

SPONDYLITIS PLUS

Winter 2015

**New Spondyloarthritis
Treatment Guidelines**

Tackling Chronic Pain

**GI Joint - A Major
In The Spondyloarthritis War**

Your Stories:

My Weakness, My Strength -
Amanda's Ride Up Pikes Peak

Andrea's Low Starch / Paleo
Holiday Recipes

 **Spondylitis
Association
of America**



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To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.

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ON POINT



Dear Readers,

As you know, since its inception in 1983, the Spondylitis Association of America (SAA) has worked with you and on your behalf on issues that matter to all of us. Examples, over time, would include the recent forward looking innovative Magnetic Resonance Imaging Workshops for rheumatologists and radiologists in axial spondyloarthritis; accelerating early diagnosis in AS through the online Back Pain Test; reigniting the US research agenda in Ankylosing Spondylitis in the late nineties following years of non-engagement in the research community after having uncovered the HLA-B27 gene in the early seventies. This research effort, specifically, is a prime example of a goal that could not have been achieved without your commitment, your financial support, and your engagement in research. None of these things are ever taken for granted by your SAA.

More recently, as you will read in this issue of *Spondylitis Plus*, SAA worked in collaboration with the American College of Rheumatology (ACR) and with our SPARTAN research colleagues to ensure that the ACR/SAA/SPARTAN Treatment Guidelines in Axial Spondyloarthritis came to fruition. The goal of SAA's Executive Director (*yours truly*) when initiating this dialogue with ACR was to commit to the development of a robust set of Guidelines that would provide a solid infrastructure to help guide your doctor's decision making process regarding your potential optimal care based on a body of research published in highly respected medical journals.

We did it! As stated in Dr. Ward's synopsis, found on page 6, these are considered to be "living" Guidelines and will be updated as need arises. I would like to thank our team of patients and research clinicians, led by our esteemed colleague and friend from the NIH intramural program, Dr. Michael Ward. The volunteers involved in this very thorough process over a period of more than two years include members of the SAA Medical and Scientific Advisory Board, and two SAA members who also serve on our Board of Directors. Without the dedication and commitment of these fine individuals this outcome never would have been achieved. And without your continued financial support, this important work would never have been undertaken.

Thank you!

Laurie M. Savage
Executive Director

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“Just read the Fall issue of Spondylitis Plus. Congrats to you! SAA has slowly come more oriented to people vs. focusing primarily on the disease. I enjoyed reading “What’s your SAA IQ?” It helps in trying to connect with SAA staff.

I scored a lowly 72 after answering questions. Did not know Robin had the cutest grand-babies. Did not know Laurie did ocean sailing and flew fixed wing aircraft. And Elin had a fairy tale wedding.

And did *you* know that: I built fixed wing aircraft? I was SAA’s Volunteer of the Year around 20 years ago? (Somewhere around here I remember having a plaque.) It was part of my 15 minutes of fame.

Great magazine... Keep up the great work!”

~Walt Lichmira
SAA’s Volunteer Support Group Leader
Philadelphia, PA

“I just read the latest issue of Spondylitis Plus (Fall 2015) and again feel as if I’m one of the luckier / blessed people with AS, much like I do each time I read your publication.

In my early teens (over 40 years ago) I was diagnosed with AS. Apparently, my rheumatologist was able to properly and quickly diagnose, unlike many who have our disease. I spent a couple years on crutches, a year using a cane (which was a pretty cool thing to do when you’re in high school) wore a back brace and arm slings for a while, took well over 20 aspirin each day (since most adult meds made my ears ring) and sporadically did my assigned exercises. Fortunately, in my early 20s, my pain went into remission and remained that way until a decade back. I’m not sure what triggered my regression but out of the blue, I began having severe back spasms - the 10 out of 10 variety on the pain scale, and they stuck around. After almost three years of fairly regular pain management treatments and receiving back and neck injections hoping one would do the trick, on January 1st, 2013, I was able to roll out of bed without much pain. It was the most incredible feeling; I tear up just thinking about it, largely because so many of us continue to suffer in chronic pain. I had absolutely no idea how much pain I could tolerate

until I lived for years in an 8 - 10 range. But the day it went away, it was truly amazing.

You can now see why I feel so blessed. I’m not completely pain-free, but it’s certainly tolerable. My doctor’s prognosis is that my back and neck will ultimately fuse (although I tend to feel otherwise despite what the MRIs show) but hopefully along the way I’ll be able to live as normal a life as can be and with much more appreciation for the good days, and compassion for those who continue to suffer.”

~Jake Miller
Granbury, Texas

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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Please note that we reserve the right to edit for space and clarity.

GI Joint – A Major in the Spondyloarthritis War



Lianne S. Gensler, MD

Inflammation of the gastrointestinal tract is common in Ankylosing Spondylitis (AS). Up to 60% of AS patients who have no gastrointestinal symptoms will have microscopic (on biopsy) inflammation in the gut when colonoscopy is performed^{1,2}. Most of these patients do not develop overt inflammatory bowel disease (IBD) like Crohn's disease or Ulcerative colitis. Recent studies show about 3-4% of patients have IBD when they are diagnosed with Ankylosing Spondylitis, but after 20 years, approximately 10% have IBD^{3,4}.

Patients with Ankylosing Spondylitis and IBD share similar important genetics⁵. The gut and joint inflammation on a shared genetic background highlights the importance of this connection and how these are related diseases. Data shows that patients with AS have first degree relatives with a 3-fold higher risk of Crohn's disease, and patients with Crohn's disease have first degree

relatives with a 3-fold higher risk of Ankylosing Spondylitis⁶. Just as patients with AS can develop IBD, patients with Crohn's disease and Ulcerative colitis can also develop arthritis⁷. This can occur in the sacroiliac joints and spine (and is identical to Ankylosing Spondylitis) and/or in the smaller joints of the extremities (knee, ankle, feet, hands etc). The most common joint manifestation is the sacroiliac joint - affecting 10-20% of patients with IBD. Note that some of these patients will not have SI joint pain, and the finding is often noted on imaging done for other reasons (like a CT scan done for IBD). The sacroiliitis (back/buttock and hip involvement) can occur when the IBD is silent or active and can continue even when patients undergo colectomy in Ulcerative colitis.

The small joint arthritis can behave differently. There are two types of small joint arthritis (along with the arthritis in the SI joint) described in Table 1 below.

Table 1. Arthritis types in IBD

	Type I Arthritis	Type II Arthritis	Spondylitis
What percent of IBD patients are affected?	3-6%	2-4%	~20%
What joints are usually affected?	Large joints in legs – knee, ankle, foot	small joints in hands – wrist, fingers	Sacroiliac & spine
How many joints are typically affected at 1 time	<5	>5	n/a
Can occur when?	At first sign of IBD	After the onset of IBD	Often in younger patients
Disease course	Acute & remitting	Chronic & relapsing	Typically chronic
With GI activity	Yes	Not necessarily	Not necessarily

Medications for Arthritis associated with IBD:

The treatment of the joint disease in IBD depends on which joints are affected and whether the IBD is also active.

If the sacroiliac joints are affected, then the appropriate treatment is either a drug class called Non-steroidal anti-inflammatory drugs (NSAIDs) which are sometimes contraindicated in patients with IBD because of the concern for IBD flares in the setting of these agents, or the biologic agents. Examples of NSAIDs are ibuprofen or naproxen over the counter; celecoxib is sometimes preferred as it may be safer in the gastrointestinal system, though the evidence of this in IBD is weak. The American College of Rheumatology recently published guidelines in Axial Spondyloarthritis and did not recommend a preferred NSAID in the setting of IBD because of the weak evidence⁸. If NSAIDs are not a possibility, then the

only other class of drugs with proven efficacy at this time is the biologic agents - Tumor Necrosis Factor Inhibitors (TNFI). For patients with sacroiliitis and IBD, a certain type of TNFI is preferred, called a monoclonal antibody⁸. See table 2 for specific drugs.

In the setting of small/peripheral joint arthritis (the arthritis affecting the joints of the extremities) the treatment depends on whether the IBD is active. If there is IBD activity, then the recommendation would be to treat the underlying IBD. If the IBD is quiet, then we would use the usual agents for small joint arthritis including sulfasalazine, methotrexate, azathioprine, and/or low doses of prednisone temporarily, or the biologic agents, like the TNFI. Besides the NSAIDs, all the medications listed below in table 2 may also help the IBD.

Table 2. Medications for arthritis in setting of IBD

Medication	Helps back & sacroiliac joints	Helps small & large joints	Taken by mouth or injection
NSAIDs	Yes	Yes	By mouth
Prednisone 20mg or less	No	Usually	By mouth
High dose prednisone	Yes, but not recommended (high risk of side effects)	Yes, but not recommended (high risk of side effects)	Either
Sulfasalazine (Azulfadine)	Not usually	Yes	By mouth
Methotrexate (Rheumatrex)	No	Yes	Either
Azathioprine (Immunan)	No	Yes	By mouth
Adalimumab (Humira)	Yes	Yes	By injection SQ (subcutaneous)
Certolizumab (Cimzia)	Yes	Yes	By injection SQ
Golimumab (Simponi)	Yes	Yes	By injection (approved by SQ but available by IV (intravenous))
Infliximab (Remicaid)	Yes	Yes	By IV injection

Another TNFI, Etanercept (Enbrel) works for the joints, but not the IBD and is generally not preferred if there is IBD in the presence of the arthritis. In this group, the TNFI listed in table 2 are preferred.

For those patients with IBD that is resistant to TNFI, their gastroenterologists might consider a new drug, Vedolizumab. This drug works by staying inside the gut, but as a result will not treat the arthritis, if this is occurring independent of the GI disease activity.

Besides arthritis with inflammation, patients with IBD can have other reasons for joint pain and arthritis. IBD patients can be more hypermobile (very flexible) which may lead to joint injury and pain. Patients with or without IBD can develop osteoarthritis – arthritis as a result of wear and tear. Though this can happen from the arthritis associated with the IBD after long bouts of inflammation, these are more commonly not thought to be inflammatory and are treated conservatively with pain control and physical therapy. Occasionally, the arthritis is severe enough to require joint replacement – especially in the hips and knees. This procedure can dramatically improve quality of life in patients who have joints with severe damage. Finally, patients with chronic disease may also develop a widespread pain syndrome called Fibromyalgia, which is not immune mediated or associated with inflammation, but can be very disabling and is treated with regular exercise, cognitive behavioral therapy and occasionally pharmacologic therapy.

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The ACR/SAA/SPARTAN 2015 Recommendations for the Treatment of Ankylosing Spondylitis and Non-radiographic Axial Spondyloarthritis

By Michael M. Ward, MD



Editor's Note: September 25th, 2015 saw the publication of the first ever Treatment Guidelines for US physicians in ankylosing spondylitis and non-radiographic axial spondyloarthritis.

As a contributing member of SAA you played a big role in bringing this to fruition through your generous support of our work. These guidelines were born as a result of the historic collaboration between the Spondylitis Association of America, the American College of Rheumatology, and the Spondyloarthritis Research and Treatment Network.

Below, Dr. Michael Ward, the Principal Investigator on the guidelines project, provides an introduction and discusses the importance of this document for the patient and the medical community.

The complete document can be found at <http://www.rheumatology.org/Portals/0/Files/Recommendations%20for%20the%20Treatment%20of%20Ankylosing%20Spondylitis.pdf> and is also linked on our website, in the News section.

These recommendations are intended to provide doctors, physical therapists, and other clinicians who care for patients with AS and related types of spondyloarthritis with guidance on approaches to treatment that are based on current and best-available medical research. Given the wide diversity of medical conditions and the breadth of medical knowledge, it is sometimes difficult even for subspecialists, such as rheumatologists, to be fully up-to-date on the treatment options and alternatives to consider in all types of situations.

In developing these recommendations, we posed questions on the most common and important treatment considerations facing patients with AS and their doctors, and attempted to answer them through a comprehensive review and summary of the medical literature on each topic. For questions that had not been studied well or at all, we relied on the judgment of a group of physicians and therapists who had a great deal of experience in treating patients with AS. We also considered the strength of the evidence for or against the treatment alternatives posed by each question, and the degree to which patients might deliberate and differ over the decision to use one treatment versus another, in considering the weight to give each recommendation.

There are three important points that patients should keep in mind regarding these recommendations. First, these are not a set of rules that doctors must follow. There are many reasons why a particular recommendation may not be followed for an individual patient, including their prior medical history, other co-existing illnesses or medications, their stage of AS, and considerations of the trade-offs between the potential benefits and harms of a given treatment choice. Think of these more as a resource guide that doctors can use to help their decision-making in recommending (or not recommending) particular tests or treatments. All treatment decisions must be individualized to fit the patient and his or her particular circumstances.

Second, the recommendations don't consider all possible issues or questions that can occur in patients with AS or spondyloarthritis. The recommendations focused on the most common questions, but many others remain. We hope that these recommendations can be expanded to include more questions in the future.

Third, these recommendations are not unchangeable. While they are based on the best evidence available to date, new research may uncover new findings that would cause us to change a recommendation. This would be unlikely for recommendations that were designated as a "strong" recommendation, because the evidence for these was considered so solid that any new research was thought very unlikely to change the conclusion. However, for "conditional" recommendations, new research may change the recommendation as more facts are learned. Also, new treatments may be developed that would change our thinking about the way patients should be treated in particular circumstances. Or new information about side effects of treatment may be produced to change our ideas about the safety of a given treatment. It is important to note that most of the recommendations were conditional ones. To make sure the recommendations stay up-to-date, we plan to review them every few years, and issue updates earlier if important breakthroughs occur that make a current recommendation obsolete.

Michael M. Ward, MD is Senior Investigator at the Intramural Research Program at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the National Institutes of Health (NIH.) Please note that the guidelines are not produced or endorsed by the NIH.

Tackling Chronic Pain: The Multi-Modal Strategy of Functional Restoration

We wrote about chronic pain and central sensitization in the last (Fall) issue of *Spondylitis Plus*. In this piece we are digging deeper and exploring chronic pain treatment options in further detail. If your spondyloarthritis is being appropriately managed, but you are still living with uncontrolled pain, additional therapies may be needed. While there are numerous options and modalities available, and pain medications can make a notable difference for some, in this article we will discuss functional restoration as it applies to pain management, and focus on active interventions.

“It helps to think of a person with chronic pain as like a car with four flat tires.”

We thank the American Chronic Pain Association for allowing us to adapt and print excerpts from their comprehensive Resource Guide to Chronic Pain Medication and Treatment. The guide is an extensive consensus document, researched, written, and kept up to date by physicians specializing in pain management. You will find a link to the extensive document at the end of this piece.

We begin with an introduction to Functional Restoration:

“Functional restoration can be defined as the process by which an individual acquires the skills, knowledge, and behavioral changes necessary to assume or re-assume primary responsibility for his/her physical and emotional well-being.

Functional restoration thereby empowers the individual to achieve maximum functional independence, to have the capacity to regain or maximize activities of daily living, and [when possible] to return to vocational and avocational activities.” (1)

But, what about THE PAIN? Can’t the right pain medication or procedure just take it all away and return us to full function? Not according to this model; medications or other passive modalities are only one part of the chronic pain solution. According to this model what is often missing here is *active intervention*.

“It helps to think of a person with chronic pain as like a car with four flat tires. Our expectation is that all we need is that one medication or treatment that will take away the pain. But [medication] only puts air in one of our tires; we still have three flat tires and can’t move forward. Perhaps the medication or treatment has provided 25 or 30 percent relief. Let’s leave that there and ask what else we need to fill our other three tires.”

For each person the necessary combination of therapies and interventions will be different, based on individual need. Unlike traditional medicine where the “patient” is a passive participant, living a full life with pain requires that we take an active role in the recovery process. We need to work with our health care providers to find what we need to fill up our other three tires.” (2)

So what exactly is meant by Active Intervention? Active interventions are treatment modalities that require the active participation of the individual.



“The overwhelming theme in the treatment of most persons with chronic pain is to keep as physically active as possible.”

Active intervention modalities include: Education, Exercise, Functional Training, and Psychological & Behavioral Approaches.

Education

“Education regarding chronic pain should start as soon as the pain has been identified as chronic. Early topics should include helping a person understand that they may not be “fixed” but instead their pain must be managed. It can be helpful to think of chronic pain similar to other chronic diseases such as diabetes. A person needs to manage their diabetes and prevent it from getting worse and causing other problems. Diabetes is not quickly cured or fixed. The same is true for chronic pain.

Further education on chronic pain should also include understanding that pain is not “all in your head” but that an active approach that focuses on the whole person is the most effective way to treat chronic pain. What someone can and cannot do should be defined as clearly as possible.” (3)

Exercise (Active Therapy)

“The overwhelming theme in the treatment of most persons with chronic pain is to keep as physically active as possible. In fact, one of the best treatments for chronic low back pain is

exercise. After consultation with a health care professional and/or physical therapist, a therapeutic exercise program should be initiated at the start of any chronic pain treatment program.

Therapeutic exercise can be classified to include 1) range-of-motion exercises; 2) stretching; 3) strength training; and 4) cardiovascular conditioning.

Active therapy is based on the philosophy that therapeutic exercise and/or activity are beneficial for restoring flexibility, strength, endurance, function, and range of motion, and can alleviate discomfort.

Persons with chronic pain can become discouraged when their pain temporarily increases due to therapeutic exercise, and they will sometimes terminate treatment too early before achieving maximal benefit. A flare-up of pain with exercise should be expected even with safe exercise, but can also be due to poor body mechanics, guarded or stiff movement, high levels of demand on an injured site, or compensatory movements. It is important to have a health care professional knowledgeable about treating chronic pain to assist not only with setting up a graded and careful exercise program, but also to assist with distinguishing new symptoms that may signify problems from the “good” discomfort that normally goes along with an increasing exercise program.” (4)

Functional Training

“Functional activity training is just as important as performing a daily exercise program. Lifting, carrying, pushing, pulling, reaching, bending, digital dexterity, and handling are all examples of functional movements that are used on a daily basis. It is helpful to think of practicing daily activities similar to performing exercises. It is important to first determine the

current ability to perform tasks. Each task is then practiced with appropriate pacing of activity, flare management and slow progression.” (5)

Some exercise forms can also double up as functional training opportunities and deliver exceptional results for some. These include Tai Chi, Yoga, and Qigong.

“ Research shows that psychological distress about pain actually amplifies one’s experience of pain. ”

Psychological & Behavioral Approaches

“The definition of pain is “...a negative sensory and emotional experience.” (International Association for the Study of Pain). This definition recognizes that along with pain comes an emotional response and reaction. People naturally respond to pain by wanting to escape it. With chronic pain, one cannot easily escape pain that is coming from inside the body. Sometimes people try to escape pain by retreating to the bed or becoming sedentary. While these strategies (known as fear avoidance) seem like a good idea on the surface, sedentarism is actually know to worsen pain over time and it leads to deconditioning and contributes to depression. A pain psychologist helps people to learn techniques and skills to calm the distress that naturally arises during pain, and this alone can help reduce pain. Research shows that psychological distress about pain actually amplifies one’s experience of pain.

A therapist can help to break this cycle by exploring ways for the individual to gradually improve function, reduce worried thoughts, and improve mood. Strategies that have been most helpful include monitoring daily activity and mood, using problem-solving techniques, challenging some of the recurrent worried thoughts, engaging in a gradual exercise program, watching body cues, maintaining a daily routine and schedule, learning to pace activities, watching diet and caloric intake, getting involved in distracting activities with others, sharing emotions associated with the pain, and contacting others for help when needed.

Therapists trained in behavioral medicine also often teach relaxation training using various mind-body interventions and techniques that include diaphragmatic breathing, progressive muscle relaxation, autogenic relaxation, guided imagery, cue-controlled relaxation, and hypnosis.

It is important to remember that the goal of psychotherapy and behavioral therapy is not to ‘cure’ or get rid of the pain and seeing a psychologist or other counselor does not mean that the pain is not real. Psychotherapy can help individuals better manage their pain to lessen its impact on activities, relationships, and other aspects of their daily lives.” (6)



Going back to the analogy of the car with four flat tires, it becomes clear why current research and best practices in pain management are increasingly recommending the holistic approach for treating chronic pain. Functional restoration is a treatment model that asks a great deal of the person living with chronic pain, but also offers a better outcome than any one intervention has thus far.

ACPA’s complete Resource Guide to Chronic Pain Medication & Treatment can be found on their website, at http://www.theacpa.org/uploads/documents/ACPA_Resource_Guide_2015_Final%20edited%20%283%29.pdf and is recommended reading for anyone living with chronic pain.

Excerpts reprinted by permission of ACPA, 2015.

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Do you know about SAA’s Action Plan to Manage Spondylitis? It’s a helpful guide for both those new to spondyloarthritis and SAA, as well as a resource for veteran spondylitis warriors. We have recently updated the document and you will find it at www.spondylitis.org/guide



It is imperative to take an active role in managing spondyloarthritis, as doing so will positively impact many aspects of life with this disease. Our goal remains providing you with a sound knowledge base with which to tackle the social, functional, and economic challenges often associated with SpA.



My Weakness, My Strength – Amanda's Ride Up Pikes Peak

I remember the day I found out I had ankylosing spondylitis. I remember the exact moment so clearly... I was in my office at work; had been having intense pain in my sacroiliac joints and lumbar spine for over a year at that point and it had only been getting worse. Some days I couldn't sit up, let alone stand, on my own. I had been calling in sick more frequently and I had been in PT for over 4 months. The pain still crept up and consumed me. I was fixated on something I could not find an answer to. I had recently had two MRIs done and found out I had bilateral inflammation in my SI joints. I was told that this may be indicative of something else, but I was given little information as to what that could be. My doctor told me I needed to have a blood test. When she handed me the order, I immediately started Googling the different tests she had ordered. One of tests ordered was for HLA-B27. I

Googled this test, immediately finding that it was linked to ankylosing spondylitis, read all of the symptoms, and knew that is what I had. I continued reading about AS and became horrified. I was certain that I matched all of the symptoms listed, but surely this could not be my fate... a fused spine? Lack of mobility? Chronic pain? TNF blockers? I was drowning in my own fear before I was even officially diagnosed...

Not long after that was the day I received confirmation. As I said, I was in my office at work, and I received a phone call from my doctor's office. My doctor's medical assistant told me that I was HLA-B27 positive and that, along with my symptoms, it was consistent with ankylosing spondylitis. She said that I needed to follow up with a Rheumatologist and gave me a referral. I thanked her quietly and hung up the phone. Do you know what it feels like when you are so sure you know something to be



“ I closed the door to my office and slid down the back of it... folding up into a ball on the floor. ”

true, but it still shocks you the moment it's confirmed? I closed the door to my office and slid down the back of it... folding up into a ball on the floor. I cried, I questioned, I feared, I prayed. I believed in that moment that AS was going to be the worst thing that ever happened to me. I believed AS was going to steal my life.

What I didn't know then was that I was actually getting stronger in that moment. That is the funny thing about strength... it doesn't come without weakness or pain. Strength comes from growing and from battling. It comes from breaking down and then choosing to stand back up. Strength comes slowly and from experience. Finding out that I had AS broke me. I felt like I had been robbed of my future. I was so scared of the unknown that awaited me. My physical pain had become an emotional hell. I was so relieved to have an answer for what my pain was, and yet so distraught to learn what it was that ailed me. I felt so much on the floor of my office that day, but the next day was about action. Okay, I have AS. Now what? How will I handle this new life? Because the truth is my life was not

stolen... it was changing. Was it possible that I could have any control in how it was going to change? I once read that “a river cuts through rock not because of its power, but because of its persistence.” AS is not something you muscle or power through... it takes persistence. Persistence in staying mobile and active. Persistence in remaining optimistic and positive. It requires persistence to keep going even though there are battles ahead.

“ AS is not something you muscle or power through... it takes persistence. ”

It is interesting talking to people about AS and my prognosis. Just tonight I was asked, “What does that mean?” In the simplest form... it means I have an inflammatory arthritis that attacks my spine and the surrounding joints. It means chronic pain and flares. It means varying degrees of symptoms throughout my lifetime. It means the possibility of my joints fusing and the loss of mobility. It means meeting with a Rheumatologist multiple times a year and blood tests 3-4 times a year. It means anti-inflammatories and possibly TNF blockers one day. It means experimenting with diet, vitamins, herbs, oil, and every other treatment that people recommend. It means lifestyle changes, stretching, and restless nights. It means fatigue and caution. It means physical therapy and soreness.



But it has meant a lot more to me as well... It has meant patience and perseverance. It has meant motivation and a greater awareness of my body. It has meant committing myself to an active lifestyle and becoming involved in active communities. It has meant being grateful for my mobility and dedicated to maintaining it. It has meant taking my weakness and making it my strength.

“ Standing on top of that mountain
I felt so alive and humbled. The
time, the effort, the soreness...
None of that mattered anymore.
I was on top of the world. ”

Finding out I have AS was horrible, but it has led to some of the best things in my life. I practice Iyengar and found a yoga community I love. I hike more, bike more, and enjoy the outdoors more. I challenge myself physically, but also have more understanding and know when my body is telling me to back off. AS has helped me create connections with other people who have this scary and challenging condition. And now? I am motivated not only to better my life with AS, but the lives of others who suffer from it.

On July 25, 2015 I biked to the top of Pikes Peak with 11 of my best biking buds in an effort to raise money for SAA. The 12.5 mile trek to the summit took me just under three hours. We climbed a grueling 4,880 feet in elevation to get there and made approximately 154 turns along the way. I took multiple breaks to stretch my back, to breathe, and to take it all in, but I made it. Standing on top of that mountain I felt so alive and humbled. The time, the effort, the soreness... None of that mattered anymore. I was on top of the world. I rode to the top of that mountain to challenge myself physically and prove to myself that my body is capable and strong, despite its weakness. But even more

than for myself, I rode for everyone else that has AS, especially those who have severe pain and can barely move. I rode for those who struggle to get out of bed and for those who cry themselves to sleep. I rode for those who have lost jobs, relationships, and hope. I rode for those experimenting with drugs and suffering from the side effects. I rode for those who are scared, tired, and lost. I rode for those who have fused and for those who fear it will happen soon. I rode for those who think mobility, drive, and energy are out of their reach. I rode for those who feel alone and feel that there is no other way of life with AS. To those people, I rode for you.

I want you to know that I have AS and I believe more than anything, my mobility is saving me. Some days I am too sore, I am too tired, and I feel helpless. Those days, I know I need movement even more. Strength comes to those who want it. Maybe you won't be biking Pikes Peak any time soon, but strength is what you make it. Yes, you have a weakness. You have a challenge. And I know you have pain. But you have got to keep moving forward. I encourage you to try new types of movement, physical therapy, or even walking every day. You may be on the floor now, but where will you be tomorrow or three years from now?

Our ride up Pikes Peak raised over \$3,000 for SAA which I know will be used for meaningful research, treatments, and growing awareness in the community. But, I also hope that the ride up Pikes Peak can help those with spondylitis believe that their weakness, their pain, and their fear can create their strength and perseverance tomorrow. We may not be able to cure AS, but we can change how people look at it, especially those who battle it every day. Let's change the face of AS, let's make it STRENGTH.

To better days and strength ahead,
Amanda

Originally posted on Amanda's Blog,
<http://carrglick.blogspot.com>

Helpful Hints: What item, modality, trick, etc. do you find helpful for daily living or SpA issues?

Helpful Hints is a recurring feature in *Spondylitis Plus* dedicated to your helpful hints, tips, and tricks on different aspects of life with Spondyloarthritis.

Have a helpful hint to share with other readers? Send it in and we might publish it in our next issue.

Next Helpful Hints topic: Open Forum

Please send your hints to Elin@spondylitis.org

I can no longer sit on anything soft; five minutes of me sitting on anything soft will bring about horrible spasms. Wherever I go, I take a wooden board with me to sit on and; if I'm at a restaurant and I find myself without a board, I sit on a serving tray. Early on, I was a bit embarrassed but it's an easy choice to avoid pain. ~ Jake M.

Anything and everything heated is great. Love my blankets. Ice bottle to roll under my feet when plantar fasciitis is flaring. ~ Jennifer N.

I have fused SI joints and am no longer able to bend down enough to put socks on. I use a sock aid tool by Carex every day and it works wonders for socks. You can find it on Amazon. ~ Joey F.

I love aqua exercise in the deep end with a flotation belt: The belt supports my lower back and reduces my pain. Having no impact and floating enables me to be pain free. The pool is probably the only place / time when I'm not in pain. ~ Clodette M.

Shoes that have great arch support, like Birkenstocks really help. ~ Gweneth A.

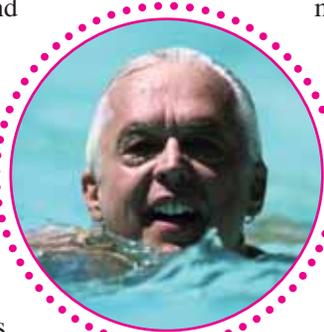
After suffering so long with morning stiffness, trying to get up from a low bed, I bought a "platform" or "chest" bed, which elevates your mattress (and allows great storage beneath!) Suddenly, it was easy to "get up", as it was just a matter of sliding off the mattress into a standing position.



It also helps in dressing - something to lean against when putting on pants and socks. Oh, don't forget you can grab your pant leg to lift and move a stiff leg! Really helps when trying to put on socks. ~ Ken J.

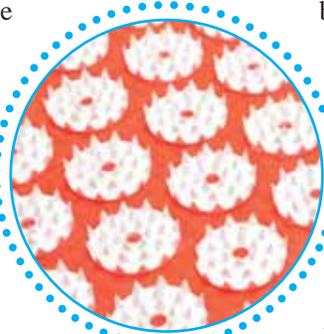
Things I love: The TENS unit! My arthritis gloves, heat pads, meditation, swimming, stretching, and warm baths with Himalayan salt. ~ Raquel R.

Yoga and core exercises; the core exercises actually feel good, for my back anyway. I can tell you what will make me miserable... Sugar. Discovered that during the Holidays last year. ~ Michelle C.



I have a Shakti mat, also called an acupuncture mat. I bought it online, it is like a little bed of nails, but it works a treat when I'm really stiff/sore and nothing else works. I also travel with it, so if I sleep on different beds it helps. ~ Maree H.

It is exercise that helps most. Believe me, you think it's bad to work a lot, but physical movement is the best option. Obviously, I am not talking about throwing rocks around, but the many odd jobs around home, and constant walking, help me a lot. ~ Chris G.



Please note that SAA does not endorse or recommend any specific medications or products for SpA, and always advises that you seek the counsel of a physician before initiating treatment. The opinions expressed in the Helpful Hints feature are solely those of our readers and our community.

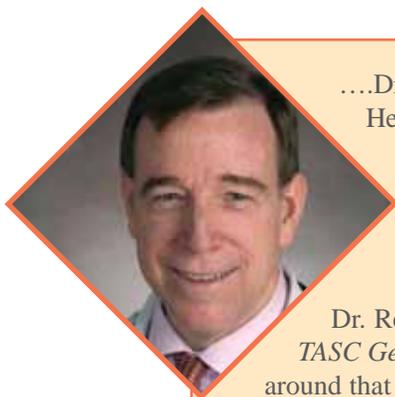
CAN YOU CREATE THE FUTURE YOU WISH TO SEE? — (HINT: You're Doing It)

As shortages in rheumatology become more pronounced, the need to get more physicians into the field becomes more critical and more time-sensitive.

According to the 2014 Physician Specialty Data Book published by the Association of American Medical Colleges, there are only about 200 first year residents/fellows practicing in the field of rheumatology, and a very small percentage of that number dedicated to SpA. Fewer still committed to research in the field. With almost half the current rheumatology population over age

55, this indicates a critical need to recruit more young physicians and researchers to devote their careers to rheumatology, and spondyloarthritis, in particular.

SAA has been leading this charge for more than 20 years. If you've been involved with SAA for any length of time, you know Dr. John Reveille. (*If Spondyloarthritis has a Rock Star, it's John Reveille, no?*) But did you know that he had no intention of making a career of spondyloarthritis? Here's an excerpt from a *Spondylitis Plus* article that ran in 2006:



...Dr. John Reveille, director of the Division of Rheumatology at the University of Texas Health Science Center in Houston picks up the story here, telling *Spondylitis Plus* that it was Jane (*SAA co-founder Jane Bruckel*) who convinced him, due to his reputation, to shift his genetic research focus to include — if not feature — the genetics of spondylitis and how it applies to the disease process, his field of specialty.

Dr. Reveille, who is the principal investigator on the AS Family Genetic Study (*now the TASC Genetic Study*), explains: “I was shifting my focus toward lupus and scleroderma and around that time, Jane approached me and asked if I would be interested in working with SAA and the genetics of spondylitis. She kept at it, and through her dogged persistence and inspiration, she convinced me that working with SAA would be a good idea.

“Subsequently, it led to the SAA, with the help of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), to set up the project along with the generous help of the people who had donated the seed money to see this happen,” Dr. Reveille points out. “Through this, and because of this, with the money being raised with the membership of SAA, the Family Genetic Project kicked off in 1998. Jane then later successfully lobbied NIAMS to increase funding for AS. She used the family genetics project as a lever to say that we were already doing this research, but that now we needed more money to bring this in the right direction.”

And SAA is still doing everything we can to encourage the next generation to commit to SpA. For the last several years, SAA has awarded the Bruckel Young Investigator Award (*newly renamed the Bruckel Early Career Investigator Award*), an unrestricted \$10,000 (*now \$20,000 as of 2015*) grant toward Axial SpA research. The award

has been given annually to the Early Career Investigator who shows the most promise to contribute to the understanding or therapy of axial spondyloarthritis.

And the benefits of those awards are already being realized.



"The SAA award came at a critical time in my career caring for AS patients and performing research in the area. I was promoted to associate professor at the University of California, San Francisco where I continue to direct the Ankylosing Spondylitis clinic. Following the award, we conducted the first study that showed that long-term use of TNF inhibitors, especially when started earlier in the disease course, was associated with less damage progression. In 2013, we continued to contribute to the genetic understanding of AS and more recently I have mentored trainees to get excited about research in AS. I continue to believe we are working towards a healthier population of AS patients and will one day be able to stop the disease in its tracks or potentially prevent it from affecting the children of the patients we treat. ~~ *Lianne Gensler, MD, 2013 Award Winner.*

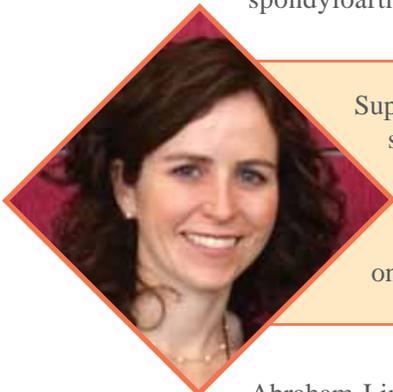
This award helped immensely during a time when I was just securing my first grants, which then led to further grants and publications. It has also provided some face recognition which has been useful for establishing an "investigative home," where I know others in the field and they know me. As a result, I have been able to become more active in SPARTAN, participating in teaching (*lectures*) and putting together treatment guidelines. ~~ *Judith Smith, MD, 2010 Award Winner.*



There is also a severe shortage of *pediatric* rheumatologists in the United States, with fewer than 250 board-certified, practicing pediatric rheumatologists, primarily clustered in and around large cities.

Dr. Pamela Weiss is an **Attending Physician** and the Rheumatology Clinical Research Director at the Children's Hospital of Philadelphia. Her current research efforts are focused on defining the clinical and imaging features of children with early juvenile spondyloarthritis. Long-term studies evaluating critical disease outcomes in children with spondyloarthritis are sparse.

Outcomes critical to study include the rate and proportion of children who experience progression of arthritis of the lower back and spine, the likelihood of maintaining remission while on medication or if medications are discontinued, and the impact of therapy on outcomes that matter to children and their families (such as anxiety, peer relationships, fatigue, pain). Studying these critical outcomes through the creation of a longitudinal registry of children with spondyloarthritis has the potential to transform the way we approach and care for these patients long-term.

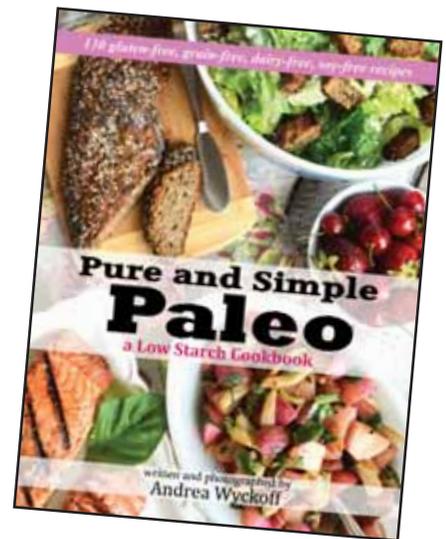


Support from SAA has allowed me to begin registry development and enhance the scope of my research. Ideally, data collection will also eventually include blood samples and imaging. This project has the potential to vastly improve our understanding of the natural history of the disease in children, contributing factors to disease onset and progression, as well as the current therapy's impact on the quality of life for patients. ~~ *Pamela Weiss, MD, 2014 Award Winner.*

Abraham Lincoln once said, "*The best way to predict your future is to create it.*" These Early Career Investigators may very well create the future landscape of spondyloarthritis. And because these awards are funded with **your** generous donations, **you**

can be the force that brings about a brighter future. So, what kind of future do *you* want to see?

Watch this space! In our next issue, we'll announce the winner of the 2015 award. The future is closer than you think!



Chocolate Walnut Fudge

I always have some sort of homemade chocolate treat in my freezer for “emergencies,” and this rich creamy fudge is a great treat to have on hand. I have found candy bars made with refined cane sugar and corn syrup to be way too inflammatory for my body, but I do really well with raw honey or real maple syrup sweetened chocolates instead. And believe me there is no sacrifice on flavor or satisfaction when it comes to this fudge recipe. If you don’t like the taste of virgin coconut oil, try purchasing an expeller pressed coconut oil which will have a very neutral taste.

Ingredients:

1/2 cup coconut oil
1/2 cup cacao powder (or cocoa powder)
1/4 cup almond butter*
1/4 to 1/2 cup raw honey or maple syrup
1 teaspoon vanilla extract
pinch of sea salt
optional: 3/4 cup chopped walnuts*

**This fudge can be made nut free by omitting the almond butter and walnuts. Or you can use a different nut or seed butter in place of the almond butter. The nut butter helps to make a firmer fudge.*

Directions

1. This fudge can be mixed in a bowl with a spatula by hand, or blended together in a food processor.
2. Start with softened coconut oil, so that it is easy to mix by hand. You can put the 1/2 cup of coconut oil into a warm oven for a few minutes to soften it, or if you use a food processor the blending action will also soften it.
3. Mix coconut oil and cacao powder together first so that you have a creamy chocolate oil. Next mix in remaining ingredients.
4. Line a bread pan or small casserole dish with parchment paper or saran wrap, and then spoon in fudge.
5. Place fudge in the freezer for an hour to firm up, or place in the fridge for a couple hours, until firm.
6. Fudge needs to be stored chilled in the fridge or freezer.



Starch Free “Pumpkin” Persimmon

This persimmon pie is a wonderful starch-free, dairy-free stand in for the traditional holiday pumpkin pie. And if you would rather make it with pumpkin, you can, just see my notes below. Persimmons don't have any starch, whereas pumpkin is somewhat starchy. (Though some who eat a low starch diet do fine with pumpkin.) The natural pectin in the persimmon thickens up the pie quite nicely without the need for eggs, but if you choose to use pumpkin puree as your filling you will want to include the 2 eggs as noted below.

Where I live in Oregon I generally find two types of persimmons in the markets and at local farms, and those varieties are Fuyu and Hachiya. If you don't see them at your local grocery store try calling around to stores that specialize in Asian and Ethnic foods. This recipe calls for Fuyu persimmons (pictured below), which are in season during the fall, just like pumpkins, and have a mild pumpkin like taste. I think the Fuyus look like an orange tomato. A trick to speed up ripening of your Fuyu persimmons is to put the persimmons in the freezer overnight, defrost them the next day, squeeze out the pulp, and discard the skin and any seeds. Five or six Fuyu persimmons should give you the 1 1/2 cups of pulp needed for this recipe.

Pie Crust Ingredients:

2 cups blanched almond flour
4 Tablespoons organic palm shortening (or softened coconut oil, lard)
3 Tablespoons honey or maple syrup
1 egg (see egg-free option notes below*)
1 teaspoon vanilla extract
2 pinches of sea salt

*Notes for Egg-Free Pie Crust: omit the egg, and use a total of 1/2 cup palm shortening (or coconut oil), and increase almond flour an additional 1/2 cup, for a total of 2 1/2 cups almond flour.



Pie Filling Ingredients:

1 1/2 cups mashed Fuyu persimmon pulp*
(or pumpkin puree)
1/2 cup coconut milk, full fat
1/4 cup to 1/2 cup honey (or maple syrup)**
1 teaspoon vanilla
1 teaspoon cinnamon
pinch sea salt
Optional: 1 teaspoon pumpkin pie spice (omit if super sensitive to starch)
(Optional: add 2 pastured eggs if using pumpkin)

***Honey: Since persimmons are sweeter than pumpkins, I found 1/4 cup of honey to be the perfect amount of sweetness. But if you are using pumpkin puree increase the honey to 1/2 cup.*

Directions

1. Preheat Oven to 325°F
2. Mix pie crust ingredients together, putting in palm shortening first, mixing in egg last.
3. Mash pie crust into a standard pie plate, forming the pie crust with your hands. Poke some small holes in the base of the pie crust.
4. Prebake plain pie crust for 12 minutes, at 325°F.
5. Puree pie filling ingredients in a food processor, stand mixer, or in a mixing bowl with an immersion blender.
6. Pour ingredients into the pre-baked pie crust.
7. Bake pie for 45 minutes at 325°F. Allow to fully cool, then set in the fridge for a few hours to firm up.
8. You can serve this pie with the dairy-free coconut whip recipe at www.forestandfauna.com or with a scoop of my vegan vanilla ice cream from my cookbook.

Gingerbread Waffles (or Pancakes)

Here is a fun low starch, grain-free recipe to enjoy with the whole family on a fall weekend or special holiday. This recipe makes approx. 8 Belgian waffles. I like to serve these waffles with a side of candied pasture raised bacon or my herb breakfast sausage patties. You can also serve them with my favorite starch-free “breakfast

Ingredients:

6 Tablespoons of creamy almond butter*
2 large pasture raised eggs
1 ½ Tablespoons blackstrap molasses**
1 ½ Tablespoons honey (or maple syrup)
1 teaspoon vanilla extract

hash” or the “hash-browns” recipes from my book. I imagine these waffles would also be wonderful with a side of spiced apples or scrambled eggs. I’ve included instructions below for a gingerbread icing so you can decorate these waffles in the same way you might decorate a gingerbread house.

1/2 teaspoon pumpkin pie spice**
1/2 teaspoon baking soda
pinch of sea salt
optional: 1 teaspoon lemon juice (or cream of tartar)
a little cooking oil



**I have had great success making this recipe with almond butter, walnut butter, and sesame butter, and I would assume most creamy nut or seed butters would also work just fine. You can also use a blanched almond butter or tahini for a completely starch-free version.*

***If gingerbread is not your thing, feel free to omit the molasses and pie spice to just make a regular batch of waffles. To make these waffles “starch-free” omit pumpkin pie spice, and use spice extracts instead. I personally do fine with the regular pie spices.*

Directions

1. Turn on waffle maker or heat a skillet up to medium low heat for pancakes.

2. Mix ingredients together in a bowl until you have a nice consistent batter. If needed you can add a splash of coconut milk to thin out the batter if your almond butter was on the thicker side.
3. If you have lemon juice or cream of tartar add it as it will react with the baking soda and help the waffles or pancakes rise, but it is okay to omit.
4. Grease waffle maker or skillet.
5. Spoon batter into waffle maker, makes approx 8 Belgian waffles. Or spoon batter into a skillet to make pancakes. Keep pancakes on the smaller side so they are easier to flip. Cook pancakes at a medium low temp and watch closely to avoid burning them.
6. Top with maple syrup or decorate with my icing recipe and chopped nuts and dried fruits.

Gingerbread Icing Recipe

Ingredients:

4 Tablespoons soft goat cheese
1 to 2 Tablespoons raw honey (or maple syrup)
1/2 teaspoon vanilla extract
tiny pinch of sea salt
optional: 1 teaspoon ginger juice (or a few drops of food grade ginger extract)
optional: little splash of coconut milk, if needed to thin

Directions

1. Mix ingredients together in a small bowl with a spoon until smooth. Add a splash of coconut milk if needed to thin the icing.
2. Spoon ingredients into a piping bag or a small sandwich baggie, and then cut off a tiny corner. You can now drizzle the icing over the waffles.
3. It’s fun to let everyone decorate their own waffles. You can drizzle a little goat cheese icing over the waffles, or simply use maple syrup (or even use a little of both if you want!) You can also sprinkle on chopped nuts like walnuts or use pumpkin seeds, chopped dried figs or raisins, and freeze dried berries.

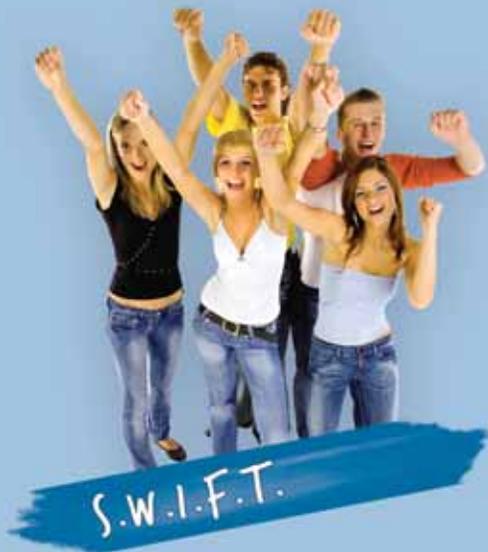
We thank Andrea for sharing these great recipes with us! “Pure and Simple Paleo: a Low Starch Cookbook” can be downloaded from Andrea’s website, at <http://pureandsimplepaleo.com>.

A note on the Low Starch Diet / London AS Diet: We’ve heard from many people over the years that avoiding starch has been beneficial for their gut as well as spondyloarthritis symptoms. The diet was born thanks to Dr. Alan Ebringer, and has been tried by countless individuals in search of relief. In the absence of convincing trial evidence on this

issue, SAA can not endorse this diet as a treatment strategy; however we also won’t ignore anecdotal evidence suggesting that some people have found avoiding starches to be helpful. Some people report feeling better by avoiding other foods—dairy, red meat, gluten to name a few. We covered the Low Starch Diet in our Summer 2012 issue of Spondylitis Plus.

If you’ve been considering experimenting with different diets, we recommend first checking with your physician, and keeping a food journal to document your reactions to foods.

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