SPONDYLITIS PLUS

Summer 2013

Looking Back While Forging Ahead
by Dr. John Reveille

Intubation, Anesthesia, Spondylitis

30 Years Of Progress:
SAA Milestones

Spondylitis Association of America
Dear Readers,

This year SAA celebrates thirty years since its incorporation in 1983 as the Ankylosing Spondylitis Association (ASA), soon to become the Spondylitis Association of America (SAA). Since those early days when a small group of impassioned AS patients and their doctors led by Jane Bruckel decided to make a difference, much has changed.

Today, SAA is a world class organization that delivers where others only promise.

Although I think it appropriate to recognize and to celebrate the advances that have been made, it is the struggle and the challenge of those who still suffer that drive us to work harder and longer and smarter every day. I thought about this short column and its potential content while on the road recently on behalf of SAA, actually writing the final piece on a plane returning to Los Angeles after attending a Food and Drug Administration hearing in Washington DC.

I could have written about the advances in genetic research that have led to new medicines currently in trials. I could have expounded upon improved techniques in corrective surgery and hip replacements and provided a detailed description of how advances in medical imaging promise accelerated diagnosis. Or I might have lauded the uncovering of 40 new genes implicated in the susceptibility toward spondylitis that has the potential to lead to improved treatment modalities.

But as important as all of those critical breakthroughs are, my thoughts kept coming back to the human side of our group of diseases; about the day to day experiences of those whom we serve and the impact chronic illness has on so many lives.

Starting with our founder, Jane, who remained misdiagnosed even whilst working as an RN in a rehabilitation facility, surrounded by doctors who should have been able to offer her some answers. Today, awareness of the disease is more widespread and many more resources exist for patients and the medical community alike.

Thirty years ago, a young woman suffering symptoms of aggressive AS was so misdiagnosed that her parents sought psychiatric help—after which she was admitted to a home for emotionally disturbed children. In contrast, today, Regan, a young man of similar age and with similar symptoms whom you’ll read about in these pages, engages in sports and lives his life with great courage, recently raising funds to support our SAA.

In yet another example of archaic practices that took place not so long ago, one of our own rheumatologists, also an AS patient, delights with self effacing humor to tell the story of honey injections to ease his back ailments — to which he credits his sweet disposition— but which did little else to help relieve his AS symptoms. Today, patients are able to self inject with medicines that have the potential to improve quality of life.

Thirty years ago, SAA had a vision — a world without the disability of spondyloarthritis. That vision has remained constant. And I believe that the goal is closer than ever before. With your continued support and confidence in our mission, we can look forward to meeting the challenges that still lie ahead.

Sincerely,

Laurie M. Savage
Executive Director
**Praise For The Spring Issue**

I absolutely loved the Spring issue of *Spondylitis Plus*. The updated overview of spondyloarthritis with Dr. Jessica Walsh was great - I never really fit in to a classic diagnosis myself because I only had one SI (sacroiliac) joint go bad at a time.

I laughed out loud reading Philip Donlay’s suggestions for Profanity Diversion Therapy and have put it into practice. Oh my - I feel better already!

~JANE, Tualatin, OR

...And More Compliments For Philip Donlay

Thanks for including “Creative Coping: Diversion Therapy” by Philip Donlay in the latest issue of *Spondylitis Plus*. I laughed my *** off! For me, the best ways of dealing with AS are laughter, exercise, and stress management. I’m going to add PDT (Profanity Diversion Therapy) to my toolbox!

~CLARKE, San Carlos, CA

**Diversion Therapy Is Officially A Hit**

I would be remiss if I did not comment about the “Creative Coping: Diversion Therapy” article in the Spring issue. Bravo, Philip Donlay! What a refreshing, quick witted approach to battling the day-to-day struggles associated with AS. It was such a light hearted, transparent look into how one man chose to get creative and not become overburdened with the disease. An occasional expletive always helps. His article brought a delightful smile to my face - and reminded me to b-r-e-a-t-h-e.

~MAGGI, Tampa, FL

*Editor’s Note:* As you can see, Philip Donlay’s article was a huge hit with readers. We had more complimentary notes, emails and Facebook posts regarding the article than we have ever received on any one piece. Thus, we have put it online for all to enjoy. You can read the article here: [StopAS.org/pdt](http://StopAS.org/pdt)

**Dr. Walsh’s article was also met with high praise, so we have added it to the website as an FAQ.** You can read her “Updated Overview on Spondyloarthritis” here: [StopAS.org/faq](http://StopAS.org/faq)
WHAT IS A PATIENT REGISTRY?
Seeded with funds provided by SAA, a “patient registry” is a database - in this case a compilation of data on people with AS. This registry will be a combination of three current patient databases that have been used in ankylosing spondylitis research. Thus, a new database will be built that can look at thousands and potentially tens of thousands of patients with AS and see health trends, disease severity over time, age, gender differences (or lack thereof), race, complications and much, much more.

I am very excited and honored to congratulate the Spondylitis Association of America (SAA) on 30 years of service and support to the Spondyloarthritis Community. During the mid 1980s when I had just completed one of the early studies of DNA markers in AS, I was asked by SAA co-founder and former Executive Director, Jane Bruckel, to join the first SAA Medical Advisory Board, having served as its Chairman in 1994 and 1995. I also have worked with SAA in research efforts, studying what causes this disease, overseeing the SAA Family Genetic Project (beginning in 1998), which evolved into the NIH-funded North American Spondylitis Consortium (NASC)(1999-2004), which in turn evolved into my NIH-Funded Program Project Grant on the Genetic Basis of Ankylosing Spondylitis. This study was initially funded in 2006 and continues to this day.

More recently I am working with SAA in creating the SAA/SPARTAN AS Patient Registry (see sidebar). I have also worked with SAA in an administrative capacity, having served on the SAA Board of Directors since 2007. Of particular importance to the rheumatology community is the fact that SAA was a partner in the establishment of the Spondyloarthritis Research and Treatment Network (SPARTAN) - an organization of rheumatologists focused on the causes, epidemiology and management of spondyloarthritis of which I was a founding member in 2003, and for which the SAA remains as the fiscal agent to this day.

In considering what are the ten most important questions facing the Spondyloarthritis Community at present, I would suggest the following:

1. What is axial spondyloarthritis (AxSpA) and how does it relate to AS?

It takes up to 10 years between the time that the back pain begins and the x-rays turn positive for sacroiliitis, the hallmark of AS. This condition has been called 'pre-radiographic' axial spondyloarthritis. More recently, as groups of patients from Europe have been followed, it has become evident that many never go on to develop radiographic sacroiliitis, yet have other classical spondyloarthritis features (inflammatory back pain, positive MRIs for inflammation around the
The hallmark of AS is involvement of the sacroiliac (SI) joint, which is the joint between the sacrum and the ilium of the pelvis that supports the spine. When diagnosing AS, x-rays are supposed to show erosion typical of sacroiliitis. Sacroiliitis is the inflammation of the sacroiliac joints. However, using conventional x-rays to detect this involvement can be problematic because it can take up to 10 years of disease progression for the changes in the SI joints to be serious enough to show up in conventional x-rays.

**Uveitis / Iritis**

Uveitis / Iritis causes eye pain and redness. It comes on over the course of about a day and it usually affects only one eye at a time. Most people have a full recovery, but it is important to seek care from an eye doctor as soon as possible, since it can cause permanent vision loss.
**RESEARCH**

**WHAT ARE TNF-α INHIBITORS?**

TNF-α inhibitors or anti-TNF agents are medications that target and attempt to block TNF-alpha in the body. TNF-alpha is a cytokine involved in the inflammatory process. Excess amounts of TNF-alpha have been associated with various forms of inflammatory arthritis. These medications are either injected or given by an IV.

4. Can we use genetic profiling to accurately diagnose AS?

Over 40 genes have now been implicated in causing AS. This has led some companies to develop panels of genes to determine if one is at risk for AS. The problem is that at present we only know about 25% of the overall risk for this disease and 80% of the known risk comes from HLA-B27 itself. The contributions of the other 39 or so other genes are individually very small in comparison. Further work is underway to determine additional genes and, more importantly, how these genes interact with each other to cause AS. Until this information is available, it is premature to recommend getting your “AS Gene Panel” checked to see if you have AS.

5. What is the best way to determine if your AS is active?

This should be done with consultation with your rheumatologist and a careful clinical evaluation. Instruments have been developed for this purpose (e.g. the Bath Ankylosing Spondylitis Disease Activity Index, or BASDAI and the Ankylosing Spondylitis Disease Activity Scale or ASDAS). The latter utilizes blood tests such as the sed rate or C-reactive protein levels (CRP). However these tests are imperfect and miss many people with otherwise active AS. What is clearly needed is a better blood biomarker for active AS and AxSpA.

6. Does anti-TNF treatment alter the course of AS? (see sidebar)

Earlier data from clinical trials with anti-TNF agents in AS did not find an impact of these agents on the x-ray progression of this disease, despite the dramatic improvement given by these drugs on symptoms and day to day functioning. Looking at recent data from a collaboration of the Prospective Study of Outcomes in AS (PSOAS) and the Toronto University Health Network Spondylitis Program, anti-TNF drugs do indeed appear to slow the radiographic progression of this disease, especially if they are given in the first 10 years of the disease. It takes a few years before these differences are seen, which likely is why the earlier shorter term studies did not detect this.

7. Should everybody who gets a diagnosis of AS take an anti-TNF agent?

Data from European AS cohorts, from PSOAS and from the Toronto University Health Network Spondylitis Program all show that only about half of patients with AS need an anti-TNF agent. At least half of AS patients are well controlled on nonsteroidal anti-inflammatory drugs alone, or in some patients, the disease may become inactive and the pain cease on its own.

8. How will the changes in health care coverage in the US affect patients with AS in their ability to receive medications and other AS treatments?

The cost of health care in the U.S. is more expensive than anywhere else in the world and has increased dramatically in recent years. Medication costs have been a major driver of these increases. Using an anti-TNF agent costs over $30,000 per year in each patient, and using these drugs to treat AxSpA, which is much more common than AS, is currently being considered by the FDA, which would cause costs to skyrocket. Whether this is sustainable in the evolving health care economy is an open question. Another question is whether TNFs may be restricted in the future to those patients who studies have
shown are most likely to benefit from them (those with elevated inflammatory markers—i.e. CRP or sed rate or positive MRIs) and denied to those with longstanding AS or with negative inflammatory markers or negative MRIs.

9. Why doesn’t everyone with AS respond to anti-TNF drugs?

There are two reasons for this. First of all, a minority of AS patients have such active disease that even anti-TNF agents, in standard doses, cannot cool off the disease. Some benefit from higher doses, others should be considered for some of the new non anti-TNF biologic drugs that are currently being tested. However, the more important reason for lack of adequate response to an anti-TNF agent is that the back or joint pain might not be caused directly by inflammation from AS. Spinal fractures, herniated discs, and bone spurs pressing against spinal nerves can cause back pain that is not helped by anti-TNF drugs. If you are not having an adequate response to your anti-TNF agent, you and your doctor need to consider if one of these other causes may be contributing.

10. Why is the frequency of HLA-B27 lower in older Americans?

Data from an NHANES 2009 study showed significantly lower HLA-B27 prevalence estimates for older adults, as opposed to younger U.S. adults (3.6% for those 50-69 years of age vs. 7.3% for those 20-49 years, respectively). The reasons for this are not clear; one explanation is that it is a statistical fluke, although another explanation is that there is something about being HLA-B27 positive that is associated with a shorter life span. This observation clearly needs to be confirmed, and if found in another group, studies done in HLA-B27 positive people to determine why.

“*The Spondylitis Association of America is honored and grateful to Dr. John Reveille for his decades-long dedication on behalf of those whom we serve and for his groundbreaking research in spondyloarthritis.*”

~Laurie M. Savage, Executive Director
"Intubation, Anesthesia, Spondylitis" is a compilation of three separate articles discussing the challenges spondylitis patients can face when undergoing anesthesia.

In the first article, Stuart shares his intubation experience with us as well as discusses his correspondence and meeting with Dr. Lee.

In the second article, Dr. Lee discusses proper intubation and anesthesia techniques as well as tips for preparing for surgery.

Lastly, SAA Member Debra O'Reilly shares her recent experience with surgery and intubation, illustrating proper and patient-centered procedures in surgery preparations, as well as in administering anesthesia in cases of difficult intubation.
The following stories were sparked by the experiences of SAA Member and Educational Support Group Leader from Baltimore, MD, Stuart Merenbloom. Stuart’s difficult intubation preceding kidney stone surgery led him to Johns Hopkins, and to Dr. Jai S. Lee, an anesthesiologist with 47 years of experience, specializing in difficult intubation. Stuart reached out to Dr. Lee to learn what other options exist for those with fusion/kyphosis who need to undergo general anesthesia, and to help raise awareness of the problems and complications spondylitis patients often face when undergoing surgery. Our immense thanks to Stuart for his tireless advocacy work on this issue, and congratulations on a job well done!

Intubation: My Modem Day Horror story

By Stuart Merenbloom

You’re lying on a cold table....an IV in your arm.......they’ve placed a donut shaped object in your mouth so you can’t talk......someone is smearing a numbing cream into your mouth while injecting something into your palate......time goes by and “it” starts: you feel something trying to make its way down your throat....you gag....an _hour_ passes and it happens again, and again, until you mercifully fall asleep.

"We must be our advocates"

Was this a scene from a bad horror movie? No….this was my real experience at a modern day hospital as I was having a procedure done to zap a kidney stone. Modern, up to date medical technology had me endure an hour’s worth of torture in order to be intubated and anesthetized. Quite frankly, this was not the first “difficult intubation” I had endured, but it certainly was going to be my last. I took it upon myself to seek out answers as to how someone with ankylosing spondylitis and a permanently curved back and neck can be intubated in a more humane manner. My initial inquiry was aimed at the hospital’s director of anesthesiology. I explained my story and he said he’d “bring it up at their next staff meeting”. This response was not what I wanted to hear so I turned my attention to the National Society of Anesthesiologists. People there listened to my story but failed to offer any positive solutions.

Living in a suburb of Baltimore, Maryland, I have the Johns Hopkins Medical Center in my back yard. A few calls there led me to Dr. Jai Lee, a leading expert in the field of difficult intubation. After exchanging some e-mails and phone calls with Dr. Lee I had the pleasure of meeting with the doctor, who not only listened to my story but showed me how he could have intubated me in less than five minutes. I also learned that Johns Hopkins Hospital encourages patients such as me to meet with their anesthesiologist before their procedure in order to develop a plan and to show the patient exactly what will be done in order to be intubated. Dr. Lee was gracious enough to share his expertise in the field of difficult intubation with me and with the SAA in order to show other patients that there is a quick, safe and more humane way to intubate patients with limited cervical range of motion.

Patient advocacy has been a buzz phrase in the medical profession for many years now, but _we must be our advocates_. We must ask the questions and _we_ need to speak up for ourselves in order to receive proper medical attention.
Airway, Airway, Airway: Anesthesia & Spondylitis

Dr. Jai S. Lee has been practicing anesthesiology for the past 47 years. He started his anesthesia residency in 1966 at the Johns Hopkins Medical Center in Baltimore, Maryland. He is currently Assistant Professor in the Department of Anesthesiology and Critical Care Medicine at The Johns Hopkins University School of Medicine.

A long time ago toward the beginning of my career, I had attended an anesthesia seminar where the speaker said that the three most important issues in Anesthesia were as such: 1) Airway. 2) Airway. And 3) Airway.

In the operating room, the number one priority is to secure the airway before providing general anesthesia for the operation. Once the patient is anesthetized, the operation may begin. For the vast majority of patients, direct laryngoscopy (what we think of as standard intubation done after a patient has been sedated, and involving the tilting of the head far back in order to clear the airway and intubate the patient) allows the anesthesia provider to secure the airway.

In an estimated 1.5-8.5% of patients undergoing anesthesia the airway cannot be easily accessed. [1] These patients have what is referred to as a difficult airway.

A difficult airway is defined as a clinical situation in which a conventionally trained anesthesiologist experiences difficulty with mask ventilation, difficulty with tracheal intubation, or both. [2]

There are several risk factors for a difficult intubation, and it is entirely up to the anesthesia provider involved to use the technique(s) that best fit their skills.

- Limited head and neck movement
- Limited jaw movement (T-M Joint) In other words, limited opening capability of mouth.
- Buck Teeth.
- The size of mandible space.
- Obesity (weight over 90 kg.)
According to ASA (American Society of Anesthesiologists) [2], Awake Fiberoptic Intubation has been the standard initial technique for difficult airway patients.

In this technique, an anesthesiologist will pass a narrow fiberoptic scope through the nose or mouth to aid passing an endotracheal tube. The Awake Fiberoptic Intubation is successful for many patients with difficult airways, but in some cases other techniques may be required as this technique can be very uncomfortable or even intolerable for some patients under moderate sedation, and can often take 30 - 45 minutes.

An alternative method for difficult airway patients has been the rigid fiberoptic laryngoscope. A Bullard scope is an example of this and was made available in the early 1990s. In 1992, I started using the Bullard scope because I thought it might be a good idea to try this scope for those patients with cervical problems, such as cervical arthritis and cervical fusion.

The problem was that the learning curve to use this scope was very steep for me as well as for others I trained. Thus, over time I developed a five-step technique I call Jai Lee’s Five Step with the Bullard Scope which allows the anesthesiologist to intubate a difficult airway patient in under 5 minutes. Since 1992, I have used the Bullard Scope for almost 5,000 cases and so far have not had to use the Awake Fiberoptic Intubation in a patient with a difficult airway. I have also trained close to 400 staff members at Johns Hopkins, including faculty physicians, physicians in training, nurse anesthetists (in practice and training) in this technique with good results.

A word about pre-surgery preparations:

While for most operations a consultation with an anesthesiologist is not necessary prior to surgery, patients with an anticipated difficult airway should be referred by the surgeon to see the anesthesiologist prior to the procedure. Any patient with spondylitis and cervical spine involvement will fall into this category, and should meet with the anesthesiologist pre-surgery. Many major centers provide a Pre-Anesthesia Evaluation Center (PEC) to facilitate this evaluation.

During this first meeting, the anesthesia provider will obtain a medical and surgical history along with information about any problems experienced with anesthesia in the past. The provider will perform a physical examination with a focus on limitation of neck movement, degree of mouth opening, and anatomy of mouth and throat.

EDITOR’S NOTE: We’d like to thank Dr. Lee for his expertise and for taking the time to write this article for Spondylitis Plus.

References

I have been dealing with the substantial pain and discomfort of ankylosing spondylitis since my early 20s - undiagnosed until my early 40s - so a bit of spotting at age 61 hardly made a blip on my “health radar”. Nevertheless, I decided to speak with my gynecology provider at the University of South Florida medical/teaching facility.

When I called, instead of obtaining an appointment with my usual nurse practitioner, I was shifted rapidly to the office of Dr. Kell Williams, Director of the school’s Division of Gynecology.

Dr. Williams performed an endometrial biopsy and hit a snag.

He sent me for a more extensive biopsy and then delivered the news: Endometrial hyperplasia, complex and atypical. In other words, probably just shy of cancer, but highly suspect. I needed a hysterectomy.

“If your wife received this diagnosis, what would you do?” I asked Dr. Williams.

“Her uterus would be out in an instant,” he said.

Ok, that put things in perspective. This was serious.

Dr. Williams sent me to the best specialist he knew, Dr. Mitchell Hoffman, USF’s Division Director for Gynecology Oncology. GYN/ONC is a rare specialty, and I was blessed to be referred to the top man at the school. Just the specialist I needed, and a compassionate, attentive doctor, as well.

The day my husband and I were to meet with Dr. Hoffman, our home phone rang just as we were headed to the car to drive to his office; because we were a few minutes ahead of schedule, I answered it. Robin Kindrick, a membership associate, was calling from the Spondylitis Association of America to thank me for my annual membership dues.

During our short conversation, she asked, “Is there anything you need to know? How can we help you today?”

I told her where we were headed.

“I’ll email you a couple of articles from the Spondylitis Association of America’s archives,” she said, “one with precautions about surgery, the other about anesthesiology. Because your back and neck are fused, your doctors need to understand your physical limitations. You also need to meet with the anesthesiology department before your surgery.”

I wouldn’t have thought to talk with Dr. Hoffman about those things. SAA’s articles were a Godsend.

Dr. Hoffman discussed the various surgeries available: vaginal, laparoscopic, and abdominal. He explained that the preferred surgery, minimally intrusive, is laparoscopic. He was ready to suggest it until I told him about my ankylosing spondylitis. He listened closely when I spoke of my kyphosis (both upper spine and neck), then ruled out laparoscopic surgery. For that procedure, the surgical table is tilted, and he worried that the lack of proper support would cause additional lasting damage to my back.
He also talked about anesthesia and intubation. Thanks again to SAA’s guidance, I explained that my singing voice is very important to me. My ribs are fused to my back. Singing is physical therapy for me; it keeps my lungs expanded and functioning. He arranged for me to speak with the anesthesiology department the week prior to surgery. Another Godsend.

I carried the two articles from the Spondylitis Association to anesthesiology on the day of my appointment. Laura, the physician’s assistant who met with me, listened as I explained my limitations. She read both articles immediately.

When I asked if a reduced-diameter tube could be used for the anesthesia, she said it would be no problem and wrote it in the orders. She talked with me about the suggestion, in one article, of using a fiber-optic guide during intubation, to minimize damage to my vocal cords. She added the fiber-optic gizmo to the orders. Godsend #3.

Days before the operation, I received a phone call from Dr. Xiaomang Stickles, who would assist Dr. Hoffman for my hysterectomy. She introduced herself and said not to worry a bit about how my spondylitis would affect the surgery. She told me she understands; her own husband has AS. She offered to explain to the operating-room staff the unique challenges they would face with my rigid spine and neck. #4!

The day of the surgery, as I was wheeled in for prep, Dr. Stickles introduced herself to me in person. I asked if she had already spoken with the surgical staff. She said, “I didn’t have to. Your anesthesiologist was in the OR with us for the last procedure, and he spent much time in surgery telling the staff what they’d be doing differently for you.” That’s #5!

The upshot? Dr. Hoffman’s skill in accomplishing the hysterectomy without an abdominal incision has significantly simplified recovery. Whew. #6.

When post-surgical lab results arrived, Dr. Williams was proven correct: The surgery was necessary. Pathology found very early-stage cancer. So early-stage, in fact, that the cells had not yet implanted themselves in the uterine wall. The doctors are confident it was all removed with that uterus. Prognosis: No need for further treatment! That’s it: A perfect 7.

At a crucial time, when I was too rattled to remember to call for information and guidance, the Spondylitis Association of America called me and provided exactly the knowledge my medical team and I needed.

I’m eternally grateful.

“The Spondylitis Association of America called me and provided exactly the knowledge my medical team and I needed.”

Debra & husband Bryan with the historic World War II B-17 bomber “Memphis Belle”
In celebrating SAA’s 30th anniversary, we’d like to revisit some of the major milestones achieved in our three decades of existence. None of this would have been possible without the generous contributions by the thousands of SAA Members, Volunteers and Donors that have supported our mission throughout the years. We thank and salute you...

1983

The organization known today as the Spondylitis Association of America holds its first meeting in a home in Los Angeles, where ten patients and two physicians create the country’s first-ever ankylosing spondylitis (AS) support group.

The organization produces the first quarterly newsletter (known today as Spondylitis Plus) specifically written for spondylitis patients.

1984

The organization becomes a tax-exempt, non-profit corporation under the name Ankylosing Spondylitis Association (ASA). Volunteer, nurse and spondylitis patient Jane Bruckel is elected the group’s first president.

The group co-sponsors the first AS symposium in the U.S. A two day event for physicians and patients. More than 100 physicians attend the first day of the program, titled “Back Pain: The Unsuspected Cause.” The second day, over 100 patients attend a program titled “AS: A Cause of Back Pain. What it is, what it is not, and how to cope with it.”

1985

ASA produces the first comprehensive patient self-management book, Straight Talk on Spondylitis, which receives high praise from medical professionals worldwide. More than 3,000 copies are distributed to patients, physicians and major medical centers. The book is translated into Japanese and distributed throughout Japan. Note: The English version was updated in 1992 and completely edited and brought current in 2009 (see page 27 for ordering information).
1987
ASA establishes a national Medical & Scientific Advisory Board, comprised of distinguished spondylitis researchers and health professionals.

1991
ASA co-sponsors a four-day international research and educational symposium with the University of Texas at Dallas, titled “The Second Simmons Center International Conference on HLA-B27 Related Disorders.” This was a first-of-its-kind in the US. A highlight of the conference is the unveiling of the three-dimensional structure of the HLA-B27 molecule, a major step forward in scientific discovery. ASA organizes a concurrent program of clinical sessions for arthritis health care professionals, such as physical therapists and nurses. The conference culminates with an educational program for patients.

1992
The organization changes its name to Spondylitis Association of America (SAA), in order to reflect a broadened mission that encompassed diseases related to ankylosing spondylitis.

1995
SAA embarks on fundraising for AS research with the leading gift of $30,000 from a generous family foundation.

1998
SAA co-sponsors a two-day scientific symposium in collaboration with and located on the NIH campus in Bethesda, MD. The purpose of the meeting is to create a cross-disciplined dialogue among research clinicians in AS and related fields.

SAA provides the seed money for Drs. John Reveille and Li Jin of the University of Houston to begin the first major, nationwide genetic study of ankylosing spondylitis.

1999
SAA and the University of Texas (UT) form the North American Spondylitis Consortium (NASC) - a consortium of 10 university medical centers and SAA. The National Institutes of Health provide the initial grant and designate SAA as clinical coordinating center for the AS Family Genetic Project.
2002

SAA sponsors and develops the first extensive, nationwide survey for AS patients. The AS Life Impact Survey results in major findings never before documented that enable physicians and SAA to better address the needs of the AS community.

SAA helps organize a meeting with the European research group called ASAS, the Food and Drug Administration (FDA), prominent researchers, and pharmaceutical companies, to draft an FDA guidance document on AS drug research and development.

2003

SAA holds an organizational meeting for US researchers to establish the Spondyloarthritis Research and Treatment Network (SPARTAN) for the purpose of advancing clinical research of spondyloarthritis in the United States.

SAA offers its first accredited Continuing Medical Education (CME) program for physicians entitled, “Ankylosing Spondylitis & Related Spondyloarthropathies: Aggressive Management of Aggressive Diseases.”

2006

SAA co-sponsors a second scientific conference with the NIH, titled “Spondyloarthritis: The Unmet Needs”. The purpose of the meeting is to create a cross-disciplined dialogue among research clinicians both in AS and peripherally associated as in “bone” and “gut” experts.

2008

The TASC Genetic Study identifies two new genes, ERAP1 and IL23R, that play a role in susceptibility to ankylosing spondylitis. This is the most significant breakthrough in AS research since HLA-B27 was uncovered 34 years ago. Together with HLA-B27, these genes account for roughly 70 percent of the overall cause. SAA played a significant role in making the study possible. SAA oversaw the nationwide recruitment of patients and families for the study.
2009

SAA completes development and production of the first-ever training video for emergency first responders, titled “Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders”. The program is accredited by CECBEMS (Continuing Education Coordinating Board for Emergency Medical Services); First Responders can receive continuing education credit for this training. The program has been adopted by hundreds of Fire Chiefs in the US and by several states, including FL, which has made it part of its mandatory curricula training for first responders.

Randy Chism (right) - an AS patient as well as Firefighter and Emergency Medical Technician (EMT) in Petaluma, CA stars in/ is featured in SAA's emergency first responder training video in 2009.

2010

Two more genes implicated in AS, ANTXR2 and IL1R2, are discovered by the TASC genetic study.

2011

SAA launches the second “AS Life Impact Study” to poll those affected about onset of symptoms, diagnosis, treatments, medications and quality of life issues.

The TASC genetic study uncovers three variants in the RUNX3, LTBR-TNFRSF1A and IL12B regions of the genome as well as additional areas that also seem to play a role - PTGER4, TBKBP1, KIF21B and CARD9. Other genetic suspects include CDKALI, TRADD and STAT3.

2012

SAA receives its fourth consecutive Four Star Charity Navigator Award, signifying that SAA outperforms most other charities in America in its efforts to efficiently manage its finances (your donations.) Fewer than 10% of the charities evaluated are afforded this level of distinction.

SAA establishes its annual Young Investigator Award which recognizes outstanding “contributions to the care and understanding of patients with spondyloarthritis.” The award winner receives a $10,000 grant from SAA for use in spondyloarthritis research.

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

2013

The American College of Rheumatology (ACR), the Spondyloarthritis Research and Treatment Network (SPARTAN) and the Spondylitis Association of America (SAA) partner to develop new ankylosing spondylitis and axial spondyloarthritis treatment guidelines, anticipated to be published in the summer of 2014.

SAA is currently in the early stages of developing a CME training program for radiologists. Titled the “Training Program in MRI for Radiologists in the Early Detection of Spondyloarthritis,” 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.

The Philadelphia, PA Educational Support Group members pose for a photo with group leader, Walt Lichmira at a meeting in 2013.
“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.”

~ Margaret Mead

“If it wasn’t for my chiropractor, I wouldn’t be able to get out of bed most days.” I’ve heard that and similar statements from friends and family members for as long as I can remember.

While many people swear by regular chiropractic sessions, doctors in general (and SAA’s Medical & Scientific Advisory Board specifically) do not recommend aggressive chiropractic treatment for those with any form of spondyloarthritis.

“Anyone with limited spinal mobility due to spondylitis should avoid manipulation of their back or neck by chiropractors and masseurs because it can be dangerous,” says Dr. Muhammad Asim Khan, rheumatologist, researcher, and AS patient. Dr. Khan explains that chiropractic treatments have sometimes led to spinal fractures and neurological complications, especially in people with fusion (extra bone growth) due to spondylitis.

Studies show that ankylosing spondylitis patients have an eleven-fold greater risk of spinal fracture.

According to a 2013 article in Clinician Reviews, a 57 year old man who had been diagnosed with ankylosing spondylitis 10 years previously was admitted to the emergency room with several fractured vertebrae after undergoing high-velocity manipulation by a chiropractor.

This individual and his chiropractor both knew he had a fused spine and, still, injury resulted. Even more at risk are the undiagnosed who, perhaps logically, assume their pain is the result of a mechanical injury and so enter into the treatment without putting any precautions into play.

Of course, gentler chiropractic modalities - such as electrotherapy, ultrasound, PT, exercises, light massage, etc., can provide a great benefit for arthritis patients, under certain conditions, including those with spondylitis. The challenge is to ensure that these medical practitioners can spot the potential signs of undiagnosed spondylitis as well as knowing their limitations when it comes to handling SpA patients who they know to have spinal or cervical fusion.
Regardless of whether or not chiropractic manipulation is indicated for SpA patients, the reality is that many will seek this treatment, either pre or post diagnosis. The goal is to ensure that the chiros know the signs to look for in the undiagnosed and the precautions to take when treating the ones with a confirmed diagnosis, including working in conjunction with the patient’s rheumatologist. This is where our supporters come in.

Back in April, Spondylitis Awareness Month, we launched a targeted appeal to our Facebook fans and friends to help us launch a campaign to educate chiros on recognizing spondylitis – before considering a regimen of spinal manipulation.

And 27 people responded (perhaps you were one of them?) Because they did, we were able to place a full-page interactive ad in the largest, most prestigious chiropractic news magazine, the ACA News. In it, we urged practitioners to log onto our website and take a short “refresher quiz.” Some interesting results from the chiropractors who took the quiz:

- Is the disease rare? (correct answer - no) – 36% got it wrong
- Is inflammatory back pain a hallmark of the disease (correct answer - yes) – 36% got it wrong
- The HLA-B27 gene test is a definitive diagnostic blood test for AS (correct answer - no) – 57% got it wrong

And — perhaps the most distressing of all -

- Chiropractic adjustments are an indicated treatment for SpA patients (correct answer - false). – 69% got it wrong

The good news? Each and every one of those chiropractors who took the time to take our quiz, the quiz these 27 donors made possible, now has the correct answers. Many have requested additional materials and even thanked us for providing them with the information.

Together, SAA and this small group of supporters went out to 30,000 chiropractors. And if we keep working together we’ll continue our campaigns to alert the ophthalmologists, the nurse practitioners, the OB-GYNs and the PCPs to the warning signs of spondylitis.

If we can achieve these results with such a small number of donors, imagine what we can do if everyone who’s reading this takes a moment to log on to spondylitis.org/donate or picks up the phone (800-777-8189) and donates even $5 or $10?

We can prove Margaret Mead right and change the world.
MacKenzie Sheppard received a unique assignment from her English teacher: Do any project you like as long as it benefits the community. So she decided to help benefit SAA’s quest for the cure of ankylosing spondylitis by holding an event called, “Songs for Sisters” - a showcase of music arranged by her family in honor of her sister, DeLaney, who was diagnosed with AS two years ago. We spoke with MacKenzie about the fundraiser that ended up raising $5,050 for SAA.

**SAA: What motivated you to plan this fundraiser?**

MS: As a high school student, I get assigned projects on a regular basis, but most of them have the same idea: read a book or write a report. This past year my English teacher assigned me a DIY (do it yourself) project, which had rather interesting directions. I had the opportunity to pick something of my choosing for my project as long as it benefited the community. From the start I wanted to sing for my project, and soon I thought close to home. My sister was diagnosed with AS almost two years ago and it has been rough each and every day. Though it has been difficult for such an athletic young woman, she doesn’t stop fighting. Day in and day out she pushes through the pain and battles the disease. She is so strong and such an inspiration. My sister DeLaney is the reason why I wanted to raise money for such a wonderful cause.

**SAA: What was the event like? How did it go?**

MS: The event itself was an amazing experience for everyone! We had all of our family there - aunts, uncles, cousins six times removed! Everyone was there and those who weren’t wished they were. We had almost 400 people in attendance and ended up raising over $5,000. The best part of the night was in the middle of the concert. I had already explained to the audience what AS is and how it has affected my family. I was in the process of telling them how blessed I am to have such a beautiful, strong, inspirational sister to be able to do something like this for, but I couldn’t help the tears that poured down my face. The knot in my throat wouldn’t let me speak, but the one thing that came out was, “I love her.” At that moment my sister, DeLaney, ran on stage into my arms and gave me the greatest hug ever.

**SAA: What tips do you have for others who are considering planning a fundraiser of their own?**

MS: Stay organized! That was my best friend! I had to be ready for things to go wrong and have a backup plan. With the help of my closest friends and family, we were able to keep things going and put on a wonderful concert.

**SAA: What would you like the world to know about spondylitis, and the people who have it?**

MS: Keep fighting! Never give up! Though it may be difficult at times, there are people out there who are willing to stand up to Ankylosing Spondylitis. People like me. So stand with me and let’s do what it takes to find the cure for AS.

*Songs for Sisters: Singing for DeLaney*

Mackenzie Sheppard received a unique assignment from her English teacher: Do any project you like as long as it benefits the community. So she decided to help benefit SAA’s quest for the cure of ankylosing spondylitis by holding an event called, “Songs for Sisters” - a showcase of music arranged by her family in honor of her sister, DeLaney, who was diagnosed with AS two years ago. We spoke with MacKenzie about the fundraiser that ended up raising $5,050 for SAA.

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Regan’s Hit-a-Thon for Spondylitis

On Saturday, June 22, Regan Sinclair - the 13-year-old first baseman and pitcher for Fort Belvoir’s Rangers baseball team - hosted a “hit-a-thon” fundraiser for the Spondylitis Association of America at Fort Belvoir, VA. Players from local little leagues and travel baseball teams hit balls from a pitching machine or coach, and with the help of donors and sponsors raised nearly $4,000 for SAA. We asked Regan about the event and why he got involved...

**SAA: What motivated you to plan this fundraiser?**
RS: I’ve had pain since I was four and I am hopeful that one day there will be a cure or better treatments for people like me. I picked SAA to fundraise for because my doctor at the NIH recommended it. After we checked SAA out, we thought it was a good organization that is trying to help people.

**SAA: What was the event like? How did it go?**
RS: The event was a lot of fun! We had about 20 kids participate and raise funds. Our goal was $2,000 and we raised about $4,000. We are very excited that the fundraiser was so successful. I had a great time hanging out with the other guys that came to support our event. I thought it was really cool that a local bat maker donated a custom bat made just for this event. One of my teammates won it by having the farthest hit.

**SAA: What tips do you have for others who are considering planning a fundraiser of their own?**
RS: Anyone looking to host a fundraiser should start early and get good volunteers. You also want to reserve your location early.

**SAA: What would you like the world to know about spondylitis, and the people who have it?**
RS: I want people to know that even though I have spondylitis, I am just like any other kid. I like to play baseball and other sports with my friends. I just have to be a little more careful about not overworking myself.

SAA thanks both Regan and MacKenzie for their amazing work in raising awareness of spondylitis in their communities, and their dedication to the quest for a cure. Their combined efforts raised close to $10,000 for spondylitis research, advocacy, education, and support! A big round of applause, and our heartfelt appreciation to both of these young people and their families.

If you’d like to learn more about fundraising for SAA, please contact Robin Kindrick toll free at 1-800-892-1616 x225, or by email at robin.kindrick@spondylitis.org.
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*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](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.
Although nearly everyone experiences the sensation of pain similarly—at least in a biological sense—studies show that there are significant differences in the way people express their pain and how they expect others to respond to their discomfort. Furthermore, the perception of pain and behaviors associated with it are influenced by an array of social and cultural variables.
In a study published in the journal *Medical Anthropology: Cross-cultural Studies in Health and Illness* in August 2012, a team of researchers from Mexico studied how the chronic pain associated with ankylosing spondylitis (AS) has altered the lives of Mexican patients. By encouraging AS patients to tell their stories, the study offers an anthropological perspective of chronic disease to obtain a better understanding of the chronic pain experience. The work of the study’s lead author, Ingris Peláez-Ballestas, MD, PhD, of the Hospital General de México, focuses on the social and cultural impact of rheumatic diseases and the role of narrative in understanding chronic diseases in Latin America.

While pain is universal, people’s response to pain is not. According to Dimensions of Culture, an organization based at the University of Colorado School of Medicine that provides cross-cultural education and resources for health-care professionals, culturally based responses to pain can be considered either stoic or emotive. Stoic individuals tend to be less expressive about their pain and are more likely to “grin and bear it.” Emotive individuals, on the other hand, are more likely to verbalize their expression of pain and expect others to validate their discomfort.

Peláez-Ballestas and her colleagues say that Western cultures consider pain an “undesirable phenomenon” against which people struggle and search for relief. Mexico, they write, has become an “analgesic society,” where pain is linked to the physical body as well as suffering of the mind.

**Narratives tell story of pain**

In their study, the researchers focused on AS because “it is a disease that can cause physical disability, which may jeopardize an individual’s productive life at any time.” AS has existed in Mexico since before Columbus sailed to North America and has been identified at Mayan burial sites dating to 600 – 1000 AD. In Mexico today, though, many patients do not clearly understand the impact of AS on health and quality of life, and many patients have difficulty coping with a future filled with pain.

The study examined 44 patients, from a wide spectrum of demographic and socioeconomic backgrounds, who met the ESSG (European Spondyloarthropathy Study Group) diagnostic criteria for undifferentiated spondyloarthropathy or AS. The researchers conducted private one- to two-hour interviews with each of the participants, recording narratives on their experience with chronic pain. They then compared the narratives with other findings reported in the anthropological literature and identified common themes as they related to medical anthropological and philosophical theories of pain. The participants’ experiences with pain were influenced by family members, the biomedical system, and Mexican culture.

Throughout the narratives, participants illustrated their pain by using metaphors that “allowed a better understanding of their suffering,” say the researchers. Some compared their pain to lights or drills—“Pain even made me see colored sparkles, like lights,” said one. Peláez-Ballestas says these metaphors are useful in helping clinicians, family and friends better understand the experience of chronic pain and to help others make sense of it. Some of the participants’ narratives fell into symbolic models of pain developed and named by Bárcena:

- The “Heroic Model”, in which pain and suffering reflect the greatness of spirit and assumes that the person experiencing pain can overcome the limitations it places on the body. One participant who fell into this category said, “This pain is not going to beat me.”
The “Victim Model”, which reflects sacrifice, suffering and resignation, leading one study participant to say, “The disease is already part of my life; there is nothing I can do about it.”

None of the participants fell into a third model, called the “Esthetic Model”, in which pain is incorporated into a person’s existence as simply another element of life.

**‘Crisis of presence’**

Through their collection of patient narratives, the researchers were able to identify a new pain model, which they coined the “Not-Belonging” model. “The person whose experience fits into this model,” says Peláez-Ballestas, “perceives pain as an entity parallel to his or her own life; while pain dominates their life, they also consider the pain to be an independent entity.”

The Not-Belonging model finds its roots in literature. In his book *Davalú o el dolor* (Davalu or the Pain), Spanish author Rafael Argullol called pain “a beast that dwelled inside me at the same time.” Of pain, María Luisa Puga, the Mexican novelist, wrote: “I lost the past and the future . . . I am in this rare and long present which keeps me from seeing where I am going, and it enclosed me with the pain, two unwilling passengers inside an empty train car.”

While experiencing AS and its symptoms, many patients can lose the structure of social and cultural belonging due to isolation, which, in part, is due to a lack of understanding—the researchers call it a lack of credibility—about their pain. For many AS patients in Mexico, the United States and elsewhere, the search for a diagnosis can lead them from physician to physician before a diagnosis is made. The experience associated with this search may also lead to social isolation, due to this lack of understanding and dearth of answers to questions about the individual’s discomfort.

Thus, the researchers conclude, AS is a “crisis of presence” for many patients. This concept refers to the loss of being-in-the-world that individuals may experience at some point during their life. Many said the disease first appeared as a crisis, a loss of sense in everyday life. AS, the researchers say, is an illness in which chronic pain and disability constitute a sense of suffering, alongside this “crisis of presence.” According to one participant, pain produces the feeling of loss of sense of self: “When I am in pain, I am not myself anymore.”

**Not Belonging, but not lost**

While the Peláez-Ballestas study focused on Mexican patients with AS, the simple fact that pain is universal means that the concept of Not-Belonging applies across cultural boundaries—from those who are stoic about their pain to those who are expressive.

“Living with pain day to day becomes a ‘habit’ or a ‘custom,’” write the researchers, “and the pain is perceived as ‘part of the family.’ People who suffer from chronic pain know that they may have company for the rest of their lives.”

Through the development of their Not-Belonging model, Pelez-Ballestas and her colleagues hope that families, the medical community and the general public—not only in Mexico but worldwide—can better understand AS patients and help them comprehend life with chronic pain. In turn, that understanding may reduce patients’ sense of isolation and bring a true sense of Belonging.

**References:**


**By Scott P. Edwards**

*Scott P. Edwards is a freelance health and medical writer based in Holliston, Mass. He has written for Harvard Medical School, Dana-Farber Cancer Institute, the Salk Institute for Biological Studies, and Nature Publishing Group.*
Connecting with others who understand and can relate to our struggles is a universal human desire. To know that we're not the only ones going through this and someone genuinely understands is a comfort and a source of strength. It is also hope. SAA provides a number of ways to connect with others and find support, share information and more...

Let SAA Help You Connect At StopAS.org/connect

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Donna Everix, PT, MA, expert physical therapist in spondylitis, gently guides four people with varying degrees of spondyloarthritis through a series of special stretching and strengthening exercises designed to help them retain strength and range of motion. Length is approximately 50 minutes. Special SAA Member Price: $15.00.

“STAND TALL” FOR YOUR CAUSE - SAA CONVERSATION STARTERS

Stand Tall Awareness Bracelets
STAND TALL against AS and related diseases with our silicone awareness bracelets! These bracelets are sold in packages of 10. The package includes 6 medium sized, 2 children sized and 2 large sized. Special SAA Member Price: $15.00.

Official SAA Mugs
Holding 14 ounces of your favorite beverage, this heavy, oversized mug features a large ear shaped handle and boasts the SAA logo on each side. A great way to get the word out about a cause that’s close to your heart! $14.00 note: limited quantity!

Order online today at StopAS.org/store or call SAA Toll Free at 1-800-777-8189
SAA participates in the Combined Federal Campaign -- the largest and most successful annual workplace charity campaign. Simply enter CFC code #89466 on your pledge card during your agency's fund drive or contact your Human Resources Department or the Office of Personnel Management (www.opm.gov).

Please contact us if you have given anonymously through CFC so you can continue to receive SAA member benefits: hhart@spondylitis.org or call 800-777-8189 x226