Standing Tall For Women With Axial Spondyloarthritis

Your Stories: Mobility Challenges And The Exoskeleton

Spondylitis Association of America™

35th Anniversary
What a Difference a Year Makes

As I was finishing up my first full year at SAA, I sat down to prepare a brief overview of the past 12 months’ accomplishments for our regular yearly audit. Before I started, I thought to myself, “Well, there might not be as much progress as I’d hoped, but it’s been a time of transitions and surely next year we’ll start to see real growth.”

And then I started writing. And writing. And writing. And then I called the staff together for a well-deserved, impromptu celebration. As it turns out, fiscal 18 was a banner year for SAA. Here’s a brief recap:

SAA has always believed that supporting research will lead to an eventual cure. To that end, last September, SAA held the third Unmet Needs Conference at the NIH campus in Bethesda to identify pressing gaps, share insights, discuss scientific and treatment issues, and provide direction for the next decade of spondyloarthritis research.

We awarded two Early Career Investigator (ECI) Awards to encourage upcoming rheumatologists to focus their careers on the field of spondyloarthritis. SAA also funded several additional research study grants outside of the ECI awards.

And education is also one of our core mandates. Patient Educational Seminars were held in San Francisco, New York, and San Diego, with livestreaming available and webinars recorded for future use through the website.

We’ve also expanded our support group network exponentially, produced several episodes of SAA’s White Board Animation series, as well as nine episodes of This AS Life Live!, a collaboration between SAA and Novartis Pharmaceuticals starring Dan Reynolds from the award-winning rock band, Imagine Dragons, and so much more.

Unfortunately, I’m running out of real estate here when there are so many more achievements to list! To wrap up, (only because I’m over word-count) I’d like to thank SAA’s volunteer Board of Directors, our Medical & Scientific Advisory Board, the dedicated staff, and most importantly, you, for making these accomplishments possible and for helping to set the stage for the wonderful work to come!

I promise, next year at this time, I’m reserving a larger column. So please stay tuned, and please stay involved!

Cassie
Editor’s Note:

We recently sent out a survey to our members and others in the community to learn about needs and preferences in educational programming.

The survey far surpassed our expectations, delivering over 2,000 responses! Our sincere thanks to all who participated and shared their thoughts with us. Your feedback was invaluable.

The top three most requested topics were:

- The Latest Spondyloarthritis Research Updates
- Complications and Related Conditions
- Pain in Spondyloarthritis

Below we share a small sample of the many comments gathered from the survey.

“As a parent with a 17-year-old suffering from AS, mental health is of great concern for me. At a young age, these children need to learn how to cope appropriately. They need to learn to cope with the many adversities brought on by the disease.”

“I’d love some tips for ‘Planning for the future.’ For example, I am currently removing most of the hedges and plants around my house to make it easier to maintain things as I age. I planted all of these over 20 years ago when I was healthier! I have also cleaned out most closets and cupboards (dejunking) to make things easier to find/maintain and in case I ever need to move.”

“Sex and intimacy with spondyloarthritis.”

“Advocacy for patients in navigating the journey at all points i.e., diagnosis, treatment, self-care, chronic disease management, employment issues and when to consider disability. Help is needed for patients when dealing with multiple health providers. I am 57 years old and an RN of 28 years who knows the challenges patients face at all levels.”

“I’d like to see a series of “short” sessions on practical management topics. Examples: Buying a car; communicating with a physical therapist/trainer/ massage therapist who isn’t familiar with spondylitis; tips for foreign travel, and what are the key words/phrases to have on hand; mixing different medications, for example taking Tylenol on top of biologics.”

“I would like you to seriously address the Pain Management issue. There is a place, responsibly, for opiates in chronic pain treatment. I want to hear about that, and about how we can fight back against the current environment of care. This is unfair to us chronic pain patients, most of whom use their meds responsibly. Please research the option of palliative care for us who have “life-long illnesses” such as ankylosing spondylitis; this should be an option for us, as per the exact definition given by CMS, right? Thank you, from one person who is in terrible, unrelieved pain now.”

“I wish you could educate more physicians/rheumatologists about diagnosing and treating women with AS or any of the subsets. Most still think this is a disease primarily for men, rarely for women and women are just crazy or have fibromyalgia.”

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.
If you’ve been using a drug manufacturer’s **copay discount card** to help with your out-of-pocket costs for a biologic or other specialty medication, you may soon be in for a surprise. Several large insurance companies and pharmacy benefit managers (PBMs) are implementing new schemes called “copay accumulator programs” that affect how contributions from those same copay cards are applied to your annual out-of-pocket cost requirements.

Before we take a closer look at these programs, it may be helpful to first review some health insurance details and key terms.

As you know, **health insurance** helps cover your medical expenses, including your medications. When you fill a prescription, you are filing a claim to your insurance company. Your insurance company (or your PBM) will verify your claim and determine the cost of your prescription. You and your insurance company will then share this cost based on a specific payment schedule detailed in your plan’s benefits.

Most payment schedules include a deductible and coinsurance or copayment. A **deductible** is the amount you need to pay before your health insurance will cover services. This amount varies, depending on the type of plan you have. Someone with a **high deductible health plan (HDHP)** will have a higher deductible amount to pay than someone with a traditional plan.

If you have a plan with coinsurance (such as a PPO plan), once the deductible is met, the **coinsurance** period starts. In this period, you split the cost with your insurance company based on a fixed percentage listed on your plan. For example, a 70:30 coinsurance means you need to pay 30 percent of the cost (after your deductible is met) and your insurance company will pay the remaining 70 percent.

Some insurance plans (usually HMOs) have a **copayment** instead. This is when you pay a fixed amount for a covered health care service, with your insurance company covering the full service after you’ve paid (or reached) your deductible. For example, you may have a $20 copayment for every visit to a primary care provider or a $10 copayment for every prescription filled.

The total maximum amount you will pay during any given plan year is called the **out-of-pocket maximum**. This amount includes your deductible, as well as coinsurance or copayments. After you reach your annual out-of-pocket maximum, your insurance company will pay 100% of medical costs accrued.

**What is a Copay Accumulator Program?**

Copay Accumulator Programs, when enacted, change the way an insurance company applies and accounts for payments from a drug manufacturer’s copay card. Normally, the contributions from the copay card go toward fulfilling your out-of-pocket obligations, including your deductible. When you use an expensive specialty medication like a biologic, a manufacturer’s copay card can shield you from having to pay a significant amount of money in out-of-pocket costs every year.

However, if your insurance company implements an accumulator program, the copay card’s contributions, though still accepted at the pharmacy, will no longer go toward fulfilling your deductible and other out-of-pocket costs.

**When the “Copay Surprise” Happens.**

People run into issues, and sometimes only realize the change, when the copay card’s dollar amount is exhausted. Only when this happens do they learn that their deductible and out-of-pocket maximum have remained untouched. They now need to start paying down any deductible they may have, and pay the co-insurance / copays, until they themselves fully pay the plan’s out-of-pocket maximum.
As you can see in this scenario, the Copay Accumulator Program changes the out-of-pocket payments from potentially $0 to now fully paying down the deductible, and then covering any coinsurance or co-pay amounts. When your copay card runs out, you’re left with the burden of the cost, and no progress on your annual deductible.

Why Do Insurance Companies Put This Program in Place?
Insurance companies have been trying to curb prescription spending for a long time, and they see Copay Accumulators as a potential solution.

The theory is that the program will encourage patients to use cheaper alternatives such as generics or other substitutes, however, patients may find that in some cases, cheaper alternatives are not available.

Insurance companies also use these programs to pressure pharmaceutical companies to lower drug prices. They see copay cards as a way for pharmaceutical companies to keep patients on expensive drugs, circumventing their efforts in reducing costs. Insurance companies are hoping to regain control in negotiating drug prices.

Which Insurance Companies and PBMs Implement These Programs?
According to the AIDS Foundation of Chicago, the following insurance companies and PBMs have started implementing these programs:

- Blue Cross Blue Shield
- Cigna
- CVS Caremark
- Express Script
- UnitedHealthcare

These insurance companies and PBMs may use different terms for these schemes. UnitedHealthcare calls it the “Coupon Adjustment/Benefit Plan Protection Program” and the one from Express Script is called the “Out of Pocket Protection Program.” Regardless of the term used, it is the same program and works the same way.

Where Can You Go to Check If You Are Impacted?
The best thing to do is to call your insurance company or PBM that covers your specialty medication. Your insurance company may have sent a letter to notify you of this change. You can also check online on your insurance company’s website.

Another place to look is in your explanation of benefits (EOB) statement, which may specify how a manufacturer’s copay card contributions will be applied.

What Can You Do If You Are Impacted or Just Want to Be Prepared?
If you’ve been impacted, call your insurance company or PBM and ask them any questions you have about Copay Accumulator Programs. Tell your insurer if you are unable to fill a prescription because of this program. Your insurer may be able to help find other solutions for you, such as referring you to a patient assistance program.

If you have an employer-sponsored plan, call your employer to let them know of any negative impact experienced as a result of the switch.

If your copay card has been declined, call the manufacturer of the medication. Some manufacturers may offer other options for you, such as providing a rebate for out-of-pocket costs.

Finally, please share your experience with us at SAA! Email us at advocacy@spondylitis.org if you’ve been impacted. We’d love to hear from you.
Physical Therapy Applications For Spondyloarthritis: Passive Interventions

By Angelo Papachristos, MBA, BSc (PT)

The overarching goal of physical therapy intervention in spondyloarthritis (SpA) should be to maximize physical function and minimize disability. To do this we use different therapeutic interventions including education, exercise and postural prescription, manual therapy, passive modalities, assistive devices/bracing and orthotics, and ergonomic evaluation. The gold standard in effective physical therapy in SpA is what we call active therapy interventions (those movements / exercises prescribed by the physical therapist, but performed by the patient.) We discussed these, and the expert recommendations on these, in the previous, summer issue of Spondylitis Plus. In this piece we will examine passive interventions (those administered by the physical therapist) and look into any applications (and contraindications) these carry for those with SpA.

Let’s begin with two manual therapy techniques that are widespread and commonly used in orthopedic and sports therapy clinics to address chronic back and neck pain, but have a limited role in the management of SpA.

Mobilization is the passive movement of a joint with aim to achieve a therapeutic effect. It is termed “spinal mobilization” when applied to the spine, otherwise termed “peripheral mobilization” for other joints, i.e. shoulder.

Manipulation, or “high velocity-low amplitude thrust,” is when a clinician applies a rapid thrust in order to achieve gapping or cavitation in the joint/spine. This modality is typically used to improve joint motion and reduce pain, and may or may not be accompanied by a “cracking” or “popping” sound. It is often called an “adjustment” by chiropractors.

Soft tissue mobilization and gentle joint mobilization may be appropriate for some with spondyloarthritis, however I strongly caution against receiving spinal manipulation. The incidence of vertebral fractures increases with overall disease duration in axial SpA. Spinal manipulation techniques in axial SpA patients have the potential to result in increased pain/discomfort and worse, to cause severe consequences of vertebral fractures. Rarely is this technique indicated in the management of SpA. Should your therapist wish to perform spinal/axial manipulation, I would urge you to stop the session, have them detail the risks of the procedure in the context of SpA, and have them discuss this intervention with your rheumatologist prior to receiving any such treatment.

Next is use of passive therapeutic modalities. These include electrotherapies such as ultrasound, laser, TENS, interferential current, muscle stimulation, as well as non-electrical modalities such as acupuncture, dry needling, cupping, and sports taping. These are some of the most commonly used treatments that you will encounter in a sports or orthopedic practice.

The short answer is that there is no significant evidence to support any of these therapies in the context of SpA. In fact, some of these modalities have the potential to cause harm. For example, there is a potential risk of infection with the use of acupuncture, particularly for those who are on immunosuppressive biologic agents such as TNF or interleukin inhibitors. If this is you, acupuncture treatment should only be performed by a clinician with experiencing in treating those with SpA who are on biologics, and only after consultation with your rheumatologist.

Another frequently used modality is therapeutic ultrasound. Patients are typically told that this treatment is effective in ‘reducing swelling’, ‘reducing inflammation’, ‘reducing pain’, and finally, ‘speeding up tissue healing’. You may have had this treatment over your patellar tendon, plantar fascia or Achilles tendon. These entheses (which are areas where tendons or ligaments attach to bone) are rather typical sites of pain in those with SpA. Unfortunately there is no evidence that therapeutic ultrasound works in the context of inflammatory arthritis, and actually may have potential harmful effects. Therapeutic ultrasound is actually not ‘sound’ but a form of mechanical energy. Think of it as a million cycles per second of vibration, or disruptive energy, being targeted to your tendon or ligaments. There are some theories that traumatic stimulus at the enthesis may trigger a cascade of events releasing interleukins and other proteins that may lead to bony formation seen in SpA. Therefore, it probably is not a great idea to use this targeted therapy in these areas.

Lastly - Don’t Forget Exercise!
Whether group exercise or lone, gym or outdoors, land or aquatic – regular exercise, stretching, and activity are far more advantageous in the treatment of spondyloarthritis than are passive interventions. Get out there and move!
Working with a physical therapist who evaluates your needs and goals, as well as considers your personal preferences, is important in order to ensure you participate in activities you enjoy and continue to provide therapeutic benefit.
When I was diagnosed with ankylosing spondylitis in 2009, we didn’t really know what was on the horizon for us. We knew things would be difficult in the future, but we didn’t know that having missed this disease for over a decade meant that a lot of damage had already occurred that simply wasn’t fixable.

“I never expected to lose my mobility, but that is what happened in July of 2014 when my body gave out on me and I could no longer move the way I used to.”

I never expected to lose my mobility, but that is what happened in July of 2014 when my body gave out on me and I could no longer move the way I used to. Year by year, I lost my energy to move and soon enough, I had an ME/CFS (myalgic encephalomyelitis / chronic fatigue syndrome) diagnosis that severely limited my mobility and left me housebound.

When I learned that I might never be able to walk again, I worked harder than ever to stay on my feet, but as I was impacted further by disease progression, it became harder to do. The first time I had to use a wheelchair, I couldn’t stop wiggling and trying to lift myself up, just to prove I could do it.

There are horrible health effects to being in a wheelchair. Depression, anxiety, dealing with people in the outside world who don’t understand your disability, pain from riding in a wheelchair all day, anger, denial, sorrow, the list goes on and on. You have no idea how many things come into play when you lose the use of your legs.

We bought a wheelchair in late 2017 after we realized I had spent more time that year at home in bed than anywhere else. I lost my freedom and my independence when I lost the use of my legs. Some days I don’t have the strength to push myself, and I found myself avoiding my wheelchair completely. I refused to go out or leave my bed. Being in a wheelchair did great damage to my pride and physical sense of well-being. Losing my freedom and independence was devastating.

The day I got a call about testing out a robotic exoskeleton...
called “Keeogo,” was a life-changing moment for me. This exoskeleton (which, if we wanted to be technical about it is more accurately referred to as a “dermoskeleton,” but that doesn’t sound nearly as cool so we’ll stick with “exoskeleton”) is specifically designed for assisting people with mobility issues, and is made by b-temia in Canada.

For one day, I got to play Robocop (and I’m now waiting for my call back to try out the newest models in the fall!) I’d like to tell you about my experience with robotic exoskeletons and how I believe they will change lives.

How will robotic exoskeletons help people with mobility issues?

Exoskeletons are used to assist people who have limited to no ability to walk unassisted, and are currently using wheelchairs and other mobility aids to move around. They allow people to move in ways that they couldn’t before, and offer users the chance to regain abilities that they’ve lost.

Robotic exoskeletons can help people with all sorts of mobility issues, from ankylosing spondylitis and other forms of arthritis or chronic debilitating conditions, to war veterans, people who have suffered tragic accidents, and more.

With an exoskeleton, the user will have to have some function in their legs and initiate the movements, which are then supported by the device using a combination of navigational sensors, artificial intelligence, and motors. You must move in order to get Keeogo moving for you. It won’t operate with a pre-determined pattern of movement.

Exoskeletons can help people navigate their home and do household chores that they haven’t been able to do because of their mobility issues. Raking the lawn, climbing stairs, doing laundry, cooking, and many other household activities that become difficult with a person who is disabled are suddenly accessible activities again. Outside the home, it can assist people in being able to navigate a city independently.

User experience: What does it feel like to use a robotic exoskeleton?

The exoskeleton I tried is composed of two orthotic structures for each leg. Each structure includes a motorized knee joint and a free hip joint, plus a detachable utility belt. The orthotic device is connected via the belt and a permanently attached glute support. A control unit is provided for turning the system ON and OFF, as well as choosing the desired level of powered assistance. The battery is detachable and rechargeable using the charger provided.

After months of being bed bound or being in excruciating pain from being on my feet and legs, Keeogo allowed me to do some things that I hadn’t been able to do in years. Every step I have taken since 2014 has been like putting my full weight on broken glass in bare feet. I was worried how much the weight of the exoskeleton contraption would affect that.

15 pounds doesn’t seem like much, but when you have a brittle spine disease and can’t pick up anything heavier than your cat, you start to really think about weight and how it will hit your body.

Would walking in this device worsen my leg pain? Would it make my feet turn purple?

To my utter delight, my first step with Keeogo was like falling into a dream. I leaned forward and the device took most of the weight load. It was like shifting into a new world.

It was the first step I had taken in years that didn’t cause pain. As I moved forward, the sensors, the advanced artificial intelligence software system, and the motor kicked in where I needed support. I was walking pain-free!
I haven’t been able to run since May 2012 and here I was jogging around in this room with the trainers next to me.

Then I started jogging. I haven’t been able to run since May 2012 and here I was jogging around in this room with the trainers next to me. I don’t know how they felt about seeing me with a big smile on my face, but they watched me take my first pain-free steps using their device. I hope they felt as proud and as happy as I did.

Squats and lunges were easy. My robotic legs effortlessly lifted me up and down and kept me steady.

Then we tried some stairs. I avoid stairs as much as possible, but with Keeogo, I was surprised to find myself moving up those stairs quickly and easily, while my new robotic legs took all the weight off my legs for descending. After one hour in the Keeogo I felt invincible!

*Editor’s Note: Watch a recording of Carrie trying out the Keeogo on our website! See spondylitis.org/Your-Stories.*

New users learn in the beginning that wearing an exoskeleton takes some getting used to. I found out about this the next day. Wearing the Keeogo required me to use my own muscle strength and then added to that. It takes the stress off your joints, but it also gives you a workout and so you have to ease into it. I spent 90 minutes in it, and my hips and lower back were sore for about a week. The discomfort of wearing the device though was nothing compared to the pain and stress my own body puts me through on a daily basis.

If I had to relate this discomfort to anything, it would be comparable to the pain of breaking in a new pair of shoes. Wearing the tech for short periods of time until you’ve built up your endurance to wear it day to day helps immensely.

**Cool Keeogo features**

Exoskeletons provide a framework of powered support that can assist the user in rehabilitation simply by putting them on their legs again. The robotic legs can also become a chair by locking into place. I could go to a concert and not have to worry about sitting down because my robotic legs provide an instant chair.

I can imagine that the developers will work on the sound the robotic legs make, but I rather liked sounding like Iron Man!

**Features to work on**

I could only think of two features that could be improved upon.

The powered ‘snap’ back on robotic legs could be a problem for users with osteoporosis, which is why it is imperative to work with professionals to ensure the exoskeleton fits properly.

The batteries have a long life, but they don’t last forever. Users would have to ensure their Keeogo is powered up.

Obviously, people will ask about price. My hope is that assistive device programs and insurance companies will see the physical, mental, emotional, and societal value of people being able to use these innovative devices to go back to living with full autonomy.

Many of us are moved to tears once we’ve tried it and realize that this technology will allow us to live with no mobility limitations.

**Changing the future**

I believe that this technology can directly impact lives, communities, and workplaces by helping individuals with mobility challenges get around safely and independently. Exoskeletons can provide users an overall physical sense of well-being, allowing freedom of movement. Many of us are moved to tears once we’ve tried it and realize that this technology will allow us to live with no mobility limitations. Robotic exoskeletons are the wave of the future and I have no doubt they will change lives in many surprising ways.

**PS: To be technical about it.**

**Exoskeleton** is a rigid external covering for the body in some invertebrate animals, especially arthropods.

**Dermoskeleton** is a human-machine interface that eliminates musculoskeletal stress on the body by injecting biomechanical energy at the joints, and providing mechanical assistance to the user for restoration, maintenance, and augmentation of their biomechanical functions.

Carrie Kellenberger is a Canadian living in Taiwan who was diagnosed with ankylosing spondylitis in 2009. She is a freelance writer and health advocate for a number of arthritis associations. For more information on Carrie’s health advocacy work, please visit “My Several Worlds” at myseveralworlds.com, where she writes about her experiences with chronic illness and her day-to-day adventures.
Historically this disease, and especially ankylosing spondylitis (also known as axial spondyloarthritis (axSpA) with x-ray damage) was thought to affect men more commonly than women. However, over the last decade as we recognize the disease earlier and in patients without the classic damage seen on x-ray, we realize this disease is actually equigender. Despite this, women continue to have a significantly longer delay in diagnosis compared to men. This may relate to persistent under-recognition of the disease (in general and in women particularly), and that women tend to have less damage on x-rays compared to men as well as less measurable inflammation in the blood (by C reactive protein [CRP]). Notwithstanding these differences, female patients have higher reported disease activity, proportionally greater functional impairment (ability to do certain daily activities), and worse quality of life.

When female patients eventually make it to the rheumatologist and are given a correct diagnosis, they have often previously been misdiagnosed. The most common incorrect diagnoses are fibromyalgia (though this can coexist with AxSpA), chronic back pain, and foot pain. Affected women tend to have more peripheral (of the arms and legs) joint involvement and a higher prevalence of inflammatory bowel disease compared to men. They often report more family history of spondyloarthritis, though this doesn’t necessarily mean the genetics are different in women. It could reflect a tendency towards women’s greater knowledge of her family history. Fewer women have significant damage on x-rays at diagnosis (AS); over time, fewer women develop bamboo spine (fusion or ankylosis of the spine).

An important area to understand for both female patients and for researchers is what happens to women in pregnancy. This is especially important as the disease starts in the woman of childbearing age, such that most patients will have the disease when they become pregnant. Emerging data suggests heterogeneity in disease activity in pregnancy. Individual
patients may actually feel better in pregnancy, though the literature reports results at a group level so the following information does not suggest this course will happen to the individual patient reading this article. Most patients report low disease activity before pregnancy, but there is a more variable course over the three trimesters, with a suggestion of increased disease activity from week 20 through the third trimester. It may be that pregnant patients stop taking their medications when they find out they are pregnant and therefore disease activity increases. It may also be that the mechanical loading of pregnancy contributes to disease activity. Studies suggest those women needing a biologic before pregnancy are more likely to flare during pregnancy if they stop their biologic. When disease activity increases in pregnancy, patients are more likely to have problems with gestational diabetes, preeclampsia, infection, preterm labor, preterm deliveries and small for gestational age babies. Another important finding is that axSpA patients tend to have more elective cesarean sections. It is important to note that most axSpA patients should not require a cesarean section, and in fact the Microbiome that the baby picks up as they descend through the birth canal may be important in decreasing the infant’s risk of autoimmunity in the future. Most studies suggest that disease activity increases

Do Female vs. Male Patients Present Differently?

- Men tend to have more radiographic damage and a higher burden of inflammation

- Women with early AxSpA have greater subjective disease activity

- Women tend to have more widespread pain (WSP); those with WSP also have a significantly longer delay to diagnosis

- Women with definite sacroiliitis may experience more fatigue, peripheral involvement, and relevant family history than men

- Women have more functional impairment, despite less damage

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in the post-partum state, but it is unclear how much of this relates to lifestyle change (less sleep and exercise) and more stress.

Treatments for axSpA are not different between men and women, except in the setting of pregnancy. Physical therapy is the cornerstone of non-pharmacologic therapy and most patients should get referred for a course when first diagnosed. First line pharmacologic therapy is a Nonsteroidal Anti-inflammatory Drug (NSAID) and when this class does not work or work well enough, or if it is not tolerated, then biologics are recommended. The biologic class currently recommended as first line is the Tumor Necrosis Factor inhibitors (TNFis), though another more recent class, called Interleukin 17 inhibitors (IL-17i) works well too.

“An important area to understand for both female patients and for researchers is what happens to women in pregnancy.”

Treatment in Pregnancy
In the pregnant state, NSAIDs are contraindicated in the third trimester and though they can be taken early in pregnancy, they are not strongly recommended. There is some animal data (not human) suggesting NSAIDs interfere with implantation (getting pregnant) and human data suggesting an increased risk of miscarriage with NSAID use early in pregnancy. Specific NSAIDs like celecoxib are not recommended in pregnancy. Though we do not recommend traditional medications like methotrexate (rheumatrex), leflunomide (arava) and sulfasalazine in AxsSpA treatment, they are nevertheless sometimes used in patients. Methotrexate and leflunomide are strongly contraindicated in pregnancy and are associated with fetal malformation and birth defects.

Sulfasalazine is safe in pregnancy, though higher doses of folic acid supplementation may be warranted. TNFi are being used more and more in the pregnant state. In fact, one of them in particular, certolizumab pegol (Cimzia), does not cross the placenta or into breast milk and has a pregnancy indication. In general, TNFi are especially safe until 20 weeks. From 20 weeks on, the placenta starts to build the baby’s immune system by avidly transporting antibodies from mother to baby. This includes drugs that are antibodies like the TNFi (except certolizumab). It is recommended that if TNFi other than certolizumab are used, they are stopped before the third trimester, whereas certolizumab can be continued though the duration of pregnancy. The major issue is that once the antibodies (and drug) cross the placenta, they remain in the baby’s system for months after delivery and at a higher dose than the mom’s own drug level. In theory this would increase the baby’s risk of infection, though studies have not suggested this. It may be that patients are stopping their biologic early enough in pregnancy to prevent this exposure. Most importantly, if a fetus has been exposed to a biologic, especially in the second trimester, live vaccines should be avoided for the first six months of life.

Treatment with Lactation
We would strongly encourage moms provide breast milk to their infants if possible. Certain drugs are contraindicated when breast-feeding. Similar to pregnancy, methotrexate and leflunomide are contraindicated. Sulfasalazine is safe, though should be stopped if a baby is preterm and jaundiced for one to two months. NSAIDs are generally thought to be safe with lactation, though those with a shorter half-life are preferred especially as the baby’s gastrointestinal system matures. Very little of this class is excreted into breast milk. The American Academy of Pediatrics recommends the following NSAIDs as breastfeeding compatible: ibuprofen, indomethacin, diclofenac, naproxen, piroxicam, ketorolac, and tolmetin - though this is mainly based on expert opinion and some observational data. Another likely safe option is celecoxib, which was not recommended in pregnancy.

TNFi are the best studied of the biologic class in pregnancy. Babies born to mothers taking TNFi do not have an increased risk of congenital malformations and there is no association with preterm birth or babies born small for gestational age. Similar to pregnancy, certolizumab pegol minimally crosses into breast milk and is completely safe during lactation. In general we worry less about biologics and lactation. The reason for this is that the biologic is really a protein. A patient taking it as a drug injects it and does not ingest it (by mouth) for absorption. When the baby sees the fractional amount in breast milk, they likely break it down like a protein and are therefore not seeing it the same way as the mother does. That said, we do not have a lot of robust or long-term data with TNFi except for certolizumab, which has been specifically studied in pregnancy and lactation. The Organization for Tetralogy Information Specialists (OTIS) is an excellent resource for patients taking any medications during pregnancy and lactation. They can be found at mothertobaby.org.

Editor’s Note:
We have included in this piece images of just some of the amazing women we know living with a form of spondyloarthritis. They are SAA friends and volunteers, as well as members of our SpA community. This piece is dedicated to ALL women living with a form of spondyloarthritis.

Our great thanks to Dr. Lianne Gensler, who has studied this topic extensively. This past June, Dr. Gensler presented the information contained in this piece to an international audience of rheumatologists and researchers at the EULAR (European League Against Rheumatism) annual conference, in Amsterdam.
Ever lose something? Does it drive you crazy trying to recreate what happened to it? Do you recruit others to help you search?

My dad lost a car key. We looked for it everywhere, assuming it was a temporary loss. “Plan B” was to use the extra key until the first key was found. A new backup key was ordered after a couple of weeks of fruitless searches. Convinced we could find the first key, we continued to look for a year; it became a kind of family contest or challenge... “Who will be the one to find the lost key?”

People with spondylitis have lots of losses. These are real losses. Not like losing a key. Activities we love to do, a good night’s sleep, feeling youthful, reaching our shins. Some of our losses are temporary, some are permanent. It’s often tough to know which is which. Either way, we need to be good at creating Plan Bs - to adjust, modify, and ultimately become resilient. To find ways to be ourselves in a slightly modified way. To honor ourselves.

Everyone has losses. I lost my mother to cancer this year. I practice loss a lot. On the yoga mat, I lose perfect balance by lifting a leg and closing my eyes during asanas (poses). Losses are challenges. They are also opportunities to detach from fear, from the chaos of the moment, and to adjust to a new reality. At religious services there are times when we - as a community - recognize losses together. Afterwards, these practices give me a small sense of understanding, one that can even elicit a smile. I’d rather have a life with minimum losses, of course. With all this practice, it doesn’t get easier for me when a real loss hits home. But it does become familiar.

During those first 24 hours of mom’s death, we knew that mom appreciated flowers in life, but in death would prefer donations in her name to charities she cared about. Charities that will use the money wisely and make a difference for the living. So we honored her in the way she’d most appreciate. SAA has received 3,208 memorial gifts such as this. Each one a blessing. A tribute.

“Plan A” is to live a healthy and long life. My wife and I want to lessen the burden of loss on our loved ones. So we made a “Plan B” for them. We let them know which charities are important to us.

There are many ways to make a planned gift.

- Donate stocks to SAA
- Add a bequest to SAA in your will or trust
- Name SAA as a beneficiary of a bank account or life insurance plan that your loved ones will not need
- Create a charitable gift annuity

Perhaps most importantly, let your loved ones know about your wishes. I’m grateful that my mother did.

Please let me know if you made planned gift arrangements for the SAA or contact me at legacy@spondylitis.org to discuss options.

My dad recently found that key in mom’s purse while he was going through her things to donate to charity. He had to smile a bit.
Ankylosing Spondylitis brings change, and most of it is bad, or really bad, depending on your point of view. I’m not describing physical pain, as we all know far too well what that’s all about. What I’m talking about is psychological injury - the kind that injures your spirit.

I used to fly airplanes for a living. I’d been that kid at the airport fence, and told myself I would be a pilot one day. I worked hard to earn enough money to take flying lessons when I turned seventeen. I continued advancing my career until I was flying jets. I flew for many years until the fatigue and pain of what I would eventually learn was AS had taken its toll. The biologics didn’t work, and the drugs I needed in order to have any kind of quality of life ended my career. Not being able to fly was by far the worst damage this disease brought upon my life. For years my spirit recoiled from that loss as I slowly accepted and then adapted to the new realities of my world. AS is all about loss; as warriors, we’re about trying to adapt.

Not long ago I was staring at the yellow paint on the rear quarter panel of my beloved car. The car is black, the yellow wasn’t supposed to be there. Over the years, AS has made sure I can’t turn my neck very far in either direction, so backing up my car was becoming problematic. I never hit anything but concrete, and in the latest case, concrete painted yellow. There have been utility pole foundations, traffic barriers, and of course the inside of any parking garage is nothing but concrete. Any dash of black paint on a concrete wall could very well be my work. Someone less stubborn would have traded in the car for one of those do-everything models they make now. Not me, though I guess I should confess that my car and I have been together nearly fifteen years, it’s a sleek, road hugging, finely tuned, high performance European dream. I bought the car new, still wrapped in plastic, sitting on the transport truck at the dealership. That purchase predated my AS diagnosis. A little yellow paint is nothing; my car is literally the last part of my old life that I still possess. With its horsepower, stick shift, and handling, it allowed me, on occasion, to still experience a small part of how it felt to be a pilot. I love that car, everyday for fifteen years it made my spirit sing.

“AS is all about loss; as warriors, we’re about trying to adapt.”
Over the years, that car never let me down - it signified a test of wills between me and the AS. I would adapt no matter what. When my left knee needed surgery, I taught myself to drive using only one foot. (It’s harder than it sounds.) My knee got better, and then I was forced to adapt how I shifted with a surgically repaired right shoulder. Though if I were being honest with myself, when I’m getting into my car, I grimace as I kind of lean down and blindly drop backwards into the seat. It’s not pretty. Climbing out of the car hurts, and I do make a straining noise that has, on occasion, turned heads in alarm. My left hip complains each time I push in the clutch, and it zings my shoulder when I have to put the car into reverse. The pain, coupled with my lack of ability to avoid concrete was making my driving experience difficult. Yet each time I thought about an upgrade, I dug in my heels on giving in to yet another AS loss, one that I feared would irreparably damage my spirit. Though somehow, that yellow paint had crawled into my psyche, and it was rattling around in there whispering for me to do something.

I had been procrastinating, I admit it, and after a great deal of deliberation, I finally found myself at a car dealership.

“My car is literally the last part of my old life that I still possess. With its horsepower, stick shift, and handling, it allowed me, on occasion, to still experience a small part of how it felt to be a pilot.”
I went straight for the brand new versions of what I’d been driving. With each sleek model I inspected, I realized I was still sitting in a hole, still making my reverse blind entry, and still emitting involuntary moans and groans upon climbing out. After trying on four or five cars I’d broken a sweat and was in pain. On the other side of the lot sat a row of SUVs. My spirit seemed to cry out, startled, and I got a little panicky. I sauntered toward the first model, and my eyes hurt from how ugly it was. Clearly, no engineer had ever bothered to put the thing in a wind tunnel. It reminded me of a platypus, the metal version. Still, I cracked open the door. I will admit I was a little peeved at how effortlessly I could slide behind the wheel. The salesman showed up with keys and convinced me to take it for a spin. I decided I should at least drive it before I walked away. As we began, I was shocked by how easy the camera made it to go in reverse. With all of the computer sights and sounds, I probably couldn’t hit anything if I tried. I then realized my growing annoyance at how effortless it was to drive, to change lanes, etc. I took these sensations as the Universe schooling me for waiting so long to do something smart. The power seat had ensured my comfort in three dimensions, right down to the millimeter. I sat up high and could see everywhere. Concrete far and wide must have breathed a sigh of relief as I brought us back to the dealership. The final slap in the face was when I discovered I could step out of the driver’s seat in complete silence.

I had no choice, really, so I sat with the salesman and went over the options. A rear camera, heated, fully adjustable seats, an automatic transmission, and finally, the proximity alert system. I looked across the desk, and since there was no way he would understand that what I needed was the Ankylosing Spondylitis package - I mumbled something about the “Elderly Package.” He laughed. Me, not so much.

The day I turned over the keys to my high performance companion of fifteen years, was bittersweet. I had mixed emotions; I clearly wasn’t going to be cool anymore, and certainly there was no sex-appeal in my mechanized all-wheel drive platypus. A reality check did remind me that my gray hair and cane had probably already diluted any coolness I thought I still possessed. Painlessly, I climbed into my new ride. What surprised me most was that my spirit seemed unaffected. In fact, it was fine. This change, though AS induced, was perhaps not a bad thing. I finally understood that my ego was the part of me that wasn’t thrilled, but spirit beats ego any day. I hadn’t really lost anything. In fact, I may have gained. I began to consider all the places this new vehicle could take me that my old car couldn’t. It crossed my mind that maybe I should get a dog, SUVs were made for dogs. I could carry lots of stuff in the back, and if I wanted, I could probably still go fast, it would just take a lot longer, and wouldn’t be nearly as much fun. Though you want to know what fun is? It’s less pain. That’s fun. I used to pat my old car lovingly on the hood from time to time, but I only give the platypus an occasional nod. As I cruise around, I invariably switch on the seat heater regardless of the outside temperature because it makes my back feel better. I understand that having AS is a constant search for ways to adapt, and we do. Change is hard, but we do it, and we get a little better sometimes because we don’t quit trying. I guess that’s why we’re called warriors, and I’m a warrior in a metal platypus.
Whether you are newly diagnosed or a spondylitis veteran, SAA’s spondylitis educational support groups invite you to connect with others living with spondylitis! Our unique in-person support groups meet in 38 cities around the United States, and are run by volunteer support group leaders who are taking an active role in managing their disease. SAA’s volunteer support group leaders live with spondylitis and share a common goal of bringing the community together. Each group strives to provide support, education, and encouragement, planning and holding informative and engaging meetings.

Have you considered attending an upcoming support group meeting in your area? Visit Spondylitis.org/Groups to find one near you!

Groups are co-created with members in their communities in neighborhoods across the country. Meeting topics vary based on a group’s interest and needs. Occasional speakers such as rheumatologists, physical therapists, nutritionists, and other wellness professionals provide group members with practical information, spondylitis education, and disease management resources.

Our leaders are crucial members of SAA’s volunteer team, and play the determining role in the success of our spondylitis support groups through their dedication, passion, and desire to make a difference in their communities.

SAA supports and guides our leaders, always there in the background to offer assistance. We provide educational and promotional materials for attendees, help promote meetings through various communication channels, and provide resources to help our valued volunteers grow in their role as facilitators and leaders.

In fact, earlier this year, SAA held a much awaited Support Group Leader National Conference, flying in our Support Group Leaders for a weekend of informative presentations, meet and greets and socializing, and fruitful group discussions on issues of concern and interest to our leaders.

From across the states, 32 volunteer leaders joined us for a two-day event held in Denver, Colorado. On Saturday April 28th, leaders participated in our Spondylitis Educational Seminar, concluding the educational part of the day with a facilitated roundtable discussion – SAA Support Group Leader style. Later that evening, our leaders rejoined SAA for an evening reception of great food, new friends, and bonding. Early Sunday morning, our conference resumed with a presentation on “Support Group Best Practices” by Joan Westreich, LCSW, followed by a Marketing presentation by SAA’s Director of Brand Experience & Public Affairs, Jason Blackwell. In addition, support group leaders led and participated in various breakout sessions chosen by them in advance. It was quite a memorable weekend for volunteers and staff alike! New friendships were made, old friendships deepened, and leaders left with new tools and ideas to implement in their groups.

Are you interested in starting a group in your area? I’d love to hear from you! Contact me at programs@spondylitis.org.

What can you expect when you contact us?

We will discuss your goals in starting the group, as well as SAA’s mission for our support groups, and if the two align, I will walk you through the steps of becoming an SAA Sponsored Volunteer Support Group Leader.

Our process begins with filling out a volunteer application, followed by an informal phone interview with me, and a veteran support group leader. Finally there is the completion of a short and simple spondylitis knowledge quiz, and the signing of a volunteer agreement. Once the onboarding is complete, each leader’s bio, contact information, and meeting details are listed on our website. Once a meeting is set, we reach out to our networks promoting the new group and its meetings. I am there every step of the way to help guide and assist in the start of a group, and planning of the first meeting.

We are currently searching for our 50th Support Group Leader to join our team. Could it be you?

Learn more about becoming an SAA Sponsored, Spondylitis Educational Support Group Leader. Visit Spondylitis.org/Groups or contact me at programs@spondylitis.org.
Corporate Support

The corporate membership program is the way for pharmaceutical members to positively impact the lives of those affected by spondylitis by contributing to the Spondylitis Association of America’s general operating budget. The following companies are current corporate members.

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Driven by science.

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PLEASE STAY IN TOUCH!
Do you have our current mailing address?
Do we have yours?

We are no longer using our old P.O. Box Address,
and mail forwarding will expire as of November 24th.
Please update your records if you haven’t yet.
We don’t want to miss your correspondence!

*Do we have YOUR current mailing address?
Please contact us to update if needed.
Email us at info@spondylitis.org,
or call Helene Hart at (818) 855-2109.
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.