Announcing The Next Generation Of Online Education & Support: The New Spondylitis.org

Rare But Significant Systemic Complications Of Ankylosing Spondylitis

Acupuncture: Breaking New Ground In Pain Relief
Heathcare reform is the issue dominating the national news and one that is critically important to every American. Especially those affected by a chronic illness like spondylitis. Recently, while speaking with members during our annual round of on-site patient programs across the country, the issue on the minds of everyone was -- overwhelmingly -- access to care.

At this writing, there are four complex bills winding their way through Washington. Each is collecting modifications and amendments as it moves through the process, and no one seems to have a clear picture of what the final version will contain. This uncertainty adds to our members’ concerns.

Here at SAA, we’re concerned as well. And we’re committed to improving access to quality healthcare for all spondyloarthritits patients. SAA is actively advocating on behalf of the community through our collaborations with the Childhood Arthritis and Rheumatology Research Alliance (CARRA), the National Institutes of Health’s NIAMS Coalition, and by supporting legislation to ensure affordable care for all those living with a chronic illness.

Still, the future remains uncertain. But you can make a difference. I urge you to contact your government representatives and demand that the issues of access -- to essential drugs, specialists and procedures -- be brought to the forefront of this crucial debate over the healthcare delivery system in the U.S., whatever form that system may take.

This issue is too important for any of us to remain silent. By adding your voice to the chorus of like-minded Americans with a stake in the future of our healthcare system, you will help shape a future where no one is denied the best possible care. To locate your representatives, please visit www.senate.gov and www.house.gov. It’s never been more important that they hear from you.

On another note, I’d like to take this opportunity to thank outgoing board members Kim Cooper and the Hon. Ellen Carroll for their many years of service on SAA’s governing board. Their volunteer efforts helped to shape this organization and their day-to-day involvement will be missed. I’m also pleased to welcome Scott Ellis, MBA to the board and look forward to the good work to come.

Also, this issue of Spondylitis Plus, weighs in at an expanded 20 pages, as will the next three issues, thanks to the generous support of Abbott Immunology. I hope you enjoy the additional content. As always, you have my sincere thanks for all that you do as a supporter, member and advocate of the spondylitis community. Together, we can affect the outcomes that affect our futures.

Sincerely,

Laurie M. Savage
Executive Director
Thank You To Richard Feingold

I wanted to share my very positive experience with Richard Feingold. He is an attorney for Social Security Disability (SSD) who helped me. The first attempt I made without him failed. The second go-around with him was quick and painless!

I heard of him through articles he had written for Spondylitis Plus. Thank you for featuring his articles - for me his help was crucial.

I have had AS for 30 years, but was just diagnosed recently. My inability to work now, after very satisfying years in the work force, has been very difficult. Fighting for disability status was extremely difficult, both physically, in gathering all necessary data, and emotionally to admit that there is so much I can no longer do.

I would also like to point out that I live several states away from Mr. Feingold. This was not a problem. He can help you wherever you live.

Thanks again!

LINDA FINN, Idaho Falls, ID

Re: EMS Training DVD

I distributed the EMS Training DVDs you sent to me and wanted to let you know I met with Port Orange EMS Chief Rafferty, and he was great. He spent a lot of time with me, and thanked me several times for informing him about AS. He said if only everyone would take responsibility to inform them of specific situations, it would help First Responders greatly. He will oversee the education with the DVDs at each of the five stations, and conduct the testing afterwards. The meeting was very interesting and informative and I learned quite a bit. He even entered my personal information in regard to my AS, etc. into the First Responder System, so it will come up automatically with 911. That was very comforting.

I can’t thank you all enough for developing these DVDs, and all the work and research you do!

Blessings,

NANCY C, Port Orange, FL

Editor’s Note: If you would like to help distribute SAA’s DVD “Ankylosing Spondylitis: Managing Patients in an Emergency Setting” to the First Responders in your community, or for more information, contact Melissa Velez Coelho, Director of Program Services, at melissa.velez@spondylitis.org.

LETTERS TO THE EDITOR

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

We reserve the right to edit for space and clarity.

Please send letters to:
laurie.savage@spondylitis.org
Letters to the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413
In the last several years we have seen massive change in how websites can be used to offer education and support to visitors. The new spondylitis.org offers a wide array of new features requested by our members, new sections, easier navigation and multimedia so that visitors to the site don’t have to just read the information from experts, but can see it and hear it straight from the source by way of podcasts (online audio interviews) and video.

The Spondylitis Association of America is excited to announce the latest generation of our website, spondylitis.org.
Visit the new spondylitis.org for:

A brand new Research Section covering SAA’s involvement in research, current studies and links to abstracts of recently published work.

Advocacy or Volunteering opportunities. We have a new Advocacy Section that can walk you through the various ways you can help raise awareness.

A new Medications Section with consolidated medications information including medication lists from our book, Straight Talk On Spondylitis.

A new Member Area where you can listen to podcasts and watch video of our webinars and seminars.

New video and audio throughout the site where you can get the information you need straight from the experts.

The new “Share This” button where you can quickly email a link or share a page on Facebook, MySpace and other social networking sites.

Does your company match donations? Use our new search function found on our donate pages to learn if your company will match gifts.

Stay informed of the latest news and site updates from SAA. An RSS feed has been added and we have a new members’ login welcome screen that alerts members to the latest site additions.

And Much More…

Message Boards  Upcoming Seminars  Educational Materials
When SAA began its campaign to fund and promote genetic research by partnering with Dr. John Reveille to form the AS Family Genetic Study in 1997, there were tremendous expectations. And tremendous hope.

Today, largely because of the successes of that first research project, SAA is a full partner in the TASC genomewide association study -- the first truly genomewide look at what causes Ankylosing Spondylitis. Through this study, our research partners have been able to examine the medical records of more than 2,000 people with AS, as well as those of 3,500 unaffected individuals to determine whether or not any of 370,000 genetic variants are associated with susceptibility toward AS.

To date, the study has identified new genes and genetic regions that have been confirmed as being involved in the risk of developing AS. As is often the case with such studies, strong hints have emerged to indicate the involvement of many other genes. Further studies are necessary to define exactly what role these other genes may play in susceptibility to the disease.

But that doesn’t mean that the discoveries we have made aren’t already changing the landscape of the spondylitis world. The recent discovery of the IL23R association served as an impetus to drive trial of therapies targeting the TH17 lymphocyte pathway, an important immunological pathway that is involved in protecting us from certain bacterial infections. Medications targeting this pathway have proven to be highly effective in treating psoriasis and inflammatory bowel disease, and our genetic studies indicate they will very likely be effective in treating AS.

The TASC Study has also given us new tools to help in AS screening and diagnosis. We expect to report the identification of several new genes associated with AS over the next few years, which will take us a long way toward understanding what causes the disease.

In the 12 years that SAA has been championing genetic research, the positive results have already exceeded our expectations and the two years remaining in the TASC genetic study provide the best hope for our future. We are grateful to you, and to all of SAA’s members and friends who have supported and participated in the various stages of this important project.

Below is more information about how you can further contribute to the continued success of TASC research efforts.

Current Studies Recruiting
If you live in the Washington, DC area or travel there frequently and would like to participate in an Ankylosing Spondylitis Research Study, contact Lori Guthrie, RN at the National Institutes of Health by telephone at (301) 435-8434, toll-free at 1-888-996-4267, or by email at guthriel@mail.nih.gov. Principal Investigator: Michael Ward, MD.

If you live in the southern California area, you can contact Stephanie Brown at Cedars-Sinai Medical Center in Los Angeles, CA, at (310) 423-2422, Toll Free: (888) 582-2226 or by email at stephanie.brown@cshs.org. Principal Investigator: Michael Weisman, MD.
A small percentage of people with long-standing ankylosing spondylitis (AS) develop rare, but serious complications. Some complications of the disease are more common than others and many can be effectively treated. Inflammation of the eye, or uveitis, is very common, while neurological symptoms are rare. Most complications occur infrequently; however, it is important for anyone with AS to be checked by a rheumatologist at least once a year. That way, potentially threatening complications can be caught early and treated before permanent damage occurs.

“AS can be a chronic, systemic disorder,” noted rheumatologist Dr. Elaine Tozman, a professor of clinical medicine at the University of Miami’s Leonard Miller School of Medicine, told an audience of spondylitis patients and family members at an SAA Educational Seminar in Miami on May 2, 2009. “I think that it’s important to recognize that this is not simply a problem in the back or in the spine, but there can be systemic features that also occur. It’s more than just a localized process; it can become a systemic illness.”

A serious complication that can lead to blindness if left untreated
One of the most common extra-articular (outside of a joint) manifestations of spondylitis is an inflammatory eye disease called uveitis. In fact, approximately 40 percent of individuals with AS will experience at least one episode of uveitis in their lifetime. Anywhere from 30 to 50 percent of people with acute anterior uveitis have or will develop AS. The incidence is much higher (more than 85%) in people who are HLA-B27 positive, a key genetic marker for spondylitis. Uveitis, regardless of AS status, accounts for about 10 percent of blindness in the United States.

“I work closely with physicians at Baskin Palmer Eye Institute, and we have a number of people who are seen for the first time with inflammatory eye disease, but no other diagnosis at the time,” said Dr. Tozman. “It’s very common for me to have a referral from the eye doctors, saying this person has had one or more episodes of inflammatory eye disease—do they have an underlying process going on like ankylosing spondylitis?”

While uveitis technically is inflammation of the middle of the eye, the uvea, it generally refers to any inflammatory process involving the interior of the eye. It is a serious complication, requiring immediate medical attention. Symptoms include redness, sensitivity to light, dark floaters in the visual field, tearing, and blurred vision.

AS-related uveitis is typically acute and occurs in one eye at a time. Attacks often come and go with treatment, usually with prescription eye drops and anti-inflammatory drugs. Left untreated, however, the condition can lead to blindness.

Chronic, silent inflammation can affect the heart
While clinically significant cardiovascular issues affect fewer than 10 percent of patients, typically those with more severe disease, they can cause considerable problems.

A small number of people with spondylitis display signs of chronic inflammation at the base of the heart, around the aortic valve and origin of the aorta, the vessel that takes blood from the heart and distributes it throughout the body. Years of chronic, silent inflammation can eventually lead to blockages in the aorta, as well as valve leakages, both of which may require surgical treatment. Dr. Tozman says this does not occur because of problems with the aorta or aortic valve, but rather because the aortic ring becomes inflamed and dilated.

“This is an important clinical manifestation that should be monitored,” she told the audience, “particularly for patients who have had their disease for a long time.”

In addition, chronic inflammation can lead to fibrosis, or scarring, of the heart’s conduction system, the process by which the heart muscle expands and contracts rhythmically as it pumps blood throughout the body. This scarring can result in atrioventricular block, a disease of the heart’s electrical system that impairs conduction between its upper chambers, the atria, and lower chambers, the ventricles. Pacemakers and implantable defibrillators are often used to treat these conditions.

AS patients also need to monitor their lipid (cholesterol and triglycerides) levels, as high levels can cause cardiovascular disease. An added benefit of lipid-lowering drugs, such as statins, is that they also have anti-inflammatory properties.
COMPLICATIONS OF SPONDYLITIS

Dr. Tozman said that AS patients should take steps to reduce their risk factors for cardiovascular disease, including quitting smoking (or never starting in the first place), eating appropriately, and maintaining an adequate body weight.

“All of us, and particularly individuals who have a chronic inflammatory condition, need to try to modify whatever risk factors we can for cardiovascular disease,” said Dr. Tozman.

Inflammation can make breathing difficult
Anyone who has had spondylitis for a while knows that the disease can affect their breathing. Over time, long-term inflammation and tissue scarring causes restrictive lung disease. This chronic disorder causes a decrease in one’s ability to expand the lungs, which makes it harder to get adequate oxygen to meet the body’s needs.

In addition, inflammation can cause scarring of tissue at the top of the lungs. With this, the lung’s air sacs gradually become replaced by scar tissue, which becomes thicker over time. This causes an irreversible loss of the tissue’s ability to transfer oxygen into the bloodstream. AS can be associated with this condition.

“In a few patients,” said Dr. Tozman, “an upper lobe inflammatory disorder can result in inflammatory changes in the upper lobes of the lungs, simulating very much what we see in patients with tuberculosis. It can be confused with and looks very similar to tuberculosis. Although I don’t see it very often, it’s well-documented in the literature.”

Uncontrolled inflammation can damage the kidneys
While very rare today in North America, AS patients with severe, active and long-standing disease can develop amyloidosis (a buildup of abnormal protein that is deposited in tissues and organs) because of long-term treatment with nonsteroidal anti-inflammatory medications. Generally, these individuals have active spondylitis, peripheral joint involvement, and elevated erythrocyte sedimentation rates and C-reactive protein levels (both are measures of inflammation), which may cause kidney dysfunction.

“All of us, and particularly individuals who have a chronic inflammatory condition, need to try to modify whatever risk factors we can for cardiovascular disease.”

“Occasionally in patients who have an uncontrolled inflammatory disorder, amyloidosis can occur,” Dr. Tozman told the Miami audience. “This can result in proteinuria [excess protein in the urine, which can signal kidney damage]. Fortunately, I think we’re seeing a lot less amyloidosis because we have better treatments available. Nonetheless, you should be aware that it can exist, particularly in patients who have uncontrolled inflammation.”

Nerve damage from inflammation
AS patients with advanced disease may have difficulty walking because of scarring of nerves at the base of the spine, a condition called cauda equina syndrome.

“Cauda equina syndrome is a neurologic problem, which occurs in the lower spine and can lead to gait-disturbance problems and other serious issues and should be at least considered in patients who have difficulty walking, particularly in those with long-standing disease,” said Dr. Tozman.

People who have had AS for a long time may also develop a condition called atlantoaxial subluxation in which the vertebrae in the neck are malaligned, with the potential to cause nerve damage. This compression of the cervical spinal cord causes neck pain and varying degrees of weakness in the neck muscles.

GI involvement
Spondylitis associated with inflammatory bowel disease, or enteropathic spondylitis, is one of the five diseases in the spondyloarthritides family but many people with AS also suffer from gastrointestinal disorders. In fact, as many as 60 percent of AS patients have asymptomatic inflammation of the colon (large intestine) and the ileum (the final section of the small intestine). Conditions such as Crohn’s disease, an inflammatory bowel disease that causes pain, diarrhea, and weight loss, and ulcerative colitis, an intermittent disease closely related to Crohn’s, can occur in people with established AS.

Dr. Tozman reminded AS patients over age 50 to have a colonoscopy on a “regular basis” to screen for these disorders, as well as for polyps and other precancerous lesions.

Long-standing AS can cause bone problems
In addition to enthesopathy, the inflammation of tendons and ligaments where they attach to bone, people with AS sometimes suffer from metabolic bone diseases. Cases of osteopenia and osteoporosis have been well documented in patients with even short-term spondylitis. Osteopenia refers to low bone mineral density but not low enough to be classified as osteoporosis, a condition in which bones become brittle, weak and can fracture.

“We really need to be aware of the kinds of complications that can occur and which organ systems may be involved to try to be proactive,” said Dr. Tozman.
Help is on the way

Dr. Tozman said the “good news” is that many people with AS will respond to newer biologic therapies, specifically anti-TNF drugs, which have revolutionized rheumatology treatments. These drugs target tumor necrosis factor (TNF), which promotes the inflammatory response, which in turn can cause many of the problems associated with AS, inflammatory bowel disease and psoriatic arthritis. TNF is a “master” regulator of inflammation in many of the body’s organ systems.

In recent months, a new monthly self-injectible, Simponi, has come to market, which makes four TNF inhibitors approved by the FDA for the treatment of AS and its related diseases.

Dr. Tozman said Simponi and the other biologic agents have “certainly been helpful” in treating patients with uveitis and should also help reduce other extra-articular features of AS. In addition, she said, they may also help reduce cardiovascular risks, “but we don’t have good evidence for that yet.”

“We really need to be aware of the kinds of complications that can occur and which organ systems may be involved to try to be proactive.”

SAVE THE DATES

UPCOMING SEMINARS

Philadelphia, PA
Saturday, October 17, 2009

San Diego, CA
Saturday, November 7, 2009

Check online at:
www.spondylitis.org/seminar.html
to register and keep updated on new events!
“Oh sure, I’ve heard of that.” How many times do you hear that when you first mention the word spondylitis to someone? Probably not very many. If you find it frustrating to continually have to explain your condition to people -- now is the time to step up to support the largest spondylitis awareness campaign in US history.

Why doesn’t anyone know about spondylitis? We hear that question time and time again as we travel the country bringing news and information to those who know it all too well.

Is it because it’s so rare? The Office of Rare Diseases of the National Institutes of Health defines a rare disease as one that affects fewer than 200,000 people in the US. Hodgkin’s disease, Lou Gehrig’s disease and Cystic Fibrosis are all considered rare, affecting less than 150,000, 35,000 and 30,000 Americans respectively.

The Centers for Disease Control and Prevention for the National Arthritis Data Workgroup released a study in 2008 that indicates that AS and its related diseases affect anywhere between 600,000 and 2.4 million adults in the US. That’s right -- spondylitis isn’t rare at all. In fact, it may be more prevalent than rheumatoid arthritis. And yet, most Americans have never heard of it.

You can help change that. SAA is gearing up to kick off an extensive national awareness campaign to coincide with the launch of the SAA Screening Tool for Ankylosing Spondylitis website. The goal of the screening tool is to encourage people who have experienced long-term low back pain to assess their likelihood of having spondylitis. The primary goal of the awareness campaign is to drive people to the online questionnaire. But its secondary goal is to educate the general public, as well as physicians, about the disease and the fact that there are resources available to them.

How far-reaching the effort will be is up to you. The more resources we can put behind the campaign, the more people we can reach.

Double Your Impact
The Jean & E. Floyd Kvamme Foundation has agreed to match all gifts, dollar for dollar, up to $25,000, in an effort to ensure that the “Persistent Back Pain? Think Spondylitis” campaign is as comprehensive as possible. That means that today, your gift goes twice as far.

The cornerstone of the campaign will be a series of Public Service Announcements that will air on television stations throughout the country. Media outlets are required to set aside a certain amount of airtime to broadcast these kinds of announcements.

Another component of the awareness effort involves mailing informational posters to 25,000 primary care physicians to display in their examination rooms. Hundreds of patients pass through these rooms each month and will leave knowing a little bit more about spondylitis.

We are also hoping to collaborate with other spine-focused sites on the internet as a means of getting the word out to more people than ever before.

But none of this can be done without the continuing support of our members and donors. Your generous donations are always used responsibly -- but now is the time to be as generous as possible as your gift will go twice as far.

A $50 gift right now will put us $100 closer to the day that average Americans will have heard about this disease and will know where to turn for more information.

As always, from all of us here at SAA, you have our deepest appreciation for all that you do as members, donors, friends, advocates and ambassadors of the organization!
Great News For Donors!

IRA Rollover Provision Reinstated through 2009

There’s good news for individuals aged 70½ or older with individual retirement accounts. Thanks to the extended charitable IRA legislation, you can once again make outright gifts using IRA funds without tax complications. This opportunity ends on December 31, 2009.

If you are required to receive minimum distributions from your IRA and you do not need the money for personal use, consider using these funds as a charitable gift. While you cannot claim a charitable deduction for the IRA gifts, you will not pay income tax on the amount.

The Guidelines

- You are 70½ or older.
- Your IRA gifts total $100,000 in 2009.
- You transfer funds directly from your IRA.
- You transfer the gifts outright to a charitable organization.

The Benefits

- In most cases, the transfer counts toward your minimum required distributions.
- The gift generates neither taxable income nor a tax deduction, so even those who do not itemize their tax returns receive the benefit.
- You may transfer up to $100,000 directly from your IRA in 2009.
- The distributions may be in addition to or to fulfill any charitable giving you have already planned.

Please consider making a gift to the Spondylitis Association of America

Be sure to contact your professional advisor and IRA administrator if you are considering a gift under this law. If you have any questions or would like a copy of SAA’s free brochure, Giving Through Retirement Plans, please contact Susan Jones, Director of Development and Planned Giving at 818-981-1616, ext. 231 or susan.jones@spondylitis.org.

This information is not professional tax or legal advice. Please consult an attorney or professional advisor about your specific situation.
Following are some of the highlights from an interview with Robert Inman, MD, a member of SAA’s Medical and Scientific Advisory Board, and Professor of Medicine and Immunology, Department of Medicine/Rheumatology at Toronto Western Hospital.

Melissa Velez Coelho: Can you talk about Simponi, the new TNF blocker recently approved for ankylosing spondylitis, and how it is different from the other TNF blockers already on the market?

Robert Inman, MD: Simponi® (its generic name is golimumab) has just been approved for ankylosing spondylitis (as well as psoriatic arthritis and rheumatoid arthritis) in both Canada and the U.S. It’s given by a self-administered subcutaneous injection. So in that sense it’s similar to Enbrel® and Humira®. It differs from those however in its frequency. Simponi is only given once a month whereas Humira is given every other week and Enbrel is given every week. Now we have a choice of three self-administered injections, Enbrel, Humira, and Simponi. Remicade® is still given intravenously, as you know, every six or eight weeks. The recommended dose for Simponi is going to be 50 milligrams subcutaneous once a month.

The impression to date is that the safety profile is going to look very comparable to the other three agents that block TNF that are currently on the market.

In terms of the degree of improvement, we don’t have a head-to-head comparison when we’re looking at Humira versus Simponi, or Enbrel versus Simponi. So we don’t really know for sure. I think what the general impression has been from the rheumatologists, if you look at the trials in the four TNF blockers agents on the market and spondylitis published to date, is that they look pretty comparable in terms of effectiveness. So that’s good news.

MVC: Are there any concerns about the long-term use of TNF blockers?

Dr. Inman: In regard to Remicade and Enbrel, we’re out to eight and nine years of follow up now and Humira is probably four to five years. Simponi is just about a year. We have different lengths of follow up in the TNF blockers and spondylitis. The good news from both the patients and the physicians is that the safety profile that has looked good in the short terms studies also looks good in the long-term studies. And in particular, one of our concerns was “is there an increase or an altered risk of any kind of malignancy, any kind of cancers?” One concern has been lymphoma because in some forms of arthritis there’s more lymphoma occurring even without any biologic agent. The current impression has been, from the registries, particularly in Britain and Scandinavia, that it doesn’t look to have a significantly increased risk of lymphoma or related types of cancers in spondylitis patients treated with a biologic. We’ll need more data on that point but, at the moment, it’s very encouraging.

Now with respect to infection, we don’t see any unusual, late-onset types of infection. It appears that unexpected and unusual types of infection are still very rare events in people treated with TNF blockers. Now, having said that, there is a general consensus that there’s a greater risk of latent tuberculosis being reactivated. I think that’s been well accepted.

And there’s a consensus that there’s a higher than expected frequency of general soft tissue infections. This would be sore throats, earaches, and urinary tract infections. These would be common and very treatable types of infections but it seems to be occurring with a little more frequency in patients treated with TNF blockers and other treatments. We’re watching the malignancy issue. We’re watching the infectious disease issue. But all the signals so far have been very reassuring that these drugs, which seem to look very safe in the short run, are also very safe in the long run.

MVC: Are there other good alternatives for patients who cannot use the biologics due to infection or other reasons, such as alternative medicines, naturopathy, homeopathy, and acupuncture? What about supplements?

Dr. Inman: Good question; physicians treating patients all over the world encounter this problem. Sometimes you have patients that may co-exist lupus or they have other diseases that might raise some issues about the safety of the TNF blockers. There are alternative biologics currently under investigation. So, for example, there are some studies going on looking at biologics that block B cells. I haven’t seen any of the data, but that’s going to be coming out this year. Option number one is to look at other types of biologics.
Second option is a group of drugs called bisphosphonates - Fosamax would be one. We and other spondylitis clinics use those drugs periodically in patients that can’t take TNF blockers. Another example would be a drug called pamidronate. Pamidronate is given intravenously once a month. There’s some pretty good evidence that this is effective. I would say that the feeling has been it’s effective, not to the same degree as a TNF blocker, but it might serve some real benefit for someone who can’t take any TNF blocker.

Third option is to make sure that NSAIDs or the COXIBS, the anti-inflammatories, have been used to maximal effect. In other words, make sure that Diclofenac or Naproxen or Motrin or any of those drugs have been tried at adequate doses for an adequate length of time.

Now once you put the medications aside, there are still other options. One important one for us is exercise and stretching programs because it’s very evident that patients with AS that are able to make a sustained commitment to regular exercises and stretching programs do much better. Their flexibility is better. They feel better. It maintains their general muscle fitness much better. And that can come in any form of exercise. Regular aerobic workouts like biking and swimming are great. A lot of patients, if they have active disease in their back have a great deal of trouble running, but the low impact exercises like elliptical, stretching, swimming, biking are great.

We have a number of patients that are very active in tai chi and yoga. They feel that both yoga and tai chi, which is low impact stretching exercises, really benefit them. A lot of those programs can be done at home on your own or with a physiotherapist or working out with a group in the gym.

With respect to naturopathy and homeopathy and acupuncture, there’s not a lot of good data. We certainly have patients that we follow, particularly with acupuncture, in the course of an acute flare, say neck pain, that actually might experience some relief, often temporary, with acupuncture. We have very little data on homeopathy and naturopathy.

Our approach to acupuncture and chiropractic treatment for spondylitis is to be cautious. The reason for saying that is, if someone has a significant flare in their back or neck pain, we would usually interpret that as medical management hasn’t really optimized control of the disease. Something like a massage therapy or acupuncture course might get them over an acute flare up but what it usually means to us is that there’s a red flag there. The reason the neck or the back pain is active is that the disease is actually not under optimal control. Our first approach there is to look very carefully to see whether we can optimize medical treatment. Massage therapy, like stretching and exercise programs, often makes people feel a lot better.

With respect to dietary supplements, there’s very little in the literature on this that’s been subjected to a randomized control study. There’s been quite a bit of interest, particularly in the UK and in Australian AS groups, in the low carbohydrate diet strategy. And I’ve had a number of patients in our clinic who have periodically gone to a low carbohydrate diet. These are pretty strict diets, no pizza, pasta, bread. In the course of losing some weight, they feel a lot better.

It’s been difficult to tease out whether this is really a carbohydrate specific event or is it because they are cutting down the total calories? Is it because they’re losing weight and they’re getting in better shape? But for whatever reason, a number of our patients tell us that they sometimes feel better with low starch or low carbohydrate diet. We actually need better research. We need some better data on the affect of dietary manipulations and supplements on AS at the moment.

To listen to this interview with Dr. Inman in its entirety, log in to the Member Area of spondylitis.org.

If you have a question you would like answered during a future podcast, please send your questions to Melissa Velez Coelho, Director of Program Services, at melissa.velez@spondylitis.org. Please indicate that your question is for an upcoming podcast.
A number of genetic factors and epidemiological patterns of ankylosing spondylitis (AS) offer potential clues to the possible initiating pathways of the disease. Dr. Alfonse T. Masi, a noted rheumatologist, however, argues that they alone are not enough to answer questions about the full range of risk factors and initiating sequences of AS. Rather, he says, integrated biomechanical concepts of AS are necessary to improve understanding and management of the disease.

Although the exact cause of AS is unknown, medical scientists suspect that a combination of genetic and environmental factors are needed to trigger the disease in susceptible people. The majority of people with AS (nearly 90%) are born with the HLA-B27 gene, which appears only to increase one’s tendency to develop the disease. While 7 percent of the U.S. population carries the HLA-B27 gene, only 1 percent has AS. Likewise in Northern Scandinavia, 24 percent of the population has the gene, but only 1.8 percent are affected by AS. Two additional susceptibility genes, ARTS1 (ERAP1) and IL23R, have been identified, though they carry lesser risk of developing AS.

The pathogenetic mechanisms by which these genes cause the development and progression of AS are not known; however, scientists believe that activation of the immune system via innate pathways may be one means by which these susceptibility genes predispose individuals to the disease.

Epidemiologically, certain patterns of AS can offer “essential clues” about how AS develops and progresses. These include age- and sex-specific onset patterns, as well as symptoms ranging from chronic low back pain and muscle stiffness to foot problems and hip involvement in certain age groups.

In his paper, “Integrated Biomechanical Influences on Ankylosing Spondylitis,” Dr. Masi, a professor of medicine and epidemiology at the University of Illinois College of Medicine at Peoria, argues that, aside from genetic factors, the initiating pathways and predisposing factors for developing AS remain largely unanswered. Dr. Masi says a “broadening of perspectives to include biomechanical system analysis” can only add to the knowledge of currently established immunogenetics and other pathways.

“As in the past,” he writes, “the focal point of AS progression continues to be viewed as skeletal changes. Research has not yet critically addressed interactions of musculoligamentous (myofascial) components on the musculoskeletal system.”

Dr. Masi’s paper lays out the biomechanical framework by which the development and progression of AS might be explained. He builds his theories around two primary concepts: biotensegrity, the system of tensional and compressional elements that give our bodies stability and flexibility, and human resting muscle tone, the idea that muscle tone is present even when a muscle is supposedly at rest.

Based on construction concepts introduced in the 1960s by sculptor Kenneth Snelson and architect and designer Buckminster Fuller, biotensegrity is a mechanical model of biological structure and function. Tensegrity theory says that structures are based on the combination of a few simple design patterns, primarily that structures stabilize their shape by continuous tension (the force that expands or lengthens an object) rather than by continuous compression (the force that acts to compress or shorten objects).

What does this have to do with the human body and AS? Our bones are essentially compression elements, while our connective tissues—ligaments, tendons and muscles—are tension-bearing elements. There is mounting evidence
that the entire fascial, or musculoskeletal, system is a continuous tension network and that at least some joints, like the shoulder, transmit tension through soft tissue and not the compression of bones.

Excessive spinal stiffness is a common characteristic of AS. Dr. Masi says this stiffness, or hypertonicity, “needs to be tested as a significant primary physiopathogenetic mechanism in the onset and expression of AS.” If confirmed, he adds, biomechanical principles based on the concept of biotensegrity can help explain some of the unique myofascial components of AS.

In addition, he says, chronically excessive biotensegrity can stress attachments and lead to the development of syndesmophytes, bony growths that originate inside a ligament. Most commonly, syndesmophytes affect ligaments of the spine, particularly in intervertebral joints, which leads to the spinal fusion common to AS.

Dr. Masi and his colleague, John Charles Hannon, introduced the concept of human resting muscle tone, or HRMT, in a 2008 paper in the Journal of Bodywork and Movement Therapies. HRMT, they write, is “integrated with other passive fascial and ligamentous tensional networks of the body to form a biotensegrity system.”

Dr. Masi and Hannon’s primary point is that there is constant tone—the continuous and passive partial contraction of muscles—in resting muscle, which serves the purpose of maintaining posture. As AS progresses and the vertebrae begin to fuse, many people develop a bent posture.

Many people with certain musculoskeletal conditions have increased resting muscle firmness or hardness, such as that seen in AS. Drs. Masi and Hannon say that this signals that HRMT is a passive myofascial property that operates within the framework of tensional elements (i.e., biotensegrity). By studying human resting muscle tone, scientists may be able to noninvasively quantitate the tension and stiffness of spinal muscles at rest and with activity.

While integrated biomechanical concepts of AS are a “work-in-progress,” Dr. Masi’s new theories of AS should stimulate additional research on disease predictors and progression. This will lead to new preventive approaches and more specific therapies for AS.

These new concepts, says Dr. Masi, “need to be critically held up to the experiences of AS sufferers and testing by scientists. If the novel concepts have virtue, improved understanding and management of AS can be expected. If these new views are seriously faulted, addressing their errors will only improve understanding of the current concepts of AS.”

New frameworks for understanding the etiology of AS “need not diminish the currently established core beliefs” about the disease, says Dr. Masi. A better understanding of the biomechanical principles of the disease, however, can only enhance our knowledge of the initiating mechanisms of AS and, thus, drive research toward the eventual prevention of what Dr. Masi calls “this mysterious disease.”
Carol Robl faced a choice. She could continue taking anti-inflammatory medications to treat her spondylitis, but whose long-term use was causing her kidneys to shut down—potentially leading to dialysis treatment to support her lost kidney function. Or she could try something less traditional to ease the pain and inflammation caused by her spondylitis without the kidney function associated risk. Robl chose the latter.

Robl, a medical educator from the Seattle area, was diagnosed with ankylosing spondylitis in 1996. Prior to her diagnosis, she says she had “subtle signs” that she might have the condition, including stiffness and soreness in her back. After suffering a flare-up in the fall of 1996, she went to a rheumatologist, who examined her and conducted a battery of tests, including genetic tests for HLA-B27, a common genetic marker for AS. The results came back positive. She had ankylosing spondylitis.

To ease her pain, Robl’s rheumatologist prescribed daily ibuprofen, a common non-steroidal anti-inflammatory drug (NSAID) used to treat conditions such as arthritis, headache and minor injuries. After about a year on ibuprofen, Robl’s doctor changed her prescription from ibuprofen to etodolac, an NSAID that blocks the enzyme that makes prostaglandins, chemicals that are responsible for the pain, fever and tenderness caused by inflammation. She was also prescribed mesalamine, an anti-inflammatory drug used to treat a form of inflammatory bowel disease that is related to AS.

She remained on those medications for several years, but then, in 2007, her kidney function began to decline. Robl says she had been warned that long-term NSAID use could lead to kidney problems in some people.

“The loss of kidney function scared me,” says Robl. “I talked to my primary care physician about it and he agreed to do some tests.”

The results were not promising. Robl’s GFR, or glomerular filtration rate, was low. GFR is a test that measures the level of kidney function and determines stages of kidney disease. People with a GFR below 30 are referred to a kidney specialist; those with a GFR below 15 typically start dialysis or are put on a list for a kidney transplant.

Robl’s nephrologist, a doctor specializing in diseases of the kidneys, thought the etodolac could be causing her kidneys to fail, so he switched her prescription to salsalate, an aspirin-like drug that has shown to be successful in reducing pain, joint stiffness and swelling in arthritis patients. After a couple of months on salsalate, however, Robl’s kidney function was even worse.

“I decided that [dialysis] was not where I wanted to be,” says Robl, whose mother had chronic kidney failure. “I knew I didn’t want to take any more medications, but I wanted to avoid ending up in kidney failure and on dialysis. That’s a horrible way to live. Who wants to be dependent on that?”

That’s when Carol Robl turned to acupuncture.

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That’s when Carol Robl turned to acupuncture.

**Breaking new ground in pain relief**

By Scott P. Edwards | August 2009

**ACUPUNCTURE:**

**Restoring Qi**

Among the oldest healing practices in the world, acupuncture aims to restore or maintain health through the stimulation of specific anatomical points on the body. Practiced in China and other Asian countries for thousands of years, acupuncture is a key component of traditional Chinese medicine.

The theory behind acupuncture as a medical treatment is very different from Western medicine. In traditional Chinese medicine (TCM), health results from a “harmonious balance” between complementary extremes—yin and yang—of a life force known as Qi. Health is achieved by maintaining a balanced state between yin and yang. Disease is caused by an imbalance, which leads to the blockage of vital energy along certain pathways, or meridians, in the body. These meridians are accessible through more than 350
acupuncture points. TCM practitioners believe that by inserting needles into these points in various combinations, Qi energy flow will be restored.

There are numerous theories about how acupuncture works. Some believe acupuncture stimulates the release of pain-relieving endorphins, while others think it influences the release of neurotransmitters that carry nerve impulses and messages to the brain. Others say acupuncture influences the autonomic nervous system (the part of the nervous system that controls involuntary actions like heart beat, breathing and blood pressure), stimulates the circulation, or influences electrical currents in the body.

Acupuncture is thought to decrease pain by increasing the release of endorphins, chemicals that block pain signals. Many of the more than 350 acupuncture points on the body are near nerves. When these nerves are stimulated, they cause a dull ache or feeling of fullness in nearby muscles. The theory is that these stimulated muscles then send a message to the brain, causing the release of endorphins, which along with other neurotransmitters, block pain signals from being sent to the brain.

This theory is backed by basic research on acupuncture’s effects on hormones such as ACTH, insulin, thyroid hormones, growth stimulating hormone and beta-endorphin, as well as white blood cell production and plasma cholesterol levels. ACTH, or adrenocorticotropic hormone, stimulates the brain’s adrenal cortex in response to stress. Growth stimulating hormone is produced by the pituitary gland to regulate the body’s growth and muscle composition. Insulin, a hormone produced by the pancreas, has extensive effects on metabolism and other body functions.

Although electrical stimulation, lasers, heat/moxibustion (the warming of acupuncture points using the mugwort herb) or pressure may be used to manipulate Qi meridians, acupuncture needles are the most commonly used technique. Acupuncturists insert and remove tiny needles quickly or leave them in for a period of time. After they are placed, the needles are often gently moved or stimulated with electricity or heat. As many as a dozen needles may be placed for each treatment and usually left in place for anywhere from five to 20 minutes.

“With acupuncture, we can physically train the body to hold its pre-injury model, which is inherent but dormant.”

The World Health Organization recognizes more than 40 medical problems, ranging from allergies to AIDS, that can be helped by acupuncture. Today, patients throughout the U.S. seek acupuncture treatment for a variety of maladies, including upper respiratory infections, acute bronchitis, eye infections, toothaches, headaches and ulcers, among others. The most common medical issues treated with acupuncture are musculoskeletal problems such as neuropathy, arthritis, sciatica and low back pain.

**Something other than ‘mainstream’ medicine**

As a health educator at Swedish Cancer Institute in Seattle, Robl often heard naturopaths talk about alternative approaches to the treatment of pain. Naturopathy, or naturopathic medicine, is a medical system that focuses on natural remedies and the body’s ability to heal and maintain itself, minimizing the use of surgery and drugs.

“I listened to naturopaths [speak about alternative treatments] and felt it was fairly convincing to try something other than mainstream approaches to treat my pain,” says Robl. “My training was pretty mainstream, but listening to these naturopaths changed my mind.”

In January 2008, as her kidney function continued to decline, Robl’s rheumatologist, Dr. Scott Pollock, referred her to Jim Blair, an acupuncturist with whom he works closely. “I talked to Jim,” says Robl, “and he was very hopeful that acupuncture would work.”

For the first six weeks, Robl had weekly acupuncture treatments, then gradually moved to one treatment every 10 days. Going forward, Blair says the plan is to move treatments to every two to four weeks, then every two months, until fading out treatment. By February 2008, only one month after she began acupuncture treatment, Robl had been tapered off all of her pain medications.

“Carol’s doing well,” says Blair. “She couldn’t continue taking medications for her pain because she was going into renal failure and would need dialysis. Within about 10 to 12 weeks after stopping all NSAIDs she was back within normal physiological limits for renal function.”

In addition, says Robl, she noticed gradual improvement in her level of pain. “I still have some stiffness and soreness,” she says. “I had that even when I was on meds, but now it’s not continuous or overwhelming.”

**Tension and compression**

Blair says the human body follows the same general structural principles as the geodesic dome created by the American architect and inventor Buckminster Fuller. A geodesic dome is a spherical structure created by an interconnecting network of great circles, or geodesics. These geodesics intersect to form triangles that have local rigidity and distribute stress across the entire structure.
Geodesic domes are built on the concept of tensegrity, which refers to the structure’s integrity based on a synergy between tension and compression components. After studying the work of Fuller and Kenneth Snelson, a sculptor whose “Needle Tower” follows the same tension-compression principles as the geodesic dome, Dr. Stephen M. Levin, an orthopedist, came to realize that the human body also consists of tension and compression elements, providing the body with its framework, stability, and flexibility. He called this biotensegrity, a concept followed closely by those who treat people with spondylitis.

“We use acupuncture needles to treat tension-bearing trigger points in the body,” says Blair. “This helps to increase or decrease tone to create a more homeostatic [regulated] environment.”

Acupuncture takes tension off these trigger points and helps to decrease compressive issues common to spondylitis. Patients with AS are at increased risk of spinal cord damage because the fused spine is weaker and more likely to fracture than it is in people without spondylitis. Such spinal injuries can cause compression of the spinal cord, which can result in changes in sensation, weakness, and mobility below the level of the compression.

“With acupuncture,” Blair says, “we can physically train the body to hold its pre-injury model, which is inherent but dormant.”

In addition to the traditional placement of acupuncture needles Blair has used a technique called intradermal acupuncture to help ease Robl’s pain. This involved the placement of tiny needles, each about 3 mm in length, in her upper back that lay flat under the skin.

“Over a period of months,” says Blair, “this knocked out the inflammation and rigidity and, in Carol’s case, increased the range of motion in her neck. We then weaned her off the transdermals to keep this structural pattern in place.”

Trying something new
While some are reluctant, more and more rheumatologists are referring their patients for acupuncture. Some of these doctors see patients for whom they can provide little or no relief, especially for those suffering from chronic pain. Indeed, it has even been suggested by some medical professionals that acupuncture may have its greatest impact on patients who have failed more conventional treatments. More research is needed.

Blair practices acupuncture services in the same building where Robl’s rheumatologist has been practicing medicine for nearly 25 years. “It’s taken [Pollock] 25 years to get to where he is in terms of sending me patients for acupuncture,” says Blair. “He’s not certain about it, but he knows it has the ability to work.”

Carol Robl no longer needs convincing. She is a true believer. “I continue to feel that I am doing well with this decision and feel like my quality of life is quite good, in spite of my spondylitis.”

In The Next Issue Of Spondylitis Plus...
Keep your eye out for the Winter 2009 Issue of Spondylitis Plus, which will include articles on:

Prescription Discounts
Anesthesia and the Spondylitis Patient
## SAA-Sponsored Educational Support Groups

The people listed below have volunteered to lead support groups across the US. If you’d like to find out more about support groups and online meetings, pick up the phone or send an email to: elin.aslanyan@spondylitis.org.

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