An Updated Overview Of Spondyloarthritis: A Family Of Related Diseases

Creative Coping: Diversion Therapy

Living with Psoriatic Arthritis
The Spondylitis Association of America (SAA) turns 30 years young this summer, and I am proud to have been with SAA for nearly a third of its existence. This past decade has been a whirlwind of progress as we have continued to lead the charge in spondyloarthritis research. During this year alone, we have driven a number of exciting, essential research initiatives:

**Spondyloarthritis Treatment Guidelines** - After helping fund the project, SAA is collaborating with the American College of Rheumatology (ACR) in developing a much needed set of standardized treatment guidelines for spondyloarthritis. These guidelines will address the most commonly encountered clinical situations when treating ankylosing spondylitis and axial spondyloarthritis patients. Additionally, the new guidelines will address preventive care, disease activity monitoring, pharmacological treatment and special patient populations including children with juvenile-onset spondyloarthritis.

This is the first time in history that ACR has collaborated with another organization in developing such guidelines.

**Spondylitis Patient Registry** - Funded initially by SAA, the patient registry is a database - a compilation of data on people with ankylosing spondylitis. In this case, the registry is a combination of three current patient databases that have been used in ankylosing spondylitis research. Thus, we are currently building a new database that can look at thousands and potentially tens of thousands of patients with AS and see health trends, disease severity over time, age, medication effectiveness, complications and more.

**TASC** - The Triple-A (Australo-Anglo-American) Spondyloarthritis Consortium, or TASC, has identified 20-plus genes linked to ankylosing spondylitis since 2007. In the future, these genes can lead to new treatments and possibly earlier diagnosis.

SAA originally ignited spondylitis genetic research in the US and continues to participate in the ongoing TASC study by encouraging enrollment. You can read more about TASC on pages 18 & 19 of this issue.

For 30 years, we have been a primary launch point for spondyloarthritis research in the US. Together with our supporters we will continue to do everything in our power in the quest for the cure.

Sincerely,

Chris Miller
Editor-in-Chief, *Spondylitis Plus*
Director of Programs, SAA
Faces of AS
The winter issue of Spondylitis Plus was the best yet. I am especially happy to see that you included the article about Faces of AS. This is an important project and a great resource. I encourage anyone who hasn’t done so yet to send in your story!
~JOY, St. Louis, MO

Editor’s Note: Thanks much, Joy. We will continue to feature new "Faces"; in this issue we feature a story from Rebecca on page 14. If you wish to submit your story, please see the information on page 16.

What About Undifferentiated Spondyloarthritis?
As much as I regret that my first communication is a negative one, I feel compelled to write. I am comforted that Spondylitis Plus exists, however, it seems to focus solely on ankylosing spondylitis (AS). My diagnosis is Undifferentiated Spondyloarthritis (USpA). It was my understanding that SAA wanted to support all of us. The large majority of articles in the Winter 2012 issue seem to discuss only AS. I look to SAA to feel supported and understood, but the content of the issue left me wondering if my diagnosis mattered or was less problematic. I suffer with great fatigue and few people get it. I was excited when I saw the article on fatigue, then felt let down when the article only mentioned AS.
~FRAN, Broomall, PA

Editor’s Note: At SAA we are here to support everyone with spondyloarthritis (SpA). In this issue we have an updated overview on all the conditions that make up this "family of diseases" and how they relate to each other starting on page 4.

Non-Medicinal Treatments: TENS Unit
Has SAA ever investigated and/or published an article on the use of electrical stimulation for AS pain relief? There is a lot of research and clinical studies to draw data from on this type of pain treatment, but almost no references specifically to the potential benefits to AS patients. My doctors have no objection to me trying this treatment, but they also have little or no experience on this subject. Therefore, they have no specific recommendations.

I just bought a combo device that does both TENS (Transcutaneous Electrical Nerve Stimulation) and EMS (Electrical Muscle Stimulation), and my initial reaction is positive for relief from my chronic AS pain.

If this subject has already been covered by SAA, would you please direct me to any sources for my education as applied specifically to AS?
~RUSS, Cathedral City, CA

Editor’s Note: Russ was able to follow up with SAA Member and Support Group Co-Leader Dr. Mike Supancich; SAA Member, Seminar Presenter, and Spondylitis Plus Contributor Sturdy McKee, MPT, as well as other professionals to have the technical aspects of his question answered. Prompted by his inquiry, we asked our friends on Facebook to share their experiences with TENS units, and other non-medicinal treatments. See pages 20 and 21.
Q: We hear a few different terms to describe ankylosing spondylitis (AS) and related diseases: Spondyloarthritis, spondyloarthritides and spondyloarthropathy...Is there a difference?

Spondyloarthritis and spondyloarthropathy are often used interchangeably. Some experts prefer the term spondyloarthritis rather than spondyloarthropathy because the ending “arthritis” indicates inflammation of the joint, whereas the ending “arthropathy” can refer to any type of joint disease. Inflammation is a key feature that helps distinguish spondyloarthritis from other types of arthritis, including wear-and-tear arthritis, such as osteoarthritis. Spondyloarthritides is the plural form of spondyloarthritis.

Q: How is this group of diseases related? Why is it sometimes called a “family” of conditions?

These diseases look and behave in similar ways because they share overlapping disease features. Common features of spondyloarthritis include inflammation in the spine, pelvis, other joints, intestine, eyes (Editor’s note: please see side bar on Uveitis / Iritis to the right), and heels. This family of diseases is divided into individual categories according to the predominant disease feature(s).

Q: What does “seronegative” mean? How does it relate to this group of diseases?

Seronegative means that specific blood tests used to help diagnose rheumatoid arthritis are negative. In some instances, these blood tests are helpful in determining whether a person has rheumatoid arthritis or spondyloarthritis. In most cases, a diagnosis of spondyloarthritis can be made without these blood tests.

For example, inflammation of the intestine can occur with any type of spondyloarthritis, but is most pronounced in patients with IBD-associated arthritis (also called enteropathic arthritis).
Q: Is ankylosing spondylitis (AS) considered the “primary” disease? Why or why not?

For people with ankylosing spondylitis, it is the primary disease. For people with other types of spondyloarthritis, it is not.

In the past, ankylosing spondylitis has been portrayed as the primary type of spondyloarthritis for several reasons including the following:

1) Ankylosing spondylitis is easier to study than reactive arthritis and IBD-associated arthritis because it is much more common.
2) Ankylosing spondylitis is often easier for doctors and patients to recognize than undifferentiated spondyloarthritis and reactive arthritis.
3) Ankylosing spondylitis has been recognized as a unique type of arthritis for hundreds of years, whereas other types of spondyloarthritis were described more recently. For example, psoriatic arthritis was not widely recognized as a distinct form of arthritis until the 1960s.

Q: Can you give us a key symptom or “feature” of each of the conditions in this group? What makes each one distinct or different from the others?

Ankylosing Spondylitis (AS):

Inflammation in the pelvis and/or spine causes inflammatory back pain. Inflammatory back pain usually starts gradually before the age of 40, tends to improve with activity but not rest, and occurs with stiffness in the morning that lasts at least 30 minutes.

Reactive Arthritis (Reiter’s Syndrome - ReA):

An infection in the intestine or urinary tract usually occurs before inflammation in the joints.

Juvenile Spondyloarthritis (JSpA):

Symptoms begin in childhood. JSpA can look like any other type of spondyloarthritis. Enthesitis (inflammation where tendons or ligaments meet bone) is often a dominant disease feature.
Arthritis Associated With Inflammatory Bowel Disease (Enteropathic Arthritis - EnA):

Inflammation of the intestine is a predominant feature. Symptoms may include chronic diarrhea, abdominal pain, weight loss, and/or blood in the stool. The most common types of inflammatory bowel disease are Crohn’s, ulcerative colitis, and undifferentiated colitis.

Psoriatic Arthritis (PsA):

PsA frequently causes pain and swelling in the small joints of the hands and feet. Most people with PsA have a psoriasis skin rash. Some people have a “sausage digit” with a toe or finger that swells between the joints as well as around the joints.

Undifferentiated Spondyloarthritis (USpA):

People with USpA have symptoms and disease features consistent with spondyloarthritis, but their disease doesn’t fit into another category of spondyloarthritis. For example, an adult may have iritis, heel pain (caused by enthesitis), and knee swelling, WITHOUT back pain, psoriasis, a recent infection, or intestinal symptoms. This person’s combination of disease features suggests spondyloarthritis, but he or she doesn’t fit into the categories of ankylosing spondylitis, psoriatic arthritis, reactive arthritis, juvenile spondyloarthritis or IBD-associated arthritis.

Q: Can one of these conditions share symptoms or complications with another one of the conditions? In general terms, do symptoms overlap? If so, how? What are the main similarities - if any?

Absolutely. The main similarities that can occur with any type of spondyloarthritis are:

- Inflammation in the pelvis and spine that usually causes inflammatory back pain.
- Pain and/or swelling of any other joint in the body (hips, knees, ankles, feet, hands, wrists, elbows, shoulders etc.)
- Sudden onset of marked pain and redness in one eye at a time (uveitis/iritis).
- Psoriasis skin rash.
- Inflammation in the intestine (Crohn’s, ulcerative colitis, undifferentiated colitis).
- Inflammation along the tendons of the finger or toes (sausage digits, also called dactylitis).
- Inflammation where tendons and ligaments meet the bone (enthesitis). This commonly occurs at the back or bottom of the heel.

Q: Why would a doctor diagnose one form of spondyloarthritis over another?

Doctors classify people as having a certain type of spondyloarthritis according to the predominant disease feature(s). For example, a person with psoriasis and joint swelling in the hands and feet will most likely be classified as having psoriatic arthritis. A person with inflammatory back pain and x-ray changes consistent with inflammation in the sacroiliac joints in the pelvis will likely be classified as having ankylosing spondylitis. A person with Crohn’s and swelling in the knees and ankles most likely has IBD-associated arthritis. Sometimes, disease features are equally dominant and a person may fit into more than one type of spondyloarthritis. For example, a person could have psoriasis, inflammation in the pelvis/spine, and Crohn’s disease. This person could correctly be said to have any of the following:

1) Psoriatic arthritis with ankylosing spondylitis and Crohn’s.
2) Ankylosing spondylitis with psoriasis and Crohn’s.
3) IBD-associated arthritis with ankylosing spondylitis and psoriasis.

Q: Can a diagnosis change from, say, undifferentiated spondyloarthritis (USpA) to ankylosing spondylitis or another one of these conditions? Why would this occur?

Yes. The diseases can evolve or change over time, since not all symptoms occur at once. For example, the previously discussed person with USpA with iritis, enthesitis, and knee swelling could develop back pain and inflammatory changes on x-rays that would lead to the diagnosis of ankylosing spondylitis.

Q: Are men and women affected at different rates between these diseases? Can you give us some details on how these rates were determined?

Similar numbers of men and women are affected with spondyloarthritis. In the past, it was thought that ankylosing spondylitis was more common in men than women. More recent studies suggest that ankylosing spondylitis occurs in similar numbers of men and women. Early estimates of the occurrence of ankylosing spondylitis suggested that ankylosing spondylitis occurred 9-10 times more frequently in men than women. However, there were problems with how these early studies were done. More
Recent studies reported that men are 2 to 3 times more likely than women to have ankylosing spondylitis. These studies use relatively narrow definitions of ankylosing spondylitis that rely on classic manifestations of inflammatory back pain and damage on x-rays. Classic inflammatory back pain may be the initial symptom in men more frequently than in women, and women may have less x-ray damage than men. Despite these differences, the overall disease severity is similar in men and women.

When broader definitions are used to identify people with spondyloarthritis in the pelvis and/or spine (axial spondyloarthritis), the prevalence is similar in men and women.

**Q: How are these conditions treated? Are there any notable differences in treatment such as prescribed medications?**

There are several treatment options for various types of spondyloarthritis. The treatments for each disease overlap, but they are not identical. For example, certain treatments may simultaneously help with psoriasis, inflammatory bowel disease, enthesitis, and arthritis. Other treatments may help with one or two disease features, but not the others. There are even some treatments that may help with one disease feature, but make another feature worse. Treatments need to be tailored for each individual, according to the type and severity of specific disease features. Many other factors must also be considered when selecting therapies, including other medical conditions, access to therapies, and the preferences of patients. [Editor’s note: Please see the medications table on page 10 for a list of commonly used medications to treat spondyloarthritis].

**Q: Is there a known cause for these diseases?**

We know that there are several specific genes that increase the risk of developing spondyloarthritis. HLA-B27 is the best studied gene and it associates most strongly with inflammation in the pelvis (sacroiliac joints) and spine. Most people with HLA-B27 and other high risk genes never develop spondyloarthritis. We don’t yet understand why some people develop disease and others don’t. There are also studies suggesting that things in our environment may cause disease. For example, specific types of infections may trigger disease. However, environmental triggers are not known for most people who develop spondyloarthritis. There is much research that needs to be done to better understand why certain people get these diseases.

**Q: Is there a cure?**

Not yet…

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**Dr. Jessica Walsh** is a rheumatologist at the University of Utah as well as the Veterans Affairs Medical Center in Salt Lake City. There, she is also the Director of Spondyloarthritis Clinics, the founder of the Utah Psoriatic Arthritis Initiative, and Principal Investigator for the Program to Understand the Long-term Outcomes in Spondyloarthritis (PULSAR) registry.

Dr. Walsh is a member of the Spondyloarthritis Research & Treatment Network (SPARTAN) and of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA).

In addition, Dr. Walsh was a keynote speaker on spondyloarthritis at SAA’s Educational Seminars in Chicago in 2011 and in Washington, DC in 2012.

We thank Dr. Walsh for her time in answering our questions for this article.
When you hear about a skin disease like psoriasis, you probably don’t link it to such things as joint pain and stiffness. But nearly 5 percent of Americans with psoriasis have a related condition, called psoriatic arthritis (PsA), which can lead to permanent and debilitating joint damage.

PsA is a type of arthritis that often occurs after psoriasis; a common, chronic skin condition that causes raised red patches on the skin, often with a silvery scale (psoriatic skin lesions). The arthritis may be mild and involve only a few joints, especially at the ends of fingers or toes, or it may be severe and affect many joints, including the spine. An estimated 600,000 Americans—and more than 12 million people worldwide—have PsA, which may strike at any age, but typically occurs between the ages of 30 and 50.

In PsA, immune cells are activated and produce too much of a protein called tumor necrosis factor-alpha, or TNF-alpha. This protein causes inflammation in the skin, which can cause skin cells to grow too quickly. As skin cells build up, raised, red patches form. The protein also causes inflammation of the joints, which can lead to pain and progressive joint damage.

PsA and ankylosing spondylitis (AS) are considered genetically and clinically related because both are inflammatory diseases related to the HLA-B27 gene. HLA-B27 is a powerful predisposing gene associated with several rheumatic diseases. The gene itself does not cause disease, but can make people more susceptible. While a number of genes are linked to PsA, the highest predictive value is noted with HLA-B27.

There are five distinct types of PsA:

• Symmetric PsA, which affects the same joints in multiple matching pairs on both sides of the body, can be disabling, causing varying degrees of progressive joint destruction and loss of function.
• Oligoarticular (asymmetric) PsA, which affects only a few joints but not matching pairs on opposite sides of the body, is often a milder form of the disease.
• Distal interphalangeal predominant PsA, which primarily affects the joints closest to the toenails and fingernails, is sometimes confused with osteoarthritis.
• Psoriatic spondylitis, which affects the spinal column from the neck to the lower back.
• Arthritis mutilans, a rare but severe, destructive form of the disease that leads to loss of joint function.

About 20 percent of patients with PsA will develop spinal involvement. Inflammation of the spine can lead to complete fusion, as in AS, or affect only certain areas such as the lower back or neck. Patients who are HLA-B27-positive are more likely than others to have their disease progress to the spine.
**Symptoms**

While PsA is a single disease, it can have many different symptoms that affect the skin and joints, including:

- Swelling of an entire finger or toe, which can cause them to look like sausages
- General joint pain and stiffness, especially in the morning
- Joint swelling
- Back pain and stiffness, primarily in the lower back, neck and upper back
- Reduced range of motion
- Painful, often throbbing, joints
- Psoriatic skin lesions
- Nail changes, including pitting of the fingernails and toenails, which occurs in almost all patients

Other symptoms include generalized fatigue and redness or pain in the eye. Thirty percent of PsA patients have eye inflammation (conjunctivitis) and seven percent have iritis, or inflammation of the colored part of the eye.

The symptoms of PsA, which vary from person to person, can change in severity. Skin symptoms typically appear before the joints become involved, sometimes up to 10 years before. Without treatment, many of these symptoms can lead to progressive, permanent joint damage.

**Diagnosis**

Diagnosing psoriatic arthritis can be tricky, primarily because it shares similar symptoms with other diseases such as osteoarthritis, rheumatoid arthritis and gout. Because of this, misdiagnosis can often be a problem. Early diagnosis, however, is important because long-term joint damage can be warded off better in the first few months after symptoms arise.

Primary care physicians and dermatologists can diagnose PsA, but a rheumatologist, who specializes in arthritis, may be able to better spot the telltale signs of the disease.

There are no definitive tests for diagnosing PsA. Doctors diagnose the disease primarily based on a patient’s clinical presentation and process of elimination (for example, the presence of rheumatoid factor in the blood can differentiate rheumatoid arthritis from PsA). A complete medical history and physical examination, as well as blood tests, X-rays and MRI scans of joints that have symptoms, can be used to diagnose PsA.

In the early stages of the disease, standard X-rays usually don’t reveal signs of PsA and may not aid in diagnosis. In later stages, however, they may show characteristic changes that distinguish PsA from other rheumatic diseases. One of these is the “pencil-in-cup” phenomenon, in which the end of a bone gets whittled down to a sharp point where it enters a joint. Changes in the peripheral joints and spine, which also occur in later stages of disease, can also support a PsA diagnosis.

**Treatment**

Treatment of PsA has changed dramatically over the past few decades. Thirty years ago, patients with PsA and rheumatoid arthritis were frequently treated with weekly gold injections. Twenty years later the use of anti-TNF drugs revolutionized the treatment of the disease and scientists continue to learn more about the disease and how to successfully treat it.

The most common treatments for PsA are often used to treat AS, and include:

- NSAIDs – nonsteroidal anti-inflammatory drugs, which are sold either over the counter or in prescription strength, help reduce pain, inflammation and stiffness and have proven effective for many patients with PsA. These drugs include ibuprofen (Advil, Motrin), indomethacin (Indocin) and naproxen (Aleve) among others.
- DMARDs – disease-modifying antirheumatic drugs, which help to limit the amount of joint damage caused by the disease. Methotrexate (Trexxal) is the most commonly used DMARD. Sulfasalazine (Azulfidine) has a moderate effect in treating PsA.
- Immunosuppressants – drugs that suppress the immune system, which normally protects the body, but attacks healthy tissue in autoimmune diseases like PsA. Azathioprine (Imuran), cyclosporine (Sandimmune) and leflunomide (Arava) are commonly prescribed. Because of serious side effects, these drugs are only used in patients with severe PsA.
- TNF-alpha inhibitors – drugs that block the action of the proinflammatory protein involved in PsA. These include adalimumab (Humira), etanercept (Enbrel), golimumab (Simponi) and infliximab (Remicade).

An experimental drug, called apremilast, has proven to be moderately effective in treating late-stage PsA compared to other leading therapies. This drug inhibits the enzyme phosphodiesterase 4 and tamps down inflammation.

Exercise is essential for preserving strength and maintaining range of motion. Isometric exercises, which contract muscles without joint motion, may be less damaging to inflamed joints. Physical therapy may also help patients maximize the function of arthritic joints.

Patients should consult with their physician to determine which of these treatments is most appropriate for their condition.

While PsA can certainly affect an individual’s quality of life, the symptoms of the disease can be managed effectively. Paying attention to symptoms of the disease and addressing them as soon as they arise can, in fact, lead to positive outcomes.

**Story by Scott P. Edwards** - Scott P. Edwards is a freelance health and medical writer based in Holliston, Mass. He has written for Harvard Medical School, Dana-Farber Cancer Institute, the Salk Institute for Biological Studies, and Nature Publishing Group.
Tell your doctor about all your prescription and over-the-counter medications, vitamins, minerals, herbal products, and drugs prescribed by other doctors. Do not start or stop a medication without telling your doctor. This list is not intended to be exhaustive and is intended only to be used as a general guide.

### NSAID (Non-Steroidal Anti-Inflammatory) Therapy

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<th>Generic or Brand Name</th>
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<th>Long Acting Formulation Dose &amp; Frequency</th>
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<th>Maximum Daily</th>
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### DMARDs (Disease Modifying Anti-Rheumatic Drugs)

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<td>Azulfidine</td>
<td>Sulfasalazine</td>
<td>500-1000 mg</td>
<td>2-3 times/day</td>
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<td>Imuran</td>
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<td>Rheumatrex, Trexall</td>
<td>Methotrexate</td>
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<td>1 time/week</td>
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### TNF-α Inhibitors / Biologic Medications

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<th>Frequency</th>
<th>Total Dose (Range)</th>
<th>Route of Administration</th>
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<td>Enbrel</td>
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<td>Remicade</td>
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<td>Humira</td>
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<td>Simponi</td>
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What have SAA support groups and support group leaders been up to recently?

Way too much to list all of it here! Some highlights:

• North Dakota
  Bonnie Smith and Gerry Fisher organized the First Northern Great Plains Autoimmune Health Fair and Educational Symposium for the community on February 16th, 2013 in Bismarck, ND.

• Indiana
  Ken Prather is once again participating in the big annual health fair in Fort Wayne, IN this April and representing SAA to over 1,500 attendees! Ken has been exhibiting at the annual “Focus on Health” community fair to educate his community about spondylitis for many years now, and we salute and thank him for his endless commitment and passion to the cause.

• Arizona
  Jacquie Gregor is preparing to exhibit at two separate conferences for teens and young adults with arthritis in April and May.

• Minnesota
  New Support Group in Rochester, MN! Led by Saad Sirop Kenderian, MD, the Rochester group held its first meeting on February 10th at the Mayo Clinic.

• Virginia
  The Richmond, VA Support Group, led by Sam Brumberg, Esq is back to its regular meeting schedule after a short break. This group will next meet on May 28th.

You will find information and upcoming meeting dates for all the groups listed here, as well as many others, at www.StopAS.org/groups
As we seek to expand the number of rheumatologists and researchers in the USA focusing on spondyloarthritis, we at the Spondylitis Association of America hope to encourage new, upcoming rheumatologists to focus on the future of treatment and research in spondyloarthritis.

To this end, one of our efforts was the creation of the Spondylitis Association Bruckel Young Investigator Award, which recognizes outstanding "contributions to the care and understanding of patients with spondyloarthritis." The award winner gets a $10,000 grant from SAA for use in spondylitis research. This past year, we were proud to present the award to Dr. Lianne Gensler.

Dr. Gensler is the Director of the Ankylosing Spondylitis Clinic at UCSF in San Francisco, CA. She is an Assistant Professor of Medicine in the division of Rheumatology and sees patients in addition to teaching and performing research in Spondyloarthritis.
The SAA young investigator award is an honor that is quite overwhelming. In my day-to-day practice in patient care and clinical research, I am already honored to work with patients that allow me the privilege of caring for them and learning from them at the same time. This award will allow me to do that to an even greater degree and pursue ideas that I believe will have a great impact in understanding how this disease works and how we can overcome its progression.

“I am thrilled to be able to continue to work on these ideas and help move the field forward.”

Though we believe that ankylosing spondylitis is strongly rooted in genetics, what we are less clear on is how we can slow down its progression. Through our research, we have been able to show that smoking is a risk for progression, doubling the odds. We have also shown for the first time that patients who use the biologic agents - (TNF inhibitors) - have a more than 50% reduction in the risk of progression! It is not clear that everyone needs these drugs as some patients may never progress, and some patients may be able to mitigate this progression by other modalities. I am thrilled to be able to continue to work on these ideas and help move the field forward.

I am most thankful to the SAA and all of the patients that we serve for helping to make this all possible!

~Dr. Lianne Gensler
Even though I have a lot to deal with, I continue to keep a smile on my face and continue to be hopeful for the future.

When I started experiencing headaches, joint pain, and several other symptoms in October of 2008, I never realized it would take more than three years to finally get the answers I sought. Between the fatigue and the pain, I was unable to attend school and had to have a tutor come out to help me with my school work. I was able to return to school off and on until my senior year, which started in the fall of 2010.

In the spring of 2011, my mom was diagnosed with Ankylosing Spondylitis (AS). She then had my sister and I examined. The Rheumatologist felt that I had AS and my sister did not based on scans. The MRI of my SI joints showed a lot of inflammation and damage, so much so in fact that my doctor had never seen anything like it. She started me on Remicade in the fall of 2011, which seemed to be helping some until April of 2012.

That is when I started to get really sick and have severe pain and nausea (which was worse than normal). I had to be admitted to Johns Hopkins Children’s Center and no one knew what the future held. I was there for four weeks and returned a few days later for another two weeks. After many tests, three feeding tubes and a six-week hospital stay, they finally were able to figure out...
that my problems were coming from my spine. I have severe kyphosis and slight scoliosis (my kyphosis is now at 77 degrees and started at 35 degrees in 2010). Although I have my moments of wishing I were a normal teen, I realize that chronic illness is a part of me. I do not let my illness control who I am, but I do make sure those around me know that it is part of my life. At the moment I am doing pretty well with my AS symptoms, although I do have my good days and my bad days.

Before I began to decline this past spring, I was taking a full load of courses at Stevenson University where I was a film/video major. I am currently in online classes and am taking 10 credits. Next semester I will be taking time off in order to have surgery and recover. I hope to return to school next fall as a full time student and live on campus again. I have not decided what exactly I want to do after college, but I do know that I want to do something in the medical field as well as make documentaries about being sick.

I have had many struggles since my symptoms began in 2008, but I am determined not to let these struggles run my life. I have had to miss school, parties and other special events due to being sick. Even though my illnesses present physical challenges, I have also had many emotional ones as well. I try my best to maintain a positive outlook and use humor to lighten my situation. I have found writing to be a great way to get things out before they build up to the point of no return. While most people think being sick could only bring struggles, I know that it has also brought positive things into my life. If not for my long hospital stay, I would not have met the most amazing friends who I can talk to about anything including medical issues and just the stress of being sick.

One last important thing I have learned is that it is harder to watch those you love be sick than to be sick yourself. I have watched my mom worry about me and advocate for me until the doctors started to listen. My mom has been the one constant in my life throughout all of this. There is no way I can repay my mom for everything that she has done for me, but what she has taught me is to always show compassion and love to those you care about especially if they are not doing well.

I am determined not to let these struggles run my life.

I have started working with the child life specialist at Hopkins to come up with new ideas to help kids who are in the hospital a lot. It may take me longer than those who are well or those who are doing well at the time, but I am determined to give back to those who have given me so much over the last year.

“I am determined not to let these struggles run my life.”
I am hopeful that one day I will be able to do normal things like anyone else, but until that day, I will continue to do my best to do kind things for others while continuing to get better. I know that this is just the beginning of my story and I have many blank pages just waiting to be filled. This journey has been bumpy, but it has contributed to making me who I am today.

“I am determined to give back to those who have given me so much over the last year.”

Editors Note: We’d like to thank Rebecca for sharing her story with us. To read more stories from teens with spondyloarthritis, please visit SWIFT - Spondylitis Web Info For Teens at teens.spondylitis.org. You can also visit the “Faces of AS” online and share your story with us at StopAS.org/faces.

The Faces Of Ankylosing Spondylitis

www.StopAS.org/faces
A
n organization is only as good as the people who band together to contribute to fulfilling its mission. For the Spondylitis Association, that means the thousands — *tens of thousands* — who engage, interact, advocate, educate, support and inform.

As an SAA member, you have a myriad of choices when it comes to how you want to participate in this people-driven community.

- Is Facebook the first thing you check every morning? Check out [facebook.com/spondylitis](http://facebook.com/spondylitis) and join in the conversation with over 5,000 like-minded folks who tackle all subjects related to spondylitis.

- Are you looking for the most up-to-date, cutting-edge information on medications and treatments, or a vetted Rheumy in your area? [StopAS.org](http://StopAS.org) has what you’re looking for.

- Have you been meaning to get more exercise and want to help get the word out about the disease? Grab your pedometer and prepare to “Walk Your AS Off”. [walkyourasoff.com](http://walkyourasoff.com)

- Maybe you’d prefer to meet your peers in a face-to-face setting. If so, check to see if there’s an SAA Sponsored Support Group in your area, or perhaps start one of your own. [StopAS.org/groups](http://StopAS.org/groups)

- Are you looking for a place to pose questions, give or get support from people who face the same challenges? SAA’s interactive Message Boards are the place to connect with a diverse group of patients, family and friends, both veteran and newbie alike. [forums.spondylitis.org](http://forums.spondylitis.org)

- Or would you like to help bring us closer to a cure by participating in research? SAA will keep you informed of research opportunities as they arise. [StopAS.org/research](http://StopAS.org/research)

- You can also share your story by participating in the grassroots “Faces of AS” Project. These personal stories highlight the very real people affected by spondylitis and help to shine a light on the personal side of an under-known disease. [StopAS.org/faces](http://StopAS.org/faces)

These are only a few of the options available to SAA members to engage with their organization and take part. I hope you’ll find one or more that fit the level of participation that’s right for you.

And as a Supporting Member of SAA, you’ve taken your involvement to the next level by also providing financial support. Your monetary contributions help us create and maintain all these avenues of engagement and ensure that you receive *Spondylitis Plus*, the only multi-issue News Magazine in the US dedicated to serving the needs of the Spondylitis Community. *(If you want to help save printing and postage costs for SAA, you can sign up for an “electronic only” version of the magazine by going to StopAS.org/elec or by calling or emailing Helene Hart at 800-877-8189, ext. 229 or hhart@spondylitis.org).*

However you choose to participate in your SAA, we welcome your involvement!
Important Ankylosing Spondylitis Genetic Research Funded: TASC

The word came in November 2012 that genetic research SAA helped originally ignite in the USA back in 1998 will continue for the next five years; and it will continue on the international scale.

TASC, the current genetic research project composed of researchers in the United States, UK, Canada and Australia had its initial breakthrough in 2007 when the first new genes related to AS susceptibility - aside from HLA-B27 - were discovered: ERAP1 & IL-23R. At the time, Laurie Savage, SAA Executive Director and Co-Principal Investigator for TASC’s administrative core, stated, “This is the most significant breakthrough in AS research since HLA-B27 was uncovered 34 years ago and SAA played a significant role in making the study possible.”

As the research continued this past half-decade, the TASC team has identified 20-plus genes linked to ankylosing spondylitis. In the future, these genes could lead to new treatments and possibly earlier diagnosis.

The team at The University of Texas Health Science Center at Houston (UTHealth) Medical School is led by John Reveille, MD, who states, “We hope to diagnose the disease earlier and more accurately and to improve outcomes.”

That said, the discovery of ERAP1 in 2007 may lead to insights into more than just AS. A study published online on August 15, 2012 in the Annals of Rheumatic Diseases helps confirm that there is an “association between several polymorphisms located in ERAP1 and [spondyloarthritis] as a whole.” Thus, ERAP1 appears to not only be related to ankylosing spondylitis, but to all of the spondyloarthritis conditions.

With TASC now funded to continue its work, one can only imagine what discoveries and new breakthroughs will be revealed in the next five years regarding the cause of ankylosing spondylitis and related diseases.
**How to Help: Participating in the TASC Study**

**Are you willing to help researchers find the genes involved in ankylosing spondylitis?**

We would like to thank all of the people who have already dedicated their time and participated in TASC. We could not have gotten this far without you. That said, we still need to enroll more patients and their non-affected family members in order to continue to uncover the genes related to ankylosing spondylitis, which in the long term will help us move closer to new treatments, earlier diagnosis and - we all hope - an eventual cure. If you have not yet participated and would like to enroll, please contact a study coordinator in your area (see study center listing and contact information to the right).

**What Is The Criteria For Participating?**

Currently, TASC is accepting on-site enrollment. To qualify, a person must meet criteria for the diagnosis of ankylosing spondylitis including evidence of sacroiliitis (involvement/inflammation of the SI joints) on pelvic x-ray.

First degree relatives of enrollees may also participate. These would be parents, siblings and offspring age 12 and up who do not need to be symptomatic or diagnosed to take part.

**What Is The Process?**

Enrollees will also be asked to complete a questionnaire at each visit.

Family members of enrollees have two options:

A one-time on-site visit for a single questionnaire, evaluation and joint assessments by a rheumatologist, as well as genetic testing and possibly a pelvic x-ray if certain criteria are met.

**OR**

Family members can enroll by mail with completion of one questionnaire and a sample of saliva that is collected at home and mailed to a study center by Fedex for genetic testing. Study centers will provide the saliva kit and Fedex mailing supplies.

**USA TASC Study Centers**

Cedars-Sinai Medical Center, Los Angeles / Southern California Area
Contact Tessa Scaffide, 310-423-2422, tessa.scaffide@cshs.org
Principal Investigator: Michael H. Weisman, MD

University of Texas, Houston / Houston Area
Contact Laura Diekman, 713-500-6852, laura.diekman@uth.tmc.edu
Principal Investigator: John D. Reveille, MD

National Institute of Health, Bethesda MD / Washington DC Area
Contact Principal Investigator Michael M. Ward, MD, MPH, 301-496-7263, wardm1@mail.nih.gov

University of California, San Francisco / Northern California Area
Contact Grace Yoon, grace.yoon@ucsf.edu, or leave a voicemail at 415-353-2305
Principal Investigator: Lianne Gensler, MD

International TASC Study Centers

Toronto, Ontario Canada
Contact Maria Morales, mmorales@uhnresearch.ca
Principal Investigator: Robert Inman, MD

Brisbane, Australia
Contact Kelly Hollis, k.hollis@uq.edu.au or Linda Bradbury, RN, l.bradbury@uq.edu.au
Principal Investigator: Matthew Brown, MD

*www.stopas.org*
Helpful Hints:  
Non-Medicinal Treatments

Prompted by a question posed to us from SAA Member Russ about his new TENS unit (see the Reader’s Forum on page 3), we asked our Facebook friends the following question:

What to do when general Western Medicine just isn’t enough?

Other than medications, what have you found to be helpful in managing spondylitis symptoms? For example: TENS unit, acupuncture, specific exercises, ‘alternative treatments’, etc. The following is a sample of the responses on SAA’s Facebook page, Facebook.com/spondylitis

Editor’s Note: Please see the bibliography on page 27 for citations to studies mentioned in this article.

Charo
Exercise, light weights, light zumba, hot pads, cold pads...

Tiffany
Yoga, yoga, yoga!!! And Pilates is great too! Hot tub/shower/bath and massage help as well...

Emily
When I am flaring really badly, the only thing I can count on to help is my TENS unit – no matter what else I try, it always helps at least a little!

Lindsay
I cannot live without my TENS machine, massage, stretching, ice packs, heating pads...

Exercise is a cornerstone of treatment in spondyloarthritis. Multiple studies have shown that exercise can have a prolonged benefit when used as part of the treatment regimen.

Published on January 9, 2013, a study looking at Yoga and Musculoskeletal Conditions in general states that, “Evidence suggests that yoga is an acceptable and safe intervention, which may result in clinically relevant improvements in pain and functional outcomes...”
Tai Chi and meditation, but nothing beats a nap when the going gets rough.

A study done in 2008 on Tai-Chi & Ankylosing Spondylitis suggests that “tai chi can improve disease activity and flexibility for patients with AS.”

Pet love and my waveless water bed - a giant heating pad that conforms to my body and lets me do breath work...if there was one thing I would not want to live without it’s my waterbed.

IMS - Intramuscular Stimulation by a physiotherapist has been a life-saver for me!

Intramuscular Stimulation is an anatomy-specific form of acupuncture performed by specially trained physiotherapists and some doctors.

I use acupuncture, Curcumin (turmeric), yoga and my bio-mat to help with my flare-ups.

A study in 2012 concluded that acupuncture may be “effective for the treatment of chronic pain and is therefore a reasonable referral option.”

There have been studies that examined curcumin (diferuloylmethane) - a yellow coloring agent extracted from turmeric - as a remedy for the treatment and prevention of inflammatory diseases. It is thought to be a natural anti-inflammatory.

Hot Baths w/ Epson salts, sometimes 2 or 3 times a day, gotta do what helps and at times that’s all that helps me...

Please note that SAA does not endorse or recommend any medications or products for spondylitis, and always advises that you seek the counsel of a physician before initiating any treatment for spondylitis. The opinions expressed here are solely those of the posters on Facebook.
Editor’s Note: We’d like to thank Kelly for allowing us to reprint her article in Spondylitis Plus. Our Medical and Scientific Advisory Board would like to preface the article with the following:

Some patients with ankylosing spondylitis are treated with a medication called infliximab or Remicade, which is given through the vein. This can be a very effective medication, but like all forms of therapy, it has risks. When medications are given by vein, allergic-type reactions can occur. Fortunately, these are very rare. The recent meeting of the American College of Rheumatology had an excellent discussion of this occasional problem. Patients who are receiving infliximab might enjoy the following information.

An infusion nurse talks about safety with Biologics

One practical session at the 2012 American College of Rheumatology (ACR) Scientific Meeting was a short talk on preventing infusion reactions presented by a nurse from Seattle, Christine Elliot. Ms. Elliot has supervised 15,000 rheumatological infusions in over a decade as an infusion nurse. She offered an overview of infusion reaction safety and shared insights she has gained from her extensive experience.

Biologics are often prescribed for moderate to severe Rheumatoid Arthritis (Rheumatoid Disease) [as well as forms of spondyloarthritis] when response to disease modifying drugs (DMARDs) is insufficient. In the U.S., four different biologic treatments are administered via IV infusion: infliximab (Remicade), rituximab (Rituxan), abatacept (Orencia), and tocilizumab (Actemra). For many people with Rheumatoid disease, infusions become a regular part of life.


What is an infusion reaction?

According to Elliot, an infusion reaction includes any signs or symptoms experienced by a patient during the infusion of pharmacologic or biologic agents or any events occurring on the first day of drug administration. Infusion reactions can be acute (occurring within two hours of infusion) or delayed (occurring up to 14 days after an infusion). The most common indicators are rash, flushing, change in blood pressure, or a “tickle in the throat.”

Management of a mild infusion reaction

Most infusion reactions are mild with symptoms such as headache, nausea, or dizziness. Stopping the infusion of the drug is usually sufficient to treat mild reactions. However, it is important to keep the IV intact in order to continue to provide saline to the patient for hydration or in case other IV medication is required. In most cases, infusion reactions resolve at this point.

Managing a moderate infusion reaction

Further signs of an infusion reaction include back pain, chills, nausea, joint aches, fever, and fatigue. Obviously, it is important that a patient and the nurse distinguish these as changes from usual Rheumatoid symptoms. Treatment is the same as with a mild reaction, except that medication may be given to treat the symptoms: usually 25-50 mg of diphenhydramine, 500-650 mg acetaminophen, or a dose of hydrocortisone pushed via the IV.

Dealing with a severe infusion reaction

Severe infusion reactions are rare. Symptoms include hypo or hypertension (a 40 mm degree difference in blood pressure), angioedema, wheezing, or stridor. Treatment is the same with care to maintain the airway and the possible use of oxygen or epinephrine to treat anaphylaxis. Cardiac arrest is extremely rare and Ms. Elliot has never seen this in a rheumatology patient.

8 more take-aways for patients about infusion reactions

5. Prompt intervention is important and may prevent a more serious reaction.

6. Medication is not always needed. Stopping the infusion or slowing the infusion rate is often sufficient, along with adequate hydration. Elliot said to keep the saline IV “wide open.”

7. Any off time of a drug increases the chance of having an infusion reaction.

8. Always maintain the IV in case it is needed to treat the reaction.

9. Rule of twos: reactions usually begin between 2 minutes and 2 hours of beginning an infusion.

10. It helps if the nurse communicates well with the patient in order to recognize a reaction early and distinguish it from anxiety, hunger, pain, or other distress.

11. Re-challenging: a decision to try the drug again must be made on a case-by-case basis.

12. A tickle in the throat, a final note

Elliot mentioned that in her research she had never seen any literature about the throat tickle symptom, but that it occurs frequently with rituximab. And only with rituximab.

FROM THE AUTHOR: I did have this symptom during some of my Rituxan infusions and I can tell you it feels like a cold virus is coming on. I’m not sure why it has not been better documented since its common and a clear sign to slow the infusion rate.
I don’t like having Ankylosing Spondylitis. It’s a crummy affliction, it hurts and makes my life miserable, painful, and then I resort to profanity. No really, I literally use every bad word I know and for a very good reason. Let me explain: When I tell people I have Ankylosing Spondylitis (AS), a particular variety of inflammatory arthritis, I carefully explain to them it’s not fatal, it just feels that way sometimes. AS is a harsh, unrelenting disease, that demands strong medicine, and I may have figured out a pain relief regimen that actually works.

I owe my discovery to a woman friend who once described giving birth as passing a bowling ball wrapped in barbed wire. It sounded painful (not AS painful mind you) and the fact that she was passing the thing meant that there promised to be some end point prior to death. Nevertheless, she got me thinking. In the midst of this woman’s great painful passing of the object, what was she instructed to do for the pain? Breathe! Whosh whosh whosh, in and out, in and out, over and over. Does it lessen the pain? Not really. Well maybe. It’s really the simplest form of diversion therapy that exists, a simple technique to compel the brain to focus on anything other than that bowling ball trying to force an exit.

My next clue that I was on the right track was a study done at Keele University in England. “Our research suggests that swearing is a useful part of language that can help us express strong emotions or react to high pressure situations.” Genius!

It was this collection of information that formed the genesis for my blueprint in dealing with AS. Over the years I’ve spent a lot of time and energy thinking about pain management without drugs, and I think I’ve finally perfected the most potent, chemical-free element available to combat the torture of chronic pain. I call it Profanity Diversion Therapy, or PDT for short.

My highly refined treatment is an alternative form of diversion therapy, the art/science of thinking about anything except the chaos taking place inside the body. I know, easier said than done, and please don’t picture me doing the controlled breathing prescribed for expectant mothers, this pain isn’t passing anytime soon. The only way to deal with a disease like AS is through expert profanity, and I’m not talking about tame words like shoot, darn, son-of-a-gun, or even the popular dad-gummit. This disease is tough, and requires vocabulary so rich and colorful it could make a seasoned longshoreman take a step backward.

I usually start early, when I’m still in bed and my feet and hips don’t really work yet and I haven’t tested the other parts of my body. A simple —usually gets the ball rolling,
CREATIVE COPING: DIVERSION THERAPY

followed by a quick burst of just to let the disease know I’m not backing down today. I’m also not shy in bringing the Lord into my process; I find his participation comforting and useful in a mysterious way, though this is always a personal choice. Once I’m up and moving, and when I say moving, I define this as any type of self-propelled forward locomotion regardless of grace or coordination. Once that’s achieved, it’s time for the all-important self-assessment. A bad day usually warrants a concentrated stream, or as I like to call it, burst therapy, such as: It takes some practice; my goal is to never use an expletive twice in the same burst. Repetition it seems, perhaps dilutes the process. I don’t get why either, I just understand what works for me. You’ll have to experiment and find what works best; perhaps duplication is the key, like the breathing thing only way better. For me, is always a good way to begin, followed by a burst like Once that’s out of the way, I say bring it on. I find that pain typically withers under such a barrage, as will anyone in the immediate vicinity, so please be careful. My experience suggests that the burst technique is so effective that it will immediately provide pain diversion to anyone within ear-shot. You’ll notice that people will typically drop everything and stare wide-eyed. Always be careful where you initiate treatment, and of course, as with all medicine, keep it out of the reach of children. Young children especially will begin to practice diversionary pain tactics and have been known to vocalize the therapy repeatedly in public, and trust me when I say repeatedly. I’ve found that children are also quick to point fingers if queried by inquisitive teachers, in-laws or clergy.

Once I’ve stabilized my particular pain level for the day, it’s a simple matter of timing. Getting out of a chair? A quick is usually effective if used at the precise moment you put pressure on the joints. A more complicated procedure like getting out of the car? Try If something happens that is particularly painful, don’t hesitate to get out in front of it with a quick burst such as:

I think you’ll find that as you practice and develop an ear for the finer points you’ll learn new words and word combinations. A recent favorite of mine is: ! Aren’t they great? I can almost feel the pain subside as I type. Once you’ve assembled and mastered the entire arsenal, try to use them in new and more creative ways, for example:

See how I did that at the end—that takes some practice, but I find it especially effective for severe pain.

All of this takes some work my friends, so be patient, as well as tirelessly creative. Stick with it and the rewards are there for the taking. Through my years of research, it’s my belief that the ultimate pinnacle of profanity diversion therapy is to effortlessly rip off a twenty-word burst and at the end, be so pleased with the result that you get an inadvertent smile. Imagine, an actual smile in the face of debilitating pain. I like to think of it as a little endorphin exclamation point. That’s right pain, I own you!

For thirty years Donlay was a professional pilot—Ankylosing Spondylitis cut that career short. He is the author of three novels: Category Five, Code Black, and his latest, Zero Separation, scheduled for release March 5th. For more information please visit www.philipdonlay.com
SAA CONNECTIONS

Connecting with others who understand and can relate to our struggles is a universal human desire. To know that we’re not the only ones going through this and someone genuinely understands is a comfort and a source of strength. It is also hope. SAA provides a number of ways to connect with others and find support, share information and more...

Let SAA Help You Connect At StopAS.org/connect

This issue of SPONDYLITISPLUS is made possible through the generous support of...

AbbVie

The Spondylitis Association of America is solely responsible for the content of this news magazine.

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An Updated Overview Of Spondyloarthritis: A Family Of Related Diseases (Rates of Spondyloarthritis / AS in Women)


Living with Psoriatic Arthritis

Navigating the Course of Psoriatic Disease: A presentation at the annual meeting of the American College of Rheumatology, November 13, 2012. Arthur Kavanaugh, MD, Professor of Medicine, Division of Rheumatology, Allergy and Immunology at the University of San Diego School of Medicine; Philip J. Mease, MD, Director of Rheumatology Research, Swedish Medical Center, Clinical Professor at the University of Washington School of Medicine.


National Psoriasis Foundation - www.psoriasis.org/psoriatic-arthritis


Spondylitis Association of America - www.StopAS.org/about/psoriatic.aspx

Helpful Hints: Non-Medical Treatments

Exercise


Yoga

Curcumin

Tai-Chi

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

To sign up for the S.M.A.R.T. Givers Program, go to www.StopAS.org/smart or contact Helene Hart at 1-800-777-8189, ext. 229 or at hhart@spondylitis.org