SpondylitisPLUS

SUMMER 2025

YOUR STORIES: THE ART OF BALANCE: LIVING CREATIVELY WITH AS

ENTEROPATHIC ARTHRITIS: WHERE GUT MEETS JOINT

GROWING PAINS, MAKING GAINS: THE REALITIES OF JUVENILE ARTHRITIS

SUMMER SELF-CARE TIPS FOR SPONDYLOARTHRITIS: STAYING COOL, COMFORTABLE, AND IN CONTROL

Spondylitis
Association
of America™
Serving the Spondyloarthritis Community

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SAA MISSION

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

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HOW CAN WE HELP?

SAA's staff and board of directors are sending our wishes for health to you and your loved ones. Is there anything we can do to help? What are your needs? Reach out to us at **info@spondylitis.org**. Now, and always, you're on our minds and we are here for you.

SAA SPOTLIGHT:

Dear Readers,

Joy can be quiet. Subtle. It often shows up in the margins, between doctor visits, on difficult days, or in the middle of a moment you didn't plan for. And yet, again and again, it finds a way in. Not always in grand gestures, but in small, unexpected ways: a shared laugh, a creative spark, a kind word. Choosing joy, especially in the face of challenges, can be its own quiet form of resilience.

Amid ongoing uncertainties and everyday hurdles—including the daily realities of life with spondyloarthritis—it can feel especially meaningful to pause and consider what contentment and peace look like, even when the path ahead isn't always smooth.

Our cover features visual artist Fiona Clark, whose work bursts with bright colors, bold patterns, and an energy that feels unmistakably joyful. In her "Your Stories" article, she says, "[T]he process of creating—of making something meaningful, even through the pain—is inherently joyful." Despite her struggles with spondyloarthritis, Fiona and her artwork lean into vibrancy.

We also see this spirit in James Roberson, one of SAA's newest support group leaders, who brings such energy and generosity to his role. Whether he's sharing a funny video in which two medications argue about which is better at treating AS or speaking to his group about the courage it takes to keep going, James exudes warmth and wit. He reminds us that support doesn't have to be just one thing: it can be humorous, heartfelt, and everything in between.

And of course, as we lace up for May's Walk Your AS Off, we carry that same mindset. We walk together all year round, but Spondyloarthritis Awareness Month gives us a special reason to step out in solidarity—to raise awareness, funding, and hope for those living with ankylosing spondylitis and related diseases. The road isn't always easy, and some days, it can feel impossible. But we look for the bright spots: good conversations, small victories, tiny reminders that we're not alone.

So wherever this summer season finds you—creating, walking, laughing, resting—I hope joy finds you, too. Sometimes it's just a flicker. Sometimes it's a full-on sunbeam. Either way, enjoy it. You deserve it.

With warmth and gratitude,
Cassie

Cassie Shafer
Chief Executive Officer

LETTERS TO THE EDITOR:

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

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

SAA's Milestone Podcast:

On April 9, 2025, SAA released its 100th podcast episode, **From Host to Guest: Celebrating 100 Spondycast Episodes with Jill Miller**. In this milestone episode, Spondycast host Jill Miller steps into the guest chair to reflect on her personal journey with spondyloarthritis. She also shares her vision for a unified, empowered patient community.

Listeners responded warmly to Jill's vulnerability and wisdom, appreciating both her reflections and the chance to learn about the experiences that have shaped her. Helgi Olafson, an advocate and longtime voice in the SAA community, praised the episode for offering "lots of relevant insight into the previous ninety-nine episodes" along with a meaningful "get to know Jill" element. Terina S., newly diagnosed at 58, shared how powerful it was to hear Jill speak openly about her life with AS, calling the episode "[v]ery inspiring and worth the listen. Very validating." For many in the community, this milestone episode felt like both a celebration and a moment of genuine connection.

Our 100th episode isn't the only one getting rave reviews. Here's a sampling of the feedback we've received from listeners over the years:

Episode 1: Spondyloarthritis and the Digestive System with Dr. Atul Deodhar

"Thank you for information that is helpful AND hopeful." ~ Claudia J.

Episode 12: Diet and Spondyloarthritis with Dr. Elena Philippou

"Thank you so much for the informative podcast on diet, nutrition and spondyloarthritis. I had already heard some of this but it's great to get a more focused overview which I know will help me make more healthy food choices in future. So beautifully and clearly presented too." ~ Úna H.

Episode 34: Physical Fitness and Spondyloarthritis with Alex Levine

"There is so much negative stuff online about AS. It is great to hear a positive spin and that we CAN do something, even if it is little. What an encouragement. I am newly diagnosed so thanks for giving me hope." ~ Leanne

Episode 50: Caring for the Caregivers with Dr. Megan Wilde

"Great to learn about emotional and financial caregiving, and also just being an ever-ready, eager to help person to others! The podcast was empowering and educational. Thank you!" ~ Pattie D.

Episode 65: Podiatric Care with Dr. Lindsey Cherry

"Excellent overview of the foot and ankle problems people with AS can suffer with. Great explanations, helpful tips and treatment suggestions. Thank you!" ~ Sara D.

Episode 72: Daily Routines and Rituals for Mental Endurance

"The discussion was well balanced between personal experiences and the intricacies of living with AS. Well done!" ~ Wayne C.

Episode 99: Navigating the Patient-Nurse Relationship

"Great interview with Historian Supervision and Infusion Nurse Specialist. This interview helps all patients with Spondylitis understand the role of the doctor's nurse. I learned new information. Most informative. Thank you!" ~ Joan P.

Visit **https://spondylitis.org/podcasts** to listen to more Spondycast episodes and to take our short listener survey to let us know what topics you'd like us to cover.

Contents:

4 **The Healing Power of Storytelling**

5 **Challenge Accepted:** Lace Up for AxSpA

6 **Enteropathic Arthritis:** Where Gut Meets Joint

8 **Summer Self-Care Tips for Spondyloarthritis:** Staying Cool, Comfortable, and In Control

10 **Summer Exercise Tips for People with Spondyloarthritis (SpA)**

11 **Resources That Help Reclaim Lives**

12 **Medical Gaslighting:** It's NOT All in Your Head! SAA Survey Results

14 **Growing Pains, Making Gains:** The Realities of Juvenile Arthritis

16 **Your Stories: The Art of Balance:** Living Creatively with AS

18 **Meet the Support Group Leader:** James Roberson

Cover photo: Fiona Clark
Photo Credit: Colleen MacMillan

THE HEALING POWER OF STORYTELLING

by the Spondylitis Association of America

On March 7, 2025, the Spondylitis Association of America's storytelling series returned with the seventh edition of "SAA Storytellers: Your Stories on Stage." Hosted by Sean Ewert, SAA's Director of Member Engagement, the virtual event gathered members of the spondyloarthritis community for an evening of honesty, humor, resilience, and connection.

This live virtual series, an extension of the "Your Stories" published in *Spondylitis Plus* magazine and our eSUN newsletter, spotlights the real voices of people living with SpA. Since launching in 2022, 35 individuals have shared their experiences through this empowering series. This latest installment featured four storytellers from across the SpA community: Sara Shaw, Joshua Lee, Geoff Lindsay, and Eric Bonanno. Each offered a deeply personal glimpse into life with chronic illness.

Sara Shaw opened the evening with a heartfelt account of how a chance meeting with another woman named Sarah (now her closest friend and co-leader of the Pittsburgh support group) changed the trajectory of her illness journey. After 17 years without a diagnosis, Sara found not only the name for her pain—ankylosing spondylitis—but also the power of friendship and advocacy.

"We're all part of a club we don't want to be in," Sara Shaw said, "but it's easier to get through it when you're…not alone."

Next, Joshua Lee, an early-retired automotive engineer and father, shared how his life shifted after a sudden onset of debilitating symptoms. He spoke candidly about the emotional and physical toll of delayed diagnosis and finding hope through perseverance, community, and movement—specifically, rediscovering his love for cycling.

"Life isn't about what we can't do," Joshua reminded the audience, "it's about what we can do. We can all find our own ways to pedal forward."

From across the Atlantic, Geoff Lindsay from the UK brought an international voice to the virtual stage. Diagnosed with AS decades after his symptoms began, Geoff reflected on the 50-year arc of his journey and how yoga became both a survival tool and a calling. Co-founder of Yoga for AS, Geoff uses his passion to fuel global movement to make yoga accessible to those with SpA.

Closing the event was Eric Bonanno, a former hockey coach whose experience with AS and other autoimmune conditions forced him to step away from a career he loved. With humor and vulnerability, Eric reframed his story, not as one of defeat, but of reinvention.

"Retirement wasn't giving up," he shared. "It was the start of a different chapter, one still full of purpose."

Through these moving stories, SAA Storytellers continues to cultivate connection and understanding within the SpA community. These peer-to-peer stories offer a powerful reminder: you are not alone.

The full event is now available to watch on SAA's YouTube channel. Whether you missed the live show or want to revisit the stories, the recording is free and open to all.

Please scan to watch SAA Storytellers.

CHALLENGE ACCEPTED: LACE UP FOR AXSPA

by Jason Blackwell, MBA

Although 1 in 100 or nearly 3.2 million Americans live with spondyloarthritis (SpA), it still has not reached the same level of awareness as more familiar diseases such as ALS, RA, and MS. SpA is more prevalent than all those diseases – combined. However, gaps continue to exist in awareness and understanding of the disease and its impact on the everyday lives of people living with this condition. World AS Day, observed on the first Saturday of May, and SpA Awareness Month, celebrated annually in May, are prime opportunities to increase visibility, drive action, and advocate on behalf of the SpA community.

Each year, SAA and our fellow SpA patient association members of the Axial Spondyloarthritis International Federation (ASIF) unite to collectively support an awareness campaign to shed light on axial spondyloarthritis (axSpA). This year's theme, "**Lace Up for axSpA**," encouraged individuals to step into the shoes of someone living with the disease—figuratively and literally. Although lacing up your shoes may seem simple to most people and taken for granted, it can be a formidable challenge for members of the SpA community due to pain, stiffness, and restricted mobility. So, the goal of illustrating this symbolic gesture is to highlight some of the daily obstacles someone living with SpA endures while mobilizing support and awareness.

AxSpA is a chronic inflammatory disease, a lifelong condition that currently does not have a cure. Given that it continues to often go underdiagnosed or misdiagnosed, it can significantly impact the quality of life, making simple tasks arduous and painful. Beyond tying shoelaces, individuals with axSpA may struggle with everyday activities such as brushing their teeth, picking up and holding their children, getting out of bed in the morning, or even turning their heads while driving. These challenges can make routine activities exhausting and frustrating, emphasizing the urgent need for increased awareness and better treatment options.

By raising awareness, we're not just shedding light on a lesser-known condition. We're also empowering individuals to eventually receive an early diagnosis and treatment, breaking the stigma of living with an invisible illness. This advocacy is crucial for better resources and treatment options, and for building a supportive community. Together, we can ensure that no one has to face axSpA alone.

SAA will continue to promote the theme of "**Lace Up for AxSpA**" throughout May, which is SpA Awareness Month. Show your support by sharing a photo on social media using the hashtag **#LaceUpforaxSpA** and encouraging your friends and family to do the same.

Together, we can make a difference and bring visibility to a condition that too often remains in the shadows. Your involvement, no matter how small, is crucial. It contributes to a greater understanding and a more compassionate world for those living with axSpA.

ENTEROPATHIC ARTHRITIS: WHERE GUT MEETS JOINT

by Michael Weisman, MD

Although inflammatory bowel disease (IBD) is often only discussed in terms of gastrointestinal signs and symptoms, its impact goes far beyond the gut. For individuals with enteropathic arthritis (EnA), this is a familiar reality. EnA, a form of inflammatory arthritis that occurs alongside IBD, exemplifies the complex ways in which the immune system can affect multiple organ systems. Understanding EnA is essential not only for those living with the condition but also for healthcare providers, caregivers, family members, and anyone interested in the intersections of gut and joint health.

What Is Enteropathic Arthritis?

Enteropathic arthritis, by definition, is most commonly associated with Crohn's disease and ulcerative colitis, the two main types of IBD. It is estimated that up to 20% of people with IBD will develop some form of EnA[1]. When a person has EnA, the inflammation characteristic of IBD does not remain confined to the intestines. It can manifest in the joints and structures surrounding the joints, leading to pain, stiffness, and reduced mobility. The condition can range from mild to debilitating, and its symptoms can often but not always mirror the fluctuations in gastrointestinal disease activity.

What Causes EnA?

The precise cause of EnA remains uncertain, but researchers believe it stems from a combination and interaction of genetic predisposition, immune system dysfunction, and what is commonly called dysbiosis, a term that describes disturbances in the gut microbiome. Individuals with a family history of IBD or other types of spondyloarthritis may have a higher risk of developing the condition. Environmental factors such as infections or disturbances in the gut microbiome are also thought to play a role in initiating or worsening the disease.[1]

When and How Do Symptoms Appear?

Enteropathic arthritis can begin with either gastrointestinal symptoms or joint pain, and the order of onset varies among individuals. In some cases, joint symptoms such as stiffness or swelling may appear before any clear signs of IBD are experienced by the patient. In others, digestive issues are the first to surface, with arthritis developing later. This variability can sometimes complicate or even substantially delay a diagnosis, underscoring the importance of a comprehensive evaluation.

However, not everyone with IBD who experiences joint pain necessarily has EnA. Joint discomfort can also arise from a variety of causes, including medication side effects or unrelated musculoskeletal conditions such as osteoarthritis or fibromyalgia. A diagnosis of EnA is typically reserved for individuals whose joint symptoms show a clear inflammatory pattern and are believed to be directly connected to their underlying bowel disease. Careful evaluation by a rheumatologist, often in collaboration with a gastroenterologist, is crucial to determining whether joint pain relates to EnA or another condition.

Signs and Symptoms

The symptoms of EnA vary widely and may involve both musculoskeletal and gastrointestinal systems. Common signs include joint pain, particularly in the lower limbs, as well as stiffness and swelling. These joint issues can often occur alongside or shortly after flare-ups of IBD, though in many cases they may appear independently.

Patients might also experience back pain if the spine or sacroiliac joints are affected. In addition to joint-related symptoms, many individuals continue to cope with the typical signs of IBD, such as diarrhea, abdominal cramping, and unintended weight loss. Some may also develop systemic symptoms like fatigue, eye inflammation (uveitis), or skin rashes.[2]

Types and Diagnosis

EnA can be classified into several subtypes based on the pattern of joint involvement. The two main subtypes are peripheral and axial. Peripheral arthritis affects the limbs, often in an asymmetrical pattern, and may mirror IBD activity. Axial arthritis targets the spine and sacroiliac joints, leading to chronic back pain and stiffness that can resemble ankylosing spondylitis. Research suggests that a large share of individuals with axial involvement in EnA test positive for HLA-B27, while the marker is not typically associated with peripheral joint disease.[3]

Diagnosis of EnA always involves a comprehensive review of medical history, physical examination, and targeted testing. Physicians may use blood tests to detect markers of inflammation and rule out other causes of arthritis. Imaging techniques such as X-rays or MRI scans can help identify inflammation or damage in joints and surrounding tissues. The diagnosis often requires collaboration between gastroenterologists and rheumatologists to examine the full spectrum of signs and symptoms.[3]

Treatments and Long-Term Management

Management of EnA typically involves a combination of medication, lifestyle modifications, and ongoing medical supervision. Nonsteroidal anti-inflammatory drugs (NSAIDs) can provide short-term relief of joint pain but must be used cautiously, as they can exacerbate gastrointestinal symptoms in IBD patients. Disease-modifying antirheumatic drugs (DMARDs), such as sulfasalazine or methotrexate, are commonly employed first line to reduce systemic inflammation and control both joint and bowel symptoms. For more severe or persistent cases, biologic therapies like tumor necrosis factor (TNF) inhibitors—including infliximab and adalimumab—have proven effective in targeting the inflammatory pathways involved in both IBD and arthritis.[4]

Lifestyle changes also play a critical role in managing enteropathic arthritis. Regular low-impact exercise, such as swimming or walking, can help maintain joint flexibility and reduce stiffness. A balanced, anti-inflammatory diet may alleviate some digestive symptoms and support overall health. Stress management techniques, including mindfulness and therapy, are also beneficial, given the strong connection between stress and IBD flare-ups.

Emerging therapies offer additional hope for patients with EnA. New biologics and small-molecule drugs, such as Janus kinase (JAK) inhibitors, are currently being employed and explored for their potential to more precisely modulate immune responses. These treatments represent a promising frontier, particularly for individuals who do not respond well to existing medications.[5] Side effects can occur with any of these medications; therefore, a critical discussion between patient and doctor is necessary in each case to make the right therapeutic decision.

Long-term management of enteropathic arthritis requires a personalized, multidisciplinary approach. Regular monitoring by healthcare providers helps adjust treatment plans in response to symptom changes. Patient education is equally important, empowering individuals to recognize early signs of flare-ups and make informed decisions about their care. Support groups and counseling services can offer additional emotional and practical support, reducing the sense of isolation that often accompanies chronic illness.

Insights into Axial Spondyloarthritis (axSpA)

A great deal of interest has been stimulated across the globe to find the ties between inflammatory bowel disease and arthritis.[6-8] The connection between EnA and IBD has provided researchers with valuable insights into inflammatory mechanisms that link the gut and the musculoskeletal system. This overlap has contributed to the development of targeted therapies for axial spondyloarthritis (axSpA), particularly for those other forms of the disease that may not be associated with IBD.

By studying how inflammation originates and spreads in individuals with EnA, scientists have improved their understanding of immune signaling pathways and genetic markers shared across different types of spondyloarthritis. These findings have helped refine treatment strategies and inform the use of new and more potent therapies to modify and improve patient outcome, such as biologic response modifiers, for both EnA and axSpA.

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SUMMER SELF-CARE TIPS FOR SPONDYLOARTHRITIS:
STAYING COOL, COMFORTABLE, AND IN CONTROL

by Esinam Bediako

Living with spondyloarthritis (SpA) requires year-round attention to your body's needs. But summer introduces unique challenges and opportunities. While warmer weather can alleviate joint stiffness for many, for others, heat, humidity, and increased social activities can prove extremely taxing. These evidence-based tips can help you enjoy the season while prioritizing your health.

Hydration: Essential for Joint Health

Staying hydrated is a simple but powerful form of self-care that keeps your joints lubricated and your energy steady, especially during hot summer months. Dehydration can lead to reduced synovial fluid (the lubricant in your joints), resulting in increased stiffness and discomfort. According to the Cleveland Clinic, even mild dehydration can cause muscles and joints to cramp and ache.[1]

Incorporate hydrating foods such as cucumbers, tomatoes, oranges, and watermelon into your meals. If you struggle to remember to drink water, try using a water-tracking app like Plant Nanny or Hydro Coach.[2] Avoid caffeinated or alcoholic beverages in excess, as they act as diuretics and can worsen dehydration.

Pro Tip: Try infusing your water with anti-inflammatory ingredients like ginger, lemon, cucumber, or mint for both flavor and potential symptom relief. Keeping a pitcher in the fridge can also serve as a visual reminder to drink.

Sun Protection

Sunny days may be perfect for a stroll or picnic, but for people with SpA, that sunlight can quickly become harmful. Summer's UV rays are stronger, so it's important to take precautions before stepping out.

Many medications used to treat SpA, including NSAIDs and certain biologics, can increase your skin's sensitivity to sunlight, leading to a higher risk of sunburn and skin rashes. The American College of Rheumatology recommends that patients using methotrexate, sulfasalazine, and TNF inhibitors use caution when exposed to direct sunlight.[3]

To protect yourself:

- Apply a broad-spectrum sunscreen with at least SPF 30 every two hours.
- Protect psoriasis plaques or patches with sunscreen, *unless* the area contains open sores or active inflammation. Cover open or cracked skin with clothing instead.
- Wear protective clothing, such as long-sleeved shirts, wide-brimmed hats, and sunglasses.
- Use sun umbrellas or seek shaded areas during peak hours (10 a.m. to 4 p.m.).

Pro Tip: Carry a compact UV index meter or use a weather app with UV tracking so you can avoid high-exposure hours more precisely, especially during outdoor events.

Appropriate Clothing and Footwear

To enjoy the season's easy, breezy vibe, make mindful choices in clothing and footwear. Loose-fitting garments allow better airflow and minimize pressure on tender areas, helping you stay cool and comfortable.

Supportive shoes are essential for people with SpA, especially for those experiencing plantar fasciitis or heel pain. Flip-flops often lack arch support and shock absorption, increasing strain on the spine and lower extremities. Instead, look for sandals with:

- Contoured footbeds and arch support
- Adjustable straps for a secure fit
- Cushioned soles and heel support
- A back strap to prevent overuse of toe muscles

Brands like Vionic, Birkenstock, and Chaco offer orthopedic-grade sandals that align with these features. Also, consider custom orthotics if needed.[4]

Pro Tip: Opt for lightweight, breathable fabrics like cotton, bamboo, eucalyptus, or moisture-wicking materials to help regulate body temperature and reduce skin irritation.

Anti-Inflammatory Diet: Seasonal Eating

For some people, summer is filled with cookouts, BBQs, and spontaneous snack stops, often featuring highly processed foods. That's why it's more important than ever to stick to the nutritional habits that support your SpA.

Nutrition can significantly impact inflammation levels. Embrace summer produce to fuel your body with anti-inflammatory benefits. Ideal foods include:

- Berries (blueberries, strawberries, blackberries) packed with antioxidants
- Leafy greens (spinach, kale, arugula) high in vitamin K and folate
- Omega-3-rich fish (salmon, sardines)
- Cold soups with turmeric, ginger, or garlic

The Mediterranean diet is one of the most recommended for SpA and other inflammatory conditions.[5] Whether you follow this food plan or not, consider keeping a food and symptom diary to track how your meals affect your pain, energy, and mood.

Pro Tip: Make your own inflammation-fighting popsicles using berries, tart cherry juice, and turmeric. They're a cooling treat with added health benefits.

Mental Health: Stay Connected and Mindful

Summer can bring joy, but it can also bring FOMO (fear of missing out)—especially if you feel limited by pain or fatigue. Living with SpA can make you feel isolated, especially during energetic summer months.

Research from Johns Hopkins suggests chronic illness can increase risks for anxiety and depression if not addressed early.[6] Tuning into your mental health can help combat anxiety and depression by helping you feel like you're engaged and active, even when your energy doesn't match the season's pace.

What can help:

- Short daily mindfulness or meditation sessions (5–10 minutes)
- Regular journaling to track pain, emotions, and wins
- Joining an online or local support group
- Talking openly with loved ones about limitations and needs
- Using apps like Headspace or Insight Timer to engage in guided practices for stress and chronic pain.

Pro Tip: Create a summer joy list—tiny things that make you feel good like watching the sunset, eating fresh fruit, or listening to crickets. Try to check off one item each day.

Daily Routine: Building Consistency

The spontaneity of summer can shake up even the best habits. Keeping a reliable routine helps you stay grounded and consistent, even when the rest of your schedule changes. In addition, small routines make it easier to cope with unexpected flares and reduce decision fatigue.

A consistent routine can reduce stress and help manage symptoms. Consider:

- Waking up and going to bed at the same time each day
- Blocking time for exercise, stretching, and meals
- Keeping essentials (water, medications, braces) in easy-to-reach places
- Planning weekly meal prep on cooler days to conserve energy

Pro Tip: Use visual anchors, such as placing a yoga mat near your bed or keeping a hydration bottle by the door, to prompt positive habits without relying solely on memory.

Helpful Tools and Technology

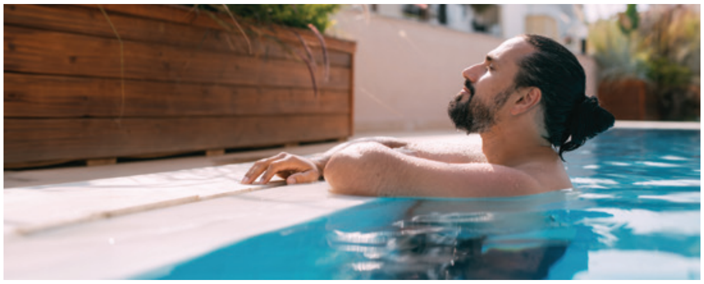
With rising temperatures and longer days, managing your SpA might feel like a juggling act. Thankfully, modern tools and wearable tech can ease the load and help you stay on track through the season.[7] Some top options include:

- **MyTherapy** (called "Med & Pill Reminder: MyTherapy" on Google Play and "MyTherapy: Medication Reminder" on Apple Store): medication reminders and progress visualization
- **Hydro Coach**: hydration tracker
- **ThermApparel.com**: wearable cooling vests for heat-sensitive individuals
- **StretchIt:** guided flexibility routines tailored to your level

Pro Tip: Explore smart home tools like voice-controlled reminders to stretch or hydrate. You can even schedule "cool down alerts" if you're prone to overheating during tasks.

Final Thoughts

Managing spondyloarthritis during the summer involves a combination of proactive strategies and self-awareness. Remember: self-care isn't selfish; it's strategic. Find what works for your lifestyle, pace yourself, and celebrate even the small victories.



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SUMMER EXERCISE TIPS FOR PEOPLE WITH SPONDYLOARTHRITIS (SPA)

by Hyun Woo (Jimmy) Kim PT, DPT

Some people with SpA may be sensitive to heat, but with thoughtful planning and a few key modifications, summer can still be a great time to stay active and manage symptoms.

Low-impact exercises like walking, swimming, yoga, and tai chi can help maintain flexibility, reduce stiffness, and improve spinal mobility. Water-based exercises provide resistance without impact, while pool stretching can cool the body and ease joint pressure. Even just 15 minutes of daily movement can offer real benefits. Let these tips guide you to get the most of your summer exercise routines.

Safety & Hydration

- **Hydrate well:** Aim for 8 to 10 glasses of water per day, especially when exercising outdoors.
- **Support electrolytes:** If you're sweating heavily, consider replenishing with an electrolyte drink or supplement (check with your health care provider).
- **Protect your skin:** Wear breathable, moisture-wicking clothing, a hat, and apply sunscreen.
- **Pace yourself:** Monitor your body's response and avoid overexertion.

Timing Matters

- **Early mornings:** Take advantage of cooler temps and ease into movement when joints are stiffer.
- **Evening hours:** If mornings are too hot, plan for a walk or stretch session as the day cools down.
- **Midday indoors:** Reserve the hottest hours for indoor movement or gentle stretching.
- **Consistency counts:** Even short, modified sessions help maintain mobility.

Hot Weather Modifications

- **Shorten your workouts:** Reduce duration during heat waves. Consistency matters more than intensity.
- **Break it up:** Divide longer sessions into shorter intervals with rest periods.
- **Have a plan B:** Keep indoor alternatives ready for extreme weather.
- **Use the pool:** Water-based exercises are cooling, low-impact, and joint-friendly.

Maintaining some level of physical activity, however gentle, is usually better than none when managing SpA. Listen to your body. Always consult your health care provider before starting new routines.

Visit **https://spondylitis.org/exercise** for articles, podcasts, videos, and more.

RESOURCES THAT HELP RECLAIM LIVES

by Sean Ewert

We hear this a lot. It is also central to who we are. For over 40 years, SAA has been a beacon of hope for spondylitis patients and their families. It is amazing how much power the right brochure in the right hands at the right time can have. Or a casual suggestion like, "You should try one of SAA's support groups, it may be just what you need."

Resources that help reclaim lives, every day.

At SAA, we are united by a shared mission: to improve the lives of those affected by all forms of spondyloarthritis. Thanks to the generosity of supporters like you, we have made incredible strides in funding research, raising awareness, and providing educational programs to help meet the needs of all those in the spondylitis community.

Because of everything SAA has done for me, I have chosen to donate to them in my will. My hope is that, long after I am gone, others facing the same struggles will have access to the resources that helped me reclaim my life. I want to contribute to further research, expanding patient support, and ensuring that no one else with AS must feel as lost as I once did. SAA gave me community, a new sense of ownership over my health and sense of self, and hope—and I want to pass that hope on to others.

~ Julianna Coughlin

Like Julianna demonstrates, there are many meaningful ways you can support our cause, beyond writing a check *(although checks and online gifts are still very much appreciated!)*

- **Donor-Advised Funds:** Recommend a grant from your donor-advised fund (DAF) to support programs that change lives.
- **Stock Donations:** Make a stock donation -- a tax-efficient way to contribute while making a lasting impact.
- **Retirement Fund Distributions:** Designate a portion of your IRA or 401(k) distribution to SAA.
- **Life Insurance Policies:** There are many ways to designate all or part of an existing policy to help support SAA's mission.
- **Estate Planning:** Remembering SAA in your will is a powerful way to extend your legacy and create hope.

We have helpful resources and over 40 years of experience thanks to you. For more information about these alternative giving opportunities visit the SAA website or speak with your financial advisor.

Your support, in whatever way you choose, allows us to continue allocating resources toward supporting our shared goal of someday living in a world free of spondyloarthritis. Together, we can create lasting changes.

Help someone else benefit from having the right brochure or the right suggestion at the right time to help them manage their disease by making a gift today.

Please help us ensure that SAA is here for years to come with a gift that fits how you like to give. You really are making an impact that is far reaching and heartfelt.

Please scan to learn more about supporting SAA.

MEDICAL GASLIGHTING: IT'S NOT ALL IN YOUR HEAD!

SAA SURVEY RESULTS

by Lisa K. Magno

"It's all in your head!" "You don't look sick…" "Your pain is normal for your age - or gender - or job situation…"

Has this happened to you? You seek a diagnosis, only to have your legitimate concerns dismissed. This is **medical gaslighting,** where healthcare professionals (HCPs) minimize symptoms or attribute them to other causes or psychological factors. It often affects people with invisible illnesses, women, and individuals from historically marginalized racial groups.

Gaslighting may stem from limited provider knowledge, biases, tight schedules, or general skepticism. It leads patients to doubt themselves, avoid future care, and lose trust in the system.

At a recent SAA Advocacy Advisory Committee meeting—featuring SAA Support Group Leaders, rheumatologists, and Spondylitis Community Advocates—concerns about medical gaslighting prompted us to launch a survey. Nearly 500 people completed the survey or shared insights on social media. **Here's what we learned…**

Question: Healthcare professionals (HCPs) have downplayed the symptoms I described. **96% of respondents answered YES.**

My rheumy "UN-diagnosed me" with my Ankylosing Spondylitis because he didn't see any signs of it. Also, and THIS one is THE worst – "your pain cannot be THAT bad; you're walking in here just fine!" **~ Jessamyn B.**

I have been told that I was a stressed-out young woman, and I needed to get it under control and that was causing my problems. I've also been recently told that so many people blame their disease for every ache and pain and my symptoms are most likely age-related. So, when I was younger, it was due to stress, now as I'm older (52), it's my age. Good grief. **~ Tracey H.**

I wasn't diagnosed until I was 65 and was told I just have a bad back, to lose weight, get a new bed, etc. **~ Charles K.**

Question: HCP told me that my symptoms were all in my head or indicated I was being irrational. **70% of respondents answered YES.**

> I have been in chronic pain since I was only 12. I was told repeatedly it was in my head or not that bad or I was doing it for attention. **~ Kelsey O.**

> I was told that only 20 Black women have AS. However, I have met over 300 Black women with this disease who were told the same thing. **~ Christi G.**

Question: HCP attributed my symptoms to another unrelated issue (such as weight) or psychological condition. **88% of respondents answered YES.**

> [For 14 years], I was told that I was suffering from depression… and that 'aches and pains were a normal part of depression.' I questioned my sanity, my ability to go to school, and my ability to live a 'normal' life. **~ Ellen B.**

> (Doctors) attributed my pain and fatigue to weight and depression for YEARS! **~ Melissa F.**

> I was told that my back pain was in my head and put on anxiety meds instead of running any tests or imaging. ~ **Stephanie W.**

Question: I feel that my HCP ignored or downplayed my concerns because I didn't "look sick." **89% of respondents answered YES.**

> [T]hey thought I was only wanting pain pills even after I told them I don't use pain pills…I was told the pain can't be that bad, there is nothing wrong, I look fine. **~ Crystal K.**

> Before my diagnosis, one MD asked me to bend over and touch my toes. When I did, he said I couldn't have AS, even though I have a brother who does. **~ Vicki S.**

Question: I have questioned what I knew to be true for myself because of medical gaslighting. **84% of respondents answered YES.**

> I'm afraid of changing doctors or seeing anyone new because of medical gaslighting… I have thoughts every day of "am I really in the pain I think I am?', 'maybe I'm doing something wrong.' **~ Rachel M.**

> My rheumatologist told me there was no pain with ankylosing spondylitis. For THREE years she said it must be something else! **~ Eileen O.**

Question: I am almost always distrustful of doctors, or it takes several appointments to gain trust. **81% of respondents answered YES.**

> As a child my symptoms were dismissed as growing pains and…as sports-related pain. Further distrust occurred when symptoms of an adverse drug reaction were not taken seriously...If not for a second opinion, I would not have survived. **~ Rich H.**

> Now that I've officially been living with AS for 12 years, you'd think mistrust would fade, but every time a provider retires or moves, it's a crap shoot with the new doctor. It never ends. **~ Amy M.**

Unfortunately, our survey indicates that medical gaslighting has lasting effects on patients, including delayed diagnoses, worsening disease activity, and ongoing emotional distress.

> My symptoms were dismissed, ignored, misdiagnosed, and downplayed for 16 years…I was treated like my symptoms weren't 'enough' and now like I waited too long. I'm grateful for a definitive diagnosis, but it came too late and caused too much damage. **~ Kristi K.**

> Medical gaslighting cost me both careers, tens of thousands in healthcare expenses, and a 14-year delay in my diagnosis. My AS progressed, leading to permanent, radiographic damage in my pelvis…These experiences devastated my confidence, self-esteem, and quality of life. **~ Gayla G.**

Medical gaslighting can seriously harm patients, so it's important to be aware of its signs. By advocating for your health and seeking support when needed, you can help ensure your concerns are taken seriously.

Key Indicators of Medical Gaslighting:

- HCPs repeatedly downplaying symptoms
- Attributing concerns to mental health or unrelated factors
- Overlooking pertinent medical history
- Suggesting that patients often exaggerate or imagine symptoms
- Using condescending language during consultations

Strategies to Address Medical Gaslighting:

- Keep a symptom journal and summarize your concerns for each appointment
- Draft a brief question list; if unsatisfied with answers, ask what might be causing your pain
- Seek a second opinion when needed
- Insist on being heard and advocate for yourself
- Bring a supportive companion to appointments to take notes and observe interactions

By acknowledging the issue of medical gaslighting, we can achieve timely diagnoses, improve health outcomes, and raise awareness of spondylitis

Have you experienced medical gaslighting? Share your story with us at **https://spondylitis.org/ advocacy**. We would love to hear from you!

Please scan to share your story.

GROWING PAINS, MAKING GAINS: THE REALITIES OF JUVENILE ARTHRITIS

by Natasha Trehan and Maggie Douglas

Editor's Note: *July is Juvenile Arthritis Awareness Month. To mark the occasion, we've partnered with Take a Pain Check, a youth-led nonprofit dedicated to empowering young people with rheumatic diseases. Founder & Executive Director Natasha Trehan and Global Development Coordinator Maggie Douglas understand life with juvenile arthritis first hand. In this piece, they share some of the insights they've gained from growing up with a chronic illness—and how community, advocacy, and support can make all the difference.*

Balancing Life with Chronic Illness

Balancing school, work, and a social life while managing arthritis is no easy feat. But over time, we've picked up strategies to help navigate it all. We start with detailed to-do lists and make sure every important date goes straight into our calendars. Breaking big tasks into smaller, manageable steps keeps us motivated—and crossing things off is incredibly satisfying.

Flexibility is key. Some days are better than others, and that's okay. We set realistic goals based on how we're feeling and try to show ourselves grace if things don't go as planned. Work brings its own challenges, especially when long shifts leave us drained and in pain. Learning to pace ourselves, adapt tasks, and ask for help makes a big difference.

Then there's the emotional side. FOMO—fear of missing out—is real. It's hard watching your peers live their lives while you're sidelined by pain or fatigue. But honest communication with friends helps them understand your condition, especially if you need to cancel plans at the last minute. Good friends get it—and they stick around. Finding others on a similar journey is validating. There's something powerful about being seen and supported by people walking the same path.

Talking About Arthritis

Explaining arthritis as a young person can be intimidating, especially when it's invisible and people assume it only affects older adults. For a long time, we were scared to share our diagnosis—worried about being judged, misunderstood, or underestimated. But we've learned that honesty is key.

It's important to talk about symptoms and how they affect daily life, even when it's uncomfortable. Downplaying what we're going through can make it harder for others to help. We've found it helpful to suggest small ways people can support us—offering to carry something, or simply being okay if we need to rest.

Some people are confused by mobility aids or accessible parking when our condition isn't visible. In those moments, we try to raise awareness and help others unlearn assumptions about arthritis. It takes time—just like it took time for us to process our own diagnosis.

What Doctors Should Know

One thing we wish more doctors understood is the emotional toll arthritis takes on young people. The journey often begins with bouncing from doctor to doctor, searching for answers. After being diagnosed, we grieve the version of ourselves we once knew—and the future we imagined.

Transitioning to adult care brings even more challenges, often while we're also starting college or moving out for the first time. We want doctors to recognize that we need more than just physical treatment—we need emotional support, validation, and hope. Even if our lives look different than expected, they're still full of meaning and potential.

Mental Health Matters

Living with arthritis can wear down your mental health. Managing stress, anxiety, and isolation is tough—but prioritizing self-care helps. Mindfulness practices like meditation, breathing exercises, or simply checking in with ourselves can ground us, especially on overwhelming days.

Distraction can be a useful tool. Low-energy hobbies that spark joy—watching a movie, journaling, listening to music—can shift focus away from pain. Staying connected is vital too. Online communities like Take a Pain Check help us share experiences and remind us we're not alone.

Practicing gratitude for even the smallest things helps reframe hard days. And when things feel unmanageable, we encourage seeking therapy or professional support. Most of all, we remind ourselves that it's okay to not be okay. Resting isn't giving up—it's part of healing.

Friendship and Chronic Illness

Friendships can be tricky when you're managing a rheumatic disease. One of the best things you can do is be open and honest. You don't have to tell people everything right away—start with what you're comfortable sharing. Letting friends know about your limits can prevent confusion or hurt feelings later on. Being vulnerable builds trust. And connecting with others—through support groups, classes, or social media—can lead to meaningful friendships with people who truly understand. Some of us have made lasting connections in the most unexpected places.

It's also okay to step back sometimes. You might need to cancel plans or take a break—and that's completely valid. True friends will understand. In fact, the quality of friendships matters far more than the quantity. Seek out people who uplift you and respect your needs.

Coping with Pain and Fatigue

Tough days are part of this journey. Managing pain and fatigue starts with pacing ourselves—breaking tasks into smaller pieces and taking rest breaks in between. Warm baths, heating pads, and gentle movement like stretching or walking can help keep us moving.

Comforting distractions like music, podcasts, or quiet creative time help take our minds off the pain. We also prioritize sleep and create bedtime routines that support our energy and mood. Simple lifestyle tweaks—hydrating, eating anti-inflammatory foods, and using ergonomic tools—can make a huge difference.

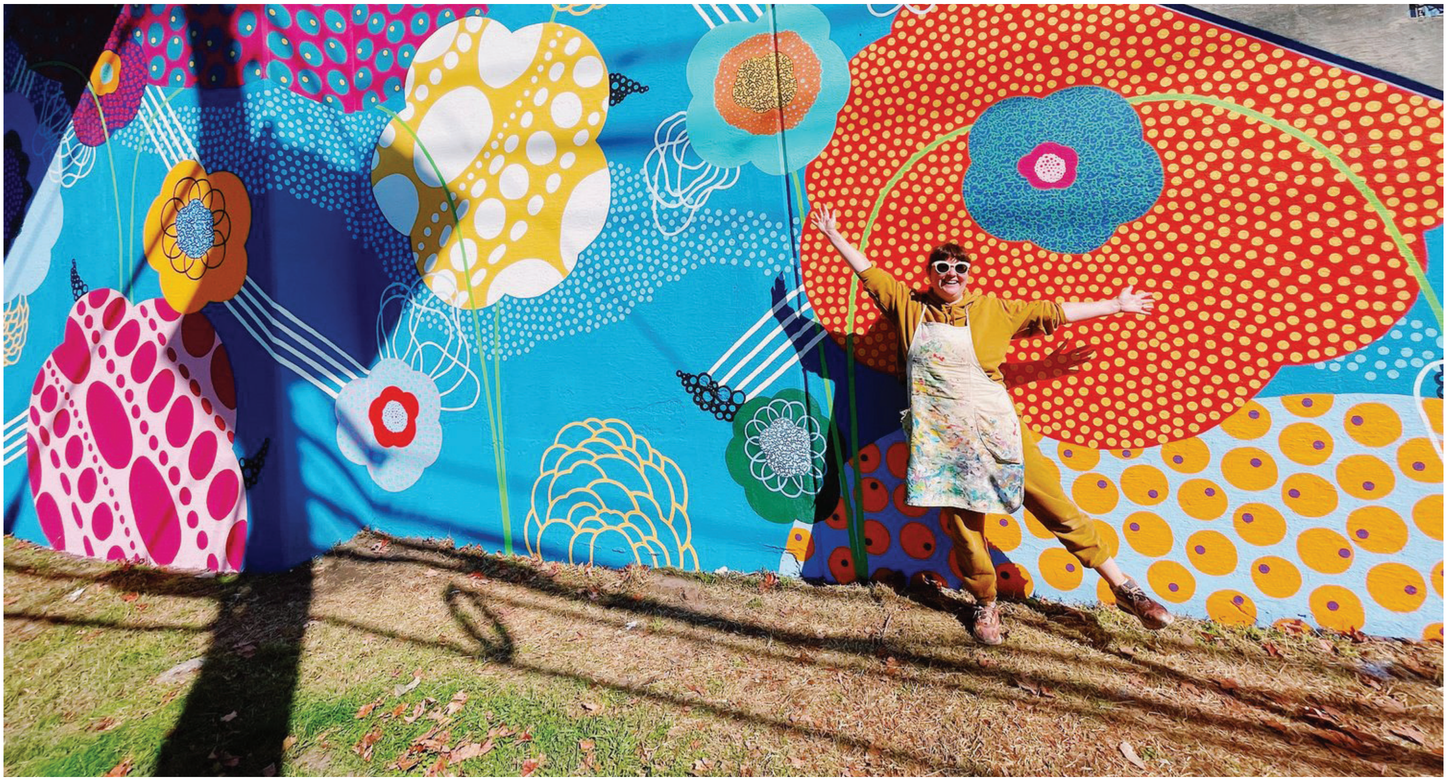
Learning to ask for help and embracing flexible routines based on how we feel each day has been a game-changer. And on the hardest days, self-compassion becomes our strongest ally.

Words for Our Younger Selves

If we could talk to our newly diagnosed selves, here's what we'd say: You are not alone, even if it feels like it. This diagnosis doesn't define you. It's just one part of your story.

You're allowed to feel scared, frustrated, or lost. Don't let those feelings stop you from living fully. Advocate for yourself. Ask questions. Speak up when something feels off. And surround yourself with people who understand or are willing to learn.

Most of all, remember that you are strong—even on the days it feels like you aren't. This journey will help shape you into someone resilient and compassionate. One day, you'll use that strength to help someone else feel seen, too.



YOUR STORIES:
THE ART OF BALANCE:
LIVING CREATIVELY WITH AS

by Fiona Clark

I was 16 when I had my first flare—or at least the first I can clearly recall. At the time, I didn't know what it was, but I knew something wasn't right. When I finally got diagnosed with ankylosing spondylitis (AS) right before my 28th birthday, I felt relief. After years of being told it might just be in my head, or that it was my fault, it was validating to know that no, I wasn't doing anything wrong. This is just my body.

There's this whole culture of blame around chronic illness. You hear, "Oh, if you just changed your diet," or "If you exercised more," or "Take these vitamins." But learning that this is a genetic, systemic, and progressive disease helped me realize that it's not because I'm not trying hard enough. There's nothing to fix about my personality or lifestyle. This is a medical condition. Getting that diagnosis gave me not just relief, but some empowerment too. Now that I knew what I was dealing with, I could start learning how to manage it.

That said, it was also scary and isolating. I didn't know anyone else in my circle with this diagnosis. I even posted on social media, "Hey, I've just been diagnosed with this—do you or anyone you know have it? I'd love to talk." And I got nothing. That silence really reinforced how alone I felt. That's when I started searching for support groups, like the ones offered by the Spondylitis Association of America (SAA). I was lucky to find other people, including younger folks, who were navigating the same thing. And I found others who'd been diagnosed for years, who had so much wisdom to share.

When I lived in New York, I was part of SAA's New York City support group. During the pandemic, we kept meeting on Zoom. A smaller group branched off—SpondyStrong—and we'd meet for movement/yoga sessions, which were really helpful. Sandra [Voss], who led the New York support group at the time, is a yoga instructor and Alex [Levine], who helped run the group, is a certified fitness coach. So we had the regular group for community, and then this smaller space for movement and mindfulness, which was great.

AS, unfortunately, doesn't have the best branding. Rheumatoid arthritis is the one people recognize. But with AS, people don't even know how to say it, let alone understand it. When I try to explain it to others, I usually say, "It's an inflammatory arthritis that primarily affects my spine, but it also impacts other organs, like my eyes." And from there, people usually ask more questions. I try to use whatever platforms I have, like my art and my YouTube channel, to bring more awareness.

Art has been part of my life for as long as I can remember. My mom likes to say that while my older brother was running around the house, I'd sit for hours with crayons and paper, completely content. Creativity has always been my way of processing the world.

I went to Hartford Art School in Connecticut and graduated in 2007 with a degree in graphic design. I worked in the fashion industry for ten years. But outside of that, I was always making fine art—painting, doing shows, going to artist residencies.

Eventually, I decided to take the leap and become a full-time artist six years ago.

Before making that decision, I saved up for a year. I'm a bit of a planner, and I didn't want to start out worried about how to pay my bills. Having at least six months of runway gave me the freedom to focus on my art and not work from a place of fear.

One of the most helpful tools has been YouTube. On Instagram, you get maybe two seconds of someone's attention. But on YouTube, people are listening, watching, following along. I post videos of myself creating a piece of art. I've had collectors find me through YouTube, watch me create a painting, and then decide to buy it because they feel connected to the process.

Being a full-time artist also gives me autonomy over my schedule, which is essential when living with a chronic illness. If I don't feel well in the morning but can be on my feet in the evening, I can shift my work hours. And if I have to be on the phone with my specialty pharmacy for four hours—which happened recently—I'm not missing meetings or deadlines.

Right now, I'm at an international residency in France called Chateau d'Orquevaux Artist & Writer Residency. When I do these kinds of residencies, I always do prep work. I check in with my rheumatologist, get bloodwork done, and make sure I'm cleared to travel. I travel with a cold case for my biologics and make sure wherever I stay has a refrigerator. And I let the residency coordinators know in advance that I'm dealing with a disorder so they're not surprised if one day I'm fine and the next I'm limping.

When I'm at a residency like this, I try to lean into the opportunity and let my creativity fly. Right now, I'm working with symbols and shapes I've found in the French countryside—everything from old churches to flowers and trees. I'm using them in my usual bright, abstract, layered mark-making. It's like a visual diary of my time here. I've also had the opportunity to create alongside so many amazingly talented fellow artists and form true lifelong connections while on this residency. A great reminder that community is so very important in life and to not take quality time with others for granted.

The disease has made me more of a planner, more organized, more intentional. Physically, I have to be mindful. I can't sit or stand for too long. I pin my work on the wall sometimes just so I can move around more. For murals or art fairs, I always hire an assistant. I learned that the hard way after trying to do my first solo fair; I ended up crying on the phone to my mom because my back and feet hurt so badly after attempting to hang my booth display alone. Now, I ask for help when I know I will need it.

If I could talk to my younger artist self, I'd say: trust your intuition. Lean into abstraction, even if school tries to push you away from it. And to someone newly diagnosed, I'd say: give yourself grace. Be patient. This is not an overnight fix. It takes time to figure out your symptoms, your treatment, your pace. And that's okay.

Balancing consistency in my art practice with the unpredictability of chronic illness is hard. It's something I'm still learning. But I do know this: art helps me cope. I think that's why joy shows up so much in my work. When you live with chronic pain, you find yourself searching for "the joy" wherever you can. And the process of creating—of making something meaningful, even through the pain—is inherently joyful. For me, it's what keeps me going.

Meet the Support Group Leader: JAMES ROBERSON

by Esinam Bediako

James Roberson makes merchandise that speaks volumes. One T-shirt reads, “This body comes with a lot of terms and conditions I did not agree to.” A black sweatshirt declares, “This hoodie turns black when I’m in pain.” (And no, the fabric doesn’t have any special color-changing abilities.) The apparel is funny, yes, but also brutally honest. And for the growing community of people living with ankylosing spondylitis (AS) who follow James online, the clothing he designs strikes a deeply relatable chord.

James, the newest Support Group Leader for the Spondylitis Association of America (SAA), is building a powerful community rooted in empathy, humor, and lived experience. Based in Washington, D.C., James was diagnosed with AS at age 22, though he first began experiencing symptoms years earlier.

“I was always in pain,” he says. “I just knew something wasn’t right.”

After leaving his job as a teacher due to the physical toll of AS, James began using his talents to raise awareness. He started making social media content—some serious, some humorous—about life with chronic pain.

His videos struck a chord. James began receiving messages from others living with AS who felt seen by his posts. What started as online engagement quickly grew into a virtual support group, where people could talk openly about the emotional, physical, and everyday realities of living with spondyloarthritis.

It wasn’t long before his work caught the attention of SAA through Minionette “Mini” Wilson, who co-leads the Raleigh/Durham Support Group. She reached out to him after seeing his content and encouraged him to connect with SAA. Though initially concerned he might have to give up the laidback style of his group, James soon saw the benefits.

“Before, I was doing everything manually—emails, check-ins, content. Now I have help,” he says. “Mini and Sean [Ewert, SAA’s Director of Member Engagement] brought more knowledge and support. It makes a big difference. And it’s still the same vibe, same flow of the group. It’s more of a family than a support group.”

Now part of SAA’s support group network, James continues to lead with compassion and authenticity.

“Everything I’ve learned is from my own research and experience. I’m not a doctor. But people still want to hear your journey—and they want to share theirs.”

James takes a holistic approach to managing AS. He tried a biologic in the past but stopped due to side effects. Today, he focuses on an anti-inflammatory diet, regular movement, and mindfulness.

“I’m not against medication. It just wasn’t right for me,” he says. “Everybody’s different.”

With his traditional career on pause, James has turned to creative work to support himself and his family. He’s a hands-on parent and a devoted partner, recently engaged. His work now includes photography, videography, and a growing line of AS-themed merchandise, which he often gifts to group members. He’s also collaborating with SAA to expand that merch further.

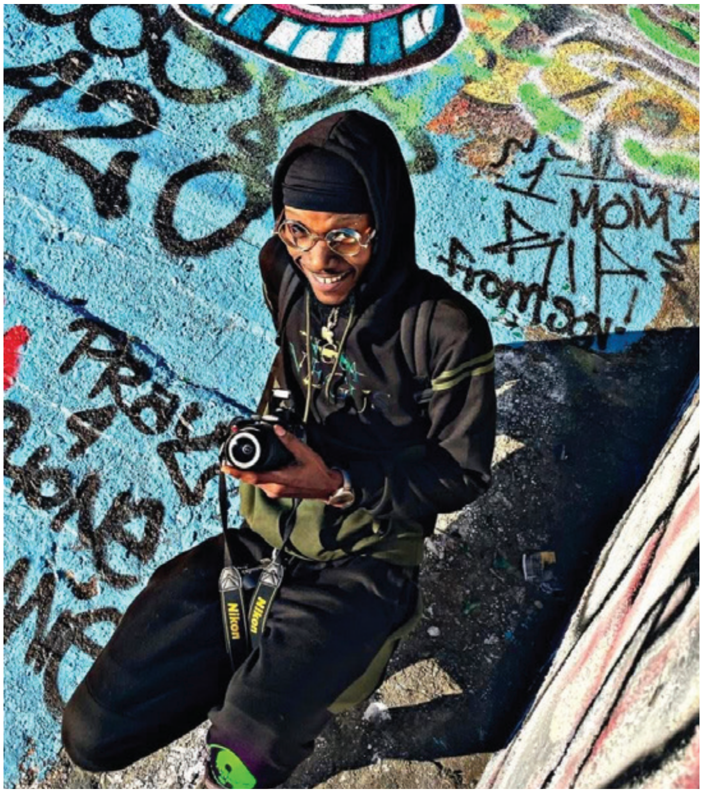
“My family keeps me motivated,” he says. “I still have my babies at home, so you know, I just can’t sit around. You gotta move it or fuse it. I have this slogan, ‘Pain into power.’ Even if I’m just making a video or a few shirts, I try to get up and be active every day.”

Though he’s listed as the support group leader for Washington, D.C., James’s group reaches far beyond the East Coast. "People join from everywhere, and that’s the best part," he says. "I just want to keep this going. It’s working."

In the future, James hopes to organize an in-person retreat for the community he’s built.

“We’ve met virtually, but people are saying, ‘I want to meet you in real life.’ That face-to-face connection would mean so much,” he says.

With warmth, creativity, and unwavering dedication, James Roberson is bringing something special to the SAA community: a space where people feel understood and uplifted.



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Learn more at
Spondylitis.org/Planned-Giving

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