, Fencing, Skating, Golf, Squash, Weight Lifting, Equestrian, Frisbee Golf, Turkish Oil Wrestling, Water Skiing, Sailing, Water Polo, Underwater Hockey, Snorkeling, Unicycling, Basically anything that moves you and gets you moving!

Sturdy McKee, MPT is a physical therapist and is Co-founder and CEO of San Francisco Sport and Spine Physical Therapy.


MEMBERSHIP

Research. Education. Awareness. These three words are the pillars that support the Spondylitis Association’s mission to change the landscape of spondyloarthritis in North America for the better.

And as all of you who have joined us in embracing that mission know, they are far more than simple words. Words alone will not change the world. But words can, and do, inspire the actions that can transform it.

It is the actions of SAA members like you that truly support the mission and provide the catalyst that keeps us moving closer to our shared goals. Whether it be participating in medical research studies, distributing educational materials to the public and your local medical community, spreading awareness through social media and other avenues or providing the financial resources necessary to make a difference in a field that is critically underfunded — all of us at SAA are grateful for your ongoing commitment to effecting the changes we all want to see.

Those efforts are paying off. Those who are newly diagnosed today face a far different path than those of generations past. And, with continued hard work and determination, the future is bright. Here are a few of the important projects your ongoing support has made possible.

**RESEARCH: Spondylitis Patient Registry**

A patient registry is a database - a compilation of data on people with AS. In this case, the registry will be a compilation of three existing patient databases that have been used in ankylosing spondylitis research. By consolidating these, we will build a new database that can look at thousands and potentially tens of thousands of patients with AS and see health trends, disease severity over time, age, gender differences (or lack thereof), race, complications and much, much more.

**RESEARCH: SAA’s Screening Tool for Ankylosing Spondylitis**

Early diagnosis is the key to more positive disease outcome. If the disease is diagnosed before serious damage occurs, patients can avail themselves of appropriate treatments and exercise and thereby ensure better quality of life. Since we launched the screening tool at [www.backpaintest.org](http://www.backpaintest.org) in July 2010, more than 28,000 people have taken the test so those with a likelihood of spondylitis can seek appropriate care.

**EDUCATION: SAA’s Patient Self-Management Tool for Spondylitis**

Now in development with CeNRG, we are creating the world’s first cross-platform application / website that will allow people with spondylitis to track, via graphic overlay, their symptoms, their medications, their medical team and appointment schedule and receive information on spondylitis through the application and SAA website. All of this will be accessible through a smart phone (iPhone or Android) or home computer (PC or Mac).
EDUCATION: “Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders

SAA’s groundbreaking educational program provides the training 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. This comprehensive DVD resource prepares an emergency medical technician to do the right thing to prevent further injury.

EDUCATION: Publications

For a newly diagnosed person, resources and support are critical. SAA has compiled a comprehensive collection of resources to address the concerns of this portion of our community. The Action Plan to Manage Spondylitis has been downloaded more than 17,000 times by those eager to learn more about living with spondylitis. From advice on choosing a rheumatologist to knowing your medications to exercise programs to tips and tricks for getting the most out of life in spite of spondylitis, this one-stop action plan is essential for anyone new to the challenge.

AWARENESS: PSA Campaign

SAA set in motion the most comprehensive spondylitis awareness campaign ever undertaken in the U.S. Public Service Announcements are currently airing on hundreds of television and radio stations throughout the country in order to raise the profile of this group of under-known diseases.

AWARENESS: SAA on Capitol Hill

By working with partners such as the NIH’s National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS) Coalition, The American College of Rheumatology and the National Health Council, among others, SAA seeks to promote earlier diagnosis and treatment; promote public awareness and education; improve access to appropriate quality health care and medications; increase federal funding and affect public policy that impacts the lives of spondyloarthritis patients.

The above is just a small sampling of the important advances made possible by the actions of committed SAA patrons like you. Together, and with your renewed support, the strides we can make in advancing Research, Education and Awareness in the field of spondyloarthritis can truly change the world for the better.
A glimpse inside

On Facebook Janice discusses her new treadmill desk.

“I got tired of being stiff in the morning and then sitting all day at my desk. So, my husband made a treadmill desk for me. I’m loving it and feeling a lot better physically.”

Also on Facebook SAA asked, “On days when you’ve done all you can but the pain is still there, can anything help take your mind off the pain? How do you cope?”

And over 50 of our friends responded. Here are a few of the posts.

“Being in the company of someone who understands is helpful.”

“Usually I try to do some stretching and massage the joint gently. Also, I apply either heat or cold depending on whether there’s swelling. Curling up with a good book is a great distraction and meditation helps to relax me.”

“Lots of prayer, rest and good thoughts. And maybe a stiff drink later on.”

“Acupuncture, tea, exercise, watching a movie, Epsom salts, get out of my ‘head’ activities.”

“Meditation ...if all else fails Bourbon.”

“Painting. Anything creative helps take you out of the pain, and lying on my trusty heating pad and watching a funny movie. I try to keep the Lush Bath Bombs on hand so if I have a bad time of it, soaking in the tub with one of these treats always makes me feel better!”

Elsewhere on Twitter SAA shares information on new spondylitis research, news stories, upcoming events, and more. Other spondylitis patients find us, and one another, through the ‘#spondylitis’ and ‘#followspondy’ hashtags and make connections regularly. We’ll be glad to introduce you to everyone if you find us and say hello.

SAA tweets, “Spondylitis Fun Fact ~ Did you know there was a dinosaur called Ankylosaurus?! YUP The word means “fused lizard” in Greek!”

@ThePositivePear shares, “#AnkylosingSpondylitis #trivia Did u know: 1st evidence of AS was uncovered in skeletal remains of 5000-year–old Egyptian mummy?”

And of course there is our original spondylitis social network, the SAA Message Boards. Open discussions go on every day on 15 different boards organized by various topics. Discussions on medications, exercise tips, relationship concerns, daily living issues, alternative treatments, as well as quirky fun topics & anecdotes are just some examples of popular discussion topics. Be sure to stop by and say hello!

On the general message board ‘Dobieigh’ writes,

“I wanted to thank you guys on the forum. Without you guys helping me with all my questions, I would not have known where to go and what to ask for… I cannot believe I found a community like this on the internet. This place is a very special place.”

We hope you will decide to visit our online communities! You might find a great new network of support and information.
SUPPORT GROUPS

What is an “SAA Sponsored Spondylitis Educational Support Group” and what can you expect at a meeting?

Each SAA sponsored support group is a collaboration between our programs department, the volunteer support group leader, and the group members. Our groups not only create supportive spondylitis communities in neighborhoods across the country, but also utilize SAA’s educational resources to empower group members to take an active role in managing spondylitis. Meeting topics are based on the group’s interests and vary from daily living issues – such as fatigue, work place accommodations, and emotional effects of spondylitis, to discussions on alternative treatments, exercise, nutrition, medications, and much more.

Whether you are newly diagnosed or a spondylitis veteran, we invite you to drop in for a meeting. If you are interested in starting a group near you, Elin Aslanyan at SAA would be happy to provide more information.

A special Thank You to our committed, passionate support group leaders who unselfishly give so much of themselves, volunteering their time and energy to help those around them.

Recent meeting highlights include:

**Oakland, CA**
**When:** Sunday, September 16, 2012  
**Topic:** Anti-Inflammatory Diets and Spondylitis  
**Speaker:** Jennifer Lanett, DC

**Tucson, AZ**
**When:** Thursday, September 6, 2012  
**Topic:** Using massage to help reduce inflammation and promote good health  
**Speaker:** Shiela Harvey

**Boise, ID**
**When:** Saturday, August 25, 2012  
**Special Event:** BBQ Picnic

**Dallas, TX**
**When:** Monday, August 13, 2012  
**Topic:** Social Security Disability - filing, how decision process works, and Q & A  
**Speaker:** Sandra Cook, Attorney at Law
The Corporate Partnership Program provides a way for the Spondylitis Association’s pharmaceutical partners to positively impact the lives of those affected by spondylitis by contributing to the organization’s general operating budget. SAA also receives additional corporate support for special programs.
In addition to well-known extra-articular manifestations, ankylosing spondylitis (AS) has been reported to be associated with a number of cardiovascular diseases, including aortitis, aortic valve disease, conduction disturbances, cardiomyopathy, and ischemic heart disease.

In the 1930s, a study found aortitis (inflammation of the aorta) in a group of patients with AS. Since then, a number of cardiovascular diseases have been linked to AS, many of which begin prior to the onset of clinical symptoms.

“Cardiac issues are found in an estimated 2 percent to 10 percent of people with AS.”

A range of cardiovascular diseases
Among the most common cardiac problems faced by AS patients are:

Aortitis – inflammation of the aorta, the large artery that takes blood from the heart and distributes it to the rest of the body. Aortitis can result in aortic insufficiency, or the inability of the aorta to carry sufficient amounts of blood to the body, and hypertension (high blood pressure). A number of people with AS have chronic inflammation at the base of the heart, around the aortic valve and the origin of the aorta. Years of chronic inflammation can lead to valve leakage, which sometimes requires surgical intervention. Management of aortitis includes controlling the inflammation with medications, treating complications, and preventing its recurrence.

Aortic valve disease – a condition in which the valve between the heart’s main pumping chamber (left ventricle) and the aorta does not work properly. There are two main types of aortic valve disease—aortic stenosis (narrowing of the aortic valve opening) and aortic regurgitation, in which the aortic valve does not close properly, causing blood to flow backward into the left ventricle. This condition, which can cause shortness of breath, chest pain (angina) and dizziness, is often treated with surgery to repair or replace the faulty valve.
Conduction disturbances – arrhythmias that cause the heart to beat too fast (tachycardia) or too slow (bradycardia) and to pump blood less efficiently. The disturbances are caused either by a disruption of the heart’s normal electrical conduction system or by heart disease. People with conduction disturbances often feel a palpitation or skipped heart beat and a fluttering sensation in the chest and neck, as well as fatigue, dizziness, lightheadedness, shortness of breath, and chest pain. In extreme cases, conduction disturbances can cause sudden cardiac arrest. Arrhythmias are treated with medication, ablation (radiofrequency energy delivered at the site of the electrical disturbance), defibrillation (an electronic shock to the heart), or with an implantable cardioverter defibrillator (a pacemaker-like device that delivers a shock to the heart to restore normal rhythm).

Cardiomyopathy – a disease that enlarges and weakens the heart muscle, making it harder for the heart to pump blood to the rest of the body. Left untreated, cardiomyopathy can lead to heart failure, blood clots, valve problems, and cardiac arrest. The symptoms of cardiomyopathy include shortness of breath with exertion or even at rest, swelling of the legs, ankles and feet, abdominal bloating, fatigue, and an irregular heartbeat. Most often, cardiomyopathy is treated by managing symptoms, preventing the condition from worsening, and reducing the risk for complications. Medications like ACE inhibitors (a type of blood pressure medication) can help improve the heart’s pumping capabilities, and beta blockers can help improve heart function as well. Some patients receive a pacemaker to coordinate contractions between the left and right ventricles or a ventricular assist device to keep blood circulating through the heart.

Ischemic heart disease – a disease characterized by reduced blood supply to the heart muscle, usually due to coronary artery disease. People with ischemic heart disease, also called atherosclerosis, often have angina, chest pressure, decreased tolerance for exercise, and difficulty breathing; many people mistake these symptoms for heartburn. Treatment includes anti-angina medications (nitroglycerin), medications to lower blood pressure and blood cholesterol, angioplasty with stent placement, and coronary bypass surgery.

Many people with AS also suffer from a condition called costochondritis, which can mimic the chest pain caused by an acute heart attack. Costochondritis is a benign inflammation of the cartilage connecting the ribs to the breastbone. The pain can often be excruciating, especially after exercise or coughing. The pain usually goes away on its own; however, in certain cases, it can last for several months or longer. Treatment focuses on pain relief, with prescription nonsteroidal anti-inflammatories like ibuprofen or naproxen or narcotics (Vicodin, Percocet) if the pain is severe. In addition, antidepressants (amitriptyline) and the epilepsy drug gabapentin (Neurontin) have proven successful in treating chronic pain. Stretching exercises, nerve stimulation, and injections of numbing medications can also help control the pain of costochondritis.

In 2011, Canadian researchers found that AS increases the risk of heart disease and stroke by as much as 25 percent to 60 percent. The increase was greatest for people with AS between the ages of 20 and 39. Compared to the non-AS population, the study found that AS patients had a 58 percent higher risk of valvular heart disease, a 37 percent higher risk of ischemic heart disease, a 25 percent higher risk of stroke. The researchers say the link between AS and heart disease exists for a number of reasons, including the chronic inflammation associated with AS, the use of NSAIDs, and a tendency to exercise less than the general population due to pain.

NSAIDs and the heart
Nonsteroidal anti-inflammatory drugs (NSAIDs) are the most commonly used class of medications to treat the pain and stiffness associated with AS. Sometimes, higher doses of NSAIDs are needed to maintain relief from AS symptoms. This can pose a problem because long-term NSAID use can cause significant side effects, especially in the gastrointestinal tract. A different class of NSAIDs, known as Cox-2 inhibitors (or Coxibs), allegedly reduce the risk of gastrointestinal complications associated with traditional NSAID therapy.

But now, research is showing that prescription-strength NSAIDs also carry significant risks of cardiovascular events. In a study published in the British Medical Journal in 2011, researchers found that NSAIDs significantly increase the risk of cardiovascular events in people who take these medications on a regular basis. In fact, long-term users of prescription NSAIDs have a two-fold to four-fold increase in the risk of heart attack, stroke or cardiovascular death.

The researchers looked at 31 studies with more than 116,000 patients who took prescription-strength NSAIDs and compared the NSAIDs with other NSAIDs or a placebo. They found that ibuprofen (Advil) carries the highest risk of stroke, etoricoxib (which is not sold in the U.S.) carries the highest risk of cardiovascular death, and rofecoxib (Vioxx,
which was withdrawn from the market) has the highest risk of heart attack. They found that naproxen (Aleve) is the safest of the NSAIDs, but that it still carries some cardiovascular risk.

"AS increases the risk of heart disease and stroke by as much as 25 percent to 60 percent."

For years, doctors have exercised caution when prescribing NSAIDs for chronic pain relief because of their well-known risk for causing ulcers and serious bleeding in the stomach and GI tract. After a study found that Vioxx, a Cox-2 inhibitor, carried a significant increase in the risk of heart attack and stroke, doctors began to wonder if other pain-relieving medications had heart risks, as well. By the time Merck withdrew Vioxx from the market in September 2004, the drug had caused a reported 60,000 deaths worldwide.

A study published in the Archives of Internal Medicine in 2010 found that people taking opioid drugs, which have long been used to treat pain, also have an elevated risk of heart attack compared to NSAIDs. Many clinicians, however, think that NSAID gels and patches may relieve pain without the adverse abdominal and heart effects that pills cause. Others say to simply use NSAIDs judiciously.

So what is an AS patient, who relies on NSAIDs for symptom relief, to do? The best advice is to talk to your doctor about the risks and benefits of NSAIDs and to disclose any pre-existing heart conditions or risk that you already have.

An ounce of prevention
Studies show that nearly everyone—including people with AS—can become more heart healthy by following a few key steps such as eating a healthful diet, exercising regularly, quitting smoking, and maintaining a healthy body weight. The National Institutes of Health says you should also know your blood pressure, cholesterol and triglyceride levels and keep them under control. Making healthy choices and managing any medical conditions you have, including your AS, can help keep your heart healthy.

Tumor necrosis factor-alpha (TNF) blockers are biologic medications that have shown great promise in treating the spinal arthritis associated with AS. A 2009 study in the journal Arthritis and Rheumatism discovered a side benefit of TNF blockers. Etanercept (Enbrel) improves the lipid profile (cholesterol and triglycerides) in AS patients and, therefore, may protect against atherosclerosis. Other studies have shown that anti-TNF medications can improve the aortic stiffness that people with AS often suffer.

People with aggressive AS should be screened with a physical exam yearly, if not an echocardiogram (a diagnostic test that may show abnormalities such as valve dysfunction or damage to heart tissue), to rule out any issues affecting the heart. If problems aren’t detected, they can’t be treated.

When it comes to AS and cardiovascular disease, the bottom-line is simple: take care of yourself, pay attention to your symptoms and manage them accordingly, and speak with a health-care professional if you have questions or concerns about your condition or your treatment, or your risk for cardiovascular disease.

Story by Scott P. Edwards - Scott P. Edwards is a freelance health and medical writer based in Holliston, Mass. He has written for Harvard Medical School, Dana-Farber Cancer Institute, the Salk Institute for Biological Studies, and Nature Publishing Group.

Special thanks to Dr. David Hallegua for assisting with this article. Dr. Hallegua is a rheumatologist specializing in Clinical Research, Patient Care and Teaching in Los Angeles, California. He is affiliated with Cedars-Sinai Medical Center and is an Assistant Clinical Professor for the David Geffen School of Medicine at UCLA. Dr. Hallegua is a member of SAA’s Board of Directors.
On February 12 of this year, SAA held a special fundraiser, “The Best Medicine: A Night of comedy to Benefit the Spondylitis Association of America” at the Comic Strip Live in New York, NY. Performers included Wilson McDermut, Bill McCarty, Michael King, Regina DeCicco, D. F. Sweedler and Michael Rakosi.

Thanks to your generous support, the event grossed over $17,000 that will be put to work improving the lives of spondylitis patients and their families.

We’d like to give special thanks to Michael Smith (spondyville.com) and Michael Rakosi for making the show happen.

We’d also like to thank yacht owner Alan B. Hirsh for donating a 3-hour cruise during an auction at the event as well as SAA Board Chair Craig Gimbel, DDS for his in kind donation.

All Photos by Barbara Alper
Need spondylitis info for teens?

S.W.I.F.T
Spondylitis Web Info For Teens
At: teens.spondylitis.org - Two new personal stories from teens have been added!

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### Highlighting The Most Active SAA-Sponsored Support Groups

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<thead>
<tr>
<th>City</th>
<th>State</th>
<th>Meeting Facilitator</th>
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</tbody>
</table>

If you’d like to find out more about support groups or for a complete list of groups and meeting dates, visit our website at: [http://www.stopas.org/groups](http://www.stopas.org/groups)

You can also contact Elin Aslanyan here at SAA by calling 1-800-777-8189 ext. 222 or by email at elin.aslanyan@spondylitis.org for more information.
Happy Holidays
from all of us at SAA!