I think that most of us have watched in awe flocks of geese migrating in their traditional precision “V” formation. Well, did you know that according to the experts, the individual birds each are critical to a successful journey? This is how it works. By flapping its wings, each goose creates an uplift for the one behind. Flying in this way, with all of the birds in synchronicity, the flock increases its flying power by roughly 70 percent in distance covered compared to one single bird flying alone.

In one of the mysteries of nature, the birds use the power of the flock to bring strength in numbers.

Here at SAA, we are also experiencing strength in numbers. All across the country we see an increasing number of volunteers raising funds, spreading the word, participating in research and dreaming up creative solutions in support of our shared mission.

From the girl scout who earned a badge by distributing our EMS training DVD -- to the barber who hosted a barbecue for 300 people -- to the DJ who held an Internet Radio benefit -- to the college student who participated in adventure racing -- to our legions of social media supporters -- to the attorney who works to help veterans obtain disability benefits, people are helping people and in the process spreading the word about spondylitis.

Another special volunteer is featured in our Public Service Announcements. These PSAs are just part of our recently launched health marketing campaign which you’ll read about in these pages. Another segment of the campaign included the big screen ad in Times Square that you see on the cover.

I would like to end this note by thanking you for your support during this past year and for your continued commitment toward our efforts. We have big plans for the next 12 months and with your help, we look forward to bringing them to fruition.

Best Regards,

Laurie M. Savage
Executive Director
An Important Note: In the Fall issue of Spondylitis Plus, we failed to acknowledge Craig Gimbel, DDS as the author of the article “Ankylosing Spondylitis & Dentistry”. We are grateful to Dr. Gimbel for his time and expertise about this critical issue for the spondylitis community. We apologize for the omission and regret the error.

As & Dentistry Response
I was excited to see the Fall Spondylitis Plus issue about AS & Dentistry. If you look back at the message boards, you will find this was a topic that I started back in September 2008! It was about that time that I really began to realize the connection between AS & oral health. Since 2008, although he is far away from my house, I have found a dentist who is willing to work with me. I am going to take him a copy of the article from Spondylitis Plus.

Thanks for all the good and interesting and helpful information you provide for us.

Joy L.

Editor’s Note: Thank you, Joy, for your support!

Ankylosing Spondylitis: A Primer for First Responders
I would like to thank SAA and Randy Chism for creating “Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders.” Just a visit to Tommy Copeland, EMT-P and Assistant Director for the Putnam County EMS, has resulted in Tennessee providing the training statewide. SAA sent hundreds of DVDs to the Tennessee Department of Health in Nashville. I received a message from Bill Sewell, the Tennessee State EMS representative, that all of the DVDs have been distributed statewide to EMS services as well as their training schools. Also, in Putnam and surrounding counties, it has been added to the First Responder curriculum, and I am told that nearly 100% of the services have had the training. Hopefully, SAA’s “A Primer for First Responders” is going nationwide.

Thank you,

Sue F.

Editor’s Note: Thank you, Sue, for your role in bringing attention to this important training in TN. Dear Readers, if you would like to help distribute these EMS Training DVDs in your community, contact Melissa Velez Coelho, Director of Program Services, by telephone at (800) 777-8189, ext. 227, or by email 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
Many genes linked to ankylosing spondylitis have been identified with a research technique called a genome-wide association study in which scientists compare the genetic makeup of people with a certain disease to those without the disease. This technique shows researchers where to look for disease-associated genes in the human genome.

A new study designed to test suspected links between these genes and two immune disorders, including ankylosing spondylitis, could open the door to better ways to diagnose and treat the conditions that affect a combined total of approximately 2.5 million people in the United States.
The genes are thought to be associated with ankylosing spondylitis and systemic sclerosis (scleroderma), a chronic, often progressive, disease of connective tissue. The Centers for Disease Control and Prevention for the National Arthritis Data Workgroup estimates as many as 2.4 million people in the United States may be affected by ankylosing spondylitis and its related diseases. Systemic sclerosis impacts about 100,000 people in the United States.

The researchers plan to conduct an exhaustive analysis of these genes and others using a research technique called targeted resequencing. The study will involve more than 6,000 patients with ankylosing spondylitis or scleroderma from the United States, China and Spain and it will focus on an area of the genome linked to immunity issues called the major histocompatibility complex. The study will also include about 3,000 people without the conditions.

“This is the most complicated region of the human genome,” said Xiaodong Zhou, M.D., a principal investigator and associate professor of internal medicine at the UTHealth Medical School. “The region contains genes linked to all types of immune diseases. In many instances, we don’t know precisely where the linkage comes from. We want to find out if these are true associations.”

While the immune system’s function is to protect the body, problems can occur. Sometimes immune systems can induce inflammation, which is called autoinflammatory. Immune systems can also generate autoantibodies that can attack their own cells - a condition called autoimmune disease. Ankylosing spondylitis is an autoinflammatory disease and scleroderma is an autoimmune disorder.

“"If we can find out which genes are responsible for these problems, we could potentially develop drugs to block their activity.”

Zhou, director of the UTHealth Research Laboratory in Rheumatology and Clinical Immunogenetics, said, “You need distinct ethnic populations for comparison purposes.”

Several of the newly uncovered gene regions, each containing multiple genes, were discovered by the two other principal investigators in the study, John D. Reveille, M.D., and Maureen D. Mayes, M.D., M.P.H.

“We are taking our research to the next step,” said Reveille, Professor of Medicine and Director of the Division of Rheumatology and Clinical Immunogenetics at The University of Texas Medical School at Houston. “These new tests will help us better understand the causes of these diseases.”

Mayes, a professor of rheumatology at the UTHealth Medical School, said, “If we can find out which genes are responsible for these problems, we could potentially develop drugs to block their activity. These tests will also help us determine which combination of genes may be responsible for these illnesses.” Reveille said researchers have already identified many of the genetic components of ankylosing spondylitis.

By comparing immune-related genes of different populations, the scientists think they will be able to zero in on the most critical genes tied to ankylosing spondylitis and scleroderma, Mayes said. “Genes can vary from continent to continent. For example, there is a gene variant in Africa that confers resistance to malaria. That is not as common in the United States,” she said. “Where these genes overlap is of special interest to us.”

Reveille, Mayes and Zhou already have access to the DNA information of patients with ankylosing spondylitis and scleroderma from established cohorts from their previous studies in both Spain and the United States.

Later this year, the researchers will travel to China to coordinate the recruitment of people with these immune disorders with the aid of Jiucun Wang, Ph.D., of Fudan University in Shanghai and Hejian Zou, M.D., Ph.D. of Huashan Hospital in Shanghai, who both will lead the Chinese effort.

Their research is titled “Studies of HLA Region Genomics in Systemic Sclerosis and Ankylosing Spondylitis.” The work is supported by a National Institutes of Health (NIH) grant covering $2 million in direct cost over five years.

SAA would like to thank Drs. Reveille, Mayes and Zhou as well as their research teams and the study participants who have helped make these and future developments possible.
Low back pain is an extremely common condition in adults, with significant socioeconomic impact. About 15% of the United States population has chronic low back pain, of whom approximately 14% (or 2% of the general population) may have inflammatory back pain. Inflammatory back pain is a hallmark of ankylosing spondylitis, which is a major subtype of a family of conditions called spondyloarthritis. Spondyloarthritis is also associated with other major illnesses such as psoriasis and inflammatory bowel disease. Most people with inflammatory back pain will demonstrate significant limitation in spinal mobility.
A major problem for individuals with symptoms of AS is that even today it can take years before those symptoms can lead to a definite diagnosis and appropriate treatment. By identifying this problem and by seeking to put the solution in the hands of the individual, in 2005, SAA set out to develop an online web tool questionnaire for individuals with chronic low back pain. Five years later, in July of 2010, the Spondylitis Association launched the website that houses the SAA Screening Tool for Ankylosing Spondylitis. This seemingly simple, 10 question survey is actually the culmination of a five year research project, led by Dr. Michael Weisman, Cedars-Sinai Medical Center, to develop and validate a questionnaire that would identify those at greatest risk for ankylosing spondylitis and for developing the associated limitation of spinal mobility over time.

The SAA Screening Tool for Ankylosing Spondylitis is a symptom-based questionnaire that will assess a patient’s likelihood of having symptoms commonly associated with AS. The online test is quick, completely confidential and will provide, in real time, a score and collateral materials that a person can print out and take to a physician in order to seek a definitive diagnosis. The questionnaire will help to identify new cases, greatly improve early diagnosis, encourage care-seeking among patients who learn they are at-risk for AS, provide useful information to patients and physicians, and will help raise awareness about AS.

“Our biggest challenge is to create awareness of the disease, so people who have persistent back pain can seek an accurate diagnosis, especially young people.”

To promote the launch of www.BackPainTest.org, SAA produced and distributed a series of Public Service Announcements. The 15, 30 and 60 second spots have been widely distributed to 400 television stations and 1,000 radio stations as well as extensive online distribution through multiple avenues. They are currently airing on radio and television stations across the country.

**SAA in Times Square**

See right and this issue’s cover with an actual real time shot of the SAA PSA announcement on an electronic billboard (Jumbotron) in Times Square, NYC. The same ad also appeared on the Strip in Las Vegas, NV during the same time frame in August, 2010.
Be aware that the SAA Screening Tool for Ankylosing Spondylitis was designed to identify undiagnosed patients with early stage AS. It is not weighted to identify more advanced disease. For this reason, it is quite possible that people who have a longstanding diagnosis will test negative. For more information about the sensitivity and specificity of the questionnaire, please see the published manuscript at http://www3.interscience.wiley.com/cgi-bin/fulltext/123227211/PDFSTART

My Name is Tyler Walker and I have Ankylosing Spondylitis

SAA’s PSAs feature 22 year old Tyler Walker (pictured left) whose AS symptoms began when he was nine years old. Tyler was one of the lucky ones who didn’t wait 7 to 10 years for a diagnosis. His mother, Sherri, had been experiencing AS symptoms for years, although she had not been diagnosed. Her own mother received a diagnosis of AS and RA right at the same time that Sherri began to notice symptoms in Tyler. At that point, Sherri realized there was a hereditary component at work and fought tirelessly with her son’s physicians until a proper diagnosis was confirmed. Only after her son was receiving appropriate treatment did she obtain her own diagnosis.
At the end of the PSA, Tyler invites people who are experiencing persistent low back pain to visit www.BackPainTest.org to fill out a brief survey that will assess their symptoms and recommend next steps. For more information, people can also call SAA’s toll-free information line at 800-777-8189.

“Our biggest challenge is to create awareness of the disease, so people who have persistent back pain can seek an accurate diagnosis, especially young people,” says Laurie Savage, SAA’s Executive Director. “Because most of the damage caused by ankylosing spondylitis occurs in the first 10 years, early diagnosis means early treatment to improve quality of life.”

Last month, a woman phoned the SAA offices in Van Nuys, California. She’d never heard of ankylosing spondylitis or the Spondylitis Association of America. She called because she had been awakened the previous night by back pain that left her unable to sleep, something she was all too familiar with.

Knowing she would get no more sleep that night, she turned on the television and soon saw the Public Service Announcement. The symptoms Tyler described fit her to a tee.

Moving to her computer, she pulled up www.BackPainTest.org and took the test. She received a positive result. (It’s important to note that the questionnaire is not a diagnostic tool but rather a “case ascertainment tool” designed to assess a person’s likelihood of having ankylosing spondylitis. Only a physician can make a definitive diagnosis of AS.)

She called SAA the next morning to express her gratitude. Now armed with the information necessary to pursue a diagnosis, she told us she felt hopeful that she might finally find the answers she’s sought and may soon have an explanation for the pain and can seek the proper treatment to put an end to her sleepless nights.
Medical research can sometimes seem to move maddeningly slow. But that’s not the case right now in regards to ankylosing spondylitis and its associated diseases.

Just three years ago, researchers knew of only one gene -- HLA-B27 -- associated with ankylosing spondylitis. Today they have identified at least seven. It is now believed that understanding the relationships between these genes will provide the key to unlocking the mysteries of spondylitis once and for all.

These discoveries have led to a renewed interest in the genetics of spondylitis and researchers are making breakthroughs at a rate never before imagined. The medical research that once seemed slow moving is now leading to new findings at a brisk pace.

And it’s not all academic. One of these genes recently determined to have an association with AS by the Triple “A” Spondylitis Consortium Genetic Study (TASC) has already led to new drug therapies.

Matthew A. Brown, MD, professor of immunogenetics at Australia’s University of Queensland and one of the study’s Principal Investigators, states, “So here is a situation where a gene finding was first published in 2007 and by 2010 has already been translated to a licensed, funded therapy in many countries around the world, which I think is an extraordinarily rapid translation. Obviously that’s not a general experience with genetics, but it does show that in some circumstances it can make real profound changes.”

Those profound changes are being made every day – in large part because of the dedication and commitment of SAA’s loyal members and friends like you.

The Spondylitis Association of America has been a long time collaborator in the TASC Study, first acting as the clinical coordinating center and later leading the nationwide recruiting efforts to provide the patient population to participate in the research project.

You’ll soon receive our year-end appeal for donations. I hope that you’ll give generously to ensure that the progress that’s been made in the field of medical research will continue at a steady pace and that all of SAA’s vital programs and services will continue to educate, inform and support the community we serve.

The researchers we work with believe that we will see truly significant breakthroughs in the next few years. With your continued support, I can’t help but believe that that’s true.

Many thanks,

Diann Peterson
Director of Membership
Leadership Circle Members

Thank You for your generous support.

Over fifty percent of the Spondylitis Association’s (SAA) revenue in fiscal year 2010 came from individuals and family foundations. 53% of individual revenue received was from Leadership Circle members – those who give $1,000 or more annually.

While SAA is appreciative of every gift we receive, we want to take this opportunity to thank the members of the Leadership Circle. Their generosity demonstrates the strength of their commitment to the mission of SAA and underscores the important role that Leadership Circle members play in helping to sustain the organization today and in the future.

Leadership Circle Members

(Gifts received between July 1, 2009 and June 30, 2010)

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Recent News Bites From
Spondylitis.org...

Psychological Status and Patient-Assessed Health Instruments in Ankylosing Spondylitis

A study published in “The Clinical Journal of Rheumatology” states that, “psychological status should be taken into account especially deciding the treatment regimen including biologic therapies.”

The study’s purpose was to determine “the relationships between disease and psychological status in ankylosing spondylitis (AS) is needed for clinical assessment and management.”

The authors of the study note that, “AS is a chronic disease, which causes deformities and workforce decline. This, in turn, might lead to psychological distress.”

Self-reporting measures by patients correlated with, “anxiety, obsessive-compulsive, depression, and hostility.”

Ortancil, Ozgur MD; Konuk, Numan MD; May, Hatice MD; Sanli, Aslan MD; Ozturk, Devrim MD; Ankarali, Handan PhD. JCR: Journal of Clinical Rheumatology: October 2010 - Volume 16 - Issue 7 - pp 313-316
doi: 10.1097/RHU.0b013e3181f3bfba

Spondyloarthritis in women: differences in disease onset, clinical presentation, and Bath Ankylosing Spondylitis Disease Activity and Functional indices (BASDAI and BASFI) between men and women with spondyloarthritides

Ankylosing spondylitis can present differently at onset in women than in men. Quoting Dr. Elaine Adams, “Women often present in a little more atypical fashion so it’s even harder to make the diagnoses in women.” For example, anecdotally we have heard from women with AS who have stated that their symptoms started in the neck rather than in the lower back.

A “brief report” in the journal “Clinical Rheumatology” looks at spondyloarthritis in women and disease differences in men and women.

The authors write that, “Compared with men, women had greater age at presentation, longer disease duration, more delayed diagnoses and greater age at diagnosis.” They continue by adding, “Women have more neck, knee, and hip pain at presentation and their main problems arise from the neck, back (lower and upper), fatigue and enthesitis during the course of the disease, whilst in men, feet pain was reported more often as presenting symptom than in women, with joint pain being the main problem caused by the disease.”

Euthalia Roussou and Shahzabeen Sultana. Clinical Rheumatology DOI: 10.1007/s10067-010-1581-5
Determinants of Early Radiographic Progression in Ankylosing Spondylitis

A study in The Journal of Rheumatology investigates, “the demographic and clinical characteristics associated with early, extensive radiographic changes in ankylosing spondylitis (AS).”

The authors found that early axial ankylosis (EAA) “was more frequent in men with AS than in women. Absence of peripheral arthritis, HLA-B27 positivity, and uveitis were associated with multiple syndesmophytes or fusion of multiple vertebrae of the lumbar vertebrae.”

Pamir Atagunduz, Sibel Zehra Aydin, Cengiz Bahadir, Burak Erer and Haner Direskeneli. Published online before print September 15, 2010, doi: 10.3899/jrheum.100094

Tell Your Senators to Pass the Arthritis Prevention, Control and Cure Act

The Arthritis Prevention, Control, and Cure Act (HR 1210/S. 984) was passed by the U.S. House of Representatives at the end of September. This legislation will strengthen arthritis prevention programs, allowing more people to be diagnosed early and avoid pain and permanent disability; expand the reach of evidence-based arthritis self-management activities, expand research for juvenile arthritis; and allow support for pediatric rheumatology training programs. Please remember to thank your Representatives for their help in passing this important piece of legislation.

But we can’t rest now. Act now! Tell your Senators to work to pass the same bill before the end of the 111th Congress.

Tell Your Congressmen to Fix the SGR

SAA is teaming with other Patient Advocacy Groups and the American College of Rheumatology to fight for a permanent solution to the SGR (Sustainable Growth Rate formula), and we need your help.

The SGR Formula is used to set Medicare’s physicians payment rates. Three times in 2010 alone, Congress has failed to avert Medicare cuts, waiting days and weeks after the deadline to act, slashing payments more than 20 percent. With repeated short-term retroactive actions, some physician practices were forced to take out loans to cover payroll, others laid off staff or delayed investments in electronic medical records. However, even more critical to the failure to permanently repeal the system, some physicians were forced to stop accepting new Medicare patients, responded by seeing more patients per day or made other changes which have negatively impacted patient access to quality care.

Send an email, letter, or make a phone call today! Tell Congress to fix the SGR because “I need my rheumatologist!”

To find out how to contact your Congressmen, visit: http://www.spondylitis.org/advocacy/contacting_congress.aspx
I have pain in my peripheral joints. How common is this among people with ankylosing spondylitis?

**John Reveille, MD:** We know that about 25 percent of people with AS will get pain in the joints of the knees, hands or feet and up to 50 percent of people with AS will get disease in the hips. In terms of research, we are trying to define if there are genetic differences between those who develop this more diffuse joint involvement versus those that have disease limited to the spine.

About one in every four AS patients will have significant peripheral joint involvement, but the treatments are similar, except the fact that drugs like sulphasalazine or methotrexate (which don’t work for the spinal disease) are very effective in this setting. (May 2010)

Do TNF-alpha blockers help stop fusing of the spine and damage in other areas such as the hands, feet, ribs and SI joints?’

**David Hallegua, MD:** We do not have any evidence that TNFs stop the spine from fusing. However, I don’t think that question has been answered completely yet. We have not been able to do trials where one group of AS patients takes a TNF drug for two years and another takes placebo for two years. This would be the best evidence whether TNF slowed down fusion or not and that said, it cannot be done due to ethical reasons.

Relief of pain does allow a person to stand up more erect and perhaps if they were destined to fuse, they would fuse in a more upright posture.

TNFs do help to stop damage in the hands and feet and knees and hips in patients who have peripheral arthritis. They will arrest this damage and slow it down. Pre-existing damage will not be reversed. The SI joints are part of the axial spine and therefore, TNFs do not inhibit fusion in these areas, but do decrease inflammation and relieve pain. (March 2010)

What are some general recommendations for people who are not getting adequate pain relief from their current treatment plan?

**Walter Maksymowych, MD:** An important question that has to be asked is “What is causing the pain?”; it’s important not to make the assumption the pain is simply related to the spondylitis. People can get pain in the spine for all kinds of reasons and we mustn’t lose sight of that. Some of these reasons can occasionally be serious so when a patient is telling me that they’re taking all the recommended treatments and they are still having pain, the first thing that I would do is a diagnostic evaluation. This means taking a history, doing a physical examination, any laboratory tests that are required and potentially other investigations like an MRI. If medical intervention fails and no other cause is found for the pain, then we start to address issues of chronic pain. Rheumatologists may not necessarily be the best people to deal with chronic pain. Occasionally we have to send patients to chronic pain clinics where there are other people with other kinds of expertise such as anesthesiologists who are very good at dealing with specific, localized sources of pain. So, the steps that should be taken are, A) a re-assessment of the cause of the pain; B) a re-evaluation of treatment; and C) If everything has been done in 1 and 2, then perhaps asking the help of other people who are experts at dealing with chronic pain. (January 2009)

What is the likelihood that a child of a parent with ankylosing spondylitis will get spondyloarthropathy?

**Robert Warren, MD:** That’s probably in the five to ten percent range. It’s probably a little higher for a boy than for a girl. So a parent can think about that, like the glass is half full or the glass is half empty. Five percent, one in 20 or one in ten is not very common. On the other hand, it’s certainly more common than would be the case if a parent did not have ankylosing spondylitis. (February 2009)
How often should spondylitis patients have scans to see if the AS has progressed and caused damage to the areas that are affected by the AS?

David Hallegua, MD: There are a number of things that can be done besides scans to look and see if AS is progressing or not. The simplest thing to do is something called metrology indices.

Metrology refers to measurement and these measurements are done in the physician’s office, usually a rheumatologist who is used to seeing patients with AS will know about that. The test involved includes a test where there is lateral bending of the spine and this lateral bending of the spine will get more limited as the disease progresses. In general, people are able to bend laterally and have the measurement be more than 15. When the lateral bending gets to be less than 10, then we start talking about mobilization with range of motion.

There are other tests that can be done. These include X-rays and MRIs. X-rays, when they are done to look and see if there are changes occurring due to ankylosing spondylitis, should probably be done once a year. Rheumatologists and radiologists look for changes such as squaring or a square shape to the vertebrae that are usually concave in shape, as well as the ligament calcification that we commonly see with ankylosing spondylitis as it’s progressing.

MRIs are sensitive to change, as well, and could show inflammation in new areas of the spine or of a particular joint or bone, such as the heel, which has suddenly become more painful and thus indicates that the ankylosing spondylitis in a given patient is more active. (April 2008)

What tips can you recommend to spondylitis patients to ensure that medical personnel who arrive in an emergency are made aware of any special needs?

Gary Vilke, MD: Communication is probably the most important aspect of this. A person who is awake and alert can usually communicate that they have ankylosing spondylitis, but first responders may not quite grasp what that means. You may have to use terms that are more basic, but are not insulting, for example, “I have ankylosing spondylitis. As you probably know that’s the brittle spine disease that puts me at risk for easy breaks in my neck or my back, with particular injuries”. It comes across as you expect them to know it even if they don’t. So that gives them a little bit more information.

If somebody can’t communicate their underlying medical condition, it’s important for them to wear some type of medical jewelry that says “ankylosing spondylitis”. “Brittle Spine Disease” probably is even more telling, because if you become unconscious during an emergency, the first responder does not have to translate what ankylosing spondylitis means.

Lastly, keep a card in your wallet. Paramedics are trained to look in there. Also, family members need to be able to communicate not only that you have ankylosing spondylitis, but what it means. It may be helpful to use lay terms such as “Brittle Spine Disease” or “bamboo spine that breaks easily”. (April 2009)

Disclaimer: Information provided in this article cannot replace treatment provided by healthcare professionals. Please consult with your physician if you have any questions.

SAA would like to thank the physicians who participated in these interviews.
Chronic pain and inflammation, like that associated with ankylosing spondylitis, can be related to anxiety. In fact, a study conducted in 17 countries around the globe found that people with chronic neck and back pain were more than two times more likely to develop an anxiety disorder than those without neck and back pain.

But what is the connection between anxiety and pain . . . and what can we do about it?

Anxiety, says Ron Glassman, PhD, MPH, a New Jersey-based behaviorist and neuroscientist who specializes in anxiety, fear and phobias, is a surge in stress hormone levels in the blood stream. When this surge occurs (adrenaline is the primary stress hormone involved), our fight-or-flight response is initiated. Our heart rate increases, our muscles tense up, our palms become sweaty. This fundamental physiologic response is our body’s primitive, inborn reaction that prepares us to either fight or flee from perceived harm. That harm can be physical—such as a man running at you with a knife; mental—such as worrying about how you’re going to pay the bills; or medical—such as dealing with the dull, throbbing pain that accompanies a disorder like AS.

Stressed-out cells
The more stress our body is under, the more distress it causes to cells in the body. Our bodies are comprised of billions of cells. Stressed cells lead to inflammation, and inflammation oftentimes leads to pain. Anything that ends in “itis” is inflammation—appendicitis, sinusitis, spondylitis.

“Anything that causes our body to be out of balance puts stress on cells,” says Dr. Glassman. “Inflammation is the body’s response to stress. Inflammation is to the human body what rust is to lawn furniture—it wears it down.”

Individuals with spondylitis know the effects of inflammation all too well: persistent pain and stiffness spreading up the spine and into the neck; tenderness in the ribs, shoulders, hips, knees, thighs and heels; and fatigue as the body expends energy to deal with the inflammation.

Stress and anxiety exacerbate the inflammation associated with AS (just as they exacerbate many other illnesses, even the common cold). While the inflammation will likely never go away, there are steps individuals can take to reduce their stress levels and improve their quality of life.

The traditional Western approach to coping with stress starts with medications like relaxants (Xanax) and antidepressants (Zoloft). These medications are effective for most people, but they do have side effects. General day-to-day anxiety, considered mild to moderate, is often best managed without medications by learning stress management techniques. Dr. Glassman’s approach to anxiety and stress management is based, in part, on the Relaxation Response, which has its roots in the East.

Five minutes to calm
Based on Transcendental Meditation, the Relaxation Response is a form of meditation that has been practiced for many years. Herbert Benson, MD, the founder of the Mind/Body Medical Institute in Boston who defined the Relaxation Response, says the Relaxation Response “is a physical state of deep rest that changes the physical and emotional response to stress and is the opposite of the fight-or-flight response.”
The benefits of the Relaxation Response are an increased awareness of whether you are tense or relaxed and a greater ability to relax when you are stressed out. Dr. Glassman says practicing his modified version of the Relaxation Response three times a day for five minutes can create a greater level of balance in the body, reducing inflammation and pain.

**Here’s how it’s done:**

- Sit in a chair or recline on a couch or bed. A quiet space is better, but not necessary. Close your eyes and take a half-dozen or so deep, cleansing breaths to get oxygen into your bloodstream. Dr. Glassman says these cleansing breaths help release the “steam valve” created by stress, increase feel-good endorphins, and decrease stress hormones.

- After completing the cleansing breaths, think about each major muscle group from your head to your toes. Tighten your face and jaw muscles, hold them for 3 seconds, then relax. Then, move to your shoulders. Raise and hold them for 3 seconds, then drop them like lead. Tighten your arm muscles, count to 3, and let your arms go limp. Continue doing this with each major muscle group right down to your feet. “In order to feel what muscles feel like relaxed,” says Dr. Glassman, “you must first tense them up. This helps you to recognize when you’re tense and understand true relaxation.”

- Visualize a situation in your mind that you associate with feeling good. For some, this may be standing on a beach, while others may find comfort on a mountaintop. Daydream about this situation and let your body and brain absorb the feeling. “There’s a direct connection between how we think and how we feel,” says Dr. Glassman. “The visualization of this feel-good situation sends calm into your body.”

**Seduce your mind**

Regardless of your medical condition, says Dr. Glassman, if you have chronic pain, this approach is where you can “seduce your mind to decrease your pain intensity. You can use your mind to improve your condition.”

About 20 percent of the patients Dr. Glassman treats have spondylitis. He says that those who practice his modified Relaxation Response diligently—three times a day for a solid month—report less discomfort and feel as if they are a part of their disease resolution.

> “Stress and anxiety exacerbate the inflammation associated with AS (just as they exacerbate many other illnesses, even the common cold).”

“It’s empowering to 100 percent of the people who try it,” he adds. “One hundred percent feel less discomfort. Their pain is not gone, but it’s less frequent, less intense.”

In today’s busy world, we can’t stop stress from happening. Stress hormones are constantly flowing because many of us are always under the gun. For individuals with spondylitis, stress and anxiety only add to the pain and discomfort they may already be feeling. But, if they can train their mind and body to be more resilient to stress [through the Relaxation Response], then they are less likely to feel that racing heart and sweaty palms—and their pain and discomfort might just go away for awhile, too.

SAA would like to thank Dr. Glassman for his contribution to this article.
We gratefully thank our corporate partners for their generous support. The Corporate Partnership Program provides an opportunity for the pharmaceutical companies who have treatments approved for ankylosing spondylitis and related diseases to positively benefit the spondylitis community by contributing funds to the Spondylitis Association’s general operating budget and to support special program services. *

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If you’d like to find out more about support groups and for a complete list of groups and meeting dates, visit our website at: http://www.spondylitis.org/patient_resources/

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: Morristown, NJ
When: Saturday, September 11
David Karlovich spoke on the topic of Acupuncture and Spondylitis.

Where: San Diego, CA
When: Saturday, September 18
Alexander Shikhman, M.D., Ph.D spoke on the topic of Medical Management of Spondylitis.

Where: Deland, FL
When: Saturday, October 2
Brent Schlapper, DO spoke on the topic of Tools, tricks and Durable Medical Equipment supplies to help in the spondylitis patient’s daily life.

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