What Is Axial Spondyloarthritis (AxSpA)?

The Tumor Necrosis Factor-Alpha (TNF-α) Blockers: An Overview

Where To Go For Assistance With Medical And Prescription Costs
Dear Readers,

There may be some good news ahead for those diagnosed with what has been described as early AS or axial spondyloarthritis (AxSpA). AxSpA includes both ankylosing spondylitis (AS) and non-radiographic AxSpA (nr-AxSpA). The two conditions share similar clinical, imaging, and laboratory features, but patients with nr-axSpA do not have radiographic sacroiliitis and are considered to have an earlier form of AS, although not all will progress if left untreated. AxSpA can be equally as painful as full-blown AS and equally challenging for the physician to manage adequately. To make matters worse, there are currently no drugs licensed for the treatment of nr-AxSpA. Furthermore, what this means on a practical level is that if non steroidal drugs do not perform adequately in managing symptoms, there are no advanced medications available to this group of patients, who are predominantly women.

Today, new paradigms have been proposed to formally identify this disease category. A definitive classification has the potential to offer not only specifically approved treatments but also mechanisms to support accelerated diagnosis at a much earlier stage after symptom onset.

Recently, a federal advisory panel voted narrowly for the approval of one of the TNF-inhibitor biologics in the treatment of axial spondyloarthritis but voted against expanding another TNF-inhibitor’s already existing indication for AxSpA to include the non-radiographic forms of the condition.

As research clinicians struggle to agree how best to classify nr-AxSpA, and drug companies, makers of TNF-inhibitor biologics, work toward advancing FDA licensing in this disease category, we look forward to a future when there will be treatments, some which already exist and some in the pipeline, that will expand medicinal options for all patients.

Laurie M. Savage
Executive Director

Editor’s Note: Please see page 4 for more information on axial spondyloarthritis.
Intubation, Anesthesia, Spondylitis

I must tell you: I was VERY pleased that you all found a way to incorporate my thank you message with a broader explanation of the challenge of surgical anesthesia after AS fusion. That was wonderful! I hope it makes a difference in many other lives.

Again, bushels of thanks! I’m awfully glad the SAA - that’s all of YOU - is here for us!

~DEBBI, Brandon, FL

Editor’s Note: We also hope the three surgery stories included in the Summer 2013 issue - including Debbi’s - will make a difference. In “Airway, Airway, Airway: Anesthesia & Spondylitis”, the second of the three articles, Dr. Jai S. Lee recommends that, “...patients with an anticipated difficult airway should be referred by the surgeon to see the anesthesiologist prior to the procedure.”

Thank You For Personal Stories In Spondylitis Plus

I do not think any part included in this letter will be published, but must finally commend your quarterly publications as being one thing in my life which have helped me realize who I really am. Many years worth of your articles are kept on file for my need of reassurance of what I am experiencing. They give validation of my health problems rather than having to defend myself to anyone, even professionals in the early years, telling me to take a tranquilizer and get out of the house.

I am not one to be able to make a point with short sentences or a quick e-mail. I am an 80 year old widow with 3 sons, a daughter, 13 grandchildren and 2 great-grandsons who make my life complete and enable me to stay in my own home and who recognize I am not always able to do the norm. My incapacities are over-ride by keeping the mind busy with word puzzle books and writing long letters at rest periods.

Due to severe allergies to drugs, foods and environment, the specialists have not been able to find anything my body tolerates as far as meds are concerned, so Tylenol, on a daily basis, ¼ of a mild muscle relaxer and five days of 100mg of Doxycycline help during the “down” times (suggested in one of your articles). Routine: work…rest, etc.

Thus, the articles of reactions from actual patients validate to me that I am not alone. The explanations of what the disease can evoke or cause to happen also have been a great help to me so that I know which path to take in as natural a way as I can.

In short: Congrats for your quarterlys.

~ARDELLE, Robesonia, PA

Editor’s Note: Our sincere thanks for your compliments and continued support, Ardelle. You can read Ardelle’s spondyloarthritis story on pages 18 and 19 of this issue.
A relatively new term has been seen more and more in medical literature over the past few years: Axial spondyloarthritis (AxSpA). Although as of this writing it is not fully recognized as an official diagnosis by the National Institutes of Health (NIH) here in the United States, it has gained traction in Europe. This specific classification of spondyloarthritis was originally developed by the Assessment of Spondyloarthritis International Society (ASAS).

Dr. Jim Rosenbaum, Division Chief of Arthritis and Rheumatic Diseases at the Oregon Health & Science University, and past chair of SAA’s Medical and Scientific Advisory Board, describes AxSpA thusly:

“Once upon a time, we refused to diagnose ankylosing spondylitis unless the x-rays of the sacroiliac joints were abnormal.

“The problem is that the disease can be mild or it can take years before the x-rays show changes. And even when the x-rays are abnormal, interpretation is always subject to some debate.

“So the ASAS group in Europe has appropriately tried to define new criteria for the diagnosis such that x-ray changes are not required and that group preferred a new name: axial spondyloarthritis.”

A study published in May 2012 in Arthritis Care & Research regarding the prevalence of AxSpA described this classification as “a form of spondyloarthritis in which the predominant symptom is back pain, and where radiographic sacroiliitis might or might not be present. If definite radiographic sacroiliitis on plain X-rays is present, the disease can be classified as ankylosing spondylitis (AS).”

The study, “Prevalence of axial spondyloarthritis in the United States: Estimates from a cross-sectional survey,” found that as much as 1% of the adult United States population may have axial spondyloarthritis. This means that as many as 2.7 million adults may be affected by the disease if the classification of axial spondyloarthritis is used. However, the study authors note that “current U.S. SpA prevalence estimates may be lower than the true value” because of the way the data was collected. Thus,
even more may be affected than is estimated in the study.

The new classification can also affect how spondyloarthritis is diagnosed in terms of gender. In the Spring 2013 issue of *Spondylitis Plus*, Dr. Jessica Walsh wrote that, “When broader definitions are used to identify people with spondyloarthritis in the pelvis and/or spine (axial spondyloarthritis), the prevalence is similar in men and women.”

In our Summer 2013 issue of *Spondylitis Plus*, Dr. John Reveille, Professor of Internal Medicine, Director of The Division Of Rheumatology and Clinical Immunogenetics at the University of Texas Medical School at Houston and member of SAA’s Board of Directors, argued that the axial spondyloarthritis classification is one of the ten most important questions facing the “Spondyloarthritis Community.”

In regards to AxSpA, Dr. Reveille wrote, “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 sacroiliac joints, HLA-B27 positivity, enthesitis, uveitis, positive family history, etc). This condition is called axial spondyloarthritis (AxSpA), and many consider AS to be part of this disease spectrum. Women with normal inflammatory blood markers who have AxSpA are more likely NOT to progress to AS. This has led to the development of criteria for axial spondyloarthritis as a disease entity, although the accuracy of these criteria as applied by doctors to patients in the general population is still being debated.”
Overview

The Tumor Necrosis Factor-alpha (TNF-a) blockers are biologic medications that have been shown to be highly effective in treating not only the arthritis of the joints but the spinal arthritis associated with ankylosing spondylitis (AS) and related diseases.

As of this writing, there are four anti-TNF therapies used in the US that have an indication from the Food and Drug Administration (FDA) to treat AS and other diseases in the spondyloarthritis family (presented in order of initial FDA approval):

Enbrel (etanercept) - Originally approved in 1998 for rheumatoid arthritis (RA), Enbrel is self-injected and normally administered 1-2 times weekly. It has received indications for use in the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Rheumatoid Arthritis
- Juvenile Idiopathic Arthritis
- Plaque Psoriasis

Remicade (Infliximab) - Approved in 1999 initially for RA. Remicade is given by infusion - through an IV drip - thus one must visit a doctor’s office or infusion clinic to receive the medication. The infusion can take around 2 hours. The infusion cycle varies per individual, but is commonly done every 6-8 weeks. It has been approved by the FDA for the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Crohn's Disease
- Ulcerative Colitis
- Rheumatoid Arthritis
- Plaque Psoriasis
**Humira (adalimumab)** - Humira was given its first indication in 2002 for RA. Humira is self-injected and normally administered 2-4 times each month. It has received approval for use in the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Crohn’s Disease
- Ulcerative Colitis
- Rheumatoid Arthritis
- Juvenile Idiopathic Arthritis
- Plaque Psoriasis

**Simponi (golimumab)** - Approved in 2009 for rheumatoid arthritis, psoriatic arthritis, and ankylosing spondylitis. Simponi is the newest TNF-a blocker to become available. Simponi is self-injected and administered once each month. It has received approval for use in the following conditions:

- Ankylosing Spondylitis
- Psoriatic Arthritis
- Rheumatoid Arthritis

### Quick Reference Table

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<th>Trade Name</th>
<th>Generic or Brand Name</th>
<th>Dose</th>
<th>Frequency</th>
<th>Total Dose (Range)</th>
<th>Route of Administration</th>
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<td>Enbrel</td>
<td>Etanercept</td>
<td>25-50 mg</td>
<td>1-2 times/week</td>
<td>50 mg/week</td>
<td>Subcutaneous injection</td>
</tr>
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<td>Remicade</td>
<td>Infliximab</td>
<td>3-6 mg/kg</td>
<td>Given at variable intervals</td>
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<td>2-4 times/month</td>
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</tr>
<tr>
<td>Simponi</td>
<td>Golimumab</td>
<td>50 mg</td>
<td>1 time/month</td>
<td>NA</td>
<td>Subcutaneous injection</td>
</tr>
</tbody>
</table>

### How do anti-TNF therapies work?

Each of the above mentioned medications 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.

The National Institutes of Health describes cytokines as follows: “Cells of the immune system communicate with one another by releasing and responding to chemical messengers called cytokines. These proteins are secreted by immune cells and act on other cells to coordinate appropriate immune responses.”

It should be noted that each TNF-a inhibitor works in a slightly different manner within the body to block TNF-a. Thus, if one does not have a positive effect in a particular individual, a different one might.

In an April 1, 2013 article titled, “TNF Inhibitors: Safer than we thought,” Rheumatologist Dr. Irwin Lim states that, “The good news is that there has been no definite signal, after a decade of widespread use, in patients all over the world, of an increase in incidence of solid cancers. By that I mean breast cancer, colon cancer, etc.

“Lymphoma was always a worry. Patients with rheumatoid arthritis already have a higher risk of lymphoma...To date, there has been no increase in lymphoma seen in patients on TNF inhibitor therapy.”

Dr. Lim adds, however, that rheumatologists should remain vigilant regarding side effects.

Please also see the following websites for important, additional safety information:
- Enbrel: [http://www.enbrel.com/possible-side-effects.jspx](http://www.enbrel.com/possible-side-effects.jspx)

### What are the Potential Side Effects?

The most serious known side effect of the TNF-a blockers is an increased frequency of infections. Latent tuberculosis is also a risk factor, therefore a TB test is required before starting any of the TNF therapies. Latent TB is an infection of Mycobacterium tuberculosis, but there is not active tuberculosis disease. Active tuberculosis is contagious while latent tuberculosis is not. It is not possible to get TB from someone with latent tuberculosis.

Fungal infections have also been reported, such as pulmonary and disseminated histoplasmosis, coccidioidomycosis, and blastomycosis.

A very rare possible complication is increased frequency of cancer, especially of the blood (leukemia) or of the lymphatic system (lymphoma). However, this has not been fully substantiated.
Patients on Biologics Should Avoid Nasal Spray Flu Vaccine

It is important for spondylitis patients planning to get vaccinated against the flu to discuss the various options of vaccine delivery with their rheumatologists.

American College of Rheumatology researchers have found that patients currently being treated with TNF-a inhibitors should not be vaccinated using a nasal spray treatment. FluMist, is a “live attenuated vaccine; therefore it is contraindicated in immunosuppressed patients. Immunosuppressed patients should be strongly encouraged to receive vaccination against influenza using the standard injectable inactivated flu vaccines,” according to a report published in ACR’s Hotline newsletter.

TNF-a Inhibitors & Pregnancy

On the use of this class of medications during pregnancy, Monika Oestensen, M.D. writes, “The TNF-alpha inhibitors have not been found harmful to the offspring in animal studies. Experience from human pregnancy is limited but thus far reassuring. At the present stage of knowledge, TNF-alpha inhibitors should not be continued during pregnancy.”

Dr. Elain Adams adds the following on the topic: “There is a categorization that is applied to drugs, a), b) and c). Most drugs are what we call category c) in pregnancy. This means we have no controlled trials in which we are actually studying the effects of this drug in pregnancy. The reality is that this is not the kind of study that we would do. However, we can look at animal data. This can be somewhat helpful. Most of the time we are stuck with ‘natural observation,’ where for instance, there is a patient who was not intending the consequences of pregnancy, who was on the drug and we follow it along. There is growing data that these drugs are reasonably safe during pregnancy. The emphasis really is on ‘reasonably,’ because we don’t know for sure, but there is growing evidence that there are patients before and during pregnancy that are okay. All other things aside, I have to say that it would be safest if you can do without it. However, as the data grows, there may be circumstances in which life is intolerable without it and the risks are small enough that you can go ahead and continue it.”

As always, speak with your doctor if you have questions or concerns about the use of TNF-a inhibitors during pregnancy.

The Problem of Cost

Depending on individual insurance coverage and medical plans, the cost of TNF-a inhibitors can vary greatly, and copays can be quite high. That is one of the drawbacks to this class of drugs that impedes patient access to them.

Starting on page 9 of this issue of Spondylitis Plus you will find an extensive listing of Patient Assistance Programs that can help with the cost of various medications including the TNF-a inhibitors.
WHERE TO GO FOR ASSISTANCE WITH MEDICAL AND PRESCRIPTION COSTS

Managing the costs associated with healthcare of spondylitis can be stressful, and for many a financial burden. Below is a list of assistance programs that can help with the cost of medications, co-pays, and other healthcare needs.

*SAA does not endorse or recommend any medications or products for spondylitis, and always advises that you seek the counsel of a physician before initiating any treatment for spondylitis.

PATIENT ASSISTANCE PROGRAMS FOR HUMIRA (adalimumab)

HUMIRA Protection Plan
(800) 4HUMIRA
From the site: “The majority of commercially insured HUMIRA patients are eligible to pay $5 or less for HUMIRA with this savings card.”

The AbbVie Patient Assistance Foundation
(800) 222-6885
http://www.abbviepaf.org/
From the site: “The AbbVie Patient Assistance Foundation provides AbbVie medicines at no cost to qualified patients who are experiencing financial difficulties and who generally do not have coverage available for these products through private insurance or government funded programs.”

PATIENT ASSISTANCE PROGRAMS FOR ENBREL (etanercept)

Enbrel Support Card
(888) 4ENBREL
http://www.enbrel.com/ENBREL-support-card-program.jsp
From the site: “The ENBREL Support™ card provides financial support to eligible commercially insured patients when presented to the pharmacy.”

ENcourage Foundation
http://www.encouragefoundation.com/index.jsp
From the site: “ENcourage Foundation® is a nonprofit patient assistance program supported by Amgen and Pfizer that provides Enbrel® (etanercept) at no cost to qualifying patients with no or limited drug coverage.”

PATIENT ASSISTANCE PROGRAMS FOR REMICADE (infliximab)

Rebate and Prescription Assistance programs for REMICADE
http://www.janssenaccessone.com/pages/remicade/patientassist/intro.jsp
From the site: “This page has information about prescription assistance programs sponsored by relevant Janssen Pharmaceutical Companies as well as up-to-date information about independent foundations that may have available funding to help minimize drug costs for REMICADE®.”

PATIENT ASSISTANCE PROGRAMS FOR SIMPONI (golimumab)

Savings Cards and Prescription Assistance programs for SIMPONI
http://www.janssenaccessone.com/pages/simponi/patientassist/intro.jsp
From the site: “Information about prescription assistance programs sponsored by relevant Janssen Pharmaceutical Companies as well as up-to-date information about independent foundations that may have available funding to help minimize drug costs for SIMPONI®.”

OTHER PATIENT ASSISTANCE PROGRAMS AND DRUG DISCOUNT CARDS (COULD INCLUDE DISCOUNTS FOR TNF-A INHIBITORS AS WELL)

Chronic Disease Fund
www.cdfund.org/
Their focus is to provide assistance to those under-insured patients who are diagnosed with chronic or life altering diseases that require the use of expensive, specialty therapeutics.

www.stopas.org
**NeedyMeds Drug Discount Card**
SAA has partnered with NeedyMeds to provide a Drug Discount Card for prescription medications (see page 11 for more information). Anyone can use this card, but it cannot be combined with insurance, Medicare or Medicaid.

**HealthWell Foundation**
(800) 675-8416
www.healthwellfoundation.org
From the site: “A nonprofit, charitable organization that helps individuals afford prescription medications they are taking for specific illnesses. The Foundation provides financial assistance to eligible patients to cover certain out-of-pocket healthcare costs, including: prescription drug co-insurance, co-payments, and deductibles, health insurance premiums, and other selected out-of-pocket healthcare costs.”

**Merck Helps**
www.merck.com/merckhelps
From the site: “At Merck, we believe that no one should go without the medicines or vaccines they need. That is why the Company provides its medicines and adult vaccines for free or at discounts to people who do not have prescription drug or health insurance coverage and who, without our assistance, cannot afford their Merck medicine and vaccines.”

**Patient Access Network Foundation**
Toll Free (866) 316-PANF (7268)
www.panfoundation.org
From the site: “The Patient Access Network Foundation is a nonprofit 501(c)(3) organization dedicated to supporting the needs of patients that cannot access the treatments they need due to out-of-pocket healthcare costs.”

**Partnership for Prescription Assistance**
Toll Free (888) 4PPA-NOW (444-2669)
www.pparx.org
From the site: “The Partnership for Prescription Assistance brings together America’s pharmaceutical companies, doctors, other healthcare providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that’s right for them.”

**Patient Advocate Foundation Co-Pay Relief**
Toll Free (866) 512-3861
www.copays.org
From the site: “Patient Advocate Foundation’s Co-Pay Relief (CPR) Program provides direct co-payment assistance for pharmaceutical products to insured Americans who financially and medically qualify.”

**Pfizer Helpful Answers**
www.phahelps.com/pages/Find/FindAll.aspx
From the site: “Pfizer Helpful Answers’ family of patient assistance programs offer different services to match the unique needs of each patient.”

**RxAssist Patient Assistance Program Center**
www.rxassist.org
From the site: “RxAssist is a website with information, news, and a database that are all designed to help you find out ways to get affordable, or free, medications. The database includes information on the pharmaceutical companies’ patient assistance programs, or programs that provide free medication to low-income patients. RxAssist was created by Volunteers in Health Care, a national, nonprofit resource center for healthcare programs working with the uninsured.”

**RxHope**
Toll Free (877) 979-4673
www.rxhope.com
From the site: “You can apply here for Patient Assistance Programs offered by hundreds of manufacturers, as well as find information on programs offered by State and Federal government and by pharmaceutical companies.”

**Rx Outreach**
www.rxoutreach.com
From the site: “Rx Outreach is a patient assistance program (PAP) for people of all ages. The program makes prescription medicines affordable for uninsured and under-insured individuals and families.”

**Together RX Access**
(800) 444-4106
www.togetherrxaccess.com
From the site: “The Together Rx Access™ Card was created as a public service by a group of some of the world’s largest pharmaceutical companies, in order to provide savings on prescriptions to eligible residents of the US and Puerto Rico who have no prescription drug coverage.”
SAA has partnered with NeedyMeds to provide a Drug Discount Card for Prescription Medications!

To receive a complimentary Spondylitis Association of America NeedyMeds card, please contact SAA toll free at 1-800-777-8189, email us at info@spondylitis.org, or visit us online at stopAS.org/card to download an electronic version. To use your card, simply present it to a participating pharmacy to receive a discount on your prescription.

In September, 2013, those who used the Spondylitis Association NeedyMeds card saved an average of $46 per transaction. And 25 cents will be donated to SAA each time the card is used.

Who Can Use the Card?
Anyone regardless of income level, insurance status, residency, or age can use the card - but it can’t be combined with insurance, Medicare or Medicaid. There is no registration, no cost, and no paperwork. Multiple people can use the same card.

What Drugstores Accept the Card?
Over 54,000 stores throughout the country including all the major chains. On the NeedyMeds website there is a pharmacy finder. Go to www.needymeds.org/drugcard

The card may help with prescription drugs, over-the-counter medications and medical supplies, as well as pet prescription medicines purchased at a pharmacy. There isn’t a savings on every drug.

How Many Times Can I Use the Card?
There is no limit to how many times the card can be used or how many people can use the card.

What if I have Additional Questions?
Please visit www.needymeds.org/drugcard
For my senior project in High School, I am raising awareness for AS by doing a Half Ironman Triathlon on October 27th, 2013 in Austin, Texas (1.2 mile swim, 56 mile bike, and 13.1 mile run). I have always been a high goal-setter, and I'm excited for the commitment that comes with this! Ultimately I would like to help find a cure for AS. But more importantly I want to inspire others to know that regardless of what they are faced with, they can get through it, and refuse to allow a label to confine or define them.

"Ultimately I would like to help find a cure for AS"

After nearly four years I was fortunate enough to find an answer and a correct diagnosis to my medical struggles. However, because AS typically takes many years to diagnose, some people may not be as lucky as I was. It is my hope that with more information and a better understanding of this disease, further suffering will not be prolonged.

Everyone in life is faced with hardships and infinite nuances that set them apart from their peers. Living on an island across from Seattle, WA, being a 1st Team All-State Varsity lacrosse captain and having a 4.0 unweighted GPA sets me apart from others. Eating kale, chia seeds and quinoa by choice (or being gluten-free, dairy-free and sugar-free) also isn’t very common for most 18-year olds. Yet long before my diagnosis on 11/11/11, the most profound thing that set me apart was living with Ankylosing Spondylitis.
As a dedicated three sport athlete, I was comfortable being uncomfortable: sore, bruised and exhausted from competition. But starting in 7th grade, I began to experience unexplained pain in my neck, lower back and gluteus muscles. I wanted to ignore it, but I had a subconscious knowledge that something was wrong and that no dosage of Advil could heal it. I went to over three hundred medical appointments trying to find a diagnosis, all while missing school and suffering with the reality that the activities I loved and lived for hurt too much to do. My life had turned into a clinical experiment with blood tests, PT, OT, Chinese herbs, neurofeedback, biofeedback, acupuncture, counseling, Strain/Counterstrain, deep tissue massage, hypnosis, Qigong and late nights at the hospital, to name a few.

I was extremely fortunate to have the means and the support of my parents and family to keep looking for answers. Countless doctors told me that chronic muscular pain was my own doing; that it was all in my head, and that if I changed my mindset it would go away. They were wrong. After multiple wrong diagnoses, on 11/11/11 at 11am (really), I was given a concrete diagnosis of Ankylosing Spondylitis. Life as I knew it was forever changed.

I am hopeful that in the coming future a heightened awareness of AS will lead to quicker diagnoses. My experiences fuel me forward and motivate me every day. Training for an Ironman 70.3 is a testament to the support I have gained along the way, and a testament to the fire within me that questions the limits of how far I can go.

This is what I am doing and working towards. I hope you’ll support me in my goal to raise $11,000 as I train to complete an Ironman 70.3! Proceeds directly benefit the SAA (Spondylitis Association of America) that helps put us on a path to find the cure. Feel free to reach out to me with any questions or comments! Thank you for your support!

~Sallie Marx

Bainbridge Island, WA

Please visit Sallie’s site at http://salliemarx.wix.com/tri-as to follow her progress and show your support. Sallie has already accomplished an incredible amount of success by raising just over $7,500! - All while swimming 48,410 yards, biking 606 miles, and running 224 miles in her training for the challenge that is the Half Ironman Triathlon. We could not be more proud of this amazing young woman.

Our immense THANKS to Sallie and her wonderfully supportive family. Best of luck on race day, Sallie!
Have You Donated to SAA Recently?

SAA relies on donations from our generous supporters to produce and deliver the broad menu of programs and services that aim to inform, educate and advocate on behalf of all those affected by spondylitis. And so, a few times a year, we appeal to our friends in the spondylitis community to help us raise the money that enables us to continue our work as the single greatest source of spondylitis information, news and support in the nation.

If you haven’t sent a gift recently, please take a moment to consider just a few of the good works your donations make possible.

As the only US organization dedicating 100% of its resources to improving the lives of the spondylitis community — your community — SAA is the leader in spearheading groundbreaking research into the causes and the cure, providing up-to-the-minute news and educational materials, producing interactive and informative seminars throughout the country, and furnishing support and aid wherever it is needed.

That’s why we hope you’ll give as generously as you can, whenever you can. Your tax-deductible gifts help SAA fulfill its mission to be a leader in the quest to cure ankylosing spondylitis and empower those affected to live their lives to the fullest.

SAA IS A GUIDESTAR EXCHANGE GOLD PARTICIPANT

The Spondylitis Association of America (SAA) is pleased to announce that we’ve achieved the GuideStar Exchange Gold Star participation level, a leading symbol of transparency and accountability provided by GuideStar USA, Inc., the premier source of nonprofit information.

This level demonstrates SAA’s deep commitment to nonprofit transparency and accountability, as we share a wealth of up-to-date information about our work to our constituents and supporters and with GuideStar’s online audience of nonprofits, grant-makers, individual donors, and the media.

In order to be awarded the GuideStar Exchange Gold logo, SAA had to complete every required field of the nonprofit report page on www.guidestar.org, providing a comprehensive look at our organization, from mission and goals to community programs.

More than 1.2 million charities are rated by Guidestar. As of this printing, only 1,031 have achieved the top rank of Gold Star.

SAA is one of them.
SAA NAMED ONE OF AMERICA’S TOP 10 CHARITIES

MSN.com posted a story in 2012 on the top 10 ranked charities in all of America. The Spondylitis Association of America (SAA) was ranked 9th in the USA overall.

MSN.com writer Greg Emerson says of SAA, “With revenue of just over $1.2 million last year (none of which came from the government), the California-based organization might not be able to dispense funds to all sufferers, but the informational materials it provides, in addition to the direct assistance to patients, multiply its reach significantly for a disease that is rarely fatal but can have important consequences for patients’ mobility and quality of life.”

SPONDYLITIS ASSOCIATION OF AMERICA AWARDED A TOP-RATED HEALTH NONPROFITS RANKING

The Spondylitis Association of America is one of the top charities in the US - and that’s not just talk. SAA has now been awarded a Top-Rated Health Nonprofits ranking by GreatNonProfits.org as well!

SPONDYLITIS ASSOCIATION OF AMERICA RECOGNIZED AS A “BEST CHARITY IN AMERICA”

The Independent Charities Seal of Excellence is awarded to the members of Independent Charities of America and Local Independent Charities of America that have, upon rigorous independent review, been able to certify, document, and demonstrate on an annual basis that they meet the highest standards of public accountability, program effectiveness, and cost effectiveness. These standards include those required by the US Government for inclusion in the Combined Federal Campaign, probably the most exclusive fund drive in the world.

Of the 1,000,000 charities operating in the United States today fewer than 2,000 have been awarded the Best in America Seal.

So, when giving to SAA you can always be sure that your donations are used responsibly. There will never be a better time to make a financial commitment to advancing the shared goals of all those affected by spondylitis.
Just after 11:30 AM on June 2nd, 2013, I crossed the finish line of the Deadwood Mickelson Trail Half Marathon in Deadwood, South Dakota. In 3 hours, 37 minutes & 45 seconds, my friends and I power-walked (and ran a bit) 13.1 miles through the Black Hills. Just four days prior to the event, we had walked a 7.15 mile portion of the trail in about 2.5 hours, so I never expected to be able to complete the half marathon in under four hours – never mind in just over three and a half!

For the average person, participating in a half marathon is a real challenge. It takes training, dedication (or insanity!) and the heart to pull it off. As a person who has lived with Ulcerative Colitis, Crohn’s Disease and Ankylosing Spondylitis my entire adult life (more years than I’d like to admit thank you very much), the idea of something like this was quite frankly….NOT an idea! At least not in my mind. I was never the athletic kid; I was the kid playing the piano or being the band geek. Running? Ha!!

Once my illnesses took over my life, worries like how my back could handle something or where the next bathroom would be found, ruled my life. So the idea of a half marathon induced panic or pain just thinking about it. My fellow Crohn’s & Colitis friends know what our thoughts are: “What if I have to poop and there is no bathroom? I SO am NOT pooping in the woods!!” Not the sexiest thing to talk about I know, but that is our reality.

Hanging around in the freezing cold waiting for the starting gun, it was fun to see the various tee shirts of people promoting their causes. It made me wonder what other stories were out there. As Batman slid through the crowd towards the runners’ starting locations, it never occurred to me that he had a story. I just figured it was something fun. I later learned in the newspaper that his name is Tim, he is 26 years old from Pennsylvania, and is a Testicular Cancer survivor. Daily running is what helped him heal and as a lifelong fan of Batman he thought he could lift others’ spirits by wearing this costume. Sunday was his first 1/2 marathon too. Gives me goose bumps, how about you?

Everyone out there on the course had their own goals. Some were hoping to cross the finish line at a certain time, others striving to beat last year’s marathon time. Perhaps
others were hoping to have their fastest mile. For me – I just wanted to get to the finish line…in one piece….without having to be carried home…or to the hospital.

Keeping up a respectable pace, I was amazed when the first hour was done and we were already heading in to our fifth mile. I started sending text messages to my husband because I was worried that we were going to finish a lot sooner than projected, and he and my mom were going to miss being at the finish line when I crossed it. I imagined crossing the finish line and tears would well up in my eyes. It was particularly important for my mom to be there – to see what I accomplished. My mom has been there through all the health crises (and then some). It was about time there was something REALLY good that happened with my health and my body. In my excitement about having my mom there, I exclaimed to my girlfriend in a loud voice with arms raised as though I was a preacher on a Sunday morning behind the pulpit, “She must bear Witness to my Accomplishment – Yes, She Must!!!!” Needless to say my friend sped up a bit, so I had to jog to catch up with her. I suddenly realized, I just jogged and it didn’t hurt!

As I crunched along the trail, I thought back to the time when I couldn’t walk because of the damage in my spine from the fistula caused by my Crohn’s and the fractures from the Osteoporosis. I remembered using my walker to take slow, painful steps from the living room to the bathroom that would bring tears to my eyes from the pain, frustration, and fear I lived with on a daily basis. I thought back to recovering from my back-to-back surgeries in 2009 and how my right hand was practically glued to my left side to provide a modicum of relief from the nerve pain from the surgical site where my kidney used to be. Every step or breath I took was like a knife stabbing me between the ribs. After every surgery I slowly regained my strength. I always pushed to get back to “normal.” When I started walking to regain my strength, I never thought of those steps as a precursor to a marathon.

Around the 7th mile, my feet really were starting to hurt. I was having some dull aching in my left side where I only have periodic nerve pain, and my hip flexors were starting to swear at me. Rather than focus on what was hurting, I changed my thought process. I brought Reiki in to my energy centers and visualized light filling my body and carrying me down the trail. I channeled Louise Hay by creating my own positive affirmation. I just repeated to myself “I am walking with ease.” I focused on anything and everything that was the opposite of pain. I brought in my lessons from one of my favorite Buddhist teachers Jack Kornfield. When my feet were sending shooting pains, I just noticed it and said “tingling….tingling….tingling….it’s just nerves tingling and its temporary.” I heard his voice over and over in my head, and the pain subsided.

This marathon…besides being an expression of my healing, was an opportunity to put into use the many things I’ve learned over the years. That investment in my personal library of inspirational/self-help/spiritual books was truly worth it. I didn’t fall back in to my old patterns of focusing on the pain. Instead my focus was on the finish line and how I would feel when I got there. My focus was on the energy of nature and our interconnectedness. My focus was a celebration of life, of my life and the ability to not just put one foot in front of the other…but to run those last few steps across the finish line and declare my willpower the winner.

About Katie:
Katie is a native of Connecticut and now lives in northeast Wyoming with her husband Dwayne. Katie’s health journey has been a long road that started with Ulcerative Colitis, took a turn adding Ankylosing Spondylitis and Osteoporosis; forked in the road to Crohn’s Disease, and finally ran into a stop sign at kidney failure...all before she turned 40. Over the past three years, she has embarked on a path of healing using a variety of methods including meditation and mindfulness, Reiki, exercise, and positive affirmations. She is sharing her story with the goal of helping and inspiring others dealing with chronic pain and illness to live more fully, no matter what.

Visit Katie’s blog at www.blackhillsreiki.wordpress.com to read more of her writing.
I am a widowed, 80 years young gal and still on my feet...wonder of wonders! As a 6th grader, after each morning of the pledge to the flag and opening prayers were done, I would be at the teacher’s desk telling her I had to go home because I was ill. There were no definite symptoms; I just felt nervous, nauseous and unable to cope. I was thought to not want to attend school, but passed 9th grade psychological tests. After seeing a “Powwow” Doctor, a chiropractor, I finally was hospitalized by a neurologist for one whole month for complete bed rest. Unfortunately, I was not personally given the proper info on what had occurred. A file of my history would have been a huge plus to my future happenings.

My teen and birthing years of having 4 children were sort of a remission though I did not realize that other gals had no continual vibrations in their backs or debilitating fatigue. It was just a common reality to my life. After a hysterectomy when I was 34, it seemed that my body went into a downhill slope, but it took 12 more years before I heard the words: ANKYLOSING SPONDYLITIS

But guess what? I was relieved to have a name for my problems. Up until this point, everyone was telling me to “shape up”, “get a life”, or “stop complaining” to the point I really did think I had a mental problem. The last straw had been a visit to a heart specialist, to whom I was trying to explain my symptoms, and who turned to my husband and said, “Me thinks she doth protest too much”! The half hour drive home was filled with my husband’s derogatory, heart-breaking comments which resulted in my not contacting another doctor for 2 years.

The answer came from an orthopedic surgeon for whom I waited to see for over 2 hours. He finally entered the examining room where I sat with my backless gown feeling this would be another lost cause. However, he looked at me, said, “Excuse me” and immediately walked back out. Okay…do I look that bad in the gown?” (Let’s just say that a sense of humor is what has gotten me this far in life and what every AS patient needs to have.) After coming back, the doctor explained that he had only looked at the x-ray and not the chart and had expected to see a 75 year old. I was only 45 and realized I had a problem. So...I may be 80, but my back is now 110 - always 30 years older.

Along with the AS problem all these years, I also developed, at the age of 45, severe allergic reactions to foods, drugs and environment. I live on wheat and soy, pasta and a few fruits and vegetables; no meats, little sugar, minimum of dairy. I do not smoke and am allergic to wine and beer, or I would probably be over-consuming them to put me in “fairy land.” I also have Fibromyalgia and when I am in a true “slump”, I reach for the Doxycyline, taking 100mg a day for 5 days. I actually requested this from my family doctor years ago after reading an article in SAA’s quarterly, Spondylitis Plus. It works for me!

I have had many broken bones...three steel rods in my left thigh; steel plate and screws in left wrist and three titanium plates in my left cheek and other breakages. Thus, I am always thoroughly absorbed in the quarterlies SAA has been producing through the years and am one person who will testify that the articles have helped me more than any doctor’s visit has done for me. I have been doing back exercises for the last 40 years which have kept my back ramrod straight. However, I have not been able to use any of the prescription medications mentioned. One by one, I had to give them up due to severe reactions. My medical routine: Extra-strength Tylenol and rest. I did find one blood pressure medication: Benicar. I needed it due to pain spiking the pressure at a moment’s notice. I am, at this point, under only a family doctor’s care due to the specialist’s having no more roads to follow for me.

I was fortunate to receive a phone call a few years ago from a member of the SAA staff and she said I sounded much younger and in good spirits. Also, I am told I look younger than I am, but my retort is that they do not see the gravity-wrinkled, wet plaster-headed hair, 104 lb bony lady getting out of the shower! I need a cane when out of the house, the legs keep getting weaker and the feet are numb and burning at night. However, with 13 grandchildren coming in and out of the house, there are a lot of smiles put into my heart to get through each day and I feel blessed. Since new remedies have not been of help to me, I zone in on the articles in your quarterlies of patients’ reactions to the disease. Those are the ones that keep me sane. I have compassion for their sufferings and it comforts me that I am not alone.

by Ardelle Staudt
“It comforts me that I am not alone.”
Plan Ahead...

“I wouldn’t wish this on my worst enemy.” Having a genetic component, it is unfortunately more likely that spondyloarthritis will affect a descendent. The sentiment of not wishing this on anyone is shared by many people living with spondyloarthritis. Shared wishes and prayers help and inspire. They build community and community values. They provide comfort and healing. They also lead to action. Action can lead to further action.

There is a story of a person traveling along a road who sees a very old man planting an olive tree. The person asks “how long will it take for that tree to bear fruit?” To which the old man stops his work, straightens up his back, pauses and replies “I think around forty years if the summers are good and the rain comes.” The person questions him further, “and are you so fit and strong that you expect to live that long and eat its fruits?” The old man answered, “I found a fruitful world because my forefathers planted for me, so I will do the same for my children.”

If spondyloarthritis plans to affect our descendents, then we need a plan to fight it. Planned gifts guarantee research, advocacy, education and support for our descendents. We show our gratitude and honor to those who have come before and worked to make our lives better by providing for people who would share our pain in the future.

Planned gifts can be the simplest and financially easiest type of gift. What could be easier than naming the Spondylitis Association of America (SAA) as one of the beneficiaries on an IRA? It literally takes 30 seconds and costs nothing. Plans intimidate people and when they hear the word, they run. It sounds complicated and involved. But, remember the statement by your middle school teacher “not having a plan is planning to fail”? Our assets will be divided and distributed when we die. The question is who is making the decision that expresses your values? If we don’t make a decision, then we are leaving it for the government to make the decision. This year more people have told us that they have made a planned gift to the SAA then ever. They are ensuring that the SAA continues the support and quest for a cure. We recognize and honor their intention through our Quest Legacy Society. Quest Legacy Society members made a special commitment and we therefore hold a special endearment for them. Quest Legacy Society members are recognized on our website www.StopAS.org/quest and annual reports in perpetuity. Perhaps their action will inspire you to join. Our Quest Legacy Members are as diverse as people that have SpA, women, men, all ages and education levels. People of all income and assets levels make planned gifts.

There are tax advantages to making a gift to SAA. There are many types of planned gifts from the naming SAA as a beneficiary on a life insurance policy to annuities that provide income to you for life. Call (800) 777-8189 with questions that you may have regarding planned gifts. If you already intend to make a planned gift, please call or use the enclosed envelope to let us know.

Like any gift, planned gifts should be made after ensuring financial security for you and your loved ones. Professional advisors and attorneys have expertise in gift giving and should be consulted.
Making the decision to remember the Spondylitis Association of America in my estate planning was a natural extension of the ongoing resources I have devoted to the SAA since I was first diagnosed with Ankylosing Spondylitis (AS) in 2002. A natural extension yes, but it is so much more than that. Making a legacy gift ensures that the SAA’s good work will continue long after I am gone, benefiting the next generation of people who have this mystifying and often demoralizing disease.

My story with AS starts in 2002, when I was diagnosed after nine months of endless doctors and tests, during which time I had to take medical leave from work. My diagnosis came from a very smart rheumatologist who had a flyer on the wall of her exam rooms for the Houston SAA Support Group.

Whatever the challenge, I tend to jump in with both feet, so I starting by attending the Houston Support Group meetings. I volunteered to help the group leader with any number of activities, from setting up a mailing list to finding speakers.

And I was fortunate because the Houston support group has one of the leading researchers in AS in its neighborhood – Dr. John Reveille. As a result, I was recruited to participate in the TASC genetic study and was proud to donate my blood toward the better understanding of this disease.

That initial participation led me to join the Board of Directors in 2006. I have chaired the Communications Committee, been a member of the Fund Development Committee, and have served as Board Secretary and currently Board Vice-Chair. It has been such a privilege to serve this organization for the past six years. I have seen it grow and flourish, despite some challenging economic times.

Why wouldn’t I want to support an organization that I know is one of the most efficient, well-run nonprofit organizations in the U.S.? My professional career was spent in Public Affairs for one of the most well managed corporations in America. I worked with non-governmental organizations (NGOs). I reviewed grant proposals. And I managed some major United Way campaigns. So I know a well-run nonprofit organization when I see one. And the SAA is a well-run organization. If you don’t believe me, take a look at pages 14 and 15 of this issue!

My other, more personal reason for remembering SAA in my estate planning is that I would like to see a greater focus on women with this disease. Don’t get me wrong, more attention is being paid to women these days. But understanding how the disease affects women is still in its infancy. And because I am an HLA-B27 negative female with AS, I have a genuine interest in this area.

In order to find these and other answers it will take time and money — resources to conduct research. So part of my reason for doing this is a little selfish, but hopefully it will benefit other women, and men, with AS in the future.
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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.
GET “BACK IN ACTION” WITH SAA’S EDUCATIONAL MATERIALS

Straight Talk On Spondylitis
Our 63 page book on spondyloarthritis. Internationally recognized, this book is the most comprehensive resource available to help people understand and manage ankylosing spondylitis and related diseases. Overviews of medications and treatments, illustrations of specially tailored exercises and stretches, as well as answers to questions such as, “Why does spondylitis cause fatigue?” and “What are some possible complications of the disease?” are detailed throughout. In addition, an exercise wall poster is included with the book. Special SAA Member Price: $20.00.

Back In Action: Exercise DVD
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

Thanks to your generous support, the event grossed over $11,000 that will be put to work improving the lives of spondylitis patients and their families.

We’d like to give special thanks to Michael Smith (spondyville.com) and Michael Rakosi for making the show happen.

All Photos by Barbara Alper
SAA CONNECTIONS

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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What Is Axial Spondyloarthritis (AxSpA)?

BREAKING NEWS: New Rate of Prevalence of Spondyloarthritis -

Prevalence of axial spondylarthritis in the United States: Estimates from a cross-sectional survey -

Spondylitis Plus - Spring 2012 - The Prevalence of Axial Spondyloarthritis - Page 11

Spondylitis Plus - Spring 2013 - An Updated Overview of Spondyloarthritis - Pages 6-7

Spondylitis Plus - Summer 2013 - Looking Back While Forging Ahead - Pages 4-5
http://www.spondylitis.org/members/current.aspx

The Tumor-Necrosis-Factor Alpha (TNF-a) Blockers: An Overview

Enbrel Approved by the FDA - http://arthritis.about.com/b/2003/08/01/fda-approves-enbrel-for-ankylosing-spondylitis.htm
Remicade Approved by the FDA - http://arthritis.about.com/od/remicade/a/fdaapproved.htm
About Remicade - http://www.remicade.com/
About Humira - http://www.humira.com/
Simponi Approved by the FDA - http://www.drugs.com/history/simponi.html
TNF-a Inhibitors: Safer than we thought - http://bjcconnectedcare.com/2013/04/tnf-inhibitors-safer-than-we-thought/
Medications for Spondylitis - http://www.spondylitis.org/about/medications.aspx

Assessment of therapeutic response in ankylosing spondylitis patients undergoing anti-tumour necrosis factor therapy by whole-body magnetic resonance imaging - Martina Karpitschka et al. European Radiology, July 2013, Volume 23, Issue 7, pp 1773-178

She can’t drive yet - but she can use your car

Kids get spondylitis too. Donating an unwanted vehicle to SAA will help ensure that they have the resources they need to live life to the fullest, in spite of the disease. The process is quick, includes free pick-up or towing - and best of all - the proceeds go to improving the lives of spondylitis patients of all ages. The vehicle doesn’t even have to run and you’ll get a great tax deduction for your donation!

Contact Helene Hart at 1-800-777-8189, ext. 229 or at hhart@spondylitis.org.