Juvenile Spondyloarthritis: An Updated Overview

New SpA Medications In Development: A Drug Pipeline

When It’s Not Growing Pains: Seth’s Story
Dear Readers,

The Spondylitis Association enjoys the good fortune of low staff turnover. In fact, all of our talented and dedicated staff of eight, plus a part time bookkeeper, have served the spondyloarthritis community for at least four years (and up to eighteen years in the case of yours truly) with many who have been on staff for ten years or more.

Right now, we are going through some changes. There is a shifting of responsibilities in process and reorganization of authority in general; plus, one dedicated staffer is moving out of state.

First, I would like to congratulate Richard Howard, our Director of Corporate Relations and Planned Giving who has recently taken on the added responsibilities of Associate Executive Director. Richard (Rich) also established, organizes and facilitates our Los Angeles area educational support group that meets on our campus once a month. Rich has been running the group since November of 2012 and has grown the number of individuals who have attended the meetings to 125. Our past guest speakers include Dr. Weismann, Dr. Yu, and Dr. Overbaugh. We have had presenters speaking on a broad range of issues including long term healthcare, public policy advocacy, SSDI & SSI, the psychological immune system, Ayurvedic medicine, exercise, affordable health care insurance, and yoga. Rich often teaches a private yoga lesson prior to the meeting.

Next, Elin Aslanyan, who was promoted to Programs Manager last year, will now be at the helm of Spondylitis Plus, serving as Editor-in-Chief. (Congratulations, Elin!) I look forward to working with her in this new role, which is not entirely new as Elin (El) has been writing a good portion of Spondylitis Plus copy for the past two years.

Robin Kindrick, Executive Associate, helps keep me on track and forms a knowledge bridge between fundraising and programs, as well as being responsible for customer service and our volunteer fundraising efforts, along with a host of other duties. We now have shifted the responsibility and authority of managing our educational support group program from Elin to Robin. Our volunteer network of support group facilitators will now rely on Robin for support and information. I know that she will do a tremendous job in this area as in all others.

Lastly, we bid a fond farewell to Chris Miller, with whom I have had the great pleasure of working these past eleven years. Chris came on board as our Web and Design Coordinator, and most recently has served as SAA’s Program Director. Although moving to Missouri to freelance and to be close to his new wife’s family, Chris will continue to provide us web and print design from afar. We will miss you, Chris.

Not to omit the rest of our dedicated professional staff — Diann Peterson, Helene Hart, Linda Powell and Inna Mednikov. Thank you, each and every one for your continued dedication to our organization.

Laurie M. Savage
Executive Director
Why We Fundraise

Most of us have friends, family, or partners who feel “helpless.” They want to “fix” us and they cannot. When we ask for help with a fundraiser, we offer a tangible way for the people who care about us to help. It is quite moving to see people take time out of their day to help raise money and awareness for a disease that they perhaps knew or know little about. I think this is one of the biggest components to a fundraiser: the joining together of our loved ones to show support. I thought that we were bringing awareness to those outside of our circle, what I didn’t realize is those inside our circle of family and friends also gain a huge amount of knowledge and with that are equipped to help at a greater level.

At the end of my most recent fundraiser for SAA I had to be walked to my car, and it was one of the most wonderful feelings to know the pain was there not because of the effort of the fundraiser; it was there because of AS. The fundraiser gave me purpose and the pain did not win! I hope more people will step out of their “pain body” and reach out to help SAA and bring awareness to this horrible disease. In turn, the love and support felt will be uplifting and more than sustaining.

Thank you for all you do!

~Jacquie Gregor
Tucson, AZ

Editor’s Note:
Thank YOU, Jacquie, for all you do! We are honored to have such passionate and generous volunteers working alongside us. Jacquie Gregor has been a volunteer fundraiser, as well as beloved volunteer Support Group Leader with SAA since 2011. This issue also includes a piece by Jacqueie on Meditation. Be sure to read it on page 17.

If you have a fundraising idea, or would like to discuss the possibility of holding an event for SAA, please contact Executive Associate Robin Kindrick. You can reach her by phone at (800) 777-8189 x225, or by email at Robin.Kindrick@spondylitis.org
The American College of Rheumatology Conference is an annual gathering of rheumatologists, researchers, and other medical professionals. It is the biggest rheumatology conference in the US with more than 15,000 clinicians and researchers in attendance. This is an event SAA attends each year to review the most current research on SpA, network with rheumatology colleagues and other nonprofit organizations, and distribute spondylitis educational materials.

Last year’s conference, held in Boston, was especially significant, as the first US Axial Spondyloarthritis Treatment Guideline recommendations were presented to the rheumatology community. A few of us here at SAA had the pleasure of attending the packed presentation, and our experience was none other than invigorating!
There had been such buzz surrounding the presentation of these long awaited guidelines that the large meeting room overflowed with clinicians and researchers alike. Every seat was taken, aisles crowded with eager attendees sitting on the floor, and even more people lined up against the walls. A second, “overflow” room was also past capacity. It was quite a scene to behold.

These guidelines are the culmination of years of work by the Spondylitis Association of America, the American College of Rheumatology (ACR), and the Spondyloarthritis Research and Treatment Network (SPARTAN), and finally bring together cohesive treatment recommendations to be considered by US rheumatologists in treating their SpA patients. The guidelines address the most commonly encountered clinical situations when treating ankylosing spondylitis and axial spondyloarthritis patients. They also address preventive care, disease activity monitoring, and pharmacological treatment.

The guidelines will be published this summer, and we will bring you a comprehensive review of their contents in an upcoming issue of *Spondylitis Plus*. Stay tuned!

The Spondylitis Association would like to take this opportunity to thank our colleague and friend, Dr. Michael Ward from the NIH intramural program, who shepherded and stewarded the Guidelines to fruition. In addition, special thanks to Amy Miller and Regina Parker of ACR, without whose tireless effort and dedication none of this would have been possible.

*Side note: It was a special honor to present SAA’s Young Investigator Award to Dr. Pamela Weiss at the conclusion of this presentation, and in front of the packed room. Read about the award on page 6.*
A crucial component of SAA’s overarching mission is a commitment to expanding the number of rheumatologists and researchers in the US who focus on spondyloarthritis. Every rheumatologist who chooses to become an expert in treating SpA, and every new researcher who contributes new insights to the search for the cure, is to be celebrated and encouraged.

To this end, we created the Spondylitis Association Bruckel Young Investigator Award, which recognizes outstanding “contributions to the care and understanding of patients with spondyloarthritis.” SAA awards the winner a $10,000 grant for use in spondyloarthritis research. This past year, we were thrilled to present this award to Dr. Pamela Weiss.
Pamela Weiss, MD MSCE is a pediatric rheumatologist at Children’s Hospital of Philadelphia (CHOP) whose clinical and research interests are focused on juvenile spondyloarthritis (JSpA). Dr. Weiss earned an A.B. in Molecular Biology from Princeton University, and her medical degree from Albert Einstein College of Medicine (2002). She completed both her Pediatrics Residency and Rheumatology fellowship training at CHOP. Dr. Weiss was co-principal investigator of the American College of Rheumatology (ACR) JIA Treatment Recommendations Update, as well as a member of the Core Expert Panel for development of the 2014 Clinical Practice Guidelines for Axial Spondyloarthritis – a collaborative undertaking between ACR, SAA, and SPARTAN. (*Editor’s note: We discuss this groundbreaking collaboration on page 4.)

Additionally, Dr. Weiss serves on the ACR Pediatric Rheumatology Special Committee. Her commitment to research and improving the care of children with juvenile arthritis is also evident in her roles as Vice-Chair of the Childhood Arthritis & Rheumatology Research Alliance (CARRA) Juvenile Arthritis Research Committee, and her recent appointment as Clinical Research Director for the CHOP Division of Rheumatology. She has lectured on juvenile arthritis and spondyloarthritis nationally and internationally.

Dr. Weiss’ research focuses on the pharmacoepidemiology and outcomes of JSpA. JSpA is an umbrella term that also encompasses three categories of juvenile idiopathic arthritis (JIA) - enthesitis-related arthritis (ERA), juvenile psoriatic arthritis, and undifferentiated arthritis (children who meet criteria for more than one JIA category). Using patient-reported data from the CHOP clinic, she demonstrated that children with ERA have worse function, poorer quality of life, and higher pain intensity than children with other categories of JIA. She confirmed and published these findings using a large national registry of pediatric rheumatic diseases. To address the knowledge gaps of this understudied condition her efforts are specifically directed to better defining the disease and developing treatment strategies for children that will directly improve both clinical and patient-reported outcomes.

She is the Principal Investigator of an NIH K23 award, “Diagnosis and Evaluation of Enthesitis-Related Arthritis.” As part of this award, she completed the first study evaluating the use of ultrasonography for the detection of enthesitis (inflammation where the tendons attach to bone) in children with ERA (Arthritis and Rheumatism, 2014). In comparison to ultrasound, physical exam of the entheses was less accurate and less reliable. This study also demonstrated that in comparison to healthy children, children with ERA had more pain at all entheses, including those without inflammation on ultrasound. The accurate diagnosis of enthesitis is important because its presence has implications regarding JIA classification, which in turn influences treatment decisions and monitoring for manifestations of disease. As part of this award she also led an international effort to develop a disease activity score for children with JSpA for use in both clinical practice and research, and validated it using a retrospective multicenter database. This disease activity score is an important metric as current JIA disease activity measures do not account for the unique features of JSpA that include enthesitis and axial (spine and sacroiliac joints) arthritis (Arthritis Care & Research, 2014). For the last part of this award she created a large longitudinal database of children with JSpA, using data from five pediatric rheumatology practices, to evaluate the comparative effectiveness of treatment strategies for children with newly diagnosed JSpA. Analyses on this data are ongoing.

Lastly, she is Principal Investigator on an NIH R03 award, “Sacroilitis in early ERA and PsA.” This is a study to evaluate the prevalence of sacroilitis on MRI in children and adolescents with newly diagnosed ERA or PsA, and to assess if physical exam and back pain are helpful in screening for sacroilitis in children and adolescents. Subject enrollment is complete and publication of findings should follow soon.

*We also thank Dr. Weiss for her piece on Juvenile Spondyloarthritis, featured on page 10 of this issue.
NEW SpA MEDICATIONS IN DEVELOPMENT:
A DRUG PIPELINE

Drugs in Development for Ankylosing Spondylitis

<table>
<thead>
<tr>
<th>Generic name</th>
<th>Trade Name</th>
<th>Brand</th>
<th>Drug Class</th>
<th>Mechanism of Action</th>
<th>Route of Administration</th>
<th>Phase of Development</th>
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<td>Small molecule (PDE4) inhibitor</td>
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<td>mAb</td>
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<td>3</td>
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<tr>
<td>Tofacitinib</td>
<td>Xeljanz</td>
<td>Pfizer</td>
<td>mAb</td>
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<td>Janssen</td>
<td>fully human FynomAb</td>
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What are Monoclonal Antibodies (mAb)?

Monoclonal antibody therapy uses antibodies that are made in the lab rather than by a person’s own immune system. Once the antibodies are administered to a patient, they may recruit other parts of the immune system to destroy the targeted antigen, such as a cancer cell.

The first monoclonal antibodies were typically made entirely from mouse cells. One problem with this is that the human immune system will see these antibodies as foreign (because they’re from a different species) and will mount a response against them. In the short term, this can sometimes cause an immune response. In the long term, it means that the antibodies may only work the first time they are given; after that, the body’s immune system is primed to destroy them before they can provide treatment.

Over time, researchers learned how to replace some parts of these mouse antibody proteins with human components. Antibodies with a mixture of mouse and human components are known as chimeric antibodies. As more human components were used in the mouse antibody, they were referred to as humanized antibodies. Some monoclonal antibodies are now fully human (“fully human FynomAb”), which means they are likely to be even safer and may be more effective than earlier monoclonal antibodies.

What are IL-17/IL-23 and subset p19, IL-6?

These cytokines play an important role in driving the immune response in inflammatory arthritic diseases. Hence, drugs that seek to target various treatments interfere with the receptors of various immune cells and by this mechanism seek to reduce inflammation. Cytokines play an important role in the inflammatory process; however when there is an overabundance of these, as has been described in inflammatory disease, they can cause harm to the body if left unchecked.
### Drugs in Development for Psoriatic Arthritis

<table>
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<tr>
<th>Generic name</th>
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<th>Brand</th>
<th>Drug Class</th>
<th>Mechanism of Action</th>
<th>Route of Administration</th>
<th>Phase of Development</th>
</tr>
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<td>IL-6 inhibitor</td>
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<td>Orencia</td>
<td>Bristol-Myers Squibb</td>
<td>anti-TNF</td>
<td>prevents T-cell activation</td>
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</tr>
<tr>
<td>Secukinumab</td>
<td>Cosentyx</td>
<td>Novartis</td>
<td>mAb</td>
<td>IL-17A inhibitor</td>
<td>Subcutaneous injection</td>
<td>3</td>
</tr>
<tr>
<td>Brodalumab</td>
<td>Amgen</td>
<td>mAb</td>
<td>IL-17 inhibitor</td>
<td>Subcutaneous injection</td>
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<td></td>
</tr>
<tr>
<td>Tofacitinib</td>
<td>Xeljanz</td>
<td>Pfizer</td>
<td>mAb</td>
<td>JAK inhibitor</td>
<td>Oral</td>
<td>3</td>
</tr>
</tbody>
</table>

**What is a JAK inhibitor?**

Oral Janus kinase (JAK) inhibitor is being investigated as a targeted immunomodulator and disease-modifying therapy for multiple conditions, including AS and Psoriatic Arthritis. Unlike current therapies for this group of diseases, which are directed at extracellular targets, such as pro-inflammatory cytokines, a JAK inhibitor takes what has been described as a novel approach, targeting the intracellular signaling pathways that operate as hubs in the inflammatory cytokine network. JAK targets a broader phase of the inflammatory process.

**What are small molecule compounds?**

In molecular biology and pharmacology, a small molecule is a low molecular weight organic compound that may help regulate a biological process. Most drugs are small molecules. The upper molecular weight limit for a small molecule is approximately 900 daltons, which allows for the possibility to rapidly diffuse across cell membranes so that they can reach intracellular sites of action. [http://en.wikipedia.org/wiki/Small_molecule - cite note-Dougherty Pucci 2012-1](http://en.wikipedia.org/wiki/Small_molecule - cite note-Dougherty Pucci 2012-1) In addition, this molecular weight cutoff is a necessary condition for oral bioavailability.

**What is a biologic?**

A biologic is manufactured in a living system such as a microorganism, or plant or animal cells. Most biologics are very large, complex molecules or mixtures of molecules. Many biologics are produced using recombinant DNA technology.

**What is an anti-TNF?**

Tumor necrosis factor-alpha inhibitor (*anti-TNF*) drugs are a class of biologic drugs that have been used for more than 10 years. They suppress the body’s response to tumor necrosis factor.
Juvenile Spondyloarthritis: An Updated Overview

By Pamela Weiss, MD MSCE

Spondyloarthritis (SpA) is a group of chronic inflammatory conditions characterized by arthritis, enthesitis, dactylitis (sausage-like swelling of the fingers or toes), acute and painful eye inflammation, HLA-B27 positivity, inflammatory back pain, and sacroiliitis. The term SpA encompasses ankylosing spondylitis (AS), undifferentiated SpA, inflammatory bowel disease associated arthritis, psoriatic arthritis, and reactive arthritis.

The term juvenile SpA (JSpA) refers to spondyloarthritis that starts during childhood (before age 16). Juvenile arthritis is the most common rheumatologic disease among children, with prevalence estimates ranging from 1-4 per 1,000 children, similar to that of Type I diabetes mellitus. In comparison to other categories of juvenile arthritis, children with JSpA have more frequent and higher intensity pain as well as poorer health status. In one study, 75% of children with JSpA had moderate or severe pain, and 50% reported moderate or severe impairment of well-being over the prior week. These children and adolescents are less likely to achieve and to sustain disease remission than those with other categories of juvenile arthritis. Less than 20% of children with JSpA achieve remission within five years of diagnosis.

Three classification systems used for JSpA include: The International League of Associations for Rheumatology (ILAR) classification of juvenile idiopathic arthritis (JIA); the European SpA Study Group (ESSG) classification; and the Amor criteria. Of these, pediatric rheumatologists use the ILAR classification most often. The ILAR classification of JIA describes a clinically heterogeneous group of diseases characterized by arthritis that begin before age sixteen, involve one or more joints, and last at least six weeks. The goals of JIA treatment are to control active inflammation and to prevent long-term damage. Poorly controlled JIA can result in growth disturbances, loss of range of motion of the joints, and blindness from chronic eye inflammation.
Most children with JSpA fall into the categories of enthesitis related arthritis (ERA), psoriatic arthritis, and undifferentiated arthritis. Editor’s note: These three conditions fall under both the JIA and JSpA classifications. (See above diagram)

- Enthesitis-related arthritis is diagnosed in children who have arthritis and enthesitis or either arthritis or enthesitis plus at least one of the following: lower back pain or sacroiliac tenderness, HLA-B27 positivity, a parent with a history of SpA, onset of arthritis in a male older than six years, or acute and painful eye inflammation.

- Children with psoriatic arthritis have arthritis and psoriasis or arthritis plus at least two of the following three characteristics: nail pitting or onycholysis (separation of the nail from the nailbed), sausage-like swelling of the fingers or toes, or a parent with psoriasis.

- Children who are categorized as having undifferentiated arthritis don’t fulfill any of the JSpA or JIA categories, or fulfill criteria of more than one category.

Other conditions not explicitly accounted for in the ILAR JIA classification but that are traditionally thought of as JSpA include: juvenile ankylosing spondylitis (JAS), reactive arthritis, and inflammatory bowel disease associated arthritis.

- JAS is AS that starts prior to age 16; 10-20% of adults with AS have symptom onset during childhood.

- Reactive arthritis is arthritis that occurs following a gastrointestinal infection; reactive arthritis can be a singular event or may progress to chronic JSpA. The classic triad of painful urination, painful eyes, and arthritis seen in adults is much less common in children.

- Inflammatory bowel disease associated arthritis is also considered part of the SpA group of diseases; as many as one-quarter of children and adolescents with inflammatory bowel disease develop arthritis.

Other categories of JIA not considered under the umbrella of JSpA include: Oligoarthritis (arthritis in four or fewer joints); rheumatoid factor positive and rheumatoid factor negative polyarticular arthritis; (arthritis in five or more joints in the presence or absence of rheumatoid factor); and systemic arthritis (arthritis with a characteristic fever pattern and salmon colored rash, often associated with full body inflammation).

JIA categories (non overlapping)

1. Oligoarticular
2. Polyarticular RF+
3. Polyarticular RF-
4. Psoriatic arthritis *
5. Enthesitis related arthritis *
6. Systemic arthritis
7. Undifferentiated arthritis *

* Included under umbrella term JSpA

Children and adolescents with JSpA tend to have more peripheral arthritis than adults with SpA. The arthritis typically involves joints in the lower extremities in an asymmetric fashion. The presence of hip arthritis and arthritis of the small joints of the mid-foot are highly suggestive of the diagnosis. As with adult SpA, children can also develop arthritis of the lower back (sacroiliitis) or spine. Prior studies report that as many as two-thirds of children with JSpA develop arthritis of the lower back or spine within 10 years of diagnosis. HLA-B27 positivity in these children increases the likelihood of developing lower back arthritis, though many children who are HLA-B27 positive never develop JSpA. The presence of lower back pain is not as helpful in JSpA as in adults with SpA in signaling the onset of sacroiliitis.

Current treatment recommendations for children with JSpA are based on those developed for adults with SpA and for all
categories of JIA. The 2011 American College of Rheumatology Treatment recommendations for juvenile arthritis group children with JSpA with the other JIA categories. Treatment suggestions are based primarily upon the number of active joints. Methotrexate and sulfasalazine are two commonly used drugs that have established efficacy for peripheral arthritis in children. Anti-tumor necrosis factor (anti-TNF) medications also have demonstrated efficacy in children with JSpA for peripheral arthritis and enthesitis. Additionally, anti-TNF medications are effective in the symptomatic treatment of lower back arthritis; the efficacy for halting progression of structural damage is more controversial. It remains unclear which patients need anti-TNF medications as not all patients have progressive disease. New and promising drugs that are being evaluated in adults with SpA, including ustekinumab, secukinumab, and apremilast, have not yet been evaluated in children but remain on the horizon.

We still have a long way to go to understand the causes and optimal treatment of JSpA. Additional studies on the evolution of disease (particularly lower back arthritis) and optimal therapy for peripheral and spinal disease in children and adolescents are greatly needed in order to improve both short and long-term outcomes in this condition.

References

MONTHLY GIVING IS S-M-A-R-T!

One of the most effective ways to support SAA is by joining the “Spondylitis Monthly Automatic Rewards Team” (SMART) Program. It’s a safe, secure and convenient way to put more of your money to work advancing the spondylitis community’s shared mission of eradicating this disease and making life easier until we do. All you need to do is specify a monthly amount and SAA will automatically deduct the contribution from your credit card. At the end of the year, we’ll send you a summary of your giving and a tax receipt. Your dependable monthly gift of $100, $50, $25, $15 or even $10 will boost the impact of your SAA membership gift many times over.

One significant benefit to this program is that it lowers SAA’s fundraising costs. SAA’s fundraising program is already one of the most efficient in the nation (as evidenced by Charity Navigator’s 4-Star rating), but making it even more streamlined is in everybody’s best interest. Postage rates have gone up, as have printing costs. An automatic electronic donation means that your gift can be put to work immediately funding the programs and services you’ve come to rely upon. And, you get fewer letters in your mailbox.

As a member of the SMART Givers Program, your support will help sustain SAA’s worldwide leadership role in promoting early diagnosis, dispensing information about effective treatment, and hastening the cure.

For more than 30 years, SAA has been a dependable, reliable source of information, education, programs and services. Having a dependable, reliable source of funding will enable us to better allocate resources and plan for future needs. By joining the SMART Givers program, you can help to ensure that SAA is able to move forward with opportunities as they arise, rather than having to shelve groundbreaking programs until funding can be secured.

To sign up for the SMART Givers Program, go to www.spondylitis.org/monthly or contact Helene Hart at 800-777-8189, ext. 229 or at hhart@spondylitis.org. Becoming a SMART Giver is a great way to support the Spondylitis Association: you’ll receive fewer renewal notices, get a tax credit for the full amount paid at the end of the calendar year, and you may change or cancel your pledge at any time.

Go Monthly and Go SMART!
When It’s Not Growing Pains: Journey From The Trampoline To Patient Advocacy

By Seth Ginsberg

Seth Ginsberg is the Co-Founder and President of CreakyJoints – a multifaceted online community for people with all forms of arthritis. This is his story about coming to terms with juvenile — and now adult — spondyloarthritis, and how doing so ignited his passion in life – helping others.
I was 12 years old when I first started noticing symptoms of arthritis. Seventh grade was a busy time when I was very active and played in as many little league games as a boy could. At that time I was in two different little leagues – one through school, and another, more competitive league through the county. I would leave school games around the sixth inning and go to the second game; the pre-pubescent version of a sports all-star.

It was during a summer camp trip one rainy day, between the 7th and 8th grade, that we visited an indoor gymnasium with huge trampolines. I vividly remember the pain caused by those trampolines, wondering why everything from my back to my hips to my knees started to hurt. Thinking nothing of it, I kept going, only to find running around the field the next day equally uncomfortable.

Having an overprotective mother is one thing, but having one who has arthritis of her own and can recognize it in others is another, compressing the time between symptoms and diagnosis to literally a week. A lot of people aren’t as lucky, and unfortunately a lot of children experience similar symptoms that are chalked up to “growing pains” – a common issue for a lot of active kids.

It was the autumn of 8th grade when I was diagnosed with juvenile undifferentiated spondyloarthritis by a doctor named Thomas Lehman at the Hospital for Special Surgery. I did not test positive for HLA-B27, but the tell-tale sign was when he laid me down and banged on my heels, causing my hips to cry out in pain (in hindsight, making the trampoline the best foreshadow).

Treatment started off slowly, and steadily. As a boy I remember being unable to swallow pills, so liquid doses of anti-inflammatory medications were prescribed. Worst tasting medicine in the world! I experimented with many techniques, like holding my nose, or pretending I was a grown up drinking a shot of alcohol (ironic side note – many years later, when I did try tequila for the first time with a group of friends who couldn’t stand the taste, I laughed and said “this is nothing compared to what I used to drink!”).

For the next handful of years, there were many ups and downs. “Good days and bad days” was what I would endure, which conditioned me to enjoy the good days, and manage through the bad days. We escalated medications throughout the years, changing around NSAIDs, and adding sulfasalazine. Then there were the peptic ulcers and other intestinal side effects, which brought about more medications specifically for the stomach. It was a hassle at the time, having to take a whole bunch of medicine twice, sometimes three times a day – this one before that one, spaced out between this meal and for that reason. But it was something I grew accustomed to at a very early age, and always took my medicine very seriously; because if I messed up or missed a few doses, I was nearly guaranteed a really bad day. So I did what worked for me: staying diligent with things like packing the right doses, getting refills in time, and remaining positive.

I am happy to say that the past few years have been very good, physically and emotionally. After so many years of managing my arthritis, my pain threshold has calibrated very well, so it’s for the worst of the bad days that I reserve the strongest treatments. My aches and pains come to haunt me usually at the worst time: my wedding week, while helping a friend in need, or after being stranded somewhere – but that’s par for the course. Some would use the word “remission” to describe this state, but I prefer “truce” because my arthritis is never really gone. It rears its ugly head at the worst times, which is why I like that word. Having a wonderfully supportive and understanding spouse makes it a lot easier, because she goes easy on me when I hit a rough patch.

I have a deal with my arthritis: I get plenty of rest, eat healthy, stretch regularly, and work out in low impact ways as often as possible, and it (arthritis) sits quietly on the sidelines.

CreakyJoints was the natural extension of how good I felt when I helped others. It was during the third week of my freshman year at Babson College, when, at 3 AM one sleepless night, I felt vulnerable and confused. Here I was, 205 miles away from anyone who understood what I was or had been going through, all alone in a bunk bed, and yet knowing...
inherently that there are so many others out there with similar experiences. “There ought to be a way to bring people together, in a positive environment, where we can share our strength and experiences with each other.” was the opening line in an email I sent to my high school internship boss back in New York, entrepreneur Louis Tharp. He wrote back that very morning “I would like to become a social entrepreneur, to help others. Why don’t we start something together?” That afternoon, we had the framework for CreakyJoints mapped out, with the aim of creating an irreverent, humorous, and supportive community for everyone out there going through something similar.

The challenge we faced in the beginning was building a site that would appeal to both the young (like me) and the young-at-heart (hopefully everyone). Even though I was a kid, I have always been an old soul, and I knew that humor would help, as would a healthy dose of perspective, since “there’s always worse.”

CreakyJoints today is part of the Global Healthy Living Foundation, the 501(c)3 nonprofit parent organization. We are a community for patients, and by patients. The community has four areas of focus: education, support, advocacy and patient-centered research.

**Education** – understanding our conditions, and accessing information from world renowned doctors to help everyone make better decisions.

**Support** – sharing strength and experience, to keep a positive mental outlook, because we’ve all “been there.”

**Advocacy** – because accessing the care we deserve is never a given, and we must overcome barriers both as a community and individually.

**And Patient-Centered Research**, the most exciting component and next frontier for CreakyJoints. This is the hunt for the truth about what we’re living with, and helping the world understand us better, through patient reported outcomes research.

~ Advocacy And Seth’s 50 State Network ~

Advocacy is very important to us. We appreciate that when you need to fight for access to care, it is usually at the time when you’re least able to fight — because you’re not feeling well! This is why we are always proactively working to improve access to care. Advocacy means education; it is helping people understand their rights as patients, and helping policymakers, regulators, and the public understand our needs as patients. Because so much of our healthcare system is governed at the state level, and each state differs slightly in its rules and regulations, we focus on each state individually.

We created Seth’s 50 State Network to allow people the opportunity to get involved locally, within their home state. Through this program we train our “Super Advocates” to educate their state legislators and regulators about life with arthritis, and the challenges we face accessing care.

> There ought to be a way to bring people together, in a positive environment, where we can share our strength and experiences with each other.”

Super Advocates don’t require an advanced degree! To become a Super Advocate, one must have a passion to help others and a willingness to learn about the process to do so. Through the 50 State Network, we allow people to advocate at the level and in the way they feel most comfortable.

~ The Road & Challenges Ahead ~

The challenge we face today, in our 16th year, is meeting the needs of such a robust community, with so many people living with so many forms of arthritis. Their experiences are so varied, and the needs diverse. Some are anxious after a new diagnosis. Others feel vulnerable because they don’t understand what’s happening to them. And still others are in need of encouragement or support because they’re being denied the care they need and deserve. Thankfully, technology can help, allowing us to engineer a dynamic website that is customized to meet these needs.


We thank Seth for taking the time to share his story with our readers, and for the tireless work he does on behalf of everyone affected by rheumatic disease. He and the rest of the team at CreakyJoints are paving the way for a brighter future for those with SpA and all other forms of arthritis.
I would like to start by introducing myself. My name is Jacquie Gregor and I was diagnosed with Ankylosing Spondylitis in 2007. As you all know, the pain of AS can be relentless, and I can say there has never been a day without pain for me. Along with the pain come many sleepless nights, days I feel I cannot go on, and so forth. I have found that for me, meditation works well to balance my mind and bring me back to a state of “peace” – with a mind that can cope with whatever lies ahead for the day or the minute.

Recently, I broke my foot for the fifth time in three years. It is through meditation that I am able to calm my mind enough to even talk to medical professionals or family members. I don’t claim to maintain a mind of peace and happiness all of the time; I can say though that I do maintain this mind frame most of the time.

I was in the hospital this past April and the Hospitalist* told me my nickname was “The Peaceful Warrior.” I can only attribute this comment to my meditation practice. I tell my doctors that pain does not mean suffering. I think that if I didn’t watch my mind carefully with meditation I would suffer greatly. Instead, I have the pain that you understand and the awful restless nights.

I have listed below some of the benefits of meditation, as well as few simple meditations (with the help of my meditation teacher). I hope you find them helpful.

The simplest kind of meditation is breathing meditation. Begin by finding a comfortable seated position. If possible, try not to slouch. Sit with your back straight but relaxed. This helps to keep the mind alert. It’s fine if your head tilts forward a bit, just naturally. Then lower or close your eyes, whichever is more comfortable for you.

Begin by making a mental scan through the body, from the top of the head to the bottom of the feet, and just notice and let go of any tension or discomfort, as best you can. Sit for a minute with your body completely relaxed. Then you can begin to relax your mind, which is usually very busy jumping from one thought or object to another. To quiet the mind, focus only on one thing – the sensation of your breathing. Try to find that place in the nostrils where you can feel the sensation of air.

“I have found that for me, meditation works well to balance my mind and bring me back to a state of “peace” – with a mind that can cope with whatever lies ahead for the day or the minute.”
entering and leaving the body. For a few minutes (five to ten is plenty), try to keep your mind only on that sensation, noticing how the air feels cool and dry as you breathe in, and warm and moist as you breath out.

Any time your mind wanders, or other thoughts arise, simply note this has happened and each time gently bring your mind back to the sensation of the breath in the nostrils. Let yourself enjoy a few minutes of a peaceful, undistracted mind.

Don’t worry if for some time (weeks, even) your mind wanders frequently. With no pushing, just keep bringing the mind back to the breath. If you are feeling pain, let it mix with your breath, feeling yourself breathing it out in the form of black smoke, dissolving away into the space in front of you. When you breathe in, you can imagine breathing in white healing light - positive energy filling your body and mind.

Using Meditation to Increase Patience.
Meditation is not just for relaxation, we can actually use it to transform our minds. For example, we can train ourselves to transform anger or irritation into patience. How does this meditation work?

First, pick something that makes you angry. Then start by contemplating the faults of anger - the mind we want to reduce or eliminate. Anger is bad for our immune system, leading to illness over time. When we are angry, our thinking processes are affected and we don’t react in the most beneficial ways. We aren’t pleasant to be around and we take our frustration out on others. It destroys our own happiness and peace of mind, and is a serious obstacle to spiritual development.

Having contemplated these faults, we then contemplate the benefits of staying patient in this situation. They are usually the opposite - better health, better reasoning, more kindness towards others, more happiness and spiritual progress for ourselves, etc. This should give rise to a determination, “I really wish to remain patient in this situation in the future.”

At this point, stop contemplating and just hold this determination as the object of meditation for five to ten minutes. If your mind wanders during this time, just notice this and gently bring it back to your determination. If you do this regularly, you will find yourself remembering your determination outside of meditation. Then, it will gradually become your new way of thinking.

Using Meditation to Develop Compassion.
When we are in pain, our mind tends to become very self-focused, and so ‘my pain’ becomes the most important suffering there is. If we are able to reduce this strong focus on our own problems, suffering can begin to reduce. We can understand this if we think of a situation where a mother is badly hurt, say, in a car accident. But if she hears her child crying in the back seat and realizes he is also badly hurt, her focus shifts to getting help for the child. Until the ambulance comes and her child is taken care of, she forgets her own pain.

This meditation, called “Taking and Giving” or “Tonglen” in the Buddhist tradition where it first developed, works similarly to the breathing meditation above. First, think about all the people in the world who are suffering (or all those suffering from the same disease, or even just one person you wish you could help). Develop a strong wish that they could be free from suffering. Then, as you breathe in, imagine that you are drawing away all their suffering in the form of black smoke. Actually draw it down into your heart where it immediately destroys any of your own self-concern, and you feel you have successfully removed their suffering. Don’t worry about whether you actually have any healing abilities. Someday, through creating these good causes, you may actually develop ability to help others directly in this way. Just use the power of your imagination to strongly believe they are relieved of their suffering.

Then as you breathe out, send them white healing light, bringing them peace and happiness. This meditation increases our compassion, giving our own suffering spiritual meaning. And there are countless stories of people whose condition improved over time as a result of moving their mind to others and off of themselves.

See News story “Add nature, art and religion to life’s anti-inflammatories.”

Meditation is one of the tools that should be in the arsenal of anyone struggling with suffering. It is bad enough that we have to deal with physical pain; mental suffering makes everything worse. If we can reduce or control the negative minds that can accompany chronic physical pain, not only would we prevent adding mental suffering on top of our physical pain, but we may actually help to reduce the sensation of pain itself.

*Hospitalist is a physician who specializes in the practice of hospital medicine. ~Society of Hospital Medicine

Jacquie Gregor is the leader of the Tucson Spondylitis Educational Support Group. She has studied meditation for over 12 years. Jacquie sought meditation when doctors could not find the reason for her breathing difficulty and severe pain issues. Jacquie used meditation to calm her mind while dealing with these problems. She uses it today to help with pain as well as maintaining a calm and balanced mind. Jacquie also teaches meditation in Tucson, AZ
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