Foods That Heal, Foods That Can Harm. An Interview With Clinical Nutritionist, Michelle Schirra

Battling Our Demons: The Emotional Impact Of Life With Spondyloarthritis

The Philip Donlay Guest Column: The Anniversary
Autumn is here. This season always reminds me of what I’m thankful for. I’m thankful for you and your many years of support. It means the world to me and all of us here at SAA. I wanted to take a moment of your day to remind you what a difference you can make by taking the extra step to join our Quest Legacy Society. It can be as easy as making a simple designation in your will to remember the Spondylitis Association of America (SAA.)

What kind of legacy would you like to leave? I am particularly excited about SAA’s expanded Juvenile Spondyloarthritis (JSpA) program. What can be better than leaving a legacy that supports early diagnosis of ankylosing spondylitis and related diseases for the next generation?

I also want to share with you the gifts that cost you nothing during your lifetime and gifts that return significant benefits back to you, even beyond a tax deduction. I’m talking about strategic planned gifts like a tribute gift through your will that leaves a lasting statement about the initiatives that are most important to you. Or a charitable gift annuity that provides you or a loved one a steady stream of extra retirement income, while at the same time supporting our mission far into the future.

There are so many benefits to leaving a planned gift to SAA. As a proud member of the Quest Legacy Society myself, it would be an honor to have you standing tall next to me. Again, thank you so much for your generosity and for your confidence in our work. With all of us working together, we will continue the quest towards the cure, one we will dedicate to the next generation and those to come after.

Thank you for all you do.

Michael Pianin
Chairman of the Board
Spondylitis Association of America
I have just read the article in the Fall 2018 Issue of Spondylitis Plus titled “Physical Therapy Applications For Spondyloarthritis: Passive Interventions.” As a Physical Therapist as well as a spondylitis patient, I feel the need to respond. While I agree with most of the points made by the author, when applied to a person during a flare up of joint inflammation, I am concerned that it leaves the impression that many passive interventions are inappropriate in general for spondylitis patients.

I have been on a biologic medication for over two years and have fortunately had a fabulous response with excellent symptom control. Nevertheless, I am 69 years old with quite a few non-inflammatory, mechanical issues with my neck, back and sacroiliac joints. I see a physical therapist about once a month for a variety of passive interventions including joint mobilization, soft tissue/myofascial work, ultrasound, and a technique of joint alignment called “Muscle Energy.” These interventions help me maintain good mobility and alignment in the areas I cannot take care of by myself through swimming, stretching, strengthening exercises and yoga. Sometimes you need another pair of hands to get the right pressure in the right areas, in the right direction. I do agree that high velocity manipulation is probably contra-indicated for all of us. Why take the risk?

Physical therapists are trained to evaluate the presentation of inflammation of a joint and should be able to determine which techniques or modalities are appropriate at any given time. You wouldn’t use ultrasound over a “hot” joint, but you also wouldn’t do much exercise on it. For that, you want to rest in good alignment and maybe provide external support until the inflammation subsides. Gentle exercise in water, or in limited range, and exercise for the non-involved joints is great. Release of tight soft tissue away from or around a painful joint can also be helpful. This is the benefit of assessment by a PT.

We patients need to be aware of all the potential help for us and not dismiss beneficial interventions due to a diagnostic label. Thank you for welcoming comments from readers.

Sincerely,

Frances Engstrom, MA, PT
Mill Valley, CA

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

Please send letters to:
Elin@spondylitis.org
Letters to the Editor/SAA
16360 Roscoe Blvd, Suite 100
Van Nuys, CA 91406

Please note that we reserve the right to edit for space and clarity.
"Bad days make me want to stay in bed, especially when I can barely put socks on. Those days remind me to move it or lose it. Today, I’m okay, thankfully."

~ Dan (AS Patient)

Did you know that exercise is an integral component of an effective treatment plan for spondylitis? Beyond helping spondylitis patients maintain good posture and balance, exercise has been shown to help reduce overall pain. SAA believes so strongly in the importance of exercise that we are launching a new Exercise Video in the Spring of 2019 as part of our ongoing commitment to helping people impacted by spondylitis live their lives to the fullest.

SAA’s Revamped Exercise Video Coming Soon

"Topics will include: Range of Motion and Stretching; Aerobic & Cardiovascular; Strengthening; and Yoga and Balance to improve posture, breathing capacity, and overall function."

Performing a regular exercise program on a consistent basis that emphasizes flexibility, aerobic conditioning, strength and balance for 20 minutes a day has been shown to significantly improve pain, stiffness, fatigue, function, and mood for people living with spondylitis.

SAA last reprinted the original Back in Action exercise DVD in 2007. Our new Exercise Video - Back in Action, Again - will feature renowned physical therapists instructing people living with spondylitis in 20-minute exercise routines. Topics will include: Range of Motion and Stretching; Aerobic & Cardiovascular; Strengthening; and Yoga and Balance to improve posture, breathing capacity, and overall function.

As a heads up, online access to the new exercise videos will only be free to SAA members. If you haven’t joined, now might be a good time as we continue to roll out even more exciting member benefits in the upcoming months. DVDs will be available for purchase through our online store.

We look forward to bringing you our updated exercise video. Stay tuned!
I had an important anniversary not long ago that almost snuck past me. I came across a file of old calendars that date back to 2007. As I flipped through the tattered pages, written in pencil was the history of different medical appointments. Dates and times chronicling an extensive process to find what was wrong with me. I flipped to the exact date, ten years ago now, of a follow up appointment with a rheumatologist. I remembered sitting in the exam room and hearing for the first time the words “Ankylosing Spondylitis.” The doctor proceeded to tell me that I am HLA-B27 positive, and some other stuff about the disease being genetic, degenerative, there being no cure, but possibly being manageable… The memory gets a little fragmented and vague at this point. I walked out of the building holding two brochures about TNF inhibitors and a thousand questions I didn’t know enough to put into words. I was, however, struck by the fact that the people in the brochures were all very attractive and that they were smiling. Whatever relief I felt vanished by the time I got home and began a Google search that has, in many ways, lasted to this day.

I picked up another calendar and flipped to October of 2008. Complications with my heart had ended my thirty-year career as a pilot, AS was beating the crap out of me, and I still didn’t know how to fight back. Not being able to ever fly again was the worst thing that could have happened. So, for lack of a more succinct description, I spun out of control. For the first time in my life, the word depression was used to describe part of my condition. I went to see a mental health professional and described my situation as having felt like I hit rock bottom. I also went on to learn that actual rock bottom comes later. The initial impact is just the introduction. The worst part came next, as I felt like I was tumbling down flight after flight of stairs, slamming into walls as I fell, until finally, I ended up lying on my back in the darkness. This was rock bottom. I’m not positive, but I may or may not have heard Satan laugh.

Those were rough times. I was given a diagnosis of transient depression. I was instructed to get up, climb up out of the hole, and that the depression would begin to abate. In other words, the best advice was to stop the pity party, roll up my sleeves, and get on with my life. Looking back on that version of myself, at that time in my life, I wish I could go back and have a chat with myself. There was one night I still remember vividly that was filled with desperation, agony, and profound loss. If I could go back in time, it would be to that exact point.

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desperation, agony, and profound loss. If I could go back in time, it would be to that exact point. There are a few bits of wisdom I’d love to impart on my younger self that would have made things much better.

If I could have this theoretical chat, I would have explained that the realization of one’s worst fear is incredibly liberating. The worst had happened, yes, but he’s still alive. I’d also point out that everything from here on out would be different, and that his life would never be the same again. He’d hear that he could save himself a great deal of angst and effort if he’d simply turn around and swim with the current. I would tell younger me that there were going to be some people who would exit his life, for no better reason than they didn’t want to deal with someone who was sick. That’s their problem.

If I could have this theoretical chat, I would have explained that the realization of one’s worst fear is incredibly liberating. The worst had happened, yes, but he’s still alive. I’d also point out that everything from here on out would be different, and that his life would never be the same again. He’d hear that he could save himself a great deal of angst and effort if he’d simply turn around and swim with the current. I would tell younger me that there were going to be some people who would exit his life, for no better reason than they didn’t want to deal with someone who was sick. That’s their problem.

By now I’d have my younger self’s full attention, so I’d tell him the most important things I’d learned in a decade of dealing with AS: Take what the day gives you. There are no medals for being in pain and pushing yourself, only more pain. Sometimes your job is to let the flare run its course.

I would explain what I wish those very first doctors had made sure I understood—that there are physiological, as well as psychological responses to chronic pain. That what all chronic pain sufferers endure are Anxiety, Fear, and Anger. There are no exceptions, because our brains are hard wired that way. From those three constants spring another group of possibilities. These, however, are not absolutes, they are our emotional responses. I call them the Big Six, they are optional, and we need to be aware of the connections so as to avoid them. They are: Depression, Helplessness, Loss of Purpose, Frustration, Guilt, and Shame. I would implore my younger self to make fighting the Big Six, the number one battle to survive this disease. It’s not just our body that’s under attack, it’s also our mind. This is where the warrior in all of us needs to be endlessly fierce.

I’d explain the value of interests and hobbies, and how immeasurable they are in the fight. There is hope for the future if there are
There are no medals for being in pain and pushing yourself, only more pain. Sometimes your job is to let the flare run its course.

dreams and interests. My theory is that if one can divert the energy of our emotions for ten minutes, or even an hour, while we put our thoughts somewhere safe, good things can happen. A song, a television show, a magazine, it doesn’t really matter what the diversion is, if we can get out of our head, our subconscious brain will work the problem while we’re away. A fresh perspective is always a win. I’d continue and carefully explain that these mechanisms can help him cope, but he needs to take it one step further. He has to do whatever it takes to find and embrace something he’s truly passionate about. I could tell him its fly-fishing, but I don’t, as he’d only roll his eyes and laugh at me. At this point in his life, he thinks fly-fishing is a monumental waste of time. He’s wrong, but there are a lot of things he doesn’t understand yet. He’s still hung up on what he’s lost, but once he starts realizing what he still has, its game on. The world will look remarkably different.

I’d go on about how we all know AS is a war of attrition, it’s a disease that takes, rarely gives back, yet we fight on. Guard your passions as if protecting your very life. Adapt, and reinvent yourself. Dreams and aspirations are powerful motivators, as well as wonderful painkillers.

Guard your passions as if protecting your very life. Adapt, and reinvent yourself. Dreams and aspirations are powerful motivators, as well as wonderful painkillers.

There will always be the pain, yet these days, the most reliable escape is only seconds away. I imagine my favorite trout stream, slowly walking the shore, being mindful of the quiet, the insects, the wildlife, the endless motion of the water amongst the rocks, and the sanctity of nature. I’ve gotten to the point where it doesn’t really matter if I catch a fish or not; I’m out there. I understand there may come a day I won’t be able to get to the water, and when that day arrives, I’ll do whatever I can to always have a sanctuary to fold me up in its arms and help save me from this disease. Every warrior needs to find their refuge, and when you find it, hold on tight until you have to do something else. It’s what a warrior does.

In my mind, I’d turn away from my mythical conversation and walk bravely toward a fictional sunset. Though in reality, I’d more than likely stub my toe, tweak my bad knee, and end up letting out a string of profanity - because that’s how this warrior rolls.

Editor’s Note: According to a recent literature review, published in Arthritis Research & Therapy, 15% of those with axial spondyloarthritis (axSpA) have at least moderate depression, with overall depression rates for those with axSpA ranging from 11% - 64% depending on criteria and thresholds used. If you feel you may be at risk for depression, you are not alone, and we urge you to reach out for help. You can take an anonymous screening online, at http://helpyourselfhlpothers.org/ as a first step.
Battling Our Demons:
The Emotional Impact
Of Life With Spondyloarthritis

By Elizabeth Maines, Ph.D

It is normal to feel depressed or discouraged after being diagnosed with a chronic illness, and oftentimes people struggle with feelings of loss. The Swiss-American psychiatrist Elisabeth Kübler-Ross developed a theory called, “The Five Stages of Grief” in her 1969 book “On Death and Dying.” I have found that Dr. Kübler-Ross’ stages have worthy application toward the losses we face as individuals diagnosed with spondyloarthritis. The five stages are not linear, and an individual can move back and forth through the process, revisiting a certain stage multiple times throughout the process. I can vividly recall my emotional process after getting diagnosed and experiencing these five stages.

• **Denial/Shock:** “This isn’t happening, it will go away.” This is a normal self-protective mechanism that occurs when you feel overwhelmed by receiving difficult news such as a medical diagnosis, death, accident.

• **Anger:** “This isn’t fair! I didn’t do anything to deserve this!” This is one of the most common emotions that occur after the denial and shock have subsided. Beneath the anger is deep emotional pain, which can lead to questions like, “Why me?” For some individuals the anger can result in emotional outburst towards family, friends, physicians, coworkers, and even God.

• **Bargaining:** “Please just don’t let this ruin my life,” or “If you make the pain go away, I promise I’ll be a better person.” During this stage, we begin to make promises or bargain with ourselves, others, or God, vowing to do anything to not allow ourselves to feel pain. Some people find themselves negotiating their way out of the hurt and pain by reflecting on their past.

• **Depression/Grief/Anxiety:** “People our age shouldn’t have to deal with things like this.” “I’m not prepared to be disabled – I have things I want to do.” “How will I support my family?” and, “I’m going to be in pain forever so why even bother.” Once we begin accepting the reality of the situation and are emotionally more aware, we start to feel the depression take over. Spondyloarthritis is a lifelong chronic illness that is often diagnosed during the prime of our life. It can have a substantial impact on our lives, and result in considerable changes to our lifestyle. And we feel the loss. These changes can convey feelings of loss, grief, and anxiety over a career loss, or loss of a physical ability, lowered energy levels, and inability to parent or connect with your spouse due to the illness.

• **Acceptance:** “I’m not going to let this disease define me. I will learn to deal with this the best I can.” During this stage, we begin to accept the situation and reevaluate our expectations for the future and the new normal for our life. We recognize that we cannot live the way we used to live, be whom we used to be, or become whom we thought we would become.

Research shows that stress and negativity can worsen the illness and impact the emotional well-being of the person. For example, an increase of stress hormones can lead to inflammation in the body causing symptoms of spondyloarthritis to worsen. Shifting your attitude and perception towards life by focusing on the positive aspects of the day rather than the negative, will help emotionally and physiologically.

There are ways to help reduce the emotional stress and instability. Initially, it is important to spend some time processing emotions and evaluating the feelings brought on by diagnosis. It is okay to take additional time if needed to fully heal.

Some concrete tools to help in reducing emotional stress:

• Talking with someone, such as a spouse, friend, therapist, spiritual advisor, who is emotionally supportive can help relieve stress and anxiety.

• Journaling and blogging can also be a great tool to help get thoughts and...
feelings down on paper. Joining support groups, either in person or online, can connect you with others you can relate to. However, keep in mind that sometimes you can come across unhappy and negative people online who can deter you.

- Gratitude. Think about one thing that you are grateful for each morning before you get out of bed and one thing before you go to sleep at night. It may be challenging some days but over time you will find that it helps to keep your mind focused.
- Find your new bliss, new passions, and ways to enjoy life within any constraints of the illness.
- Find meaning and purpose to your new way of life. Start a support group in your area to help guide others.
- Find new ways to communicate and connect with family and friends.
- Nurture the new you, be good to yourself, set limitations with others, and practice self-care.
- Establish a new routine that better fits with your new lifestyle. Adapt to your new role and manage changes in your routine based on daily needs. Establish boundaries, learn to ask for help and communicate concerns with loved ones.
- If you have lost some independence, empower yourself by incorporating tasks to complete independently that are within your means and ability.
- Be patient and kind to yourself. Again, this is our new normal; just because we are living with a chronic illness doesn’t mean that we can’t find joy - make new friendships, have good days, weeks, months, and even years.

Lastly, I want to discuss the difference between Clinical Depression and feelings of grief. Unfortunately, a person who is diagnosed with a chronic illness is at a greater risk for Clinical Depression. Depression is a REAL illness and should be treated by a professional. Some of the warning signs of Clinical Depression are feelings of sadness that last longer than a few weeks. Clinical Depression affects your ability to carry on with your daily activities. The health effects of depression go beyond mood. Depression is a serious medical illness that can include physical symptoms that are also common in spondyloarthritis patients.

Other symptoms of Clinical Depression include:
- Feeling sad, irritable, or anxious
- Feeling empty, hopeless, guilty, or worthless
- Loss of pleasure in usually-enjoyed hobbies or activities, including sex
- Poor self-care such as not bathing, not taking your medication, not getting medical care
- Fatigue and decreased energy, feeling listless
- Trouble concentrating, remembering details, and making decisions
- Not being able to sleep, or sleeping too much. Waking too early
- Eating too much or not wanting to eat at all, possibly with unplanned weight gain or loss
- Thoughts of death, suicide, or suicide attempts
- Aches or pains, headaches, cramps, or digestive problems without a clear physical cause and/or that do not ease, even with treatment.

Be aware of your body and mind, and seek help if needed. Please remember that you are not alone. There are people who have gone through what you are experiencing and are better because they reached out for help. I am one of them.

Dr. Maines is a licensed clinical psychologist from Santa Fe, New Mexico. She is currently employed by a large government agency, but prior to that she was in private practice and worked with individuals with chronic and terminal illnesses. Dr. Maines and her wife (also a psychologist) enjoy the arts, history, and the music scene in Santa Fe. Dr. Maines, like many women, was diagnosed with Ankylosing Spondylitis later in life. She was first diagnosed with chronic iritis in 1995 and has struggled with chronic back pain her entire life.

We thank Dr. Maines for sharing her expertise, and a bit of her story with us! For an additional resource on this topic, please see a presentation by Dr. Lomax, recorded during our Denver, CO Seminar. You’ll find it on our Seminars and Webinars page, under the main Community heading.
Editor’s Note: We sat down with Michelle Schirra, CN, MS to discuss how diet and nutrition can play a role in reducing pain, inflammation, and other spondyloarthritis symptoms. Michelle is part of an allopathic and functional medicine team at WellHealth Medical Center in West Hills, CA. Our thanks to Michelle for lending us her time and expertise.

Spondylitis Plus: What are your clients generally hoping to accomplish when they come to you?

Michelle Schirra, CN, MS: Most of our patients seek us out because they have been what we call “doctor shopping,” and are very frustrated with traditional medicine. Most patients are looking to accomplish one thing: TO FEEL BETTER. We have specific protocols we use for many situations such as food allergies, gut or gastrointestinal issues, diabetes, arthritis, chronic fatigue, insomnia, intercystial cystitis (inflammation of the bladder), SIBO, candida … just to name a few. Our approach is to hear their story, understand how their symptoms started, and design a path to begin their healing process with a slow but methodical approach. My part of the practice involves nutrition, individualized diet plans, supplementation, rebuilding their G/I system and healthy lifestyle tools.

SP: Are you currently treating anyone with spondyloarthritis?

MS: Yes, we currently have two patients.

SP: Could you walk us through the steps you and your colleagues would generally take with a new spondyloarthritis client?

MS: Well, as we know, spondyloarthritis is an inflammatory rheumatic disease that typically attacks the spine and other joints. The patient’s first visit will be to see Dr. Tigalat Shalita, DO, so he can assess the situation and get lab work if needed. We use the Genova G/I Effects stool test, and the Genova Nutra-Eval test to screen for nutrient deficiencies, and the food antibody /allergy test to screen for abnormal immune responses to over 90 foods. Next, they are usually referred to our osteopathic manipulative medicine (OMM) specialist Dr. Christian Dellacorte for her hands-on approach to the pain, and to further diagnose. She feels their tissues, and works hands-on to provide pain relief where possible. She will assess their situation, review their test results, etc. and refer them to me to start the nutritional component. I always start the patients with an anti-inflammatory diet, and usually an anti-inflammatory shake to reduce the load on the immune system. After reviewing their test results, we will begin to treat any pathogenic bacteria that have been found in the stool that can be causing the gut microbiome to be out of balance, possibly leading to further problems. After a few weeks on this protocol, I will have them follow up and we evaluate their progress and move slowly through each step of the protocol. We have found that when moving slower, we...
get better, longer lasting results. Each patient is an individual, so there is no one set process. It typically takes 9 months to a year to reach the 80-85% mark of feeling better.

**SP:** Are there specific foods that you recommend those with spondyloarthritis try reducing or cutting out?

**MS:** Yes, I take the patients off inflammatory and high allergen foods such as sugar, processed foods, gluten and starchy carbs (pasta, breads, potatoes) red meat, caffeine, alcohol, dairy, and egg yolks.

Then I begin the patient on an anti-inflammatory diet used for many inflammatory diseases to bring down their gut inflammation and calm the body’s response mechanism. Patients with spondyloarthritis or rheumatoid arthritis, their bodies are usually very stressed trying to manage the pain, and this diet can help to calm things down. I often recommend an anti-inflammatory shake we carry in our office to supplement and blast the body full of nutrients to speed up the process a bit.

**SP:** Are there foods and supplements that you suggest that they add, or eat more of?

**MS:** I ask them to increase their leafy greens such as spinach, kale, chard, cilantro, celery and salads, to eat more berries, papayas, beets, sweet potatoes, lean proteins such as whitefish and salmon, and some chicken. A note here on those who have IBD along with spondyloarthritis -- (both of which are inflammatory diseases) -- adding leafy greens can be very irritating to the gut of those with IBD, so in this case, I would have them add these foods very slowly, in very small portions, and cook or lightly steam everything. No raw veggies for this population.

When it comes to supplements, I generally recommend Curcumin/Tumeric, Vitamin D, Fish Oil (unless the patient’s diet already includes a sufficient amount of fish) and a good multi-vitamin with phyto nutrients (plant based nutrients.) In some cases I will also suggest a probiotic if needed. These would be the essentials. I like to incorporate many other products as we are working together and I see their needs.

**SP:** What are your thoughts on the Mediterranean diet for those with spondyloarthritis?

**MS:** That is a good question and I do love the Mediterranean diet for the greens, olives and olive oils, lean proteins, and low starch carbs; however, it still includes cheese, and it being a high allergen food for many, I do not like cheese products for those suffering with arthritic pain. Cheese is high in fat and sodium. It is a dairy product and sometimes contains lactose, which is a sugar some patients do not tolerate; it can lead to gas and bloating. Cheese also contains casein, which is the protein portion that many people are allergic to.

**SP:** What about a plant based diet?

**MS:** I love plant based diets… or whole food diets. When you are eating a plant based diet you have eliminated many of the additives, food dyes, and preservatives that we feel are adding to the G/I issues we are seeing so often. Plant based foods ramp up B vitamins, potassium, magnesium, etc. which we need for our cellular production and overall health, along with increasing antioxidants which protects our immune system. However, I am not a complete advocate of a vegetarian diet…I feel you can eat a plant based diet along with healthy lean proteins. I feel it is difficult to get enough protein from plants and the necessary amino acids for muscle building or maintaining lean muscle without animal protein.

**SP:** Is this way of eating something people generally need to stick with? Is this a life-long diet? Or can certain foods be reintroduced after a period of time?

**MS:** Many of the added, anti-inflammatory foods I do recommend that patients continue to keep in their diets, but we can carefully re-introduce some foods that have been eliminated back into their diet after months of being on a gut rebuild protocol. I would prefer to see the patient and assess when this is appropriate, because every rebuild is different, as is each person.

**SP:** Lastly, with the Holidays approaching, do you have a few favorite healthy, anti-inflammatory holiday recipes to share with our readers?

**MS:** Yes! Many people can feel deprived on this diet since they have to give up bread and sugar…two big treats we love, especially at the holidays, so I am sharing a “Chocolate Covered Macadamia Nut Fat Bombs” recipe from the Simply Keto Cookbook below, and would really suggest looking up and trying the “Garlic Herb Paleo Grain-Free Dinner Rolls” recipe from Paleorunningmomma.com.
Chocolate Covered Macadamia Nut Fat Bombs: (THESE ARE TO DIE FOR!)

**Ingredients:**

- ¼ cup stevia–sweetened chocolate chips (Lilly’s or Enjoy Life-dairy free)
- 1 tablespoon macadamia nut oil (MCT oil)
- Coarse salt (I use pink Himalayan or sea salt)
- 24 raw macadamia nut halves

**Directions:**

1. In a small microwave-safe dish, microwave the chocolate chips for 50 seconds or until melted. Stir until smooth. Then add MCT oil and a pinch of coarse salt. Mix until blended.
2. Place 3 macadamia nut halves in each of 8 wells of a truffle mold or mini muffin pan or in each of 8 mini baking cups. Spoon some of the chocolate mixture into each well or baking cup, completely covering the nuts. Sprinkle additional salt over the chocolate.
3. Transfer the mold or baking cups to the freezer for a minimum of 30 minutes, until chocolate is solid.
4. Store extras in a zip-top plastic bag in the freezer for up to 6 months.

**truffle mold can be ordered online. They work great in these because they pop out very easily.**

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My Favorite Holiday Roasted Vegetables:

And a bonus Thanksgiving recipe, while I’m at it:

**Ingredients:**

- 1 large sweet potato
- 1 large yam
- 2 large onions
- ½ pound mushrooms
- 1 large bell pepper
- 4 large carrots
- 4 cloves of garlic, peeled
- Olive oil
- 2 teaspoons fresh or dried oregano
- 2 teaspoons chopped fresh parsley
- ¼ cup fresh chopped basil
- ½ teaspoon pepper
- ¼ teaspoon salt

**Directions:**

Preheat oven to 325.

Wash all the vegetables and cut or quarter them into pieces of equal sizes. Leave the cloves of garlic whole. Drizzle a small amount of olive oil in the bottom of a 9x11-inch baking dish and layer the veggies on the bottom. Sprinkle the herbs, salt and pepper on top of the veggies and drizzle a little more olive oil on top.

Bake for up to 1 hour or until tender. About halfway through the cooking time, stir the veggies so they do not dry out, making sure they are covered with oil. Keep an eye on them; you want them to be soft and crunchy, not dry. Cooking times may vary.

Michelle Schirra is a Clinical Nutritionist at WellHealth Medical Center in West Hills, CA. She received her BA in Liberal Arts from the University of Houston and later returned to school to obtain her MS in Science & Nutritional Counseling. Michelle has practiced functional medicine with Dr. Tigalat Shalita and Dr. Christian Dellacorte for the past 9 ½ years. Michelle works with her patients by helping guide them through a process of rebuilding their bodies with healthy nutrition and working to reduce pain and symptoms. She is a cat lover and enjoys spending time with her family, exercising, traveling and snow skiing. You can contact Michelle at michelle@wellhealthmedical.com.

Please note that SAA does not endorse or recommend any specific medications, diets, or products for spondyloarthritis and always advises that you seek the counsel of your physician before initiating treatment.
Connect With Others Living With Spondylitis!

There are SAA-Sponsored Spondylitis Educational Support Groups in 24 U.S. states. IS THERE ONE NEAR YOU?

Find all of our support groups at Spondylitis.org/Groups
More ways to connect at Spondylitis.org/Community

Want to speak with someone at SAA?
Call us *Toll Free at (800) 777-8189 and speak with a real live human being Monday through Friday!

*Toll Free available in U.S. only.
International members can call us at (818) 892-1616.

Available at spondylitis.org/Shop

Ring in the New Year with the Very First SAA Member Calendar!

$15 for SAA members.

Each month features unique artwork, with a playful take on the SAA logo. All artwork is original, and created by members of the spondylitis community.
As I sit down to write a piece for the Winter issue of Spondylitis Plus—a piece that will hopefully compel you to make a financial commitment to our Year-End Appeal—I find myself, like countless Development and Philanthropy Officers across the country at this very moment, struggling with a type of writers’ block. I’ve battled the feeling before over the course of a long career in fundraising.

“What were our most successful programs?” “Which ones were most popular with our donors?” “How can I best make the case for support?”

But this year, my problem isn’t that I can’t think of what to write; it’s that I can’t decide what achievements I’ll have to leave out. As we near the end of SAA’s 35th year as the leading U.S. nonprofit serving the needs of the spondylitis community, all I can think is, “How can I possibly paint an accurate picture of all that was accomplished in 2018 and even begin to touch on the plans for 2019 and beyond?”

The answer is, “I really can’t. Not in the space allotted.” It’s been a whirlwind of activity—furthering our mission from LA to NYC to DC to Amsterdam to Fort Lauderdale to Houston to Anaheim to Chicago to China.

A brief recap will have to suffice (and I may have to delete every third word but I’ve been told the human brain can adjust for that kind of thing).

**RESEARCH & SCIENTIFIC CONFERENCES**

Thanks to generous supporters like you, in fiscal year 2018 SAA funded more research than ever before. We awarded a $20,000 grant to an Early Career Investigator to continue her work in the complications of spondyloarthritis and the side effects of treatment; and an additional $20,000 to another for her efforts to examine SpA in patients with overlapping Inflammatory Bowel Disease.

Three larger grants were provided to three teams of investigators seeking advancement in multiple areas of study—evaluating children at increased risk of developing SpA based upon family history and a positive HLA-B27 marker; determining the potential role of fungus in the pathogenesis of SpA; and examining the various alleles of HLA-B27. Each of these research programs seeks to uncover new information that could help us better understand the causes, provide clues for prevention, and potentially lead to better treatment options, and eventually, a cure.
And the conferences! Every year, SAA exhibits at the American College of Rheumatology (ACR) Scientific Conference to more than 15,000 rheumatology researchers and clinicians from around the globe. This meeting is just one venue at which SAA presents the results of the research we fund and direct. We also participate each year in the Spondyloarthritis Research and Treatment Network (SPARTAN) Annual Meeting where the SpA community comes together to set the stage for future initiatives.

This past year, SAA also attended and exhibited at the European Congress of Rheumatology (EULAR) meeting in Amsterdam; multiple nationwide/regional Primary Care Medical (PriMed) conferences throughout the U.S.; and the bi-annual meeting of the Ankylosing Spondylitis International Federation (ASIF) in China. Whew!

EDUCATION, SUPPORT & AWARENESS

On the patient-facing front, Patient Education Seminars were held in Denver, New York, and Chicago with livestreaming available and recordings available for future viewing through the website.

SAA’s support groups continue to be active across the United States, with 40+ groups offering one-on-one and group support to those ranging from newly-diagnosed to long-time SpA warriors. A two-day Support Group Leader training was held in Denver, Colorado in April 2018, with 32 support group leaders coming together to learn from each other and share tips for better serving those seeking help.

SAA has also been partnering with Dan Reynolds and Novartis Pharmaceuticals to bring This AS Life Live, to the community. SAA provides guidance on the project, suggests interviewees, attends the video shoots, and ensures accuracy of SpA information recorded and shared.

PLUS, a third SAA Life Impact Survey was conducted with patients to identify the proportion of patients with delayed diagnosis; assess quality of life issues; and explore treatment options and outcomes. The results of this study have been accepted for inclusion in a peer reviewed professional journal coming soon!

This list doesn’t come close to giving the full picture of everything that’s being done within the new “Growth Mode SAA,” or touch on the plans for 2019. For that I would need several more pages. (But I’ll slide these three in – look forward to a greatly expanded commitment to JSpA, a series of newly revised and redesigned brochures, and a completely re-invigorated advocacy program. You’ve been warned. And let in on the ground fl oor!)

The bottom line is, absolutely none of this could have happened without your financial support. As you know, SAA receives no government funding. Each and every achievement noted above came about because you, and others like you, chose to support the mission.

There has truly never been a better time to recommit to partnering with SAA for the future that is within our reach. We’ve never been in a better position to turn goals into realities. I hope you’re with us and I hope you’ll visit Spondylitis.org/yearend and give a gift to support the cause, because the future really is at our fingertips!

But, before you go, a cute dog pic. Just because – well, why not?

Diann
Delia Barrantes manages an independent pharmacy in southern California, and is passionate about patient access to medication. In this interview Delia shares tips and advice on overcoming obstacles when fulfilling prescriptions.

Spondylitis Plus: Could you tell us a bit about yourself, and what you do?

Delia Barrantes: My name is Delia and I am a pharmacy manager at the Medical Center Pharmacy in Northridge, CA. We are a retail pharmacy that also takes mail orders, and provides delivery services within Los Angeles County. I also provide teaching seminars to other pharmacists regarding medication use and patient care. I should also add that my aunt, who is like a mother to me, has ankylosing spondylitis. She was diagnosed when I was a child and she’s likely the main reason I entered the medical field, and why I have such a passion to help people with chronic illnesses. I always tell my aunt that I wish I knew what I now do, back when she was first diagnosed, so that I could help guide her and fight for her back then. So now, I want to fight to help others like my aunt, and everyone who depends on prescription medications. Patient access to medications is my passion.

SP: What are some common issues that your patients and your pharmacists encounter when trying to fill a prescription? How do you and your team go about solving them? And what advice do you have for patients encountering access to medication issues at the pharmacy level?

DB: One of the bigger issues we face is in our dealings with insurance companies in terms of prescription coverage, and patient out of pocket costs. Every insurance policy is different, and the coverage varies within the patients’ plans. In addition, copay amounts can sometimes change without notice, without explanation. If the patient isn’t knowledgeable about their policy details they can find themselves paying more than what their copay should be. A good pharmacist will work with you as an advocate to get the medications you need, at the correct and lowest price possible for you.

For instance, we might have a patient whose copay was $5 last month and now all of a sudden it’s $55. Nothing was sent to the patient to alert them to this beforehand, and they are caught off guard when they come to fulfill the prescription and the copay is now up tenfold.
So in this instance, I would get on the phone with the insurance company for the patient (with their permission and authorization of course) to try and figure out for the patient why the copay has increased. The insurance company will often tell me that the formulary has increased. However, I can see on my side that the formulary has stayed the same. So I then communicate that to the rep, contesting what they are telling me. The next question I will get is – has the medication changed? And if the answer is no, then something interesting happens. I often hear something along the lines of, “Ok, let me input a code.” I hear some typing, and then many times the medication copay goes back down to what the patient had paid at the previous visit. I don’t have access to what the insurance company rep is doing on their end, so unfortunately I can’t explain what they are actually doing when the patient and I contest a copay amount. All I can share is that it often works. For me, it’s a matter of guiding the insurance rep into properly inputting the correct coding into the system so that it can adjust the rate on both ends.

So my advice for someone encountering an obstacle like this when filling their prescription would be to first find and partner with a pharmacy where the pharmacist will work as an advocate for you, will take the time and go the extra mile for you. Once you have a partnership like this then you can ask or just give authorization for the pharmacy to call the insurance company on your behalf to contest a copay increase, refusal to cover, or whatever the issue is. If all three are involved; the pharmacist, the insurance company and the patient, there will be no way that the insurance can get away with saying something that isn’t true. The pharmacist should try their best to get the patient the medication they need, at a price they can afford. Many times we have been able to get a medication covered for the patient when they were told elsewhere that it just wasn’t covered. You really benefit from creating a relationship and partnership with a caring pharmacist. Don’t overlook the importance of that. We can be much more effective working together rather than having the patient doing this alone.

SP: This sounds like outstanding service that you and your team provide to your patients. How does one go about finding service like this? How can our readers spot a true patient advocate at a local pharmacy, and where would they be more likely to find them?

DB: I would have to say that you’re more likely to find this type of service, this type of a pharmacist at smaller, independently owned pharmacies. I wouldn’t expect this kind of care at your average retail chain pharmacy. There really isn’t much profit at the smaller pharmacies, so if we’re doing it, we’re doing it because we love this work, and have a passion for it; because we want to make a difference and help the patient standing in front of us.

The truth is that for pharmacies the pay difference on our end for correcting the issue is a very small amount. Which is one reason why some pharmacists won’t take the time to call in, because it can take hours to go through the process. It isn’t worth it for them financially to spend the time on it. I get many patients who transfer from a big chain, retail pharmacy stating that their medication was not covered, and asking what our cash price is. I don’t take another pharmacist’s word for it, and always call it in myself. And sometimes I can get the medication covered for them. Sometimes, it’s a matter of submitting a document to the insurance company to get it approved and covered.

Furthermore, a comment on forced switches of medications - I never recommend a patient switch medications just because the insurance company is refusing to cover a medication. If I can’t get the insurer to cover what the patient has been prescribed, then I (with the patient’s authorization) call the doctor and let them know of the issue. Between the pharmacist and the doctor, there are authorizations that can be submitted and exceptions that can be made. With the doctor and pharmacist going at this together with the insurer, sometimes that ‘no’ can be turned into a ‘yes.’ It takes time, but that’s our job – at least that’s how I look at it.

SP: Thank you Delia! This was very informative.

DB: Of course! And I want to add that I’d love to offer my services to your readers and would be happy to answer questions and help if I can. I’d also love to learn more about issues others are experiencing outside my area. We are looking into becoming a nationwide mail order pharmacy so hearing from others would be helpful for us. I can be reached at DBarrantes@nutrishare.com.
It’s that time again!
We will soon be emailing you to request feedback on this publication.

“What topics should we cover in the coming year?”
“What are we doing right and what can we do better?”

We need your input to ensure we are keeping Spondylitis Plus effective, timely, and relevant to you. So please, look out for our email shortly after receiving this issue, and complete the brief survey.

Thank you in advance for sharing your thoughts!

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