RESEARCH:
Structural Biomechanical Concepts of Ankylosing Spondylitis

Your Stories:
“A Helping Hand Or Two!”
by Ken Prather

DIET & AS:
The Low Starch Diet Revisited
Dear Readers,

As most of you who have been long time supporters know, SAA’s commitment to advancing spondyloarthritis research has always been central to our mission. Even while defining and re-defining, as necessary, the other cornerstones of SAA’s mission, the core objective -- research -- has remained constant. And we’ve kept our eyes unblinkingly on the ball.

I believe it is because of this focus, and the collaborations we have entered into along the way, that spondyloarthritis has made unprecedented gains in recent years.

Due to the efforts of research clinicians who have dedicated their careers to this mission and because of the ongoing commitment of people like you, the past few years have seen advances in genetic research as never before. We now have a firmer grasp on the prevalence of this group of diseases and contrary to decades of accepted “truth”, spondyloarthritis is anything but “rare”. In fact, SpA impacts 2.7 million Americans, according to a recently published manuscript by the Centers for Disease Control and Prevention, indicating it is more prevalent than rheumatoid arthritis.

Of course, there is much more to learn. Genetic research has accomplished more in the last five years than in the previous century and we have compelling reasons to believe that the next five years will see more such breakthroughs. SAA, in conjunction with our research collaborators, is proud to be leading the effort to advance genetic research into the causes, treatments and, ultimately, the cure for spondyloarthritis.

But we are also looking to other avenues of research that may, on the surface, seem less intuitive, but that may prove just as auspicious in the fight, as you will read in this issue. When it comes to the central pillar of our mission, we will keep an open mind and seek answers wherever they might be found. While our eyes remain unblinkingly on the ball – it’s always good to have more than one ball in the game.

Sincerely,

Laurie M. Savage
Executive Director
Thank You, Tony Coats

Please convey my heartfelt thanks to Tony Coats for his story titled, “The Long Road to Diagnosis” that appeared in the Spring 2012 issue of Spondylitis Plus.

I am 67 years old, and as I read Tony’s story, I almost felt as though I was reading my own. It is amazing how many of Tony’s points I can relate to.

Thank you, Tony. It’s comforting to know that “we’re not alone.”

Sincerely,

~JEFF C.
Minneapolis, MN

Editor’s Note: If you wish to read Tony’s Story in the Spring 2012 issue, you can find it online in the Spondylitis Plus Archive, at StopAS.org/members. If you’d like to share your story, you can email it to us at info@spondylitis.org for consideration of publication.

Why We Fundraise

My husband has lived with [ankylosing spondylitis] for more than 20 years and I have watched his pain and watched the disease progress and watched in the beginning how he was misdiagnosed until his neck became completely fused and how frustrating it is when people don’t understand.

He looks pretty normal, and thus some people think he is faking. It’s sad really.

Now I have a daughter diagnosed with this disease and I am afraid I will have to see this happen with her.

So I am very passionate about this cause. If I can even get the word out in this small town and someone finds out that they may have it then it is even more worth it.

I just thank God there is an organization like yours to help with all of this.

Thanks,

~TINA L.
Angola, IN

Editor’s Note: We would like to thank Tina and her daughter for creating their “Cure AS Walk 2012” and donating the proceeds to SAA. You can read more about their efforts and about many of the events that took place during Spondylitis Awareness Month and World AS Day on pages 10 and 11 of this issue.

If you have a fundraising idea, or would like to discuss the possibility of holding an event for SAA, please contact Development & Membership Associate Robin Kindrick. You can reach her by phone or email:

Toll Free Phone: 800-777-8189 x225
Email: Robin.Kindrick@spondylitis.org
FOR MANY YEARS, a number of genetic factors and epidemiological patterns have offered potential clues for the possible biological pathways through which ankylosing spondylitis (AS) begins. But noted rheumatologist Dr. Alfonse T. Masi of the University of Illinois still had questions. Three years ago, Dr. Masi proposed new biomechanical concepts to answer those questions about the full range of risk factors and other biological influences that start the AS disease process.
Dr. Masi laid out his framework in a paper published in Spondylitis Plus in the summer of 2009. He built his theory around two primary concepts: the system of muscle stretching and shortening, called biotensegrity, which gives our bodies stability and flexibility, and human resting muscle tone (HRMT), the idea that muscle tone is present even when a muscle is supposedly at rest. Biomechanical principles based on biotensegrity can explain some of the unique components of AS, including forward curvature of the spine (kyphosis), lower back stiffness, and spinal fusion. Regarding HRMT, Dr. Masi says there is constant tone—continuous and partial contraction—in resting muscles, which helps us maintain posture. As AS progresses and the vertebrae begin to fuse, many people develop a bent posture, suggesting that HRMT operates within the framework of biotensegrity.

Dr. Masi has spent the past three years further developing his theory on the structural biomechanical concepts of AS, culminating in a review paper in the journal Arthritis (December 2011) and an editorial in The Journal of Rheumatology (October 2011). His novel concept, called innate axial myofascial hypertonicity, or natural spinal muscle stiffness, reflects basic biomechanical principles in human function, tissue reactivity, and pathology. These processes likely interact with other recognized hereditary and disease pathways of AS. “The early suspicion that muscle stiffness in the spine could predispose to AS has remained consistent with advances in clinical research, immunogenetics, and molecular biology,” he writes in Arthritis; however, because quantitative measurements and research on such mechanisms don’t exist, Dr. Masi’s hypothesis has not yet been confirmed.

In addition to biotensegrity and HRMT, Dr. Masi’s framework includes several other components, such as:

**Biomechanical links to enthesis-related lesions**

Hallmark AS lesions in entheses (sites of tendon or ligament attachment to bone) have generally been interpreted to result from an inflammatory mechanism. Dr. Masi’s hypothesis, however, proposes a centralized mechanism for the increased stress from stretching of the postural musculoskeletal system that places excessive force on entheses in the spine and girdle. Stiffness of the muscle and connective tissue deep in the spine increases tensional forces at the spinal entheses, resulting in postural rigidity. The spine is naturally more susceptible to microinjury (small injuries to muscle and connective tissue) at the interface of intervertebral discs and bony vertebral bodies. When stress in these areas is increased, says Dr. Masi, the core spinal muscles have greater stiffness.

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Parallels with tendon injuries
AS and tendon injuries, such as tears and ruptures, share biomechanical features. Although these tendon injuries were previously thought to involve an inflammatory process, many clinicians now consider them to be caused by over-loading, over-stressing, or other excessive forces. AS, on the other hand, is thought to be primarily due to inflammation; however, says Dr. Masi, structural biomechanical influences are not being properly considered in disease risk or progression.

Mechanical stress activation of inflammatory pathways
It is well known that mechanical stress can activate certain inflammatory pathways in the body. For example, mechanical stress can induce an enzyme to make a hormone-like substance in cartilage that causes the inflammation and pain common in osteoarthritis. These pathways may also explain how increased mechanical stresses, including tension (stretching) and compression (shortening), can lead to bony proliferations, like those seen in AS. Dr. Masi’s theory posits that such inflammatory reactions may be initiated by small proteins released from microinjuries resulting from congenital irregularities in the musculoskeletal system. In this scenario, he says, excessive spinal HRMT could be a structural variant that predisposes to entheseal microinjury.

Genetics
Scientists are interested in examining potential genetic pathways that might contribute to biomechanical differences in AS, using the adolescent form of scoliosis (adolescent idiopathic scoliosis) as a counter-opposing condition. The genetics of these two progressive conditions, says Dr. Masi, are likely to be extremely complex and involve contributions from many different genes. He is currently seeking collaborators for an AS genome-wide association study to further explore this.

Although Dr. Masi has fleshed out his structural biomechanical concepts of AS, he considers his theory to be a work in progress. Two critical barriers exist to definitively prove his hypothesis: the dearth of significant research on the relevance of axial HRMT to body biomechanics in AS and a lack of technical innovation to quantify biomechanical influences on AS. With those, he says, “the incorporation of these concepts and the utilization of structural mechanical modeling promises to enhance our understanding of spinal disorders, like AS.”
THE
LOW STARCH DIET
REVISITED

By: Professor Paul Wordsworth, Consultant Rheumatologist

EDITOR'S NOTE: The following article has been reprinted from the Spring 2012 issue of ASNEWS, a publication from the National Ankylosing Spondylitis Society (NASS) in the UK. As always, we thank them for allowing SAA to use one of their stories.

Many people with AS express an interest in trying low starch diets to treat the condition as proposed by Professor Alan Ebringer of King’s College, London.

The original rationale for this was based on some very interesting findings by Alan and his brother Roland at the Middlesex Hospital in the early 1980s. They identified antibodies to a bacterium called Klebsiella in the blood of individuals with AS, and also found that they could culture this organism from the stools of many people with active disease. Such antibodies are typically made by the immune system in response to infections, and are one of the means by which viruses and bacteria are eliminated from the body. Furthermore, these anti-Klebsiella antibodies potentially bind not only to proteins in Klebsiella but also to certain human proteins including HLA-B27, which is one of the tissue transplant antigens that have to be matched between organ donors and recipients.

I have vivid memories of Alan and Roland carefully sifting through thousands of stool samples and blood tests from patients with AS, trying to correlate their laboratory findings with the activity of the disease. Their work led to the idea that these anti-bacterial antibodies might also bind to human proteins like HLA-B27 to stimulate inflammatory responses in some way. Subsequently, the Ebringer team also reported similarities between HLA-B27 and another Klebsiella protein called pullulanase-A, which helps break down starch molecules. They also noted that pullulanase-A had some similarities not only to HLA-B27 but also some other human proteins, called collagens, found in joints and also the eyes (both of which can be affected in AS).

The role of Klebsiella antibodies in AS has proved highly controversial over the years. It is now recognized that molecular mimicry between different proteins as described above is not that uncommon in nature. Whether or not Klebsiella antibodies are relevant to AS, there may well be an important role for the gut in causing AS. For example, about 10% of people with AS also have inflammatory bowel disease (IBD, Crohn’s disease or ulcerative colitis), and many people with AS without overt IBD symptoms have evidence of low-grade bowel inflammation if one looks hard enough for it. Furthermore, many of the genes that predispose to AS also predispose to IBD, including CARD9, IL23R and IL12B. This lends credibility to the idea that altering the gut flora (the population of bacteria living naturally in the gut) might have an influence on bowel inflammation and, perhaps, susceptibility to AS. Anyone who has seen the natural yogurt ads on TV will also be familiar with the idea that it is possible to increase the number of “good bacteria” in the gut while reducing the number of “bad bacteria”.

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Various studies have found that bowel bacteria, including Klebsiella, grow on undigested starch and therefore a reduction in starch in the patient’s diet might produce a reduction in symptoms by denying those bacteria the nourishment to multiply. Once starch has passed through the small intestine and enters the large bowel, it is available to feed those bacteria. There are simple starches which are sugar molecules attached together rather like a necklace or chain. Simple enzymes break up the chain and the sugars are readily available for the bacteria to grow. Some of the starch is of this simple type (20%) but most of it (80%) is hard starch and the sugar molecules are in branched structures, which appear like the branched twigs of a tree and can only be broken down by de-branching enzymes. Klebsiella has the correct pullulanase enzymes to break down the hard starch which allows the bacteria to grow and multiply, so it is very well adapted to life in the human bowel. The rationale for the Low Starch Diet is to make life less easy for the Klebsiella organism to thrive.

There are no formal trials that have assessed the efficacy of low starch diets in AS. In common with many other inflammatory disorders, the natural history of AS is rather unpredictable. It is therefore very difficult to tell whether improvements in symptoms merely reflect naturally occurring fluctuations in disease severity over time rather than the influence of treatment. Some patients trying low starch diets have had very gratifying improvements in their symptoms but high quality randomized controlled studies of this type of diet in large numbers of patients have never been performed. Consequently, it is very difficult to know whether the diet is truly effective. This is not an unusual position for the rheumatologist to be in when asked about unorthodox treatments and our advice is usually the same. If the treatment is not harmful there seems no reason not to give it a trial, remembering that it could be 3 months or so before you notice any difference. Furthermore, even if you notice a difference this does not necessarily establish that there is a real therapeutic effect. For example, in the trials of anti-TNF drugs in AS, it has not been unusual for those patients in the dummy arm to experience very significant benefit in the first 3 months—a phenomenon known as the placebo effect.

In the absence of convincing trial evidence of proven benefit, it is quite impossible for a patient organization such as NASS (or SAA) to endorse low starch diets as a treatment strategy. On the other hand, there is some circumstantial evidence that they might have an effect—and, of course, the testimony of individuals, who have apparently had considerable benefit, can be very persuasive.
89466 -- This number can help change the face of spondylitis

That’s because 89466 is the only number you need to know to donate to the Spondylitis Association through your government employer.

Each year Federal employees and retirees are given the opportunity to support the charities they care about by designating a portion of their earnings to a specific cause. If you receive a paycheck, or a pension, from the Federal government, you can choose to support SAA through the Combined Federal Campaign.

Nearly four million federal employees and military personnel are able to contribute to the charities of their choice during the annual charity drive, which runs from September 1 through December 15 of each year. Pledges made by Federal civilian, postal, and military donors during the campaign season support eligible nonprofit organizations, like SAA, that provide health and human service benefits throughout the world.

The mission of the CFC is to promote and support philanthropy through a program that is employee focused, cost-efficient, and effective in providing all federal employees the opportunity to improve the quality of life for all.

The Combined Federal Campaign annually reviews charities wishing to participate, applying strict criteria designed to ensure that donated money truly reaches those in need.

This year, SAA can benefit from your thoughtfulness and generosity. By signing up for your workplace giving program, you can make a difference in the fight to cure spondylitis and make the world a better place for those affected.

To make a donation through this campaign, simply enter CFC code #89466 on your pledge card during your agency’s fund drive or contact your Human Resources Department or the Office of Personnel Management (www.opm.gov).

Not a Federal employee? You can still spread your SAA contribution out over the year by becoming a member of the Spondylitis Monthly Automatic Rewards Team (SMART). By becoming a SMART Giver, you can designate an amount to be charged to your credit or debit card each month.

Your dependable monthly gift of $100, $50, $25, $15 or even $10 will boost the impact of your SAA membership many times over.

It’s easy, convenient and your monthly donation will be put to work right away -- providing the programs and services you’ve come to rely upon. Sign up online at spondylitis.org/smart or by calling Helene Hart at 800-777-8189.

However you decide to support SAA, you can be confident that your donations will be used wisely, responsibly and effectively to respond to the stated needs of supporters like you. All of SAA’s programs and services are undertaken in direct response to the concerns raised by our members.

Your ongoing support is what enables us to continue to respond to those needs and we Thank You!
The mother-daughter team of Tina Lundquist & Shawna Snider-Connelly from Fremont, IN created a “Cure Ankylosing Spondylitis Walk” that took place in Angola, IN. Their walk went quite well and they raised a total of $1,015.00 for SAA!

“It’s amazing how many came together for this event and supported our cause.”

Joe Eder from Shakopee, MN ran a 10k race for spondylitis awareness in Minneapolis, MN. He has raised close to $300 for SAA, as well as raised awareness during the race by including SAA’s logo on his running outfit - along with a catchy phrase to grab attention! Follow his continuing efforts at: http://www.crowdrise.com/JoeEder/

William & Michelle Thies from Caldwell, ID participated in their local Arthritis Walk to raise spondylitis awareness in honor of their son, Zach Thies, who was diagnosed with AS two years ago.

“53 people joined Team Sound Hound walking for Zach.”
Jennifer Dye Visscher started the “Walk Your AS Off” campaign challenging teams worldwide to walk enough steps to circle the globe before World AS Day on May 5. 63,978,087 total steps walked by everyone who participated!

“We did it! We circled the globe in steps made in the name of Ankylosing Spondylitis!”

Michael Smith from New York, NY, created a “video tribute to the organizations and support groups that ‘shine a light’ on AS awareness every single day” and posted it on YouTube. The video is entitled, “Shine a Light on Spondylitis Awareness.”

SAA’s 2012 Spondylitis Awareness Project: Sending *Spondylitis Plus* to Physicians’ Offices.

We asked, “Donate $10 to Educate 5 Doctors About Spondylitis!”

We had an idea and a goal, “By World AS Day on May 5, we’d like to raise $1,000 to get 500 copies of *Spondylitis Plus* into doctors’ offices around the country.”

YOU had bigger plans. You met our initial goal in less than two weeks! You told us to double our goal. And we did. At the end, over $2,400 was donated by YOU to raise spondylitis awareness for medical professionals, and TOGETHER we told over 1,000 physicians and their staff, “You should know more about spondylitis!”

Causes (the platform we utilized for this project) was so impressed by your dedication, that they interviewed us and wrote an article on the project, helping spread spondylitis awareness to their readers and constituents. More people were reached by this project than we had dreamed!

Our heartfelt thanks to YOU for making our 2012 Spondylitis Awareness Project a resounding success!

“Thanks everyone at SAA for all you do for me and everyone else suffering from AS. Your help has been invaluable!”
When I got out of the nursing home after almost a three year stay I started an outreach program counseling with the elderly, disabled, and mentally challenged. I was called upon to counsel with people who nobody else could get through to. You might say that I got them at ground zero. My mission and purpose was to give them not only love and compassion, but also let them know that they still had self-worth, self-pride, and something to share with others. In other words, to not only give them love and compassion, but to show them that they could still GIVE love and compassion, and that they had to start with themselves. But I tell them all, if you want my love, I’m here. If you want pity, then you have the wrong person.

I received a call from one of the nursing homes I worked with about a gentleman named *Bill, who wouldn’t respond to anyone. Not to his family, chaplain, doctors, social workers, absolutely nobody. You see, Bill had just had his leg amputated due to a major, life threatening blood clot. Bill was 42 years old and had always been very active in sports. He had been a Marathon runner and a postal delivery worker. So, as far as he was concerned, when his leg was amputated his life was over.

When I first arrived to see Bill he was a little surprised. Due to my physical condition (I have Ankylosing Spondylitis) I just wasn’t what he was expecting. Even though he accepted my company he was still very angry and depressed, and feeling extremely sorry for himself. I asked Bill if I could come back the next day to see him and if I could bring a friend with me. That’s when he said to me, “You can stop by for about two minutes, but I will guarantee you that I don’t like you, and I know I won’t like your friend.”

So the next day I picked up my friend, *Tom, from another nursing home and took him with me to see Bill. Tom and I went into Bill’s room, and Bill was sitting on the edge of his bed with one leg dangling. Bill looked at Tom and said, “What do you want? You want to just stare at me or something?” Tom said, “Well that’s not the reason I really came here with Ken. Ken wants me to write a sports newsletter for him and I need someone to help me,
and Ken thought we might be a good fit. “Bill then said to Tom, “What’s the matter, is your hand broke or something?” Tom replied, “Not really, I don’t have any hands.”

It was at that very moment that Tom looked at me and said, “Ken, will you do the honors, please?” “No problem,” I replied, and proceeded to untie the strap behind Tom’s back taking both of his arms and hands off. Bill could only sit there and stare. Tom then said, “Ken, we’re not done yet are we?” I then proceeded to take off both of Tom’s legs. There sat Tom with no arms or legs, just a torso of a body in front of Bill. Bill was stunned to say the least. You see Tom had been born with no arms, but lost his legs due to a circulation disorder. But in my eyes, Tom had NO disabilities at all. After about five minutes of pure SILENCE Bill said, “My God, I feel so sorry for you.” Tom replied, “Why should you feel sorry for me? I don’t. Besides that, this is the way God wants me.” It was at that second that Bill really let go and started crying. He apologized to both of us about how cruel he had been and wanted to know if we would forgive him. That’s when Tom said, “Hey there’s nothing to forgive. As long as you forgive yourself, that’s what matters the most.” Tom, Bill, and I spent three hours together that afternoon and Bill’s attitude changed right away.

As we were getting ready to leave I was helping Tom put his arms and legs back on, and I said to Tom, “How would you like to go do something?” Tom looked at me and said with his great sense of humor, “I would love to, just don’t take me swimming again.” The nurses told me they could hear Bill laughing all the way down the hall, and that was the very first time that he had laughed. By the way, that was three months ago and today Tom and Bill are writing that newsletter together. Tom talks and Bill writes. In this case, it’s not what Tom had that inspired Bill, but it was Tom’s attitude about what he didn’t have.

A two minute stay turning into a three hour stay, PRICELESS!

“...if you want my love, I’m here. If you want pity, then you have the wrong person.”
A primary objective of SAA’s mission is our commitment to research, and none of the studies we have been involved with would be possible without your ongoing support and participation. In recent years many of you have participated in genetic studies in SpA that have greatly increased our knowledge and understanding of the disease, potentially leading to improved quality of life. In addition, in the past several years many of you have participated in surveys and polls, including the recent SAA Life Impact Study that confirms the urgency associated with solving the problems of delayed diagnosis and woefully inadequate funding for research.

Most recently, Robert D. Inman, MD, BA and Dharini Mahendira BSc, MD, FRCPC from the Toronto Western Hospital Spondylitis Program conducted a survey looking at women with Ankylosing Spondylitis and the potential effect of hormones, in the form of oral contraceptive pills, on AS. (Dr. Inman serves on SAA’s Scientific and Medical Advisory Board.)

The response was tremendous: We had over 600 participants with 557 women completing the entire survey - well over double the required participant numbers.

SAA, Dr. Mahendira and Dr. Inman would like to extend our gratitude to all those who participated in the survey, as well as all those who have participated in research in general. We wish both doctors the best of luck with their work and hope the data yields results we can share with you in the near future.

Overheard on Facebook:

“I was pleased to see researchers interested in women and AS. Even with my fused spine I was able to carry my baby to term. She is 5 now. I can’t keep up with her, but I have so much fun on the sidelines!”

~Heather

“So glad to see more info and interest in women with AS.”

~Debi
Key Factors in Proving Social Security Disability Benefits: A Case Study

by Richard I. Feingold, Attorney at Law

Richard I. Feingold, Attorney at Law, is a nationally respected Social Security disability attorney, former chair of the Chicago Bar Association’s Social Security Law Committee and a sustaining member of the National Organization of Social Security Claimants’ Representatives (NOSSCR). Founder of Richard I. Feingold & Associates, P.C., he has practiced law for over 25 years and represents disability claimants nationwide. He answers questions in the Spondylitis Association of America’s message board forum entitled “Questions About USA Social Security Disability Benefits” and has previously published articles in Spondylitis Plus. You can visit his website at www.USADisabilityLaw.com

In Social Security disability claims, claimants and their doctors will often allege that the claimants would miss several days, or more, per month from work due to their illnesses. It is unusual, though, for an administrative law judge (ALJ) to use this as a basis to grant benefits, particularly where the ALJ finds that the claimant could otherwise perform a substantial range of work activity. This is precisely what happened, though, in a recent Social Security disability claim of one of my clients.

This client was under age 50, had a past employment history working in a warehouse. Besides ankylosing spondylitis (AS), this claimant had a past medical history of a lumbar fusion surgery with residual degenerative disk disease as well as chronic radiculopathy, liver disease, obesity and an adjustment disorder, with anxiety.

Usually, a favorable ALJ decision will state that the claimant’s impairments meet, or equal in severity, one of Social Security’s listed impairments. For AS, this would involve fixation of the cervical or dorolumbar spine of at least 30 degrees. In the alternative, a disability claim can be granted because the claimant’s mental and/or physical impairments are so severe that they would prevent the claimant from performing his or her past relevant work, or any work, taking into account the claimant’s age, education, past work experience and residual functional capacity. The fact that we were able to prevail in this case based upon primarily the number of days expected to be absent from work each month illustrates at least several key factors in successfully representing disabled claimants in their Social Security disability claims:

1. Obtain and submit to the Social Security Administration medical records concerning your impairments. Disability claims are won and lost most importantly based upon the medical evidence. A disability claimant can allege that they suffer from any one of a number of disabling impairments, but for Social Security to consider the effect of these symptoms on your residual functional capacity, there must exist some medical evidence establishing a “medically determinable” physical and/or mental impairment, consisting of signs, symptoms and laboratory findings. By the way, I discussed the role of symptoms in establishing disability in the Fall 2008 issue of Spondylitis Plus in an article titled, “Symptoms and Social Security Disability Benefits: Are They Enough to Prove Disability?”

2. Present evidence regarding all of the disabling physical and mental impairments, not just AS. As mentioned above, this claimant in this case suffered from a number of other severe, medically determinable physical and mental impairments. In his decision, the ALJ acknowledged and evaluated the limiting effects caused by these impairments. Had the diagnosis only been ankylosing spondylitis, it is not clear whether or not the decision would have been favorable. This does not mean that it is necessary that a claimant be diagnosed with multiple impairments to obtain Social Security disability benefits. Certainly, the loss in range of motion as well as constant fatigue and pain alone caused by AS can be disabling. However, when multiple impairments do exist, it is advantageous to submit medical evidence, as well as opinions from treating doctors, concerning those other impairments. SSA is required to consider the combined effect of multiple impairments upon the claimant’s functioning.

3. Obtain the opinion of a treating physician, preferably a specialist for the particular disabling condition, addressing the medical and legal issues in the claim. One must know the legal basis for an award of benefits in order to properly argue what is the legal effect of these illnesses as reflected in the medical records. For example, if an impairment meets or equals in severity one of Social Security’s listings at step 3 of the 5 step adult sequential evaluation process, then it is not necessary for SSA to determine whether or not the

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On March 18, 2008, the Social Security Administration (SSA) published final rules in the Federal Register revising medical criteria for evaluating immune system disorders, such as ankylosing spondylitis (AS), in SSA's Listings of Impairments (the “listings”). 73 Fed Reg. 14570 (March 18, 2008). These rules became effective 90 days later, on June 18, 2008. For adults, the listings are examples of impairments that SSA considers severe enough to prevent you from doing any gainful activity. Whether you “meet,” or “medically equal” in severity, one of the listings is the third step in SSA's five step sequential evaluation process.

The other steps follow: In step 1 of the five step sequential evaluation process, SSA determines whether or not you are working. If you are working and the work constitutes “substantial gainful activity (SGA),” then you will be found not disabled. If the work is not SGA, then SSA goes on to step 2.

In step 2, SSA determines if you have a “severe” impairment under the law. If you do not have a “severe” impairment, then you are not disabled. If you do have a severe impairment, SSA proceeds to step 3. As mentioned above step 3 considers whether one or more of your impairments “meets” or “medically equals” one of the listings for at least twelve consecutive months. If at least one impairment does, then you will be found disabled; if not, SSA proceeds to step 4.

In step 4, SSA determines whether you have the residual functional capacity (RFC) to do your “past relevant work.” If you do, then SSA will find you not disabled. If you do not, then SSA will proceed to step 5.

In step 5, SSA determines whether your impairment(s) prevent you from doing any other work that exists in significant numbers in the national economy, considering your age, education, work experience, and RFC. If it does and you have been disabled for at least twelve consecutive months, then you will be found disabled. If it does not, SSA will find that you are not disabled.

With respect to AS and other spondyloarthropathies, the final published rules removed the language in the listing that required the diagnosis be established by findings of unilateral or bilateral sacroiliitis and a history of back pain, tenderness and stiffness. SSA believed these findings to be unnecessary because the criteria in the final listing were sufficient.

The revised Listing 14.09(C)(1) requires: “1. Ankylosis (fixation) of the dorsolumbar or cervical spine as shown by appropriate medically acceptable imaging and measured on physical examination at 45° or more of flexion from the vertical position (zero degrees).” SSA stated that the requirements found in this portion of the listing were in themselves “indicative of an impairment that precluded any gainful activity.”

Part two of the AS and other spondyloarthropathies listing, 14.09(C)(2) clarified a prior listing to read as follows: “2. Ankylosis (fixation) of the dorsolumbar or cervical spine as shown by appropriate medically acceptable imaging and measured on physical examination at 30° or more of flexion (but less than 45°) measured from the vertical position (zero degrees),” SSA stated that the requirements found in this portion of the listing were in themselves “indicative of an impairment that precluded any gainful activity.”

Given AS's extra-articular features, unfortunately, it may not be too unusual to demonstrate the involvement of two organs/body systems to meet this listing.
SAA participates in the Combined Federal Campaign -- the largest and most successful annual workplace charity campaign. Simply enter CFC code #89466 on your pledge card during your agency’s fund drive or contact your Human Resources Department or the Office of Personnel Management (www.opm.gov).

She can’t drive yet - but she can use your car

Kids get spondylitis too. Donating an unwanted vehicle to SAA will help ensure that they have the resources they need to live life to the fullest, in spite of the disease. The process is quick, includes free pick-up or towing - and best of all - the proceeds go to improving the lives of spondylitis patients of all ages. The vehicle doesn’t even have to run and you’ll get a great tax deduction for your donation!

Please call 1-888-SAA-3424

Education, Support & Awareness
Books, brochures and more at spondylitis.org/store
Your website states that “The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues.” What sort of work accommodations specifically? Can you give us some examples?

JAN: We will brainstorm accommodation ideas for any workplace situation involving employees with any type of limitation, working in any type of job, and in all types of industries. Accommodation ideas are customized for the situation and can range from modifying policies to making the workplace accessible to purchasing equipment or technology. Currently, the most frequently discussed accommodation in JAN consultations is modifying schedules, including attendance policies, rest breaks, and work hours.

Can you also give us some examples of “disability employment issues”?

In addition to accommodation ideas, employees with disabilities often need information about their right to reasonable accommodations under the Americans with Disabilities Act (ADA). In a majority of cases, employees are experiencing limitations from a disability and are looking for ways to keep their jobs. JAN provides practical guidance about what accommodations might be useful, how to ask the employer for accommodations, and what accommodations employers must consider under the ADA. JAN offers a document that summarizes the practical guidance provided to employees with disabilities:


What do you feel are your most important resources?

JAN’s most important resource is its staff. JAN consultants have years of experience talking with employers, employees, family members, service providers, unions, and legal representatives about all aspects of workplace accommodations. Based on this experience, consultants offer practical solutions to most workplace accommodation issues through a comprehensive Website at [AskJAN.org](http://AskJAN.org) and through customized, one on one consultation.

How does a “one on one” consultation work?

One on one JAN consultations begin when someone contacts JAN. Most people still use JAN’s toll free telephone service, but JAN also responds to questions via email, a live chat, a Web tool called JAN on Demand, and all the major social networks. When you contact JAN, you will be routed to the appropriate consultant to handle your questions. You do not have to have any particular information or knowledge – JAN consultants can help you wherever you are in the accommodation process.

What information for “job seekers” can you provide (noting that JAN does not help individuals find employment)?

Although JAN is not a placement service, JAN does provide information that may be useful for people with disabilities who are looking for work. Consultants can discuss such issues as when to disclose a disability, how to request an accommodation for a job interview, and ADA rights and responsibilities during the application process.

In addition, JAN offers the following publication: Finding a Job that is Right for You: A Practical Approach to Looking for a Job as a Person with Disability at [http://AskJAN.org/job](http://AskJAN.org/job)

What are some examples of resources that you provide to employers?

Employers can contact JAN for accommodation ideas, ADA information, sample policies and forms, referral to local resources, and practical solutions to workplace accommodation situations. Employers also can use the customized employer portal on the JAN Website at [http://AskJAN.org/empl](http://AskJAN.org/empl), which includes a link to JAN’s Searchable Online Accommodation Resource (SOAR). SOAR allows users to research their own accommodation solutions with an easy to use 5-step process.

Is there anything else you would like to add about your services?

All JAN services are absolutely free! JAN is able to provide its free services through funding from the U.S. Department of Labor’s Office of Disability Employment Policy. You can reach JAN from 9 a.m. to 6 p.m. EST at (800) 526-7234 (Voice) or (877) 781-9403 (TTY) or on the Web at [AskJAN.org](http://AskJAN.org). We look forward to hearing from you!
SAA-Sponsored Educational Support Groups

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: 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.

Recent Meeting Highlights:

- Where: Tucson, AZ  
  When: Thursday, July 5, 2012  
  Topic: Facing Spondylitis with Physical Therapy  
  Guest Speaker: Andrea Tuijl, PT

- Where: Charlotte, NC  
  When: Sunday, June 3, 2012  
  Topic: First Meeting! Various Topics - Spondylitis & Emergencies, Exercise, and Health Fairs.

- Where: San Diego, CA  
  When: Saturday, May 19, 2012  
  Topic: Updates on Spondylitis Research and Q & A  
  Guest Speaker: Michael Weisman, M.D.

- Where: Woodlands, TX  
  When: Saturday, May 12, 2012  
  Topic: Physical Therapy Options & Activity Management  
  Guest Speaker: Ann Campbell, PT, President of Access Rehab Clinics and Fitness Centers

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