

SPONDYLITIS PLUS

Summer 2014

Raising Awareness Of
Spondyloarthritis At PriMed:
Primary Care Physician
Conference In Anaheim, CA

The Faces of
Ankylosing Spondylitis:
Your AS Stories



**Spondylitis
Association
of America**



SPONDYLITIS ASSOCIATION OF AMERICA

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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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ON POINT



Dear SAA Members & Friends,

I'd like to break from the style of our usual "On Point" column here to share an open letter I recently had cause to write. We learned that the American College of Rheumatology had created a video to raise awareness of rheumatic diseases. As we watched the video we were dismayed to find that while other, less common forms of arthritis were discussed in detail, spondyloarthritis was completely left out of its awareness efforts. We had to speak out. We posted the below letter on our website in response to the omission, publically sharing it with ACR. I include it here to make sure you are aware of the issue, and to give you a chance to share your thoughts as well. If you'd like to read ACR's initial response, please see the news item posted in our news section: <http://www.spondylitis.org/press>

There's a problem when the preeminent rheumatology organization in the country - the American College of Rheumatology (ACR) - omits spondyloarthritis (SpA) from its new rheumatic diseases awareness video.

We're flabbergasted that spondyloarthritis was not even mentioned. At SAA, we're collaborating with ACR on new treatment guidelines for ankylosing spondylitis and related conditions, and yet ACR somehow overlooked this group of diseases in their new "Raising Awareness: Rheumatic Diseases in America" video?

World Ankylosing Spondylitis Day was on May 3rd this year. The website where the video is hosted boasts, "May is a big month for the rheumatic disease community! It is Arthritis Awareness Month, Lupus Awareness Month and Vasculitis Awareness Month, and includes World Autoimmune Arthritis Day and Gout Awareness Day." Even World AS Day was left out. The website continues, "...we thought May was the perfect time to launch a video that helps to explain the numbers of people living with rheumatic disease, the diseases themselves, the impact of these diseases and the role of rheumatologists in their treatment." Excellent sentiments, but with the glaring omission of SpA.

By focusing on the 1.3 million people with rheumatoid arthritis and the estimated 1.5 million with lupus, the video marginalized the 2.4 - 2.7 million people living with spondyloarthritis.

Delayed diagnosis is an immense problem for ankylosing spondylitis and other forms of spondyloarthritis. As reported in the medical literature, the average diagnostic delay for ankylosing spondylitis is 7 - 10 years in the US. One of the factors contributing to that delay is the fact that spondyloarthritis though not rare remains largely unknown... and this extends to the physician community as well.

We need to work together to fill this gaping hole in awareness and recognition of spondyloarthritis. We expect more from ACR in the future - and will work with them - so that the 2.7 million who have SpA can, and will, be better served.

~Laurie M. Savage
Executive Director, SAA

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AS In Women

I would like to say how much I appreciate it that the information you have on AS is accurate and helpful. I had my flare of AS when I was 19 years old. It wasn't until I was in my late 20s that I was finally diagnosed. For many years, there was no accurate information on it anywhere. All the online information stated that women usually have mild cases, but mine was not.

In researching the disease, it was a great relief to see that it no longer says that when it does affect women it's usually mild. I lived without a diagnosis for a decade and even today still encounter physicians wrongly assuming that it is mild in women. I hope that your work will continue to help people. I have met two other women who have it, and all of us have suffered greatly, which was compounded by these false assumptions.

Thank you.

~BESS T., Alabama

Editor's note: Thank you, Bess. We are glad we could help. We continue to do our best to raise awareness within the medical community, and to provide the latest information to health care workers whenever we are able. See our article regarding the "PriMed" convention on page 4 for one example of our efforts.

The "Human Side" Of Spondyloarthritis

Well, World AS Day [May 3, 2014] is now officially over. I wanted to take a moment and say thank you for all that you do for the AS community. I want to personally thank you for believing in me and my vision of Faces of AS. I want to thank you for always taking time out of your busy day and listening to my ideas. Thank you so much for always seeing the HUMAN side of this disease and not dismissing the most important issue this disease causes, and that is lack of self worth. Thank you for always having our backs in our endeavors to make a difference no matter how

large or small it may be. Thank you doesn't seem to be enough to honestly convey the gratitude I feel for all that you do.

~COOKIE H., Texas

Editor's note: Thank you for your kind words, Cookie. You can read three more "Faces of AS" stories starting on page 6 of this issue.

LETTERS TO THE EDITOR

Question, comment or concern? We want to hear from you!

Please send letters to:
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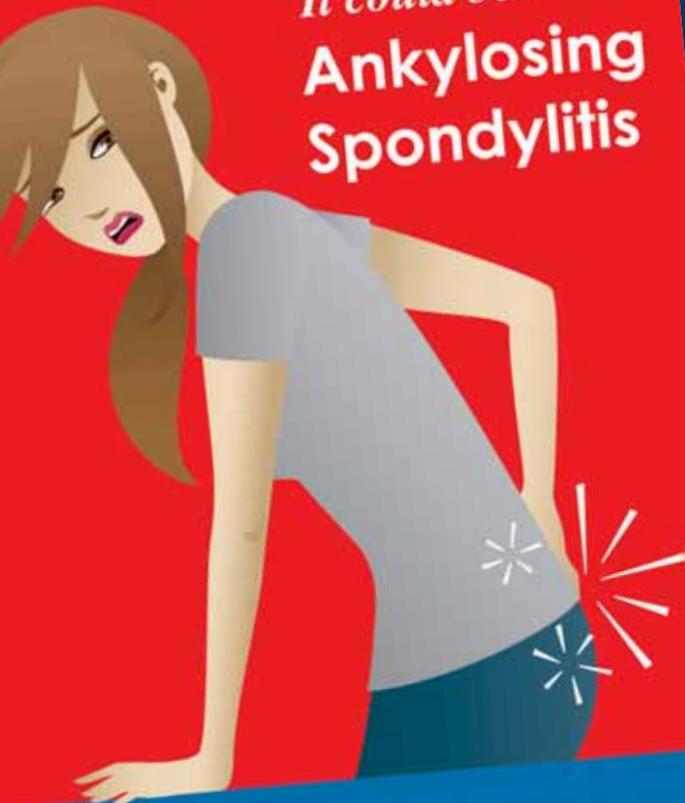
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Spondyloarthritis
Association
of America™
www.StopAS.org

Has your patient had
BACK PAIN for **MORE**
HAN 3 MONTHS ?

Learn about:
Inflammatory back pain
Mechanical back pain

It could be...
**Ankylosing
Spondylitis**



Raising Awareness Of Ankylosing Spondylitis At PriMed: Primary Care Physician Conference In Anaheim, CA

In March of this year, SAA had the opportunity to exhibit at a medical conference for Primary Care Physicians (PCPs). The Pri-Med West Annual Conference took place in Anaheim, CA with over 7,300 Primary Care Physicians and other medical professionals in attendance. As this was our first time exhibiting for this population we weren't sure how we would be received. How much interest would there be in speaking with us? How do we grab their attention with the many competing disease states PCPs must screen for and diagnose? We designed new display banners, we created new ankylosing spondylitis screening brochures for PCPs, and we streamlined our message: "Has your Patient had Back Pain for More Than 3 Months? It could be Spondylitis." And it worked.

“How do I diagnose this?”
“Is there a screening test?”

“How do I treat it?”

“I have a patient who may have this!”

From an OBGYN: “Obviously I only see women so this isn't for me...”

“I didn't realize there was a juvenile form of Spondylitis...”

“Oh yes SPONDYLOSIS, it’s important to know about....”

“Iritis is one of the signs? Hmm....”

“How do I diagnose it?”

“How do I diagnose it?”

“How do I diagnose it?” ”

We discussed blood work and that sometimes it can be normal, HLA-B27 and how it’s not a diagnostic test, important signs and symptoms, patient and family history, the delay in seeing x-ray changes, other areas affected in addition to the spine, and the importance of referring to a rheumatologist at the suspicion of spondyloarthritis.

By the end of our two day exhibiting experience we had given away nearly all of our screening and educational brochures, every single *Spondylitis Plus* News Magazine, all of our diagnostic criteria flyers, and were exhilarated to be reaching so many doctors.

While the majority of those we spoke with had never diagnosed or even seen anyone with spondylitis and wanted screening information, there were also those who were currently treating patients with AS.

““I have two AS patients and wanted to see if you had anything for them.”

“I didn’t know there was an association for this.” ”
 “Can I refer my AS patients to you?” ”

And then there was, “Thank you for being here. <pause> There’s a patient I have to call. I think she has this.”

We were delighted to learn that among the conference sessions available to attendees were two that discussed Spondyloarthritis. There was an “Approach to Rheumatologic Diagnosis” session, and also a “Recognizing Inflammatory Back Pain” session, which was actually a ticketed event and one that proved popular enough to sell out quickly.

Perhaps the most apt quote of the event was when a Primary Care doctor saw our booth right after leaving the Inflammatory Back Pain talk and approached us saying, “Wow. This is really big this year.”

Indeed, doctor. As it should be every year.



FACES OF ANKYLOSING SPONDYLITIS:



Melissa

MELISSA

My name is Melissa and I am 24. I have suffered from AS for an estimated five years, though I was only diagnosed two years ago.

Before my diagnosis I was referred to a chiropractor, who spent an hour each session clicking the bones in my back; something that I later found out could have done far more harm than help. After suffering from a sciatica attack which lasted four months and stopped me from walking properly, I went to the doctor and was referred to the hospital for tests. After x-rays, MRIs, blood and urine samples I was finally diagnosed with AS and prescribed Ibuprofen and Physiotherapy. I attended Physio every day for a month, however had to leave the program early to embark on my first master's degree. I am only now being referred to a rheumatologist as my files were apparently mixed up, but hey, two years late is better than never!

When I was first diagnosed with AS I felt incredibly relieved to finally have an answer for so much pain, however on realizing how complex and potentially awful the answer was, I became quite bitter and resentful. It took me a long time to find happiness again knowing that I would find it very difficult to do all of the things a normal girl in her twenties could do. Watching my friends pull off extravagant dance moves and sit cross-legged on the floor drove me to despair, knowing things as little as running up the stairs were virtually impossible for me. Hobbling up one step at a time and trying to find the comfiest looking chair in the pub to watch my friends dance became my depressing lot in life

for months. However I finally began to accept that AS was real, and I had it, and I realized slowly that moping would not change that. I finally overcame the depression, admitted that I was never much of a dancer anyway, and promised myself that I would start living again.

I'm now feeling much better within myself. Through exercise and various tricks of the trade my movement has improved and pain has reduced. I've just completed my second master's degree and currently work in a school, which is I feel a perfect career choice given the lack of strenuous physical activity required to complete my job. On an average week I complete various stretching activities, lie prone for at least an hour, go to bed every evening with hot water bottles pressed to my back, and attempt to swim or go to the gym as often as possible. In the new year I intend to create a monthly video blog regarding living with AS in the hope that it will bring recognition and help other sufferers.

There is not a day that goes by that I am not in some form of physical pain, but there is also not a day that goes by that I do not overcome it. AS is a horrible affliction, one that creates an old temperament in a young body, that shackles movement to pain and requires constant optimism to achieve even basic tasks. AS has made me stronger than I ever thought possible, it has given me the determination to succeed and is responsible for my stubborn optimism; and so in the midst of all the pain and ache and stiffness, there is always some light to be found in the dark.

FACES OF ANKYLOSING SPONDYLITIS:

Kevin Stevenson

KEVIN



I began experiencing symptoms around the age of 23. Although I had periodically experienced symptoms

prior to then, my first distinct memory was when my roommate, some friends and myself went to the movies. I had been experiencing what I would come to learn was SI nerve pain. Following the movie my roommate dropped me off at the duplex we lived in. He drove off as I limped to the front door in the rain. When I got to the 3 or 4 steps to the door I collapsed in pain. After some time I was able to drag myself up the steps and into the house where I laid just inside the front door for over an hour from exhaustion.

Shortly after that incident I saw the first of what would be several doctors and was told everything from “we all get old” to “it’s all in your head”. After a while I started to believe them and learned to live with it. Almost ten years later I met my wife Kelli. Even though I was willing to give up she wasn’t. She just kept saying, “We need to get you in front of the right people.” After another 10 years we finally did when as a last resort I was sent to a Rheumatologist.

At my first visit to the Rheumatologist he did some basic movement tests and went over all of my previous x-rays, MRIs, etc. At that time he didn’t think there was

anything within his realm that was wrong and didn’t feel he would be of much help. However, just in case, he was going to do a full blood workup. He told me to expect to hear back in a few days that everything was ok.

A few days later I heard back, but it wasn’t the news I expected. It was his nurse saying he wanted to see me and when could I come in. I was back in front of the doctor within the week and he was explaining this disease I had never heard of called Ankylosing Spondylitis and handing me a pamphlet on Remicade infusions. Of course I was in shock to say the least.

I was sent for a second opinion that went much faster than the first. The second rheumatologist reviewed my information and asked why the first thought there was a need for his opinion. In his opinion it was a no brainer and he didn’t need to see the films.

That diagnosis was in the Fall of 2012. Since that time daily life continues to be a struggle, but with the support of my wonderful family and a few very dear friends, I’ve been able to continue doing most of the things I enjoy, albeit not as often or without consequence.

As I do the best I can with my two boys (8 and 5) I can’t help but worry whether or not they’ll inherit AS as well.

Kevin Stevenson
South Carolina

FACES OF ANKYLOSING SPONDYLITIS:

Amy Hicks



AMY

I first began having pain in my very early 20s. I went to my primary doctor, who told me it was a pulled muscle, gave me pain pills and sent me on my way with a “come see me in a few weeks if it still bothers you”. I didn’t last a few weeks: I was back in her office by the end of that same week. She then decided to send me for blood work and an x-ray. Results came back and, besides a vitamin D deficiency, everything was normal. I left the appointment with no more information than I had gone in with, and another pain pill prescription.

I decided to give her one more chance before I sought another opinion. A month after I had originally gone to seek help I was back in her office for the final time. She told me to try physical therapy to see if that could possibly help. I reluctantly agreed and off I went for 2 months of physical therapy. I was attending 3 sessions of hour-long treatments a week for 8 weeks. I do admit that it helped, but not as much as it probably should have. So after the treatment was finished and I was better but still hurting daily I sought out a different doctor in the same practice. Unfortunately he turned out to be worse than she had been.

At this point I was about 3-4 months into my “condition” and no one had given me any useful

information. Doc #2 wanted to send me for MORE physical therapy! I asked why more when the first round did me little to no good...He had no answer for that question. So he handed me yet another round of pain pills and an MRI. A few weeks later I returned for the results and got the first “there’s nothing wrong with you” speech. I couldn’t say too much since I had no clue what could be wrong with me and I trusted that these two medical professionals knew what they were talking about.

So I suffered, for the most part in silence, for the next 5 long years until I woke up one day and couldn’t walk. Each time I tried to put weight on my legs they collapsed underneath me. I was scared out of my mind and went to the ER. More x-rays, scans, blood work and a very insulting ER doctor who was the first to tell me it was in my head and I was making it up. Still having no answers I thought that I was going nuts. I again sucked up the pain and frustration for a few more years.

From all the pain and aggravation and stress of life plus my physical problems I went into depression, and sought the same primary doctor I had seen for a second opinion on my back pain. I explained my symptoms and the fact that I was always exhausted and cried frequently to cope with my stress. He was so kind as to inform me that if he had a magic pill for every person he saw with my problems he would be writing ‘scrips out all day long....

I had hit my ceiling at that point. I left that practice and went for a third opinion for my back and a second opinion for my depression. I was very lucky and extremely grateful to have found my current primary care physician. She spent 2 hours talking with me and looking at tests and scans and x-rays. She asked me to go for one simple blood test: hla-b27. I came back positive for this marker. She called me with the results and suggested I seek out a rheumatologist.

She was kind enough to recommend a group practice. I went in and saw the first of 2 rheumatologists at this group. The first one informed me that my hla-b27 status had nothing to do with what I was seeing her for. She told me I have arthritis and that's it. She prescribed methotrexate and I started taking it. I had taken it for about a month when my hair started to fall out and I noticed no improvement.

It was at this point that I lost my job, and so with no insurance had to halt all treatment as I couldn't afford to continue. Once I had insurance again I went back to see the rheumatologist to resume my treatment. However she no longer wanted to do the methotrexate. I got sent

for x-rays and MRI imaging and when I went back for a follow up for the results, I received her "it's in your head, there's nothing wrong with you" diagnosis.

I was beyond frustrated and returned to my primary care physician. She recommended a different rheumatologist who had recently joined the same group. I went in again, prepared for the same treatment. However I was pleasantly surprised when he went through all of my records and came out with "have you ever heard of ankylosing spondylitis?" To which I, of course, said no. He proceeded to tell me about AS, and answered my questions. He also immediately started a course of treatment which included Humira and Mobic.

I've been officially diagnosed with AS for 18 months now and have been taking my medication as directed. I feel a million times better than I had since the pain reared its ugly head. I'm very thankful for all the support and advice I have received from all of my fellow AS warriors!!

Amy Hicks
Pennsylvania

Editor's Note: "Faces of Ankylosing Spondylitis" is a website dedicated entirely to the stories of those with AS. As of this writing, over 1300 stories have been published on the site, and more are being added regularly. Men, women, and children from numerous countries and continents have shared their stories and photos, and we are pleased to share a few of them here, with our gratitude to all. You can read all of the stories on the Faces of AS Site, as well as read a selection of the stories on SAA's site, StopAs.org/faces.

The woman behind "Faces of AS", SAA member Cookie Hopper, explains her reason for starting the website: *"It was important for me to do this, not for myself, but for each one of the Faces on this site and those who are still unknown. I wanted to show the reality of this disease and the courage it takes to live our lives. I wanted to honor those who have Ankylosing Spondylitis, who I admire and respect."*

From the Desk of the Director of Annual Giving

Like most nonprofit organizations, the Spondylitis Association relies on the generosity of its supporters to raise the critical funds needed to provide the programs and services that so many have come to rely on. *Unlike* some organizations, SAA receives no government money and while some special projects are funded through corporate or foundation grants, the majority of our operating budget is the direct result of individual donors like you.

Another thing that sets us apart from many other nonprofits is that our donated funds come from the very people we serve. In many ways this is what ties the spondylitis community together as a whole – there is no disconnect between the people supporting the programs and the people benefiting from them. Every donor has a stake in the success of the projects they help to fund.

Simply put, we're in this together and *together we can make a difference.*

Here are just a few examples of the ongoing work that your generosity makes possible:

SAA Leads the Quest for the Cure

- SAA is seeding a national patient registry in ankylosing spondylitis. By combining three existing patient databases that have been used in research, the composite database will look at thousands — and potentially tens of thousands — of patients, and be able to track health trends, disease severity over time, age, race and many other factors to improve understanding of the disease.

- The American College of Rheumatology (ACR), the Spondyloarthritis Research and Treatment Network (SPARTAN) and the Spondylitis Association of America (SAA) have partnered to develop new ankylosing spondylitis and axial spondyloarthritis treatment guidelines, to be published in coming months.



SAA Educates the Medical Community

- In September 2014, SAA will present a CME Training Program for Radiologists in the Early Detection of Spondyloarthritis through MRI scan interpretation. This program will educate radiologists to recognize early inflammatory changes in bone marrow and soft tissue at symptom onset, leading to earlier and more accurate diagnoses.



SAA Advocates for Patients' Rights

- As an active and vocal member of the *Coalition for Accessible Treatments*, SAA is championing the fight to do away with exorbitant co-payments and other inhibitive cost-sharing requirements currently imposed on specialty tier prescription medications (such as TNF inhibitors) - also known as specialty tier pricing. By advocating for the passage of **H.R. 460, the Patients' Access to Treatments Act of 2013**, we seek to strike down the discriminatory practice of imposing an unfair economic burden that delays treatment, compromises the ability of physicians to prescribe essential medications, increases prescription medication non-adherence, and increases the risk for avoidable hospitalizations, medical complications and diminishing quality of life.



I hope you believe, *as I do*, that it's important to continue to make advances in the areas of scientific research, physician education, and patient advocacy. If so, please consider taking action today.

We recently mailed our Spring Appeal letter asking for your support for these and other critical programs. I hope you responded generously. Whether you did or not, won't you consider using the enclosed envelope to show your support for these projects as well as SAA's other important works? Any amount, or even a note of encouragement, will tell us that we're on the right track and are using your donated funds in ways you approve of.

As the staff member responsible for raising funds from individual donors, I, of course, hope the envelopes are returned with gifts enclosed; but I also welcome your suggestions and opinions. This is *YOUR* organization. Whether or not you can make a donation right now, use the envelope to tell us what your priorities are. You are an active participant, a full partner, a member of the community, and your voice can and will be heard. We're listening.

I hope to hear from you soon.

Diann Peterson
Director of Annual Giving

ANKYLOSING SPONDYLITIS AWARENESS MONTH & WORLD AS DAY 2014 RECAP



SAA'S 2014 SPONDYLITIS AWARENESS PROJECT: REACHING THE PRIMARY CARE PHYSICIANS

Earlier this year SAA exhibited at a conference for Primary Care Physicians. You can read about our experience at the conference on page 4, but one thing was abundantly clear: there is an urgent need to raise more awareness among PCPs. As the medical professionals people turn to first, PCPs hold a big part of the key to earlier diagnosis, and we need them to have spondylitis firmly on their radar.

To this end, we created an AS screening brochure with information on AS signs and symptoms, blood work & x-rays, and other important points to look for in patients with inflammatory back pain. The brochure was a hit at our PCP conference, and we think it will be a hit with your PCP as well.

Will you get involved and help us reach more Primary Care Physicians? Please sign up to deliver these specialized brochures to YOUR physicians, to your loved ones' physicians; share this project and ask family and friends to do the same. We need your help, and so do the thousands still searching for an answer to their pain. Get involved today. Please send an email to info@spondylitis.org with the subject "PCP Brochure Request" for information and to order brochures.





WORLD AS DAY

In 2010 the Ankylosing Spondylitis International Federation (ASIF) designated the first Saturday in May* as “World Ankylosing Spondylitis Day” with the stated purpose of raising awareness for AS and spondylitis focused organizations worldwide. Each year since then SAA has contributed to the global awareness efforts in various ways. This World AS Day we called on our social media community to Go Blue for ankylosing spondylitis - showcasing their AS awareness items, sharing AS awareness posts, and changing their profile pictures - all to raise awareness online.

In answer to our call, our Facebook, Twitter, and Instagram feeds turned a beautiful blue with hundreds of pictures and AS awareness status updates. SAA also participated by sharing our staff awareness pictures, as well as an AS educational post which was shared close to 800 times on Facebook (making it the most shared social media item SAA has ever posted). We hope you enjoy some of these awareness pictures below!

**World AS Day falls on the First Saturday in May each year, unless May 1st is a Saturday – in which case World AS Day will fall on the following Saturday to avoid interfering with worldwide May Day activities.*

WALK YOUR AS OFF: MISSION TO MARS

“Walk Your A.S. Off” is an annual community Walk for Ankylosing Spondylitis. Each year WYASO invites participants all over the world to log their daily steps from March 1st to World AS Day, submitting them to the project to be counted towards a grand total. Started in 2011 by AS advocate and SAA member Jennifer

Dye Visscher, the walk entered its 3rd year with a new goal: Mars or bust! 10 years is the average amount of time it takes a person with AS to get diagnosed. It is also the number of years WYASO hopes it will take to collectively walk to Mars. SAA has been a proud participant since WYASO’s inception; walking as “The Home Team” SAA contributed 3,398,141 steps to the project this year. And the grand total walked by the WYASO community in 2014? A whopping 674,571,987 steps! Congratulations and big thanks to everyone who walked! Be sure to join the great AS Walk to Mars next year. Visit www.walkyourasoff.com to learn more and get involved.



OVERHEARD:

Crazy S#@% Doctors Say

Sometimes we at SAA hear about the really crazy things doctors say about spondylitis. Some of these make us scratch our heads and wonder at the logic of it (could a doctor really think or say, *THAT*). Some comments frustrate us, adding to our determination to keep educating the medical community. Others just plain make us laugh in amazement. We thought we would share some of the best/worst with you. While there are many wonderful, caring, and brilliant doctors who get high praise from their patients, there are also the ones who are quoted below; and *they* are the ones we most need to reach.



EDITOR'S NOTE: *These comments come directly from Facebook and SAA cannot vouch for their validity.*

Overheard from our Facebook page:



Charlie I was told, "You can't have AS because in all my years practicing, I've never diagnosed anyone with AS."



Chris An OBGYN said, "Obviously I can't have anyone in my practice with spondylitis..."



Keith While trying a new rheumatologist, they said: "AS: wow I've heard about it and read about it in textbooks but I've never met anyone with it, please tell me about it."



Michael "There's really nothing else we can do for you. What exactly do you want from me?"
...I thought maybe do more research and do your damn job.



Stephen "Doctor: You have pink-eye. Me: It doesn't feel like pink-eye, it feels like someone is stabbing my eye with a hat pin. Doctor: it's pink eye - I know what I'm talking about, I'm a doctor. (Hint: it wasn't pink eye - anyone with AS knows what it was)"



Lisa "Only men have that. I've never had a female patient with that." (I wanted to say, I bet you have and I bet they were misdiagnosed!)



Jessica "You couldn't possibly have AS because you are female and are part African American."



Jennifer My PCP rejected my rheumatologist's diagnosis based on my gender..."women don't get AS".



Sandra "Women (with AS) don't fuse. And if I could give men estrogen they wouldn't fuse either."



Nicola "You can't be in that much pain or have that much trouble walking. It's only AS."



Chris "I was told by my doctor that I couldn't have AS as I was a big guy...he said only slim people get AS...I changed doctors after a few years and got diagnosed."





Christopher “I actually have a lot of experience with ‘Ankylosing SpondyLOSIS’...” I walked out.



Jaiden Doc: “Your pain is psychosomatic.” Me: “wouldn’t you like to at least touch my neck first or examine me before you decide that?” Doc: “I don’t think that is likely to help.”



Jaiden “Maybe your underlying sleep issue is causing the pain.” “Um, I can’t sleep because I’m in pain.” “Well, maybe you should try sleeping.”



Mindi “I asked to be tested for AS and the doctor said no, because “even if you do have it, there is nothing that can be done about it.”



Johanne “Best one I had was, ‘You’re thinking of pain so therefore you give yourself pain, which makes it worse. It’s all in your head!’”



Ana “I had a doctor tell me there was nothing wrong with me, but scheduled me for SURGERY just to take a look!”



Michael “I asked my chiropractor if he knew about AS. He told me of course and he had some special adjustments for that. That was the last time I saw him.”



Nancy “I’m not testing you for AS. I don’t know what it is & wouldn’t know how to treat it.” I don’t see him anymore.



Kathleen I was told that “pain is your friend, now.” And “have you considered seeing a psychiatrist?” “ You have pms”.. Etc., etc



Cookie The phrase I heard over and over was “You are stressed and that is why your neck doesn’t move.”



Richard “People with AS can’t cross their legs”



Have you heard any of these or have others you’d like to share? Join the conversation on Facebook at <https://www.facebook.com/spondylitis> or send your note to Chris Miller at Chris.Miller@spondylitis.org.

We’d also like to thank all the great doctors, clinical researchers and members of our Medical and Scientific Advisory Board who work tirelessly to help improve the lives of those with spondyloarthritis each and every day. Need help finding a knowledgeable rheumatologist? Send an email to info@spondylitis.org and ask for our Rheumatologist Directory.



Volunteer Fundraising: "Ice Fishing 4 A Cause"

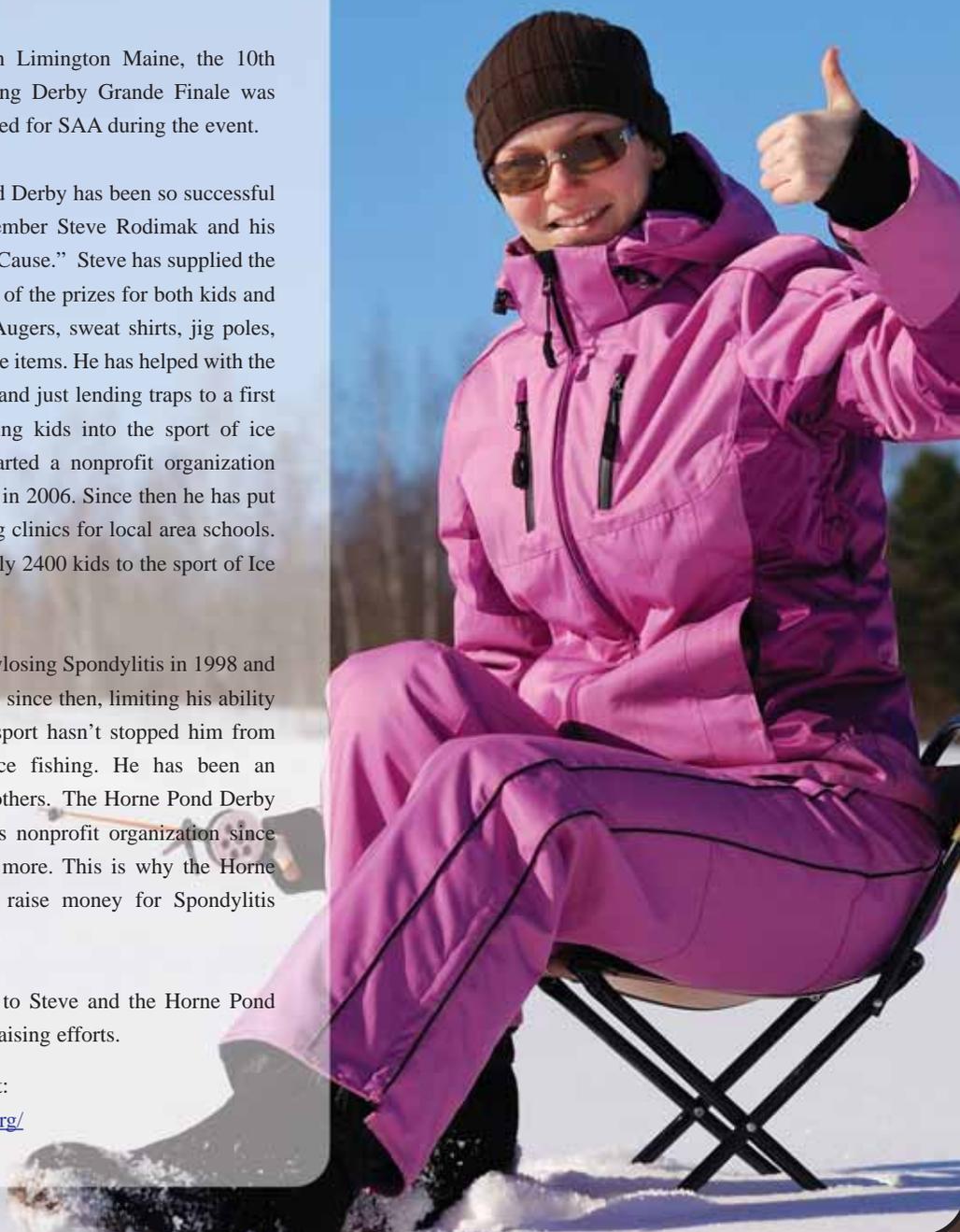
On January 25, 2014 in Limington Maine, the 10th Annual Horne Pond Ice Fishing Derby Grande Finale was held. A total of \$1,564 was raised for SAA during the event.

For many years the Horne Pond Derby has been so successful due to the efforts of SAA Member Steve Rodimak and his organization, "Ice Fishing 4 A Cause." Steve has supplied the derby with a very large portion of the prizes for both kids and adults ranging from Jiffy Ice Augers, sweat shirts, jig poles, traps, hats and many, many more items. He has helped with the casting contest, jigging clinics and just lending traps to a first timer. His main focus is getting kids into the sport of ice fishing. This is why Steve started a nonprofit organization called "Ice Fishing 4 A Cause" in 2006. Since then he has put on approximately 75 ice fishing clinics for local area schools. He has introduced approximately 2400 kids to the sport of Ice Fishing since 2006.

Steve was diagnosed with Ankylosing Spondylitis in 1998 and has had several major surgeries since then, limiting his ability to walk. Steve's love for the sport hasn't stopped him from introducing young kids to ice fishing. He has been an inspiration to us and to many others. The Horne Pond Derby has been a big sponsor for his nonprofit organization since 2006, but felt they should do more. This is why the Horne Pond Derby decided to help raise money for Spondylitis Association of America (SAA).

We offer our immense thanks to Steve and the Horne Pond Derby for their volunteer fundraising efforts.

You can visit Steve's website at:
<http://www.icefishing4acause.org/>





Curious About Volunteering Or Advocating? ***Volunteering***

Our volunteer fundraisers have been extremely inventive in creating projects that have helped benefit the spondylitis community. Some more athletic SAA members have run races and asked for pledges, one held a very successful fundraising dinner in New Jersey, and one amazing teen even organized a baseball "Hit-a-Thon" derby - all on their own initiative.

To learn more about ways you can fundraise visit our website at:

StopAS.org/volunteer

Questions? You can also contact Robin Kindrick at SAA toll free at 1-800-777-8189 or by email at robin.kindrick@spondylitis.org.

Advocating

SAA is the only non-profit organization in the United States dedicating its resources to the active support of spondylitis patients to bring about awareness, education, and research to ensure a better life for all spondylitis patients.

SAA's Advocacy Priorities

- Promoting earlier diagnosis and treatment of spondyloarthritis
- Promoting public awareness and education about spondyloarthritis
- Improving access to appropriate quality health care and medications for all spondyloarthritis patients
- Increasing federal funding for arthritis research
- Affecting public policy that impacts the lives of spondyloarthritis patients

For more information about our advocacy efforts, or to learn about becoming an advocate, please visit us online at:

StopAS.org/advocacy





**Highlighting The Most Active
SAA-SPONSORED EDUCATIONAL SUPPORT GROUPS**

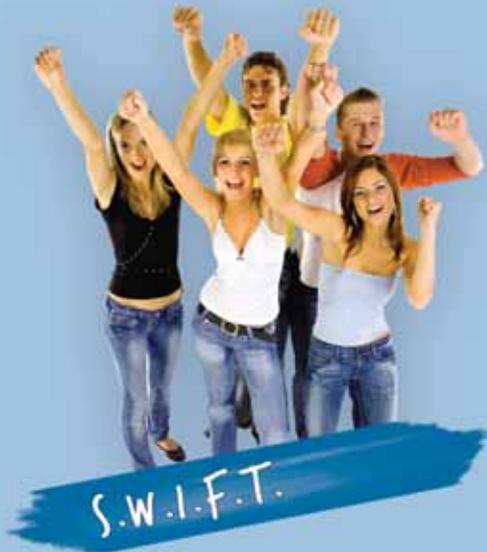
City	State	Meeting Facilitator	Email address	Phone Number
Phoenix/Tucson	AZ	Jacqui Gregor	mjgregor@cox.net	(520) 241-7064
Los Angeles	CA	Richard Howard	Richard@spondylitis.org	(818) 892-1616 x231
Oakland	CA	Howard Tevelson	hotbyht@yahoo.com	(510) 479-3220
San Diego	CA	Mike Supancich (CL)	msupancich@att.net	(760) 889-5760
San Diego	CA	Tim Tompkins (CL)	tim@digitallightmedia.com	n/a
Sebastopol	CA	Tom Hickey	namastetom@hotmail.com	(408) 505-3273
Denver	CO	Noel Miles	Milessterl@aol.com	n/a
Hollywood	FL	Randall Sapadin	randallsapadin@mariacoppolafoundation.org	(646) 240-5689
Atlanta	GA	Means Davis	meansd@mindspring.com	(770) 529-5272
Boise	ID	Debbie Westervelt	irishdeb@clear.net	(208) 573-9153
Chicago	IL	Joyce Terzick (CL)	alden41@aol.com	(815) 744-5017
Chicago	IL	Kathy Lange (CL)	kcl58@comcast.net	(847) 577-9940
Fort Wayne/Indianapolis	IN	Ken Prather	pratherken@yahoo.com	(260) 637-1705
Augusta	ME	Michelle Andrews	qualey28@roadrunner.com	(207) 313-3871
Charlotte	NC	Deanna Williams	deanna@inspiredbyas.com	(704) 993-8259
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Morristown	NJ	Craig Gimbel (CL)	believe5154@optonline.net	(973) 476-8976
New York	NY	Andrea Shapiro	Andrea.Shapiro@gmail.com	(347) 766-8362
Columbus	OH	Megan Lawless	meglawless89@gmail.com	(630) 567-6362
Portland	OR	Kathryn Houston	houston.kathryn@gmail.com	(360) 635-3238
Philadelphia	PA	Walt Lichmira	waltlichmira@comcast.net	(215) 688-3145
Dallas	TX	Lynda DeGrow Kingsley	degrowkingsley@gmail.com	(214) 542-2869
Houston	TX	Stephen Haskew	haskews@verizon.net	(281) 337-3997
The Woodlands	TX	Wilson McCoy	wass@GISolutionsTX.com	(281) 460-1033
Richmond	VA	Sam Brumberg	sbrumberg@odec.com	(804) 968-7164
Seattle	WA	Thomas Herwick	thomasherwick@hotmail.com	(360) 929-4010
Spokane	WA	Joan Polzin	joanp115@webband.com	(509) 624-8214
Web-Meeting @SpondyCafe	Online	Michael Smith	spenser23@aol.com	n/a

*CL designates Co-Leader. These are two leaders working together to lead their group.

If you'd like to learn more about support groups or for a complete list of groups and meeting dates, visit our website at: <http://www.stopas.org/groups>

You can also contact Elin Aslanyan here at SAA by calling 1-800-777-8189 ext. 222 or by email at elin.aslanyan@spondylitis.org for more information.

Need spondylitis info
for teens?



Visit **S.W.I.F.T**

Spondylitis Web Info For Teens

At: teens.spondylitis.org - Two new personal stories from teens have been added!

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SPONDYLITIS PLUS ONLINE SURVEY

We'd love your feedback!



Please take a few minutes to share your thoughts on SAA's Spondylitis Plus Magazine by taking a brief, 15 question survey online. We endeavor to pack each issue with information and articles that are helpful and important to YOU, and your feedback is crucial to us. Thank you in advance for completing our brief survey!



Online on Survey Monkey at:

<https://www.surveymonkey.com/s/SpondyPlus>