SPONDYLITIS PLUS
Fall 2017

Half A Billion Reached: SAA And GRAMMY Award Winning Singer Raise Awareness

Q&A With A Medical Professional: Pain Management Edition

When It Comes To Supplements, What You Don’t Know May Harm You

Non-Medicinal Approaches To Treating Spondyloarthritis
Dear Readers,

This will be my last column to you in Spondylitis Plus. As mentioned in a previous column, I have been dealing with severe illness for the past two years, supported successfully by modern medicine, and I continue to do very well, working on your behalf. However, from a leadership and responsibility perspective, we have decided to welcome onboard a new CEO, Cassie Shafer, for the SAA. Cassie joined our SAA family on September 19th and I sincerely look forward to working with her. I will remain involved with SAA as a consultant on research and associated projects for the foreseeable future.

Cassie brings with her a unique set of skills, acquired over her many years of experience with national healthcare nonprofits, where she has distinguished herself as a nationally recognized leader.

She’s held executive and management positions in various nonprofit organizations, including the National Kidney Foundation, the American Lung Association, the American Heart Association, and most recently, as the Executive Director and Pacific Region Vice President of the American Diabetes Association. Her focus has been on performance management through best practices and benchmarks, revenue forecasting and optimization, coaching staff and volunteers, and community organization and board development.

It has been a wonderful time spent with you all these past twenty-one years, and I know that you will welcome and steward Cassie just as you have me from my first day on the job…because you are the real experts.

We look forward to and anticipate your continued support of our mission. Thank you from the heart.

Gratefully and fondly,

Laurie M. Savage
Executive Director
Readers Forum

“Your magazine is excellent. I would like to see more on the complications and the various types of spondylitis. Perhaps readers could share some of their treatment successes and failures. After TNF failure, I am now on Rituxan and it seems to be helpful. I don’t think I have seen anything in your magazine about Rituxan.”

~ Anonymous comment from our recent Spondylitis Plus Reader Survey

Editor’s Note:

Thank you for the kind words, and the wonderful suggestion of asking readers to share their treatment successes and failures! We love the idea. Please look for this in our 2018 issues.

As for Rituxan (rituximab), it is a B-cell inhibitor biologic medication, currently used for rheumatoid arthritis, along with other non-rheumatologic conditions. We’re glad to hear you’ve been having success with this medication for spondyloarthritis (SpA). While there have been no large-scale clinical studies on the effectiveness of this medication for AS or related diseases yet, there is preliminary research suggesting possible future applications in AS, in cases where TNF therapy has failed.

One notable case study, published in the February 2017 issue of the American Journal of Case Reports, shows promising results. The study titled, “Rituximab Can Induce Remission in a Patient with Ankylosing Spondylitis Who Failed Anti-TNF-α Agent” concluded, “Rituximab can be a potential target therapy for patients [with AS] who start to lose response to TNF-inhibitors or for those who develop solid malignancies. Further placebo-controlled studies are required.”

We will keep an eye on this medication and keep our readers updated in these pages.

“I love getting the magazine in the mail. I look forward to sitting down and reading it. I have learned so much from it and it has given me a lot of hope. I am currently taking Humira. I was terrified to take it for years and reading your magazine was what gradually, over time, calmed my fears and allowed me to take the risk. By the way, the results have been remarkable and amazing. Thank you!”

~ Anonymous comment from our recent Spondylitis Plus Reader Survey

“No one really talks about flares; my doctor certainly doesn’t. I would like more information on this subject - what it is, how to deal with it, how to cut down frequency (a diet change to eating pescatarian has helped me.)”

~ Anonymous comment from our recent Spondylitis Plus Reader Survey

“Spondylitis Plus is one of the few magazines that I read cover to cover as soon as it arrives - though that is not hard since it is not thick enough!”

~ Anonymous comment from our recent Spondylitis Plus Reader Survey

LETTERS TO THE EDITOR

We want to hear from you! Send your thoughts, questions, opinions, and rebuttals.

Please send letters to:
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Letters to the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413

Please note that we reserve the right to edit for space and clarity.
Editor’s Note: This is a recurring column in the 2017 issues of Spondylitis Plus. The column features questions from our readers on various aspects of spondylitis, and answers from experts.

This installment of our Q&A series is with Pain Management Specialist, Robert Overbaugh, MD. Dr. Overbaugh is the Medical Director of Pain Management Services at Cancer Treatment Centers of America, Philadelphia Hospital, and himself an Ankylosing Spondylitis patient.

Have your own questions for this series? Please send them to elin@spondylitis.org. Please keep your questions general in nature, and keep in mind that physicians will be unable to provide medical advice about your specific case through this format.

If you have already submitted your questions through the online survey emailed earlier this year, rest assured we have them!

Your Questions Answered by Robert Overbaugh, MD.
“Is there a better way to deal with pain instead of taking pain medication?”

Q: I’m HLA-B27 positive and was initially diagnosed with ankylosing spondylitis at 25, now am 51. My SI joints are fused/fusing, but my spine instead has severe DDD and more issues than I care to list. My pain management doctor told me that with new State and Federal regulations coming, at some point soon he won’t be able to prescribe the amount of morphine I am currently taking. He suggests trying an intrathecal pain pump (implant) instead. Can you give any feedback on these possible Federal/State regulations to be coming and the use of pain pumps?

A: Pertaining to your first question. Confusion over Federal Opioid Prescribing Laws is a question I receive frequently from my patients. In general, there are NO official U.S. Laws that have recently arisen precluding the writing of specific amounts of particular opioids. Also, although state laws vary, I am not aware of any current specific states that have officially mandated that any licensed physician (MD or DO) is precluded from prescribing opioids, or laws that state how high a dose or how many “pills” can be prescribed by a treating physician who possesses a current DEA Number/License to prescribe controlled substances.

Many of my patients come to me as referrals from their primary care providers and tell me, “My doctor says she/he cannot prescribe these medications, and only Pain Physicians can do so.” As I have practiced mostly in the Federal System and in Texas, I can only definitively tell you that neither Texas nor Federal Law stipulate a dose that is “too high” from being prescribed. Many physicians unfortunately believe that the DEA will arrest them if they write too many opioid prescriptions. However, the DEA Diversion Section is mainly concerned with whether these medications have been prescribed to appropriate patients, and that the medical record clearly states that the patient is properly monitored “closely” for side effects, efficacy (usefulness), is using the medicine as prescribed, and generally looks for evidence of misuse or abuse of the medications. This is where the states may vary. Some states stipulate how frequently a patient on these medications must be seen. For instance, Pennsylvania law mandates a patient be seen at least every three months by their provider to document and assess the appropriate use of the pain medication. Most states have similar requirements. As long as your doctor is doing the appropriate monitoring, which may also include urine drug screening, I do not believe he/she to be at risk of losing their license.

Concerning intrathecal (spinal) opioid pumps. The most recent literature in this country and in Europe has not shown significant benefit in the use of intrathecal opioids over the oral route in most non-cancer pain syndromes. The major indication for intrathecal pump implantation is reserved for patients who cannot tolerate these medications via another route. Over the past few years, the use of intrathecal opioids has significantly declined in most areas of the U.S. This is because it has been shown that most patients who undergo an implantation are very likely to go back to the use of oral medications in conjunction with the pump. Implantation is generally reserved for cancer patients or patients with very specific nerve pain disorders. These pumps are also not without potentially serious complications, which include infection after implantation and complications associated with refilling them. As the drugs in the pump are extremely concentrated, any error occurring in refilling or programming the pump could be fatal. Patients really must be very closely screened for the appropriateness of pump implantation. I generally reserve the use of this modality for very rare situations. The rule of thumb I use is if a patient can and is tolerating oral medication without significant side effects, I do not recommend pump placement.

Q: I have had ankylosing spondylitis for eight years, and have been dealing with pain in my left shoulder. I also can’t move my neck up or down or sideways due to fusion in my spine. Is there a better way to deal with pain instead of taking pain medication? I have a long list of medications I already take and I really don’t want to add any more.

A: Absolutely! There are a number of possible reasons patients experience shoulder pain. Even simply not utilizing one’s arm can lead to a very painful condition called a “frozen shoulder” or adhesive capsulitis. Physical therapy, TENS therapy, and the injection of medication into the joint can all
be helpful. In addition, many patients with shoulder pain may suffer from entrapment of the suprascapular nerve, which runs from the base of the neck over the scapula. This nerve innervates about 80% of the joint itself, so nerve blocks in conjunction with physical therapy can offer significant relief. There are also a number of topical gels, such as Diclofenac gel for example, that can be rubbed into the skin over the joint to decrease both pain and inflammation of the shoulder. Although shoulder pain can be related to nerve entrapment in the cervical spine, a full examination of the shoulder and suprascapular (shoulder blade) region should be performed to better determine a cause.

**Q:** Would the new laser treatments work to clean up old scar tissue from multiple invasive spinal surgeries? At present I receive RFA (radiofrequency ablation) about every six months to relieve chronic pain due to those surgeries.

**A:** This is always a difficult question to answer, and a rather common one, as a number of my patients have seen television commercials concerning “laser surgery.” The answer is not very clear and depends very highly on the location and type of scar tissue. The use of lasers is not new, and lasers, just like cautery or good old-fashioned scalpels, can still cause scar tissue. Anytime a patient undergoes spinal surgery, the risk for scar tissue development occurs. Consequently, most surgeons do NOT advocate continued surgery for scar tissue because it can and often does cause worsening of the scar tissue.

RFA is a completely different “animal.” It is used to temporarily destroy the small nerves within the facet joints along the side of the spine. This nerve (the medial branch nerve) is located on the “outside” of the spinal canal and is a very small branch of a part of the main spinal nerve. Thus, RFA will not treat scar tissue formed from spinal nerve roots. However, if you are obtaining good relief from this procedure I would recommend continuing it. I am not aware of any clinical evidence that utilizing a laser to ablate the medial branch nerves has any benefit over RFA in treating pain coming from the facet joints, which is a common source of pain in AS.

**Q:** Is there evidence supporting the use of medical marijuana to relieve pain from ankylosing spondylitis? If so, is there a recommended dosage?

**A:** Unfortunately No. There are no good double blinded, controlled studies currently available in the U.S. that show Cannabinoids significantly relieve pain in AS patients. That does not however mean that it does not offer relief to the different pain syndromes seen in AS. Concerning dose, as there are multiple different THC molecules and routes of THC ingestion, it is extremely difficult to extrapolate a specific dose or serum concentration. However, the FDA is now making it easier for drug companies to study the use of Cannabinoids for different medical conditions. This should allow the medical community to have a much better understanding of the use of Medical Marijuana.

**Q:** What can be done to minimize pain in the neck when there has been significant deterioration and stenosis, particularly in the C2 to C7 range?

**A:** This really is a very specific question, and I wish I could give you a more thorough answer. A complete examination and history concerning the location and type of pain you are experiencing by a Board Certified Pain Management Specialist would be very valuable. The word “stenosis” can often be confusing to both doctors and patients. Stenosis can be related to either narrowing of the spinal canal itself or narrowing of the neural-foramina, as is seen in a “pinched” nerve. Deterioration is often a very general term. It could refer to the facet joints of the spine or the discs themselves. In x-rays and MRIs, all of the above can be present, and usually is in many patients suffering from neck pain. For pain coming from nerve entrapment, procedures such as epidural steroid injections can be helpful, especially if the pain radiates to the arms. For pain that is mostly localized to the neck itself (also called axial pain) procedures such as radiofrequency ablation (see above) of the facet joints can be tremendously helpful. Lastly, I cannot say enough about the benefits of physical therapy. A true “multidisciplinary” approach to neck pain is often the best way, and going to a Pain Management Center that offers this approach is often the best first step.

**Q:** Is there a particular diet that has proven beneficial towards slowing disease progression, reducing inflammation, and/or pain management?

**A:** Many of my patients ask me about specific diets and I must admit I am far from an expert on any of them. However, when looking at the scientific literature, the diet associated with most evidence-based improvement of symptoms is the Low Starch or Starch Free Diet. SAA’s website has some terrific information pertaining to this specific diet and is a great resource.

(Editor’s Note: Please see spondylitis.org/Diet-Nutrition for more on the Low Starch and other diets. We also offer an e-cookbook written by three nutritionists. You will find “Anti-inflammatory Eating: Recipes From Your Dietitian’s Kitchen” in SAA’s online store, at Spondylitis.org/shop.)
The slums of Kolkata birthed me. She left me in a clinic abandoned and alone. That is how my life began. Weighing less than two pounds and barely clinging to life, I was picked up by the staff of the International Mission of Hope Orphanage during one of their trips to the city’s birthing clinics. The orphanage’s nurses would go from clinic to clinic with large woven baskets to collect the babies and transport them back to the orphanage. My veins were so small from being premature that my head still bears the scar - a patch of skin as tough as an orange peel, and the size of a dime - where an IV was inserted to keep me alive. Most of the babies in my condition didn’t make it, and I had almost succumbed to death multiple times in the first few weeks I was alive. Eight weeks after I was born, a few of the nurses from the orphanage boarded a flight, with myself and a few other babies and we were transported from India to Seattle, WA, where my family met me for the first time. Surviving the first few weeks of life made me a miracle baby. I suppose that makes me a fighter, which is why ankylosing spondylitis will never define me. My life has been plagued by battles, yet I have always persevered in the end, no matter how long or difficult the fight.

I grew up in Washington State between Seattle and Spokane in your typical middle class American family with two loving parents and three siblings. I was the only adopted one - having two boys, they wanted a girl and knew that in India, girls were often unwanted. I was a daddy’s girl, like most little girls are. I have fond memories of summers at camp, running around in the sprinklers outside during hot summer days, and being involved in drama club, band, and jazz choir.

"Surviving the first few weeks of life made me a miracle baby. I suppose that makes me a fighter, which is why ankylosing spondylitis will never define me."
My childhood holds fond memories. It was a time with no worries or pain. I attended Visible Music College after high school, where I studied vocal performance and music business. It was during my time there that I met my husband through a mutual friend. We married about six months after meeting, which I realize is slightly crazy, but it worked for us. I was soon pregnant with our first child - a daughter. Newly wed and receiving orders, he was going on a trip to Iraq, compliments of the US Army. Deployments are never fun, but they are even worse for newlyweds.

Three weeks after our daughter was born, he left to serve our country, and fight the “bad guys” in a war that had the potential to take him from me permanently. Real war is very different from what you see in movies or read in books. Real war sucks big time, and he never returned to me the same. War broke him, and by default, it broke me too.

Eleven years later we are still enduring the consequences of that war - a man who never made it home. The guy who came back experienced brain damage, a severe frontal lobe brain injury, that changed his entire being; changed his personality forever. “Mrs. Shaw, don’t be surprised when your world falls apart and your marriage can’t survive. He literally is nothing like the guy you married.” I will never forget the words echoing from the mouth of that sweet woman, a Neuropsychiatrist at Brooke Army Medical Center. Her words crushed my soul, yet they turned out to be so true despite years of trying to fix it all.

Everything was about being a caregiver in those years, and helping other wounded warriors and caregivers in the post 9/11 Military world. Advocacy suited me well, but secretly I was dying inside. It’s something that was neither his fault nor mine, it just was. I knew my marriage was dying, and there was nothing that could be done to repair him. He wanted me to change, to match his new personality, but that isn’t how this works. I couldn’t become a new person; I have always been who I am. We didn’t want to ruin our kids, and we did care deeply about each other, but eventually we realized that sometimes tragedies happen in life, and no one is to blame. I will always respect the hero that he is, and appreciate the great father he is to our kids, and I still help take care of him, despite my own pain.

Working with disabled Veterans for the last eleven years has taught me so much about the medical community. My work with caregivers translates well to what those of us with ankylosing spondylitis face on both sides. Speaking of AS….

I felt frozen in time. "Anky Spondy whaa?" I couldn’t say ankylosing spondylitis, let alone grasp the gravity of what it was.

"Life as I knew it would never be the same.” Damn, that sounds dramatic, yet it was all I could think of when I was diagnosed. I felt frozen in time. “Anky Spondy whaa?” I couldn’t say ankylosing spondylitis, let alone grasp the gravity of what it was. I knew that the years of soul-crushing pain finally had a name, but what did it really mean? Would I still be able to enjoy life? What would I have to give up? I was overwhelmed, and remained that way for months after my diagnosis.

You see, I had suffered mysterious pain for fifteen years. Not that I was counting, I really wasn’t, I just knew it had been so many exhausting years of pain - enough to feel crazy at times. I remember my pain starting in my early high school years. PE was tough, and though I didn’t like running, there shouldn’t have been any reason why it hurt as bad as it did. The same was true of my dance team. Though I loved it, I had to give it up due to the pain, which I didn’t vocalize back then. When I finally did, doctors made me feel as though my pain was all in my head because they were unable to find a cause. If I just exercised more, or lost the weight, I would be fine. I had never struggled with my weight until after I had kids, and the mysterious pain increased.

The physiatrist before my rheumatologist was convinced that I was just overweight and consequently suffering from mechanical pain. Still, to cover his own booty, he did blood work and that was my saving grace. It isn’t abnormal for those with spondylitis to have normal blood work results so I guess I was “lucky” that my inflammatory markers were sky high. I could no longer be ignored, but at the same time I didn’t want to have a disease that would be a life-long battle. My physiatrist gave me a half-assed apology, and

Real war is very different from what you see in movies or read in books. Real war sucks big time, and he never returned to me the same. War broke him, and by default, it broke me too.
sent me to the wonderful rheumatologist who I am still with today. It’s been a tumultuous journey, but I am stronger for having gone through it all.

I didn’t know anyone with spondylitis, so I turned to online support groups, and eventually found the Spondylitis Association of America. While on a Facebook page for women with AS, I came across someone who wasn’t too far away and we decided to meet up. I had been recovering from neck surgery after a texting and driving teen hit me, and I needed the pick-me-up a friendly face could offer. I had no clue that I would meet someone so awesome that day, a soul sister who would be a life-long friend. Sarah and I (yes, we have the same name) became fast friends realizing we had a ton in common. On her way to meet me at a local bakery, Sarah was on the phone with her mom. Sarah’s mom was concerned that I might have been some crazy serial killer with an ax. We had a good laugh over that story, and when I told Sarah that I was fresh out of axes so she would be fine, she knew we would get along well.

Sarah and I have become close these last few years. We can share things in our lives that others will never understand, being bonded by something neither of us want, but that makes us appreciate life. Sarah is also adopted, and a musical genius. Her singing is featured in Tidy Cats commercials. I have never met someone with such a love for the bass clarinet, and mint chocolate chip ice cream. Being that we are ambiverts (an equal balance of extroverted and introverted traits), we are two peas in a pod. I have met other people with spondylitis who I adore, but no one that gets me quite like she does.

We all need a Sarah in our lives - someone who loves unconditionally, and someone you can laugh with. I encourage everyone to reach out to your local SAA group for support, or connect with others through social media. It is easier to isolate and feel like you are alone, but strength comes in numbers. Sarah has made my journey easier. I always have a sympathetic ear and someone who can understand all my aches and pains, but also someone who I can hang out with, who needs no explanations if I get tired or start to hurt. I don’t feel like I am slowing Sarah down during those times. We all need someone who can be that friend who just gets us without extra questions. Sarah came into my life when I needed her most.

About a year ago, Sarah and I both tore our wrists in the same spot, on opposite hands, and have since both undergone an initial surgery and then a revision. Life in general, but especially life with AS, is not meant to be endured alone. You run the risk of burning out if you don’t find someone who can relate to you. Those of us with AS must often live a more regulated life, and at times, that can be depressing. It is so much easier with a buddy to walk this life with. I have met a handful of my fellow AS peers, and my life truly is richer for it. Together we are warriors, and our strong community helps us advocate for ourselves and for further awareness. Should you start to feel down, remember that you are not alone. I never in my wildest dreams thought I would find myself chronically ill, but if I must be stuck in a club I don’t want to be in, I am happy that I have made friends to walk alongside me.

I never in my wildest dreams thought I would find myself chronically ill, but if I must be stuck in a club I don’t want to be in, I am happy that I have made friends to walk alongside me.

Editor’s Note: You will find local and online support resources, stories from others living with spondylitis, and more ways to connect with others living with spondylitis on SAA’s website, at spondylitis.org/community.

www.stopas.org

Sara Shaw (left) and Sarah (right)
The use of natural or herbal based supplements goes back a long way. Indeed, even in our lifetime, medicines that benefit many have been developed by extracting the active ingredients from natural substances to bring to market important drugs, including DMARDs (disease-modifying anti-rheumatic drugs), pain medications, anti-inflammatories, and anti-cancer medications.

Medical research reports that close to two thirds of individuals with some form of rheumatic disease, including spondylitis, take supplements along with their prescribed and over the counter medications on a daily basis. Additionally, according to well-respected population surveys, many of us believe that supplements are benign and safe because they are “natural.” However, it’s important to note that while herbal supplements may be derived from plant or other natural sources, the active ingredients can nevertheless be potent, and sometimes dangerous chemicals. Arsenic, hemlock, and belladonna, for instance - all having a natural provenance - are lethal when ingested in certain quantities.

Supplements can have drug/drug interactions with each other, with food or beverages, with alcohol, and of course with medications. Supplements can also interfere with how certain drugs are broken down in the body; they can increase, reduce, or even block the intended therapeutic effect of a drug. Along the same lines, some supplements can be highly problematic for individuals with certain medical conditions.

Lastly, there are several common misconceptions regarding the regulation or rather non-regulation of supplements. Unbeknownst to many, supplements are not regulated by the FDA. In fact the FDA is not authorized to review supplements for safety and effectiveness before they come to market. The FDA will get involved only when and if adverse events are reported by consumers or watchdog agencies.

So, with all of this said, are supplement in general safe? How does one know which specific supplement is safe and which is not? These questions certainly present a challenge - one that we might first tackle by consulting with our doctors and pharmacists. There also are several powerful database driven online tools to turn to for a bit of cross sectional sleuthing. Examples include the “drug interaction checker” tools on Medscape.com, Webmd.com, and Drugs.com.

In this article, we are going to cover commonly used herbal supplements, discussing how some of them might interact harmfully with the medications we take and potentially lead to serious negative unintentional outcomes.
To Supplements, What You Don’t Know May Harm You

So here is a list of the most well researched supplement-drug interactions:

**BLACK COHOSH**
There is a concern that this supplement may be toxic to the liver and may increase liver impact when used with drugs such as Lipitor, Tylenol, and Alcohol.

**COENZYME Q10**
Use with anticoagulant drugs may decrease the blood thinning effects and thus potentially increase the risk for blood clots.

**CRANBERRY**
Data is conflicting. May increase the effect of blood thinners and may lead to bruising or bleeding.

**ECHINACEA**
May change how the liver metabolizes drugs. May slow down how the body metabolizes caffeine leading to side effects such as headaches or insomnia.

**EVENING PRIMROSE OIL**
May increase the risk of seizures for individuals on anti-seizure medication or phenothiazine drugs. May slow blood clotting.

**VALERIAN**
The German Commission E, which evaluates herbal products in Germany, has approved Valerian as a mild sedative. That said, there are over 500 recorded possible drug interactions with Valerian. Some of the more widely used categories of drugs that Valerian may interact with include:

- Muscle relaxants
- Sleep and anxiety medications
- Painkillers
- Anti-depressants
- May increase drowsiness when taking other medications that cause drowsiness.

**ST. JOHN’S WORT**
Has one of the highest number of published reports of negative drug interactions. It can interfere with the following medications:

- Selective serotonin reuptake inhibitors (SSRIs)
- Tricyclic anti-depressants (TCAs)
- Monoamine Oxidase inhibitors (MAO)
- Nefazodone
- Triptans for migraine
- Dextromethorphan
- Warfarin
- Birth control pills
- Some HIV medications

**SAW PALMETTO**
May slow blood clotting. May increase the risk of bleeding and bruising. May reduce effectiveness of oral contraceptives and estrogens.

**MELATONIN**
May cause excessive drowsiness when taken with the following classes of drugs:

- Benzodiazepines, sedatives, and hypnotics
- Antihistamines
- Opioids
- Muscle relaxants
- Diabetes medications
- Anticoagulants

**KAVA**
There are hundreds of reported drug interactions with Kava, some involving liver toxicity. Has been reported to lead to serious respiratory distress and coma when used with Buprenex, Butrans, and Probuphine.

**GINSENG**
There are many different origins of ginseng and many reported different drug interactions. Long term use of the American ginseng may decrease the effectiveness of blood thinners, while some types of ginseng may have blood-thinning effects. Ginseng may also affect blood pressure treatments and diabetes medications.

**YOHIMBE**
Several interactions have been reported relating to problems with individuals with hypertension and heart disease. Its stimulatory effect has been reported to increase blood pressure and cause a rapid heart rate.

**FEVERFEW**
May increase the risk of bleeding. May interact with:

- Aspirin
- Plavix
- Warfarin
- Pradaxa
- Heparin
- Xarelto
- Enoxaparin and Dalteparin
  (low molecular weight harparins)

**GINKGO BILOBA**
May decrease anti viral effects of some HIV drugs. Ginkgo has been reported to interact with close to 500 drugs. Best to check before use.

**GOLDENSEAL**
Over 60 interactions have been reported. Two of the most serious occur with certain anti-psychotic drugs leading to irregular heart rhythm. May also effect liver enzymes negatively.

**GARLIC**
May lessen the effectiveness of blood thinning medications. May impact negatively the effect of HIV medications.

**References**


I wish I had a nickel (buck) for every time I heard someone say, “If we only had a celebrity.”

Over the last 25 years I’ve spoken with a lot of people living with AS. Not infrequently, people have voiced their frustration about having a common disease that no one has seemingly heard of. We have all had to explain what AS is, sometimes even to medical professionals. The lack of awareness has consequences - ineffective and costly treatments stemming from misdiagnosis, disease progression caused by delayed diagnosis, poorer quality of life due to delays in starting effective treatment, feelings of isolation, relationship strife with friends and loved ones - all exacerbated because of lack of awareness.

Not that anyone would wish this disease on someone, but statistically we do know some celebrities must have AS. We also know the potential risk to a career by becoming public about living with an illness.

Last November someone sent me a video clip of an Imagine Dragons concert where the lead singer, Dan Reynolds, stood painfully still at his microphone and apologetically told 15,000 fans that he was having a painful night from his ankylosing spondylitis. He was sure that some of his fans had AS and perhaps didn’t even know it.

“ I’ve spent many hours chatting with Dan on film sets and doing media interviews. He’s open, empathetic, and sincere - both on camera and off."

I contacted the band. So did one of our corporate members, Novartis Pharmaceuticals Corporation. The band was already committed to a nonprofit cause creating a foundation for a form of pediatric cancer, which remains the cause they
“Last November someone sent me a video clip of an Imagine Dragons concert where the lead singer, Dan Reynolds, stood painfully still at his microphone and apologetically told 15,000 fans that he was having a painful night from his ankylosing spondylitis.”

support. However, Dan did want to make a difference for people living with AS. Out of this new collaboration between the SAA, Dan Reynolds, and Novartis came a novel idea - rather than acting as a traditional spokesperson, Dan would do a series of interviews with people living with AS. The concept was to share real experiences with this serious disease, but do so in a light and sometimes fun way. Think ‘carpool karaoke’ - entertaining and informative.

The concept stuck, and a brand new online video series was created. As of this writing four wonderful episodes of “This AS Life Live!” have been released, each as different as the people featured in them. If you haven’t seen them yet, you will find them all on SAA website, at spondylitis.org/Community/Living-with-Spondylitis/This-AS-Life-Live. Additional episodes will be produced and rolled out over the course of the next year or so. Hopefully there will be something said along the way that touches a chord with you. Something you will want to share with others.

I love Dan in these videos. He is a wonderful host. Dan knows the AS struggle. He knows the pain. Like most of us, it took him years to be correctly diagnosed and start an effective treatment plan. And that’s despite having an older brother with AS. He doesn’t have answers; he is learning what works for him and is passionately interested in what works for others. With all his fame and resources, he is one of us. Like for all of us, there is a cost to living with AS. When Dan has a flare, it may mean that he’ll go from his high energy, exuberant showmanship on stage to canceling a sold out concert for thousands of fans and people that depend on him.

I’ve spent many hours chatting with Dan on film sets and doing media interviews. Like the rest of us, he is genuinely interested in hearing and comparing AS stories. He’s open, empathetic, and sincere - both on camera and off.

Riding on the coattails of Dan’s musical success, more people are becoming aware of AS. The band’s success has been explosive and meteoric. They have won domestic and international awards, including a GRAMMY. Albums with songs such as Radioactive, Demons, Believer, and Thunder have remained on top of the charts for over a year, all of them peaking at number four or higher, and winning them a huge fan base with millions following them on social media.

In promoting this project, Dan has done interviews with media outlets around the country - with national magazines, newspapers, and on television (appearing on the popular show, The Doctors). At each media interview, he has spoken candidly about living with AS, shining a bright light on this common disease that more and more people are hearing about. And so, it seems, we have our celebrity.

"It was such an honor to be a part of this amazing project that is showing the world the “human” side of ankylosing spondylitis. Please consider supporting the Spondylitis Association of America in whatever capacity you can. SAA is made up of just a handful of wonderful people who sacrifice so much and are so dedicated to making our lives with spondylitis better. They not only work hard on our behalf but they sincerely care about making a difference."

~ Cookie Hopper
AS Advocate and Co-Star of Episode 4 of “This AS Life, Live!”
In recent years, experts in patient care in spondyloarthritis have recognized that a hands-on, multi-use approach that puts the patient at the center of their own treatment, involving them closely in the decision-making process, can lead to the best outcomes. One of the reasons for this may be that it can lead to greater patient satisfaction on a psychological level. One might argue that individuals who are dealing with a chronic progressive illness have already experienced numerous losses pre and post-diagnosis, and thus being in charge just feels better.

“...A patient centered approach - including pharmacological and non-pharmacological modalities and interventions – is recommended as the cornerstone of treatment in those with spondyloarthritis.”

As such, a patient centered approach - including pharmacological and non-pharmacological modalities and interventions – is recommended as the cornerstone of treatment in those with spondyloarthritis. The aims of this approach, as concluded by the experts, include pain reduction, and an effort to improve muscle strength, endurance, flexibility, mobility, balance, and fitness, as well as maintaining/increasing participation in a healthy social life to prevent feelings of aloneness. Preventing postural abnormalities and joint contractures are also important goals.

In this article, we are seeking to present evidence, based on rigorous study, to describe various elements of a multi-disciplinary non-medicinal intervention in axial spondyloarthritis.

Physical Therapy
Often includes physical modalities such as exercise, heat, cold, electrotherapy, and manual techniques. The goal of physical therapy is to maintain and/or improve an individual’s comfort, independence, social integration, and quality of life.

Though all physical therapists are trained health professionals, some have additional expertise in musculoskeletal and rheumatologic disease support and would be the most qualified to treat individuals with spondyloarthritis.

It is important to note that not all patients are good candidates for physical therapy management. A physical therapist is trained to measure and evaluate this, and construct a personalized treatment protocol to suit the patient’s needs and abilities.

Exercise
Despite the medical advances during the past twenty years, exercise remains a critical element of a successful management strategy in all stages of the disease. Throughout the literature, exercise remains the most studied physical modality in the management of ankylosing spondylitis and axial spondyloarthritis. Some physicians go as far as to say that exercise is the universal treatment in these conditions. A well-respected group (Cochrane) investigated the effect of exercise for ankylosing spondylitis in 2008. The review reported that individual home-based exercise programs are better than no intervention and exert a positive effect on spinal mobility and physical function. They also confirmed that group-supervised physical therapy was superior, resulting in better outcomes when compared to home exercise. Still, in examining the body of research on exercise and spondyloarthritis, it becomes apparent that various difficulties found in many exercise studies prevent firm conclusions in their findings. (Please see Box 19.1 for more on this.)

Aquatic-based Therapies
In comparing aquatic therapy to conventional exercise therapy across the board, aquatic therapy showed greater improvement in all measures, especially in pain scores and quality of life. However, it has been suggested, but not substantiated, that aquatic therapy combined with conventional exercise seems to increase anti-inflammatory hormones in the body; further study is needed to either confirm or not.

Electro-physical Agents and Thermotherapies
Though these modalities have been used rather successfully in other rheumatic diseases, up until recently there had been little evidence to support their use in spondyloarthritis. That may
be changing however, as several recent studies investigating *TENS use in ankylosing spondylitis specifically have shown promise. Improvements in pain, stiffness, and fatigue, which are all significant factors in spondyloarthritis, have been reported. A double-blinded placebo controlled trial was unable to demonstrate useful outcomes in *magnetic field therapy when applied to the bilateral joints in AS. There was also no demonstrated usefulness in pain, fatigue, morning stiffness, functional ability, nor disease activity. One small study did show promising preliminary results in *whole-body hyperthermia on cytokine levels in the blood, showing a TNFa level (inflammatory marker) reduction of 50% as compared to baseline levels after a 24-hour initiation. A different study however, using infrared sauna to apply whole-body hyperthermia in AS and RA patients, failed to show significant improvements in pain, stiffness, or fatigue.

*Editor’s Note:
TENS is short for “Transcutaneous Electrical Nerve Stimulation” which is a machine that delivers a low-voltage electrical current to designated areas of the body, stimulating the nerves in the area in an effort to reduce pain.

Magnetic Field Therapy involves the use of different magnets in an effort to balance and re-align a person’s magnetic field. This is believed by practitioners to treat certain conditions, including pain from arthritis, and increase overall health. The thought behind magnetic field therapy is that certain problems happen because your magnetic fields are out of balance. If you put a magnetic field near your body, it’s believed things will go back to normal.

Whole-Body Hyperthermia is a treatment in which the body’s core temperature is elevated (up to 107 degrees Fahrenheit in controlled environments) to effect certain changes within cells. It is most commonly used as a complementary cancer treatment.

**Patient Self-management and Education**

It has been well established among experts that the treatment of spondyloarthritis benefits enormously from self-education with regard to disability, patient global assessments, psychological status, and depression. *(Please see Table 19.3 for more on this.)* However, current reporting in this area suggests that only 40% of patients in axial spondyloarthritis are being referred for education, a number that shows much room for improvement.

**Complementary and Alternative Medicine (CAM)**

CAM, as supported by funding for studies at NIH, is considered an approach to healthcare and disease management that falls outside of conventional medicine.

The term “complementary” usually refers to therapies beyond standard treatments that are used in combination with mainstream medical approaches. The term “alternative” refers to therapies outside of the conventional that are used in place of mainstream medicine.

Currently, there is little evidence to support CAM use in axial spondyloarthritis. That said, in terms of nutritional and dietary approaches it is thought that a full 95% of patients have used this sort of approach at some time. Often complementary approaches,
such as massage therapy, acupuncture, or naturopathy, are used to support traditional medicines. Though evidence in support is not available, many individuals find great comfort in various alternative approaches to symptom relief. More study is needed.

### Table 19.3 Key self-management and patient education topics for patients with spondyloarthritis

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<thead>
<tr>
<th>Disease-related</th>
<th>Diagnosis</th>
<th>Prognosis</th>
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<td>Management-related</td>
<td>Pharmacological</td>
<td>intervention</td>
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<td></td>
<td>Non-pharmacological</td>
<td>intervention</td>
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<td>Symptom-related</td>
<td>Fatigue</td>
<td>Pain</td>
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<td>Joint dysfunction</td>
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<td>Function-related</td>
<td>Activities of daily</td>
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<td>Psychological impact</td>
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<td>Social-related</td>
<td>Recreation</td>
<td>Community involvement</td>
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<td>Employment</td>
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**Massage Therapy**

There are various forms of massage therapy that, according to many self-reported claims, can aid in relaxation, decrease stress and muscle tension, reduce chronic pain, and improve overall wellbeing.

**Acupuncture**

Mainstream available information regarding acupuncture has grown rapidly since the mid nineties. In tandem, the scientific evidence supporting its use has steadily expanded. Blinded studies have demonstrated that acupuncture can support its claims of biophysical impact with the release of endorphins – feel good hormones – and that it can provide immediate short term pain relief, as well as improve function. In spite of this, robust evidence to support its use and positive benefits in axial spondyloarthritis is lacking. It is suggested that further exploration and well designed clinical trials are warranted.

### Chiropractic Treatment

Chiropractic is a term used to describe many different types of treatment modalities. These include but are not restricted to a combination of manual therapies, high-velocity spinal manipulation, passive modalities, exercise programs, touch therapy, no touch therapy, and pain education.

The Treatment Guidelines in Axial Spondyloarthritis published in 2015 by the American College of Rheumatology, Spondylitis Association of America, and Spartan strongly recommends against spinal manipulation with high-velocity thrusts in AS patients who have spinal fusion or spinal osteoporosis.

Spinal manipulation in any patient with established axial spondyloarthritis should be avoided due to risk of undiagnosed osteoporosis and the unknown effects of joint manipulation in actively inflamed joints. Extreme care should be taken prior to undertaking chiropractic treatment. Risks in those with axial spondyloarthritis include spinal fractures, spinal cord injury, and even paraplegia.

**Natural Health Supplements and Products**

Please see page 10 of this issue for an article discussing supplement use, and their potential interactions with conventional medications.

### Conclusion

Evidence-based literature has demonstrated that exercise and education remain the foundations of non-pharmacologic treatment in spondyloarthritis. Conventional exercise consists of flexibility, stretching, and strengthening with adjunct therapies including aquatic exercise. It has been postulated that a combination of biological treatments and exercise therapies provide enhanced outcomes with regard to symptom relief, physical function, activities of daily living, mobility, and quality of life indices.

Further well-designed studies are needed to measure outcomes and the potential usefulness of incorporating other non-pharmacological approaches in a successful management strategy of spondyloarthritis.

### References:


When I die, SAA will get a check.

Sound morbid? To me, it’s life affirming. It affirms that a solution to spondylitis is possible. My life has been one AS accommodation after another. Some minor adjustments, some major. You, my SAA community, have been there every step of the way. From diagnosis through progression, SAA’s community is engaged every day, all day.

SAA has earned an international reputation for getting things done. Thirty-four years ago our founders decided spondylitis needed to be taken seriously. The status quo wouldn’t cut it. They said, ‘Not on our watch.’ From its humble beginning as a patient support group, they grew SAA in leaps and bounds, and reigned spondylitis research in this country. Seeing the void in spondylitis research, they brought independent researchers into the same room to say, “Let’s work together on spondylitis.” Seeing a need for research funding, they went to SAA’s ever-generous membership to secure funding for pioneering research. And it paid off. Research that began thanks to SAA and our community produced results warranting NIH funding, turning into the first major, nationwide genetic study of ankylosing spondylitis.

Our founders left a legacy of creativity, a network of support, and a commitment to grit that lives on and shapes the work SAA does today. SAA is focused as ever on research, still spearheading novel research concepts, and still bringing the right people together to make things happen. We are also working hard to raise awareness, as we understand that effective awareness projects will lead to earlier diagnosis and improved outcomes. Treatments will improve as more lay people and medical professionals become aware of spondylitis.

Imagine if everyone knew about spondylitis. Imagine telling your Pilates teacher you have AS, and they knew what to do.

Your child’s soccer coach understood that there will be great days and flare days.

Imagine a spondylitis educational video playing in the waiting room of your doctor’s office.

Today’s SAA takes raising awareness to a whole new level. We have literally put spondylitis on the billboard in Times Square. We have traveled to Washington DC to speak to our elected representatives, delivered spondylitis educational materials to countless physicians, and so much more. Each year our community comes up with new and creative awareness projects, jumping into advocacy mode with gusto.

Together we are capitalizing on today’s changing technology to build on our foundation. In this issue of Spondylitis Plus is an article on This AS Life Live videos, which have already reached half a billion people.

In the past few years, electronic wallboards have been installed in the waiting rooms of 231,000 healthcare providers - and growing. And, 585 million patients are already exposed to the messages played on these screens. Nine hundred rheumatology offices around the country have these boards. This past year SAA has been collaborating with a company called Outcome Health to play accurate information on spondylitis on these boards. Our spondylitis poster has been shown 934,640 times. Our white board animation videos have played 239,911 times. We have three new live videos in production for these boards.

With your help, SAA will capitalize on whatever new methods of communication are developed. This check that SAA will receive on my behalf will ensure the continuation of all the things SAA does. “Please let me know at Legacy@spondylitis.org if you will join me in committing to a planned gift to say, “This is our watch.”
Corporate Support

The corporate membership program provides a way for the Spondylitis Association’s pharmaceutical members to positively impact the lives of those affected by spondylitis by contributing to SAA’s general operating budget. SAA also receives additional corporate support for special - and costly – programs, such as our live patient educational seminars.* The following pharmaceutical companies are current corporate members.

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you are not alone

There are SAA-Sponsored Spondylitis Educational Support Groups in 21 U.S. states. **IS THERE ONE NEAR YOU?**

Find all of our support groups at [Spondylitis.org/Groups](http://Spondylitis.org/Groups)

More ways to connect at [Spondylitis.org/Community](http://Spondylitis.org/Community)

Want to speak with someone at SAA?

Call our *Toll Free Hotline at (800) 777-8189* and speak with a real live human being Monday through Friday!

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Upcoming Spondylitis Educational Seminar In San Diego, CA

Join SAA on Saturday, November 4, 2017 for an informal and informative seminar with expert guest speakers!

Learn more and register online at spondylitis.org/sd-seminar

Contact Cynthia Rodríguez at (800) 777 – 8189 ext 225 or at Cynthia.Rodriguez@spondylitis.org

The schedule includes:

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- **Physical Therapist Angelo Papachristos, MBA, BSc (PT)**, who will discuss Spondyloarthritis and Exercise

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